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# Managing the Medicalization of Madness: A Narrative Analysis of Personal Stories about Mental Illness Online

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UNIVERSITY OF CALGARY

Managing the Medicalization of Madness:  
A Narrative Analysis of Personal Stories about Mental Illness Online

by

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A THESIS

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## **Abstract**

Emancipatory in spirit this thesis asserts personal narratives are an essential and active contributor to the development of meanings in discourse about mental illness and they have an influential role managing medicalization. The medicalization of madness is increasingly contested as people describe and explain how medical approaches and definitions of mental illness at best fail to adequately account for personal experiences of distress, and at worst are the cause of increased physical and psychological trauma. This thesis examines personal narratives posted publicly on medical, social care, and activist websites by organizations and individuals offering support and information about mental illness, community care options, psychiatric survivorship, activism and advocacy. Initial reviews indicated personal stories are included on websites by organizations and individuals with differing views, either for or against medical approaches, suggesting narratives are valued as a way to support or challenge various perspectives on medical approaches to mental illness. In this thesis the objective is not to determine which view is correct or truthful, rather it is to examine how people manage discourse about mental illness as it relates to their personal experiences, whether they identify as health care consumers, patients, ex-patients, or psychiatric survivors. Drawing on Habermas's (1987) Theory of Communicative Action and Fairclough's (1992) Social Theory of Discourse this thesis conceptualizes personal narratives as discursive practices and active sites where meaning is negotiated as people work to express lifeworld experiences in ways that fit with, yet challenge system discourses about mental illness. Using Gubrium and Holstein's (2009) methodology of Narrative Ethnography the analysis identifies and examines personal stories about what it's like being a patient, how social relationships matter, and why recovery is personal. The analysis shows people manage medicalization of their experiences in their stories by making meaningful

connections between personal experiences and discourse about mental illness via a narrative practice (introduced here) called narrative bridging. To accomplish this people use narrative strategies of resisting, re-informing, and reinforcing discourse about mental illness, and it is through these strategies and the consequences of narrative bridging that medicalization is managed in personal narratives.

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*and*

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## Table of Contents

Abstract.....	ii
Acknowledgements.....	iv
Dedication.....	v
Table of Contents.....	vi
List of Tables.....	x
Epigraph.....	xi
CHAPTER 1 INTRODUCTION.....	1
Introduction.....	1
Regarding Language: Madness or Mental Illness?.....	2
The Issue: The Medicalization of Madness.....	5
Background: The Historical Dominance of Medical Discourse to Explain Madness.....	10
Background: The Development of the Consumer/Survivor/Ex-Patient Movement.....	13
The Significance of Personal Narratives for a Study of Medicalization.....	15
Being present to personal stories.....	16
The authorial significance of stories.....	18
Theoretical Framework.....	22
Theory of Communicative Action.....	23
Social Theory of Discourse.....	27
Connecting Personal Experience with Dominant Discourse.....	29
Methodological Approach.....	32
Outline of Thesis Chapters.....	34
CHAPTER 2 LITERATURE REVIEW.....	39
Personal Narratives about Madness.....	39
Outline of the literature review: Narrative as a bridge.....	40
Social Science Literature and Personal Narratives about Madness.....	42
Narrative Identity, Recovery, and Sense-Making.....	44
Narrative Context and Construction.....	52
Narrative Types and Themes.....	57
Narrative and Consumer-Survivor-Ex-Patients.....	62
Medical Literature and Personal Narratives about Mental Illness.....	66
Improving psychiatry and psychology with patient narratives.....	66
Supplementing medical education.....	71
Literary Studies and Personal Narratives about Madness.....	76
Connecting historical, societal, cultural, and medical views of madness.....	76
Challenging traditional views of madness.....	78
Metaphor in autobiographies as resource for understanding madness.....	81
Summary of Literature Review.....	86
CHAPTER 3 THEORY.....	90
Introduction.....	90
Habermas’s Theory of Communicative Action.....	91
Lifeworld, System and Colonization.....	92

The Public Sphere and Ideal Speech Situations .....	98
Communicative Action and Validity Claims .....	100
Fairclough’s Social Theory of Discourse .....	104
Three Dimensional Analysis of Discourse .....	106
Summary of Theory .....	109
CHAPTER 4 METHODOLOGY .....	112
Narrative Inquiry.....	112
Narrative Ethnography.....	114
Theoretical Traditions: Taking up a position on the “analytic catbird seat” .....	116
Interpretive Practice.....	119
Analytic Bracketing.....	122
Discourses-in-Practice .....	123
Discursive Practice .....	124
Narrative Context .....	126
Narrative Environment .....	129
Narrative Practice .....	134
Narrative Work.....	137
Summary of Narrative Ethnography.....	141
Method .....	142
The Internet as a Site for Researching Personal Narratives .....	142
Ethics. ....	146
Website Selection .....	147
Coding and Analysis.....	151
Presentation of Narrative Excerpts .....	152
Summary of Method .....	153
CHAPTER 5 ANALYSIS: WHAT IT’S LIKE BEING A PATIENT .....	155
Introduction.....	155
Personal Narratives about What It’s Like Being Diagnosed with Mental Illness .....	156
Narratives explaining what it’s like to be labelled with mental illness.....	157
Narratives including and aligning life events with diagnosis.....	165
Narratives challenging diagnostic practices .....	171
Section Summary: What it’s like being diagnosed with mental illness .....	176
Personal Narratives about What it’s Like Taking Psychiatric Medications .....	177
Narratives explaining the experience and effects of psychiatric medication .....	177
Narratives describing problems with prescribing practices.....	183
Narratives describing the pressures to take psychiatric medication .....	187
Section Summary: What it’s like taking psychiatric medication .....	196
Personal Narratives about Being in Hospital.....	197
Narratives describing hospital and clinical settings .....	198
Narratives describing what it was like being treated in hospital.....	203
Narratives explaining experiences of being a good ‘bad’ patient .....	208
Section Summary: What it’s like being in hospital .....	214
Chapter 5 Summary Discussion.....	215



CHAPTER 6 ANALYSIS: HOW RELATIONSHIPS MATTER .....	218
Introduction.....	218
Personal Narratives about Relationships with Family and Friends .....	219
Narratives explaining the contradictions of care in relationships with family .....	221
Narratives emphasizing mental illness as a result of family life .....	227
Narrative describing the importance of support from family and friends .....	233
Section Summary: Relationships with Family and Friends .....	236
Personal Narratives about Relationships in the Workplace.....	237
Narratives describing job loss and what “I was...” before mental illness .....	238
Narratives describing relationships with employers and co-workers.....	243
Narratives explaining the challenges of getting assistance and returning to work.....	248
Section Summary: Relationships in the workplace .....	253
Personal Narratives about Relationships with the Health System .....	254
Narratives describing how the health system re-victimizes people.....	255
Narratives describing experiences in and out of the system.....	260
Narratives explaining the challenges of public disclosure .....	265
Section Summary: Relationships with the health system.....	271
Chapter 6 Summary Discussion.....	272
 CHAPTER 7 ANALYSIS: WHY RECOVERY IS PERSONAL .....	 274
Introduction.....	274
Personal Narratives Redefining Recovery .....	275
Narratives describing preferred language for recovery .....	276
Narratives explaining personal definitions of recovery.....	281
Narratives describing the importance of hope in recovery.....	286
Section Summary: Narratives redefining recovery .....	292
Personal Narratives about Recovery Practices .....	293
Narratives describing the importance of acceptance and choice.....	294
Narratives explaining the importance of watching for personal triggers .....	298
Narratives describing personal alternatives that help with recovery .....	302
Section Summary: Narratives about personal recovery practices .....	307
Personal Narratives about Peer Support and a Community of Recovery .....	308
Narratives giving advice.....	309
Narratives describing advocacy and activism .....	312
Narratives describing peers as a “bridge” .....	316
Section Summary: Narratives about peer support and a community of recovery .....	320
Chapter 7 Summary Discussion.....	321
Summary Review of Analysis Chapters 5, 6, and 7 .....	323
 CHAPTER 8 CONCLUSION .....	 325
Introduction.....	325
Contributions and Implications.....	326
Studying Personal Narratives and Medicalization of Madness (why it matters) ...	326
Personal Narratives and Social Change.....	329
Relating Lifeworld and System .....	332
Limitations of the Study and Considerations for Future Research.....	335
A few reflections.....	337

REFERENCES .....	339
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## **List of Tables**

Table 1. Requesting Permission to Research Online Personal Narratives: The email message sent to organization administrators.....	148
Table 2. The websites from which personal narratives were collected .....	149

## **Epigraph**

This, then, might be our contribution as researchers: that we unravel tensions, articulate them, and cast them in the words that allow them to travel—so that they may be more widely reflected on.

Annemarie Mol, *Proving or Improving: On Healthcare Research as a Form of Self-Reflection*

## CHAPTER 1 INTRODUCTION

### Introduction

In this thesis I research and analyze personal stories posted on eleven websites that offer personal, social and medical support and information about mental illness and psychiatric survivorship. A quick look at the websites indicates personal stories are posted to support differing organizational objectives, including medical and social care, patient advocacy, peer support, and consumer/survivor/ex-patient activism. With similar content and form personal stories appear to support and refute medicalized constructions of madness, suggesting the meaning stories convey is adaptable, and even negotiable in discourse about mental illness. The main idea of this thesis is that medicalization of madness is managed in personal narratives as people connect their experiences with discourse about mental illness. I argue that in their stories people connect their experiences with the various meanings in discourse about mental illness and that, just as this accomplishes things for individuals in particular circumstances, it also influences the direction and development of medicalization.

With my analysis of online narratives from across a variety of websites I show how people make connections between their experiences and the many societal discourses that rationalize, inform and shape them. My analysis indicates people make connections between their experience and discourse about mental illness as they share stories that express what it's like being a patient, how relationships matter outside of medical contexts, and why recovery is personal. In their stories people can be seen to accomplish a number of things including (but not limited to) the negotiation of identity, demonstration of social worth, securing a sense of belonging in social contexts, and establishing personal independence and individuality. In the practice of storying experiences meanings about mental illness shift to include other perspectives

and contexts. In telling personal stories people engage in what I call *narrative bridging*, which is a term I use to refer to the ways people make meaningful connections between experiences and discourse. In this thesis narrative bridging involves three *narrative strategies*, which include resisting, re-informing, and reinforcing discourse about mental illness. Specifically, I examine how these narrative strategies play out in individual stories and consider what influence this has for individuals and for medicalization.

From my analysis I suggest that as people alternately engage in narrative strategies to bridge meaning between personal experience and discourse about mental illness, they also manage the direction and development of medicalization. This happens in three ways: first, people direct and extend medical discourse when they describe and explain their experiences as patients, second, people draw out the meanings of their experiences to include social relationships and contexts outside of medicine, which inadvertently brings medicine into more and more social spheres, and third, people describe how they challenge and reinterpret discourse about mental illness by suggesting alternative approaches and attitudes that have helped them find individuality and independence, and as a result the process of medicalization shifts and adapts to integrate these personal perspectives.

### *Regarding Language: Madness or Mental Illness?*

The ongoing negotiation of meaning about madness is keenly noted when deciding what to call experiences most commonly referred to as either madness or mental illness, and this continues to be identified as a challenge across academic and popular writing (Covell, McCorkle, Weissman, Summerfelt, & Essock, 2007; Deber, Kraetschmer, Urowitz, & Sharpe, 2005; LeFrancois, Menzies, & Reaume, 2013; Speed, 2011; Wurtzel, 1994). Few texts or articles about

madness appear without some reference to the ways the authors struggled to determine the limitations and connotations of referring either to madness or mental illness. And although there are many possible euphemisms and alternatives that respect a polysemic, multivocal, and inclusive approach, making use of these variations in writing and reading a text becomes confusing as these variations all require some level of contextual explanation.

In this thesis the challenge seems greater given the analytic intent is to examine the ways people story personal experiences, which includes how they refer to themselves and the people they interact with in their experiences as patients, in their relationships, and in reflecting on the personal nature of recovery. In proposing the research I initially used the term mental health/illness/distress (MHID), with ‘health’ referring to an overall physical and emotional state, ‘illness’ giving recognition to medical views, and ‘distress’ used to respectfully recognize non-medical references to mental and emotional difference that may or may not have led to social or medical interventions.

As the research developed I used phrases and definitions I encountered on the websites to reflect the broader context within which the stories were situated, and this indicated to me that the most used terms are simply madness or mental illness. So for a time I wrote drafts using the term mental illness throughout the text, and then switched to using the term madness. The term mental illness is used most readily in current society and this has implications for people no matter if they subscribe to a medical perspective or challenge it. I would argue that discursively people have an experience of mental illness merely by being part of the subjectivity the discourse creates. Similarly the use of madness carries connotations that advance certain meanings and beliefs. People use the term madness in positive and negative ways, as a reference to disruptive

behaviours or frightening thoughts, in reference to feelings of extreme happiness, and to reference a position of agency and community activism as in the Mad Pride movement.

With each iteration of this thesis I aimed to be inclusive, but the resulting text read as though I was positioned on one side of a debate or the other, further indicating how potentially subtle (perhaps subversive) is the influence of societal discourse on how we construct meaning about human experiences in our everyday talk and texts. Additionally, using either madness or mental illness gave the idea that there is a singular dichotomous debate between proponents of medical approaches and people opposed to medical perspectives. This vastly oversimplifies the complexity of peoples' experiences and the influence of social systems in which their experiences take place (LeFrancois et al., 2013).

Reflecting on this I can only explain my use of either madness or mental illness in this thesis is not intended as a statement about which view is more authentic or correct. The intent of the thesis is to consider the way discourse about mental illness—that is, the medicalized meanings that have come to define madness—are managed by people in their personal narratives. Therefore throughout the thesis I use phrases such as “people who identify...or are labelled with psychiatric disability...”, “people who experience...”, and “people who share stories about...” either madness or mental illness. I do so to indicate people respond and manage the broader discourses their experiences are discursively situated in, in order to tell their stories, and make them meaningful. With this approach I am able to examine and describe stories about a variety of personal and social contexts, and I aim to show people manage medicalization in stories about their experiences as patients, about their close relationships, and about their experiences of recovery.



## **The Issue: The Medicalization of Madness**

In 1976 Ivan Illich used the term medicalization in his book *Medical Nemesis: The Expropriation of Health* to describe the encroachment of medicine onto all aspects of life. According to Illich (1976) “medicine undermines health not only through direct aggression against individuals but also through the impact of its social organization on the total milieu” (n. p.). The book brought the idea of medicalization to a broader audience and raised awareness about the iatrogenic effects resulting from the increasing expansion of medicine into everyday experience. The concept initially emerged in the 1960s and since that time philosophers and social scientists including Peter Conrad (1992, 2007), Arthur Kleinman (1988d), Nikolas Rose (2007), Thomas Szasz (1961, 1970), and Irving Zola (1972) have developed the concept further. Today medicalization is viewed as a powerful, controlling force with a multitude of negative consequences.

Defined, the term medicalization refers to the increasing application of medical knowledge and practices to explain and manage everyday life events and experiences. According to Conrad (1992) “medicalization describes a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders” (p. 209). From the outset the idea of medicalization has been used to critique the growing power and professionalization of medicine as an “institution of social control” (Zola, 1972, p. 487). However, according to Zola (1971) medicalization is not about physicians blatantly exercising medical knowledge to have political influence, rather it is “largely an insidious and often undramatic phenomenon accomplished by ‘medicalizing’ much of daily living, by making medicine and the labels ‘healthy’ and ‘ill’ relevant to an ever increasing part of human existence” (p. 487). Kleinman (1988d) suggests medicalization is the “arbiter” of social

behaviour displacing other forms of social control such as religion or law. He points out that in some cases initially focusing on medical aspects of social issues helps create increased support for marginalized communities, but more often medicalization restricts and limits how social issues are addressed by emphasizing measurable, medical assessments of these problems as due to illness. This is particularly evident in historic and recent accounts where medical diagnosis of mental illness has been used to manage or control individuals and groups deemed to be troublesome or behaving outside of social norms (Kleinman, 1988d).

More recently attention to the concept examines medicalization for both positive and negative effects, and looks at how medicalization is itself influenced by changes in culture and society (Conrad, 2007). For example, Tomes (2007) describes how early approaches to addressing medicalization in doctor-patient relationships focused on highlighting the issues caused by medicalization. She explains these approaches dichotomized relationships between doctors and patients reducing the forces of medicalization to what she calls “an oversimplified cast of heroes and villains” (p. 698). She adds that despite the inclusion of patient experience as a way to counter medicalization and improve medical and social care, the process continues, but rather than blame doctors now “ignorant, irrational patient-consumers provide an easy explanation for the persistence of problems” of medicalization (Tomes, 2007, p. 698). This suggests that recognizing and naming issues and stakeholders involved in medicalization, and describing its effects are no longer enough. What is needed is a better understanding of how medicalization works in society and what influences the way it changes and develops.

Conrad (2007) provides a comprehensive discussion of the development of medicalization as a theoretical construct and characterizes medicalization as a process. Viewed this way, he maintains the power of medicalization essentially comes via its “authority to define”

human experience and this changes over time (p. 8). Conrad (2007) points out there are degrees of medicalization, and that categories created by medicalization “expand and contract” indicating it is also “bi-directional”, thereby suggesting that experiences and events can be both medicalized and demedicalized (p. 7). Additionally, he describes medicalization as a “form of collective action” mobilizing not only the efforts of the medical community, but also the lay community (which may include patients, consumers, activists, advocates, social groups) (Conrad, 2007). Consumer/survivors and advocates in the area of mental illness are most active in criticizing and challenging medicalization.

Since the 1960s Thomas Szasz (1961, 1970, 1974) has arguably been the most notable critic of the medicalization of madness. His use of the term to explain how mental illness is a socially constructed myth continues to be recognized and adopted as a foundational point from which to criticize medicalization. The early criticisms of the anti-psychiatry movement have become increasingly focused on specific areas in the psy disciplines (LeFrancois et al., 2013). Whereas medicalization refers to the broader application of medical explanations to everyday life experiences, more specific terms such as psychiatrization and psychologization refer to close critiques of the way the psy disciplines reduce human experiences and behaviours to biochemical and psycho-social categories, respectively. Today criticisms of medicalization are prevalent and prominent in popular and scholarly literature, and involve demands to displace and demedicalize madness, covering topics such as over prescribing of psychiatric medications, and marked expansion and application of diagnostic terms such as depression. Consumer/survivors, advocates and activists, alongside healthcare practitioners and social science scholars are critical and calling for the demedicalization of madness.

According to Rapley, Moncrieff, and Dillon (2011),

Resisting the psychiatrization and psychologization of almost every aspect of human experience, and finding a way to place what are, frequently, essentially *moral and political* – not *medical* – matters back at the centre of our understanding of human suffering is a massive and multifaceted task. (Rapley et al., 2011, p. 5) (Emphasis in original).

Given the powerful developments in medical knowledge and technology, and increased public acceptance of medical explanations for mental and emotional distress, this task would require vast and endless resources for convincing professionals and the public to forego medical explanations and replace them with an equally compelling perspective and approach to madness. A more productive approach is to examine the ways medicalization happens, how it relates to the development of meanings about madness (as mental illness) in society today, and how expert and lay communities and individuals are involved and implicated in the process and its development (Ignaas & VanHoyweghen, 2011). As Rose (2007) points out “the term medicalization might be the starting point of an analysis, a sign of the need for an analysis, but it should not be the conclusion of an analysis” (p. 702). Medicalization is a rallying point for analysis and studying its effects or resistance to it should not obscure the value of exploring how people actually manage it everyday, such as in the case of mental illness. Perhaps the force of medicalization may be considered a catalyst directing attention to what and how people construct alternate meanings about what madness is, what it is not, and how it will be made meaningful in the future.

In this thesis I take a critical position on the medicalization of madness that provides a starting point for my analysis. In my view madness cannot be demedicalized because discourse about madness today so prevalently and prominently features medical references, to the near

exclusion of other possible explanations. However this is not to say that medicalization is a fait accompli, as I show in my analysis people manage medicalization in everyday narratives and in doing so I suggest they help to shape and direct its development as they interrogate and integrate personal interpretations and conceptions of mental illness into medicalized discourse. From this medicalization of madness is disrupted, agonized, and displaced by personally and socially constructed meanings, which are based upon personal experience. It is important to be critical of the influence of medicalization on society and on individuals, but I argue we can learn more about the process of medicalization by paying close attention to what people are doing, and have been doing, all along to manage medicalization in their everyday lives. And with attention to what happens in personal narratives we may explore opportunities for considering how medicalization can be influenced, what or whom directs its development, and how this may be made relevant for more concerted efforts to manage medicalization.

In my view personal narratives are a site where meaning about madness—medicalized or not—is negotiated and as such there is much to be learned from the ways people manage medicalization in stories about their experiences. Managing medicalization is not necessarily made in overt claims presented in personal narratives rather it involves a bridging of meaning, or a making of connections, between experience and discourse about mental illness. In my analysis I notice people do not just directly contest medical discourse when they story their experiences, instead they move back and forth connecting their experience with discourse about various medical, social and personal contexts and relationships. By drawing on a variety of roles and contexts, including medical ones, people make sense of their experiences for themselves and others and validate claims that resist, re-inform, and reinforce discourse about mental illness, thereby managing medicalization.

In 1976 Illich argued that “the layman (sic) and not the physician has the potential perspective and effective power to stop the current iatrogenic epidemic” called medicalization (p. 4). My thesis demonstrates people have the perspectives and power not to stop it, but rather to shape and influence the course of its’ development. In the next section I briefly review the historical developments of discourse about madness leading to the dominance of medical discourse to explain madness as mental illness.

### **Background: The Historical Dominance of Medical Discourse to Explain Madness**

Madness has been, and continues to be, defined in terms of hegemonic discourses that represent social systems aimed at controlling and explaining madness. For over two thousand years peoples’ experiences of mental distress and difference have been interpreted and explained by dominant discourses, such as religion, literature, art, theatre, and medicine (Foucault, 1965; Horwitz, 2002; Rosen, 1968). Throughout history madness has been conceptualized as a profound religious experience, weak morality, personal lethargy, or a failure to fit social and cultural norms, and although it may not have been freely accepted in society, people who experienced it “generally led a free-wandering existence” (Conrad & Schneider, 1980, p. 44) and, as long as they did not create a public disturbance, they “were left at liberty” (Rosen, 1968, p. 139). Foucault (1965) points out that some people expressed their experiences in art and literature, for example during “the Renaissance, madness was present everywhere and mingled with every experience by its images and its dangers” (p. 70). At other times poverty, criminality, and even unemployment were viewed alongside madness as forms of social deviance in society. These perspectives on madness separated troubled souls, minds and bodies from proper society

and bound them together under a general discourse of deviance. People who experienced whatever was deemed madness were segregated, punished, or re-educated according to the doctrines of the times, and this set the tone for discourse about madness to be negative and controlling (Horwitz, 2002; Rosen, 1968).

As society moved into the Age of Reason a shift in meaning about madness influenced how people were treated, and people deemed mad were pushed out of discourses about humanity altogether (Foucault, 1965). Madness was no longer linked to discourse about human values, morals and spiritual beliefs, but was accounted for in discourse that conceptualized it in terms of animalistic tendencies and de-evolutionary processes (Foucault, 1965). According to Foucault (1965) “madness, had become a thing to look at: no longer a monster inside oneself” (p. 70). The population of institutions and mental asylums grew rapidly during these times as places to “consign the awkward and unwanted, the useless and potentially troublesome” (Scull, 1979, p. 240). People who experienced madness became social spectacles in “museums” or “theatres” of madness (Reiss, 2008; Scull, 1979) and had no stories apart from the ones the audiences told about them, which further silenced personal views and eliminated the social standing (if any remained) of people deemed mad. And yet, the physical and social presence of madness and the challenges it produced remained unaccounted for in society. Madness lacked a clear explanation—presenting a discursive opportunity for more powerful groups in society to become the storytellers of the mad. Enter psychiatry.

The development of psychiatry and the recognition of so-called “mental diseases” began with definitions of mania and melancholia in the 1600s. By the late-1800s Freud, with psychoanalysis, defined and described “madness at the level of language,” and claimed it for medicine by offering “the possibility of a dialogue with unreason” (Foucault, 1965, p. 198). In

1911 Bleuler defined and categorized experiences as dementia praecox and schizophrenia thereby setting the foundations for what would become the a diagnostic categorization of mental illnesses, now known as the American Psychiatric Associations Diagnostic and Statistical Manual better known as the DSM (Geekie & Read, 2009). By the early 1900s personal experiences of madness were almost completely storied as medical cases, with symptoms, diagnosis and treatment as the primary discursive characterizations. The spectacle of madness was officially re-named mental illness.

Early on psychiatry made claims about mental illness and developed language, theory, methods, and meanings to explain it based upon theoretical constructions about subconscious motivations and desires. However, these claims were challenged from within the field of medicine. Psychoanalysis was not able to answer questions about the meaning of madness that fit with empirical constructions of science, and it could not offer sure-fire cures. It was apparent the language of psychoanalysis could “neither liberate nor transcribe, nor most certainly explain what [was] essential” in madness (Foucault, 1965, p. 278). Nonetheless, madness remained under the discursive purview of medicine, and approaches shifted from the subconscious to the organic. Claims about madness were constructed and shaped by scientific discourse focused on physical states of the body and eventually biological and chemical qualities of the brain.

With the positivist approaches of science, medicine offered the possibility of clear and definite explanations for madness. Medicine re-storied peoples’ experiences using medical language and explanations and the cost of care and support was cooperation, compliance, and adherence to doctor’s orders. This still holds today and as Bassman (2001) explains, “diagnosed into being objects, imprisoned with or without walls, cut off from meaningful dialogue, the



psychiatric consumer/survivor/ex-patient (c/s/x) must adapt to an other-constructed, authority blessed reality” (p. 15).

### **Background: The Development of the Consumer/Survivor/Ex-Patient Movement**

Challenges to medicalization began slowly, gaining momentum over the last sixty years with focused demands that patient perspectives be acknowledged and included in approaches to care. Early advocates, psychiatrists, and patients opposing medical treatments publicly called for humane treatment and care of the mentally ill. The changing social and political landscape of the 1960s and 1970s brought a concerted rise and resistance against medicalization and the medical establishment (Crossley, 2006; Everett, 1994, 2000; Starkman, 2013). The anti-psychiatry movement grew, supported by mental health professionals who spoke out for their patients “against pharmacological treatment, coercive hospitalizations, and other authoritarian psychiatric practices” (Rissmiller & Rissmiller, 2006, p. 863). New perspectives based upon the stories people told about their experiences offered alternative ways to explain and understand madness—not as mental illness. Mental illness was redefined as political, manufactured, and a socially constructed myth (Laing, 1967; Szasz, 1970, 1974). Psychiatry was losing its grip. Since that time people identifying themselves as consumers, survivors, ex-patient, activists, and advocates have taken a leading role challenging medicalization and medical approaches to madness.

The development of the activist consumer/survivor/ex-patient (c/s/x) movement provided alternative perspectives on madness based on peoples’ shared personal experiences. The movement is described as a “loose coalition of advocacy and activist groups” whose collective intent is to change attitudes and approaches to mental health (Morrison, 2005, p. 57). It emerged

out of the broad range of collective and individual responses to medicalization and systems of mental health that have presided over the discourse and the experience of madness for centuries. According to Szegedy-Maszak (2002) “the movement is a curious hybrid of the 1960s civil rights movement and more-recent health advocacy efforts – for example, AIDS and breast cancer” (p. 55). Members of the movement re-claim discourse about mental illness by telling personal stories in ways that support the goals of the movement. While still tethered to issues of health and illness, the c/s/x movement now expands outside of the bounds of the health system by engaging with other movements, and encouraging independent alternatives that embrace lifestyle changes and advocate for human justice (Morrison, 2005, p. 173). Today scholars who identify as psychiatric survivors and mad-identified people are engaged in theorizing and analysis of their experiences, and are contributing to deeper understandings of madness that challenge medical approaches and discourse (Burstow, LeFrancois, and Diamond, 2014).

Taking their personal stories public, members of the c/s/x movement energize a broad mandate to re-inform and re-direct practices, perspectives and discourses that have medicalized madness. Calling upon movement members to share their stories the c/s/x movement gains legitimacy as a collective and representative voice. People are demanding inclusion in decision making about health and social care in attempts to displace and agonize existing approaches. They are asserting their presence and abilities to be regarded as “active narrators to their own stories” (Bassman, 2001, p. 25). With personal stories members of the c/s/x movement have gained legitimacy to influence issues of health and social care, which displaces purely medicalized perspectives.

## **The Significance of Personal Narratives for a Study of Medicalization**

Personal stories are an influential form of experiential knowledge. They provide insight into social and clinical issues faced by people diagnosed with chronic illnesses, such as cancer, AIDS, and multiple sclerosis (Charmaz, 1983; Charon, 2006; Frank, 1995; Horne, 2011; Mathieson & Stam, 1995; Mattingly, 2004; Riessman, 1990). However, although autobiographical accounts about madness dating back as far as the fifteenth century hold the interest of scholars, media and the general public, personal narratives have only recently enjoyed closer attention as an important contributor to understanding madness (Sommer, Clifford, & Norcross, 1998). However, considering the increased interest in these stories there is limited empirical examination of the ways personal narratives work to manage dominant discourse and how this relates to medicalization.

Certainly there is great interest and a mass of scholarly and popular information written about, for, to and by people who experience all manner of madness. There are numerous descriptive autobiographical accounts about mental illness in popular and scholarly literature, which take positions with regard to the benefits and/or challenges of using medical discourse to explain and understand madness. These accounts are viewed as either for or against medicalization. Narratives are used in a variety of ways to both support and counter medicalization suggesting personal experience and stories about it are central to a struggle for meaning in discourse about madness. For instance, personal narratives are used as examples to strengthen and enhance claims made in medical discourse. They are central to discussions of mental illness as a social construction and are used to raise awareness about relationships between mental illness and social issues (Hornstein, 2009; Horwitz, 2002; Szasz, 1974). Additionally, narratives are recognized in an ancillary role and presented as agonistic claims

aimed at disrupting medical discourse and the colonizing force of medicalization. Storied accounts are used to directly resist and contest medical constructions of madness and highlight the negative consequences of traumatic medical treatment. Stories do more than convey information or recount previous experiences, they are used in various ways to raise issues and support particular views in particular situations. According to Brenneis (1996),

Narratives are used to stir up trouble, to further one's particular goals, and to help draw the dispute to a close. At each particular juncture, very different stories may be told, in very different ways and with very different implications. (Brenneis, 1996, p. 43).

Although personal stories are recognized and used to support various parties and perspectives involved in the struggle for meaning about madness, they have yet to be closely examined for *how* they work in discourse to contribute to and influence meaning, and what this accomplishes with regard to medicalization. Generally, narrative content and form are examined as products of social interaction useful for raising awareness about issues and while this is changing there are many reasons and opportunities to examine “narrative production and reception as situated social activities that play a crucial role in constituting—not merely reflecting—everyday life (which) has seldom been explored in any depth” (Briggs, 1996, p. 4).

### *Being present to personal stories*

Discussions about madness across a variety of topics in discourse about mental illness include excerpts from personal narratives that present haunting images of anguish and confusion, where sympathy and empathy are pale solace for both reader and narrator.

From the accounts you will learn the unique contingencies faced by those plagued by profound sadness, by flights of psychotic mania, by the insistent demands of terrorizing voices, by the need to ritualistically repeat behaviors (sic) to the point of exhaustion, or

by cravings so powerful and insistent that they dominate one's life.  
(Karp & Sisson, 2010, p. 13).

The act of being present to these experiences as they are expressed in the familiar form of a story makes them accessible for interpretation (Carr, 2008). Carr (2008) describes how a personal story “borrows its form from the very action it is about”, it “never strays far from ordinary discourse”, and how it “opens up immediately recognizable strategies for dealing with the situation” (p. 20). While DeYoung (2010) suggests that the compelling nature of madness narratives is in part their complexity and their inability to provide a “well-knit narrative” or a “tidy conclusion” (p. 264). However, not all personal stories about mental illness fit this profile. Stories may include actions and orientations that are hard to follow, the discourse may combine events and “believed-in imaginings” (Sarbin, 1998) that provide no clear insight or explanations about behaviour or events in a person's life.

Personal accounts of madness are like what Frank (1995) calls “chaos narratives”. They are stories that emerge from within the chaos of immediate experiences or include recollections of confusing and traumatic events. These types of stories are “an anti-narrative of time without sequence, telling without mediation, and speaking about oneself without being fully able to reflect on oneself” (Frank, 1995, p. 98). The chaos of these narratives is difficult to hear and prompts readers to draw on personal knowledge and available discourses about mental illness to make sense of and interpret the story. As this thesis shows people make meaningful connections between their experience and discourse about mental illness, and in doing so they offer experiential insights and explanations that resist, re-inform, and reinforce discourse about mental illness, thereby influencing medicalization.

### *The authorial significance of stories*

The greatest challenge for people whether they identify themselves as patients in the mental health system or as psychiatric survivors of traumatic health care experiences is to interpret personal experiences both independent of, and including other available meanings in discourse. While there is a call for medical discourse to be inclusive of patient experience, people are still compelled to accept medical meanings of madness if they are to receive help when they are in distress. According to Beresford (2005) medical discourse “offers some kind of explanation which, at times of great individual difficulty and pain, may seem helpful. It is likely to be the only framework for understanding that many people are offered or can access” (p. 37). In this way medical discourse has the definitive advantage in claiming how madness is talked about and what it means. During times of crisis people are reliant upon others to help them make sense of their experiences. Hornstein (2009) explains,

Events don't come with labels hanging around their necks, saying “This is a crisis,” or “This isn't what it seems,” or “You'll feel better in a few hours.” We are hugely dependent on the reactions of others to make sense of what is happening to us, especially if it's sudden or dramatic. (Hornstein, 2009, p. 97).

Wrestling with physical, social and discursive constraints people are sharing personal stories, but continue to struggle in efforts to assert personal meaning of their experiences into medical discourse. The goal is to construct meaning that “mitigates or at least makes comprehensible” to themselves and others, the experience of madness as it is situated in everyday contexts (Bruner, 1990, p. 49). Predominantly cast in terms of medicine the problems of madness continue to be “shackled to the wrong conceptual framework and terminology” (Szasz, 1974, p. 4). Historically “the mad have often spoken in code, and with good reason. Until very recently, most were

institutionalized against their will. If they wanted to record their experiences or tell others about them, they had to disguise their words somehow” (Hornstein, 2009, p. xii).

As evidenced by the many current and historic autobiographical accounts of madness, people find solace by writing during times of crisis, despair and mania so much so that authors go to great lengths to write about their experiences. Historically writing was risky when committed to an institution where “pen and paper often were forbidden, especially to women” and personal letters were confiscated and read by hospital staff (Hornstein, 2009, p. xii). However, these challenges did not deter patients and the great number of historic narratives is evidence of the fact that patients found ways to write. For example, Lara Jefferson (1947) recorded her experiences and reflections on scraps of paper and the backs of envelopes, which were later pieced together after being found by a hospital superintendent to construct her autobiography.

In one instance, Jefferson (1947) describes how she calmly, and in a straightforward manner, asks the ward nurses for writing paper. Her request is denied, but undeterred she reframes it by telling the nurses she is Shakespeare. They accept her delusion as harmless and she is given a ream of paper. “Go to it Shakespeare!” says the nurse. The example suggests an astute ability to manage a medicalized experience. Throughout her story, Jefferson (1947) returns often to the significance of writing and the value of the small chewed pencil she uses as an anchor to life outside of madness and the institution she is held in.

The flood that was swirling about me was sucking me under – and the pencil I had in my hand was a straw to be caught. It was just a straw—but I caught it—and now I have kept my head above water for a while—even if what I have written does not make sense to anyone—at least—it has helped me a little. I have been able to find a few inadequate phrases. And anything that can be whittled down to fit words—is not all madness. (Jefferson, 1947)

This passage indicates how much language and the ability to construct a narrative—no matter how limited—are an essential connection between madness and (so-called) reality for the author. Other authors create a degree of distance from their experiences, and the stigma that accompanies the label of mental illness, by writing fictional accounts that represent their experiences, such as Charlotte Perkins Gilman's (1892) *The Yellow Wall Paper*. And the popular mid-20th century novel, *I Never Promised You a Rose Garden* was initially published under the pseudonym Hannah Green, only later to be released using the author's real name, Joanne Greenberg (1964).

In some cases people write full accounts of their experiences later in life, drawing from diaries and journals to reconstruct and reflect on what happened to them and how they managed the trauma of their experiences. Authors describe detailed accounts of relationships with clinical staff, family members, and other consumer-survivors often using irony, sarcasm, humour, and a variety of metaphoric constructions to describe their experiences. They interpret their most severe emotional moments, describe hours of boredom, the fear they experienced in institutions, and detail with great clarity the harsh and inhumane treatments they were subjected to in the name of medical treatment. For example stories such as *The Snake Pit* by Mary Jane Ward (1946) and *The Prison of My Mind* by Barbara Field Benziger (1969) present haunting descriptions of living and surviving madness and medical treatments under the most difficult of circumstances. Whereas more recent autobiographies such as *Girl, Interrupted* by Susanna Kaysen (1994) and *The Centre Cannot Hold* by Elyn Saks (2007) challenge medical expertise, knowledge, and social attitudes to call into question old and new approaches to treatment. The intensity and details in these stories are examples of how madness has been medicalized, and



more significantly demonstrate that as people describe personal experiences they manage the medicalization of their experiences by giving medical discourse personal meanings.

For scholars and advocates, for consumers, survivors and ex-patients, for their family and friends, and even for medical professionals, personal stories play a significant role as a catalyst for challenging medical meanings and developing new meanings about madness. According to Hornstein (2009) personal narratives are significant because they highlight what is wrong with medical approaches to madness as well as offering alternatives that shift attention to experientially informed alternatives. She explains, “first-person accounts of psychological distress serve two powerful functions—they expose the limits of psychiatry’s explanations and treatments for mental illness and they offer competing theories and methods that might potentially work better” (Hornstein, 2009, p. xxii). Viewed this way autobiographical accounts are active expressions of personal experience aimed at negotiating and influencing medicalized conceptions of madness.

As Estroff, Lachicotte, Illingworth, and Johnston (1991) explain challenges to medical conceptions of madness made in narratives are not necessarily direct calls for action (though this is also evident in narratives), but rather involves on-going efforts to negotiate meaning.

A sequence of individual responses to altered experiences of self, and the ideas and actions of others, work in a continuous reciprocal relationship, resulting at time in consensus and at other times in conflict between practitioner and patient, or individual and institution. Distinct private and public processes, and the intersections between them, are involved. (Estroff et al., 1991, p. 332)

In their research Estroff et al. (1991) demonstrate narratives are significant for people on a personal level as they work out and respond to medical definitions of madness. Wood (2013) suggests sharing personal narratives is also significant because it offers people the “chance to

shape their stories as they wish and contrast those stories to the dominant narratives” that “circulate in the popular imagination on the one hand and in the medical imagination on the other” (p. 86). In this thesis I hope to add to discussion regarding the ways narratives are significant by showing that through personal narratives people manage the medicalization of their experiences, and as a result personal meanings are integrated into discourse about mental illness and this in turn influences medicalization. To best examine how medicalization is managed in personal narratives and the influence this has, involves analysis of the relationships between individual discourse and dominant social discourse, and in the next section I discuss my choices regarding theoretical frameworks that support this approach.

### **Theoretical Framework**

In this thesis I take the view that meanings of illness are initiated and constituted in ongoing everyday interactions as individuals engage in discourse that develops as a result of the social systems in which their experiences come to be explained and rationalized, such as medicine, technology, economics, and politics. My intention is not to define once and for all the actual meanings of madness, because the ongoing, relational, social and multi-vocal nature of experience and discourse would quickly discount any attempts at a definitive answer. For me the more productive task is to explore how meanings are negotiated and what this accomplishes for individuals and in dominant discourse. This is achieved by taking a close look at the narrative strategies used to bridge meaning between lifeworld experiences of mental illness and the constellation of system discourses that endeavour to rationalize, organize and explain madness. With this as the goal I draw on two theories that regard communication and narrative as essential

to the construction of meaning in discourse and to the consequent social actions arising from the development of discourse.

### *Theory of Communicative Action*

With the Theory of Communicative Action (Habermas, 1987), I find a framework for conceptualizing relationships between personal experience as it is expressed in narratives and dominant discourses as they are informed by social systems. Connecting my thesis to Habermas's (1987) theory I build my ideas on a theoretical foundation that views communication as the central social and relational practice that informs and shapes society. Using Habermas's (1987) distinctions between lifeworld and system I define personal narratives as an expression of lifeworld experience where people aim to have their experiences understood by others in order to create shared meaning, but also in ways that leave room for resistance and contestation in discourse. As such I see personal narratives as an active practice by which people make claims about their experiences, and in order for these claims to be considered valid by others people align them with already existing shared and common understandings and values. Habermas (1987) explains that people relate their personal experiences to other experiences in the world that others can understand in order to make their experiences meaningful and valid. For my thesis this conception works to indicate people make meaningful connections between personal experience and discourse about mental illness by relating their experience to social understandings of patient roles, various social contexts of mental illness, and expectations regarding personal reflections and resistance to medicalized notions about mental illness. Habermas (1987) explains communicative action is not merely an individual effort to describe for others a true or correct accounting of their experiences, but involves active negotiation and

the work of relating personal experience to individual, social and ideologically acceptable discourses.

Communicative action relies on a cooperative process of interpretation in which participants relate simultaneously to something in the objective, the social, and the subjective worlds, even when the thematically stress only one of the three components in their utterances. Speaker and hearer use the reference system of the three worlds as an interpretative framework within which they work out their common situation definitions. They do not relate point-blank to something in a world but relativize their utterances against the chance that their validity will be contested by another actor. (Habermas, 1987, p. 120)

With their efforts to relate lifeworld experience with system discourse people bring interpretations of their experience into the public sphere where personal claims enter broader discourse and are taken up, reworked or rejected. The resulting inclusion and incorporation of personal narratives into discourse informs and changes socially shared meanings, which has effects on the development of dominant discourses and system forces that inform them, such as medicalization.

Although Habermas (1987) does not spend a great deal of time addressing the specifics of personal narrative as a theoretical construct he explains that examining narratives gives us a chance to see how people make sense of lifeworld experiences and how these experiences are related to and organized socially. Narratives are points where personal experience is performatively expressed with intentions to explain everyday contexts of experience, and lifeworld becomes a referencing point for constructing new meaning based upon existing understanding.

In the grammar of narratives we can see how we identify and *describe* states and events that appear in a lifeworld; how we *interlink* and *sequentially organize* into complex units members' interactions in social spaces and historical times; how we explain

the action of individuals and the events that befall them, the collectivities and the fates they meet with, from the perspective of managing situations. In adopting the narrative form, we are choosing a perspective that “grammatically” forces us to base our descriptions on an everyday concept of the lifeworld as a *cognitive reference system*. (Habermas, 1987, p. 136) (Emphasis in original).

With this Habermas (1987) suggests it is through narrative that everyday interpretations of lifeworld can be discerned and a study of narrative form can provide insight into how socio-cultural life is organized and explained and how interactions between people are managed. This becomes theoretically valuable when considering how lifeworld and system are reproduced. In narratives we can see thematically how people contribute to new meanings as they invoke and make claims about, but still relate to, existing socio-cultural traditions. For this thesis this indicates narratives are involved in the development of meaning, and can be examined for the ways they are seen to manage discourse because they describe, interlink, organize, and explain everyday conceptions of experience as they relate to social contexts.

In the theory of communicative action Habermas’s description of how system colonizes lifeworld is well suited for explaining medicalization. According to Chouliaraki and Fairclough (1999) Habermas’s ideas about system and lifeworld indicate that even as colonization is viewed as the slow encroachment of system over lifeworld, the influence moves in both ways; an idea which supports my conception of a communicative bridge between personal experience and discourse. They state, “there are thus channels between lifeworld and systems which in principle allow flows in either direction – systems can be shaped by lifeworlds, lifeworlds by systems” (Chouliaraki & Fairclough, 1999, p. 86). Where medicalization is concerned, medical discourse continues to define and direct meanings of madness, but by conceiving of a two-way channel

between lifeworld and system, this thesis takes up an opportunity to explore narratives as an expression of lifeworld that is influential in shaping discourse about mental illness.

Habermas's contributions to social theory are substantial, and the extent and scope of his works have not been lost on scholars interested in health and illness, however there are few direct applications of his concepts to the study of narrative, and few in-depth applications of his ideas to specific issues in mental illness. In the literature I find no application of the concepts of lifeworld, system and colonization to the negotiation of meaning in personal narratives and discourse about mental illness. At this time I am not aware of studies that apply Habermas's (1987) detailed conceptions and discussions of communicative action to personal narratives and/or medicalization. As Jones (2001) points out "Habermas' work seems under-utilized in relation to medicalization" (p. 172). And Mishler (1984) who was the first to use Habermas's theories in studies of doctor-patient relationships, suggests today there is a need to focus on peoples' stories in contexts outside of clinical encounters and to "engage them critically as socially positioned persons with alternative understandings of what has been happening to them" (Mishler, 2005a, p. 443). In my thesis I aim to provide an alternative to discussions that focus on clinical encounters or look at social care issues, and using Habermas's (1987) theory I expand the scope of analysis to consider narratives people share about their experiences and how they connect them in meaningful ways to various contexts. To accomplish this I draw on the work of Fairclough (1992), which offers theoretical conceptions of how narratives and everyday discourse contribute to change in society.

### *Social Theory of Discourse*

Grounded in Critical Discourse Analysis Norman Fairclough's (1992) Social Theory of Discourse brings into focus three levels or dimensions of social experience to explain how discourse and language function to inform social change. The theory emphasizes that social change comes about through changes in language practices and discourse. This is particularly relevant for my thesis as I propose that as people negotiate and manage discourse about mental illness by interpreting and integrating personal experience into discourse they influence meanings and shape the development of medicalization. With the Social Theory of Discourse, Fairclough (1992) provides a conceptualization of how language and discourse may be implicated in processes of social change. I draw three essential ideas from this theory to conceptualize how personal narratives manage medicalization. First, discourse is viewed as a social practice. Fairclough (1992) defines discourse as a social practice of meaning making, rather than merely as the way people describe activities and events. He explains discourse is dialogic not only for the ways people respond in actual instances of talk, but also in the ways people respond to pre-existing understandings about social identities, relationships, and overall ideological values and beliefs that circulate in society. This supports my idea that as people share stories about their experiences they are responding to and managing existing meanings in dominant discourse about mental illness.

Second, discourse is seen to have "constructive effects" which Fairclough (1992) states "directly and indirectly" influence how social structures develop (p. 64). Focusing on how discourse works in practice and characterizing "key aspects of the constructive effects of discourse" is helpful for discerning and organizing the thematic contexts that are evident in personal narratives. Fairclough (1992) explains that discourse is influential on three levels

including the level of personal identity, at a relational level, and at an ideational (or ideological) level. Recognizing the dominating influence of hegemonic discourses Fairclough (1992) also aims to emphasize and explain the ways everyday language has an influence in society. He explains, “discursive practice is constitutive in both conventional and creative ways: it contributes to reproducing society (social identities, social relationships, systems of knowledge and belief) as it is, yet also contributes to transforming society” (Fairclough, 1992, p. 65). The idea that everyday language and discursive practices influence social change on these three levels (individual, relational, ideational) supports this study of narratives as participants and contributors to the development of meanings about mental illness—and by extension this supports the idea that personal narratives influence system discourses and the hegemonic forces guiding these discourses, such as medicalization.

Thirdly, the Social Theory of Discourse (Fairclough, 1992) focuses on the specifics of how language is produced and reproduced at and between the three dimensions of discourse (individual, relational, ideational). It emphasizes the importance of looking at the struggles in language that occur as people reproduce and re-work dominant discourses and construct new meanings. It allows for consideration of the ways dominant social systems influence personal experience and also the ways people give meaning to their experiences and relate this back into system discourses. On this point I suggest people connect their experience to prevalent discourses in order to manage the influence of that discourse. That is, in telling personal stories about their experiences of distress, psychological trauma or madness people respond to and influence dominant discourse about mental illness by invoking discourse from a variety of other contexts to explain their experiences. Drawing on the theories of Habermas (1987) and Fairclough (1992) provides me with concepts whereby I connect personal experience and



dominant discourse about mental illness in an analysis of how narratives work in society as an influential form of discursive practice. As I describe in the next section this involves paying analytic attention to the relationships between dominant system discourses and everyday discourse as it is communicated in personal narratives.

### *Connecting Personal Experience with Dominant Discourse*

Over the last fifty years scholars in philosophy and social science have offered theoretical approaches aimed at conceptualizing health and illness in society by looking at systems of care or personal experience (Foucault, 1965, 2009; Freidson, 1988; Goffman, 1961; Kleinman, 1988a; Parsons, 1951; Svenaeus, 2000). These approaches have focused on the social structures or systems that serve the sick such as structure-functionalism (Parsons, 1951), or the personal and social experiences of “being-in-the-world” with illness, such as phenomenology and hermeneutics (Gadamer, 1996; Heidegger, 2010), as well as the power of institutions to influence and control how illness—including mental illness—is understood and treated in society (Foucault, 1965; Goffman, 1961). In these works the focus is on the structure, function, and development of social systems, and how these systems are configured to address illness in society.

Consequently, Kleinman (1988a) points out that due to a focus on systems of medical practice and health care delivery less attention is paid to what illness means or how meaning about illness is challenged or changed in discourse. He explains the dominance of medical perspectives also “turns the gaze of the clinician, along with the attention of patients and families, away from decoding the salient meanings of illness for them, which interferes with the recognition of disturbing but potentially treatable problems in their life world” (p. 9). Because

medical discourse provides the most readily acceptable discourse it is drawn on to construct, understand and explain the unexplainable. However, Westerbeek and Mutsaers (2008) point out in the case of mental illness when “the medical story of a chemical imbalance is not enough: it is the personal narrative that can create such an understanding” by providing lifeworld meaning and values (p. 48).

In this thesis I contend that a theoretical and methodological inquiry into how narratives work in discourse, and more broadly how this manages medicalization, requires that attention be given to individually storied experiences *and* dominant system discourses. It involves recognizing the interplay of a number of social discourses and consideration of how people manage these discourses to give them meaning for themselves and for others. As Lupton (2003) explains people draw on a variety of discourses to give meaning to their experiences.

Giving meaning to illness experience involves drawing on a range of dominant discourses and cultural resources, including those from folk knowledges about the body and illness, as well as expert discourses originating from biomedicine and alternative medicine and those circulating in the mass media. People draw selectively on these sources in making sense of illness. They often choose narrative as a means of organizing their experiences, giving them meaning and representing them to others. (Lupton, 2003, p. 84).

People draw on various discourses and integrate and shape them to fit with personal experiences and in this way narratives are active practices that can influence dominant discourses, which results in new meanings and changes in discourse and society. According to Jorgensen and Phillips (2002) people “select elements from different discourses which they may draw from mass mediated and interpersonal communication. This may result in new hybrid discourses. Through producing new discourses in this way, people function as agents of discursive and cultural change” (p. 17). Additionally Stone-Mediatore (2003) points out narratives bring light to

previously unspoken ways of knowing and understanding socially marginalized experiences that usually remain in the background of fixed dominant discourses. To characterize the influence of narratives in discourse involves a close look at the workings and environments implicated in story practices, and how these relate to dominant discourses.

Souto-Manning (2014) suggests to understand how people make sense of and contribute to shifts in meaning it is important to examine the influence of both sides of the so called discursive equation—the dominant discourse and the individual narrative. Attending to both offers a glimpse into how institutional or dominant discourses are taken up, re-worked, and given new meaning, which is then re-worked back into broad social discourse (Souto-Manning, 2014) According to Souto-Manning (2014) “a discourse is only powerful when it is recycled in stories everyday people tell” (p. 163). An assessment of institutional or dominant discourses without analysis of how they are reproduced in everyday stories provides only half of the story. Although such an analysis examines the influence of institutional discourse in society, it does not account for how these discourses circulate in everyday talk and text, or how they are altered or influenced as they are given meaning in personal stories. To gain understanding of how personal narratives engage with dominant discourse and how this manages the development of the dominant discourse requires methodological tools that have analytic flexibility to attend to narratives and dominant discourses, alternately considering their influence on one another. To that end I use a methodological approach by Gubrium and Holstein (2009) called Narrative Ethnography, which is introduced in the next section.

## **Methodological Approach**

Narrative research explains the social function, form and presence of stories in everyday life. It offers descriptions of stories in terms of their form or structure, the perspective or points-of view they express, and the relationships and contexts they signify or describe (Davis, 2002). Narrative is taken up as a phenomenon of study, as a method of analysis, or both. Its appeal is a focus on lived experience, recognition of past, present and future contexts, and how it brings together personal and social discourse (Clandinin & Rosiek, 2007). This variety of dimensions make narrative analysis a most fitting way to research the ways medicalization is managed in personal stories.

When it comes to understanding and exploring personal experiences and discourse a narrative approach is particularly pertinent. Narrative inquiries are used to describe how people make sense of illness (Charmaz, 1983; Frank, 1995; Hyden, 1997) and how social and cultural understandings of illness are constructed (Garro & Mattingly, 2000). First-person accounts are “especially viable instruments for social negotiation” and as such they are powerful vehicles for demonstrating how people navigate a variety of social contexts (Bruner, 1990, p. 25). According to Clandinin and Rosiek (2007) narrative inquiry falls somewhere between critical theory and post-structuralism. They explain it is a method that highlights how people are situated in discourse by examining the ways they story their experiences.

Concern about the way broad systems of social oppression obscure people’s ability to see their own participation in those systems inspires a search for language that can express ambivalence about insights that arise from within stories as lived, without completely discounting first-person experience as a source of important knowledge. (Clandinin & Rosiek, 2007, p. 66).

A narrative approach embraces variety and ambivalence in discourse by centralizing personal experience and examining it as situated, yet fluid, knowledge. Stories are examined as they are taken up and circulate publicly to see how they are transformed and translated to fit the dominant discourses. While this highlights the influence of dominant discourse on personal accounts, it also indicates narratives can be examined for the work they do in discourse as sites where meaning is negotiated. It of equal interest and importance to examine the characteristics and workings of personal narratives for how they manage discourse, and what effect this has on colonizing forces such as medicalization.

In this thesis I needed a methodology that would help me see the way narratives are invoked in dominant discourse, and also an approach that would allow me to closely follow what happens in stories as they work to construct and convey meaning between experience and discourse. I used Narrative Ethnography (Gubrium & Holstein, 2009). Drawing from a number of qualitative methodologies including phenomenology, ethnomethodology, and discourse analysis, narrative ethnography provides a way to attend to the relationships between various levels and forms of discourse. This methodology defines narratives as a practice in discourse, and examines the narrative work and the narrative environments involved as people construct meaning in their storied accounts of experience.

Gubrium and Holstein (2009) explain, narrative ethnography “is a method with sufficient alacrity not only to take note of the substantive dimensions of accounts, but also to document the accounting process in the various circumstances that shape it” (p. 17). To accomplish this the methodology involves two complementary analytic tasks. The first is to focus on the “internal organization of stories” by examining the character, content, and form of stories, and the second is to use an ethnographic approach to hone in on the “process of storytelling” (Gubrium &

Holstein, 2009, p. 7 & 21). This approach forms an “analytics of interpretive practice”, which accounts for what is said in a story, how it is said, and the contexts about which (and in which) a story is told (Gubrium & Holstein, 2009, p. 96). The analysis highlights thematic contexts and issues by viewing extended networks of stories that circulate around a particular person, topic or experience. The appeal of this methodology is that analysis is done “with an eye to the consequences for the storyteller of storying experience in particular ways” (Gubrium & Holstein, 2009, p. 21). Using narrative ethnography I examine how medicalization is managed in personal narratives as people make meaningful connections between their experience and discourse about mental illness, using the narratives strategies of resisting, re-informing, and reinforcing this discourse.

### **Outline of Thesis Chapters**

My examination of personal narratives and my analysis of the ways people connect their experience with discourse, and how this manages medicalization begins with a review of the broad and growing literature on personal narratives and madness. In **Chapter 2** I identify three areas that relate most directly to this study. Beginning with social science literature I describe a range of studies that draw on concepts from the field of illness narratives to identify characteristic narrative types and themes, narrative context and construction, narrative identity and recovery, and consumer-survivor literature. The second section of the chapter reviews medical literature and describes how medicine draws on personal narratives to enhance medical approaches and supplement medical education. The third section of the chapter outlines literary studies that examine autobiographical accounts of madness as a genre of writing, and as a centralizing point for understanding human experience.

Evident throughout the literature is the idea that narratives are a bridge between professional and lay communities. Although this is a common metaphor there is little in the literature to indicate what or how narratives are a bridge connecting these communities, moreover, there is little empirical focus on what this bridging accomplishes. I use this metaphor to develop a concept for my analysis that I call *narrative bridging*. With this concept I refer to the ways people connect their personal experiences with discourse about mental illness using three *narrative strategies* which include *resisting*, *re-informing*, and *reinforcing* these same discourses.

In **Chapter 3** I describe two theories that centralize the study of discourse in society and provide a framework for understanding relationships between social systems and lived experience based on communication. In the Theory of Communicative Action, Habermas's (1987) conceptualization of the relationships between lifeworld and system and the development of colonization is an ideal framework for considering how personal experience expressed in stories connects to broader social discourse. The idea that communication in the public sphere is motivated by a search for consensus helps explain how, and perhaps why people story their experiences using discourses they wish to resist or re-inform. Habermas's (1987) explanation of the differences between communicative imperatives that emerge from lifeworld and those that are used by system, is significant for examining when and how people use stories to resist, re-inform, and reinforce discourse about mental illness. With the Social Theory of Discourse Fairclough (1992) describes the "constructive effects of discourse" and three related and interactive functions of language to show how everyday discourse influences social change (p. 64). The theory is significant for this thesis because it suggests everyday language use both reproduces existing social systems and transforms them. Fairclough (1992) explains it is through

discourse that we construct identity, relationships, and social belief systems, and he outlines the effects of discourse on these dimensions as they relate to “three functions of language and dimensions of meaning” (p. 64). Both theories provide ways to explain how discourse and language work as a communicative connection or bridge linking lifeworld experience with dominant discourses.

**Chapter 4** discusses Gubrium and Holstein’s (2009) methodology called Narrative Ethnography, which is used to examine personal narratives collected from the websites. This methodological approach conceives of narratives as a practice in discourse, and involves critical analysis of narrative contexts and narrative practices people use as they tell their stories (Gubrium & Holstein, 2009; Holstein & Gubrium, 2000). Drawing together ethnomethodology and critical discourse analysis, the methodology involves analytically bracketing either everyday narratives to consider how meaning is constructed, or the dominant system discourses to consider what influence they have in society. In my analysis I use this approach to set out the relationships between the narrative contexts people refer to in their stories and the narrative work they do to connect their experiences with dominant discourse. Chapter 4 also includes a description of the methods used to collect and analyze narratives for this thesis.

**Chapters 5, 6, and 7** present my analyses of a selection of personal narratives collected from the websites. Each chapter presents a major narrative theme evident in the stories and within these themes I describe how people connect their personal experiences with discourse about mental illness by a practice of narrative bridging.

In **Chapter 5** I examine and analyze narratives about what it’s like being a patient. The narratives in this chapter describe peoples’ experiences with diagnosis, medications and hospital treatment. In order to connect their experiences with discourse about mental illness in



meaningful ways people invoke their roles as patients. As a result they substantiate claims for and against medical practices thereby resisting and re-informing discourse about mental illness. However, in doing so they call on medical discourse thereby also keeping attention focused in the medical sphere, so while narratives provide experiential knowledge that re-informs medical discourse they also reinforce medicalization.

In **Chapter 6** my analysis focuses on stories people tell about the relevance of their relationships with family and friends, relationships in the workplace, and relationships with the health system. The narratives in this chapter demonstrate how people connect their experiences to discourse about mental illness and make them meaningful by drawing on and emphasizing contexts outside of medicine. These narratives indicate medicalization is managed as people describe experiences outside of medical contexts, because to resist and re-inform discourse about mental illness they invoke roles which are challenging to fulfill without some form of medical or social support. Additionally, the descriptions people give of the influence of their relationships expands the medical gaze further into the public sphere and lifeworld.

In **Chapter 7** I examine narratives about recovery that describe how people take personal action to shift away from medicalized constructions of their experiences. In these narratives people re-define medical discourse and re-inform approaches to mental illness by describing how they made lifestyle changes, and benefited from the support of a peer community. Stories about personal meanings of recovery indicate people make direct efforts to reclaim medicalized constructions of madness. They do so by challenging medical language used to construct meaning about madness as mental illness, by asserting recovery practices outside of medical approaches, and by highlighting the value of peers and developing a discourse community that resists and re-informs medical approaches. Even as these stories encourage shifts away from

medicalized discourse they can be seen to encourage greater inclusion of personal narratives in medical discourse. Narratives about why recovery is personal redefine medicalized constructions of madness and are supported by consumer/survivor discourse which positions people as active participants in the construction of meanings about madness, rather than passive subjects within discourse about mental illness. However, this places responsibility for outcomes of care on individuals, increasing the likelihood that problems with the medical system and medicalization will be attributed to consumer/survivors rather than the medical community (Tomes, 2007).

In **Chapter 8** I consider the significance of addressing the medicalization of madness by discussing the main implications of the thesis as it relates to understanding and approaching the study of personal narratives, medicalization, and madness. I describe implications for theory and methodology, and implications for the study of narrative as a contributor to social change. I outline the limitations of my study and future considerations for the study of personal narratives and madness.

Overall in this thesis I am asserting that the work of integrating and negotiating meaning between lifeworld experience and system discourse happens in personal stories. From my analysis of personal narratives I conclude that although madness continues to be medicalized, personal narratives are central to shaping and influencing this process because personal stories bridge meaning between lifeworld experience and dominant system discourses by resisting, re-informing, and reinforcing dominant discourse. It would be of interest for future studies to map out other ways personal narratives accomplish narrative bridging in other contexts and what this achieves in society, and for people who share their personal stories online.

## CHAPTER 2 LITERATURE REVIEW

### Personal Narratives about Madness

The literature about personal narratives and madness overlaps and integrates a number of scholarly disciplines that have all had historic influence on how madness is understood in society today. This chapter reviews studies drawn from three areas of literature including social sciences, medicine, and literary studies. This thesis is situated within social science literature and is most closely aligned with social science studies in the areas of narrative identity and recovery, and narrative context and construction. From social science literature I gain insight regarding the character of madness narratives, what people do with their stories, and what this accomplishes for them in society as they make sense of their experiences of mental illness. However, in this literature I do not find any direct empirical studies that focus on how connections between individual personal narratives and broad social system discourses work, or how and what these connections may accomplish with regard to medicalization. Studies in medical literature highlight that narratives are useful for informing and enhancing medical knowledge, indicating they have presence and influence in medical discourse, yet narratives are viewed as data for improving medical approaches and not for how they connect to social discourses or manage medical discourse. Literary studies examine narratives on a broader scale with interest in how culture, history, and other societal forces are expressed in literary forms such as autobiographies and fictional accounts of madness, but this literature does not address how narratives work in everyday discourse or what they do to manage dominant discourses.

Each of these three bodies of literature offers insight about narratives and madness, either on a broad scale or individually, but I do not see a study that specifically connects how narratives work in everyday practice and how this influences or shapes discourse on a broad scale. I aim to

do this with this thesis. From these three bodies of literature I draw insight for my analysis of the narratives strategies people use to make meaningful connections between their experiences and the dominant discourses that have rationalized and shaped these experiences. My objective with this thesis is to look at how medicalization is managed in personal narratives as people bridge meaning between their experiences and dominant discourse about mental illness, by resisting, re-informing, and reinforcing these same discourses.

*Outline of the literature review: Narrative as a bridge*

During my review of the literature I became intrigued by the broad use of a metaphor that refers to narratives as a bridge. The metaphor appears in all three bodies of literature, however I was surprised to find there are no studies (to my knowledge) exploring what exactly narratives bridge, how this is accomplished, and why. Generally across the three areas of literature personal narratives are described as a bridge, assumedly for connecting lay and expert communities. In my review I find a common assertion that personal stories are a bridge that can offer insight into the experience of mental illness, and further that the inclusion and integration of peoples' stories can enhance and improve understandings and practices of care for mental illness. However, how this works in practice, and what consequences this has is not evident in the literature I reviewed.

In what follows I review these bodies of literature paying close attention to how narratives about madness are studied and in what ways this literature implies they are a bridge. From my review I conclude there is an opportunity to study what it is that personal narratives bridge, how it works in practice, and why it is relevant for an analysis of how narratives manage medicalization. My analysis of personal narratives (presented in Chapters 5, 6, and 7) demonstrates narratives bridge meaning between experience and discourse as people resist, re-

inform, and reinforce discourse about mental illness in their stories. I argue that by bridging meaning between experience and discourse, personal narratives manage medicalization and direct and shape the course of its development. Overall the literature reviewed in this chapter demonstrates although personal narratives are referred to as a bridge, to date there is little (or no) discussion connecting how this works in practice, what it accomplishes, or why it is important.

I begin the chapter with a review of the ways personal narratives, madness, and mental illness are approached in social sciences literature. I identify and delineate four areas in social science literature including 1) narrative identity, recovery and sense-making, 2) narrative context and construction, 3) narrative types and themes, and 4) narrative and consumer-survivor literature. Social science literature is most relevant to this study because it includes research on how people make sense of traumatic or challenging personal experiences, and what this accomplishes for individuals. What I do not find is an empirical study of how personal narratives work—in content, organization, type, theme, or identity management—to connect to or influence broad societal or system discourses with regard to medicalization. Generally literature focuses on how social, historical, and cultural forces influence discourse about madness and mental illness, and consequently has influence on peoples' experiences, or it examines the ways people use narratives to manage personal experiences. However, less evident in the literature is a study that is positioned between the two with an approach that looks at how system discourses about mental illness are invoked and engaged with and in personal narratives.

In the second section of this chapter I review the way narratives about mental illness are examined in medicine. Here I find that personal narratives are studied as sources of information to enhance and improve medical education, and clinical approaches in psychiatry and therapy. This literature emphasizes the value of personal narratives and takes up or integrates (co-opts)

the content of narratives into medical discourse. In this literature the bridge metaphor is evidently used to refer to the relationship between the lay-patient community and the professional-expert medical community. Narratives are valued because they provide information that can be incorporated and translated into medical discourse and support efforts to improve clinical treatment. But the narratives are not studied for how they manage or directly influence medical discourse rather they are looked at as a form of data to be interpreted medically. As I show in Chapter 5 of my analysis, medical discourse is itself managed in everyday discourse as people share personal narratives.

The final section of this chapter is where I discuss the way personal narratives are considered most broadly as providers of insight into human experience, and as a bridge or vector where cultural, social, and historic forces meet. Literary studies of madness narratives have the longest history of the three areas of literature reviewed in this chapter, and in some regards provided initial insights into the value of studying personal narratives as a way to understand madness, society and humanity. My review describes how the study of literary works about madness continues to shed light on broad social issues, but do not specifically examine what or how narratives work as a bridge.

### **Social Science Literature and Personal Narratives about Madness**

The study of narratives as resources in social sciences literature is most relevant for this thesis. These studies most inform my approach to studying how medicalization is managed in personal narratives. In these studies there is a close focus on how narratives work and what they do for individuals, such as manage identity and make sense of mental illness. With its focus on what stories accomplish in discourse and what people do in (and with) narratives to manage their

individual identity or the contexts in which they find themselves, this body of literature offers an excellent starting point for considering how medicalization is managed in personal narratives. With this literature I am most able to theorize how people narratively bridge meaning between their experience and dominant discourse about mental illness by resisting, re-informing, and reinforcing these same discourses in their stories.

Social science literature emphasizes the content, types, and construction of individual narratives about madness and relates this to how individuals manage identity and their individual experiences in the health system and in society generally, however, less has been said about how personal narratives manage or influence dominant system discourse about madness. This is not to say that social science studies do not recognize or promote narratives as a way to make sense of discourse, it is just that to my knowledge no one has looked at the specific ways this happens (or what happens specifically) in individual accounts, and how this influences meaning about mental illness or manages system discourse, and colonizing influences such as medicalization.

Social science literature examines personal narratives for the ways people make sense of their experiences of madness. Unlike literary and medical approaches studies of narrative in the social sciences view narratives as both a form of discursive practice and a product of social interaction or resource for understanding lived experience (Taylor, 2006). DeFina and Georgakopoulou (2008) provide a definition of the difference between analysis of narrative as a resource and analysis of narrative as a social practice. They explain analyzing narratives as resources involves focusing on structure, temporality, and organization and emphasizing that stories are a “fundamental mode for constructing realities” (DeFina & Georgakopoulou, 2008, p. 380). On the other hand, analysis of narratives as a social or discursive practice involves focusing on the contexts and construction of stories.

As such narratives are analyzed as,

...dynamic and evolving responses to recurring rhetorical situations, as resources more or less strategically and agentively drawn upon, negotiated and reconstructed anew in local contexts. Emphasis is also on the strategies that speakers use to deal with the gap between what may be expected (e.g. generic representations) and what is actually being done in specific instances of communication. (DeFina & Georgakopoulou, 2008, p. 383)

This distinction is significant for an analysis of how personal narratives manage medicalization because it supports the idea that narratives bridge meaning. First, viewed as resources narratives are studied for the meanings they construct or represent in discourse and as such they can be analyzed for their content or form and how this influences or gives meaning to madness. Second, recognizing narratives as discursive practices highlights the active and influential character of narratives in discourse and encourages analysis of the ways narratives work in society and what people do in their stories, to convey meaning, such as what strategies come into play as people negotiate identity or draw on other discourse to make sense of their experience to themselves and others. In the next section I review literature that is most relevant to my thinking about how personal narratives manage medicalization. In the literature about narrative identity, recovery, and sense-making personal narratives are analyzed as a discursive practice that accomplishes things for individuals in discourse, and also as a source of information (a resource) that provides insight into issues about mental illness.

### *Narrative Identity, Recovery, and Sense-Making*

Research that explores the ways narrative is involved in accomplishing or managing identity, recovery, and sense-making comes closest to indicating that personal narratives bridge experiential and medical knowledge. Viewing narratives as a resource and a practice gives this



area of narrative study the most flexibility to address questions about the strategies people use in their stories as they manage dominant discourses about madness. Generally these studies recognize personal narratives as an active and intentioned practice in discourse and appreciate what they accomplish. Roberts (2000) explains, “stories give cognitive and emotional significance to experience, they are a means of constructing and negotiating a social identity, and give moral weight to and existential significance to actions and events” (p. 434). Understanding the relationships between personal experience and social and medical discourse about mental illness requires attention be given to these points, and to the ways people draw on various discourses to construct identity as they manage said discourses.

Studies about narrative identity, recovery and sense-making draw on a broader body of research about chronic illness that suggests people who experience a “biographical disruption” caused by the onset of chronic illness such as rheumatoid arthritis, face the task of re-constructing identity to include illness experiences (Bury, 1982). Notwithstanding the evident differences between chronic physical illnesses and experiences of mental illness, the underlying idea is that both situations involve some form of identity management of what has been referred to by Goffman (1963) as “spoiled identity”.

Personal narratives are foundational in the management of identity, whether this involves talking about intimately personal experiences in close relationships, participating in everyday conversations, or sharing stories in support of movements for social change. The ongoing work of constructing, maintaining, and managing identity is both a public and a private affair as people attempt to “establish coherent connections among life events” (Gergen & Gergen, 1983, p. 255). However, traditional medical and psychiatric approaches have long asserted people who are diagnosed or labelled with psychiatric disabilities, particularly severe mental illnesses struggle

to, or are unable to, present a coherent narrative regarding their lives or identity. Despite discussion and analysis to the contrary these views are still evident in the literature (Raffard et al., 2010).

The growing number of studies of narrative identity, recovery and sense-making in the social sciences literature is providing increasing evidence that narratives are essential to recovery, and to redefining recovery in mental illness. In an empirical analysis of narratives using various psychological scales and clinical ratings, Lysaker, Ringer, Maxwell, McGuire, and Lecomte (2010) conclude “personal narratives may be a unique domain of recovery, one which is relevant to wellness in daily life” (p. 275). McAdams and McLean (2013) highlight two major themes across the literature on narrative identity including development of identity and adaptation of identity. They describe an emphasis in the literature regarding the importance of identity construction throughout life, and suggest people who find meaning in adapting and reconstructing their stories throughout their lives enjoy better psychological well-being. According to McAdams and McLean (2013) “narrators who find redemptive meanings in suffering and adversity, and who construct life stories that feature themes of personal agency and exploration, tend to enjoy higher levels of mental health, well-being, and maturity” (p. 233), which has particular significance for people who identify as having experiences of mental and emotional distress.

Roe and Davidson (2005) challenge the negative views about schizophrenia that suggest people lose their sense of self and the ability to construct a coherent narrative about their lives. They present an analysis of personal narratives about schizophrenia and develop five thematic categories that describe the process people move through in identity construction and sense-making. The categories include narratives where people talked about themselves as having a

“healthy self “and an “ill self”, to narratives that integrated health and illness and led to empowerment (Roe & Davidson, 2005, p. 92). Roe and Davidson (2005) advocate the process of narrative identity construction is a positive one and “to facilitate this process, we suggest focusing on the person’s active efforts to regain and strengthen an effective sense of self and coherent life narrative rather than dwelling on the fact that these have been lost to illness” (p. 93). The significance of this for people who experience mental distress or have been labelled with psychiatric disabilities is highlighted throughout social science literature in studies where personal narratives are viewed as a positive resource for understanding identity, recovery and sense-making.

Wisdom, Bruce, Saedi, Weis, and Green (2008) reviewed and analyzed published personal accounts about mental illness and describe five common themes or dimensions evident in the stories with regard to identity and recovery. In their stories people wrote about a “loss of self”, a “duality of self” that included both a well self and an ill self, they wrote about “perceptions of normality”, “specific concerns about parenting and identity”, and wrote about “hope and reconciliation”. Wisdom et al. (2008) point out in their stories people demonstrate efforts to make sense of their experiences and to manage changes in their sense of self and often these efforts take place in negative contexts that are less than conducive to the construction of a positive identity. They note, “individuals’ self-perceptions and sense of optimism can also be affected by interactions and feedback from others, such as family, and by available role models, including those available in published accounts” (Wisdom et al., 2008, p. 490). They suggest the presence of positive and hopeful narratives about recovery will provide a stronger and more efficacious narrative resources for others to follow (Wisdom et al., 2008).

The best way to understand narratives as a resource for others requires recognizing recovery

as a process rather than a goal. In a study of recovery narratives, Jacobson (2001) explains there is a difference between traditional views of recovery that view it as an objective outcome, and subjective views of recovery that view it as a process. She identifies four dimensions involved in the process of recovery based on analysis of thirty published autobiographies about mental illness. Jacobson's (2001) analysis indicates recovery narratives are structured around a specific problem, and may involve "subdimensions" of "*cause, effects, and solution*" (p. 251; emphasis in original). Narratives about self, others, and the health system serve as explanatory models, and according to Jacobson (2001) "the problem" is the narrative pivot around which stories of recovery are structured" (p. 251). The analysis of published narratives reveals a number of explanatory models people use when telling a story about recovery including whether the problem was explained as biological or environmental, whether people gave a spiritual or philosophical interpretation of the problem, and whether they took a political view that incorporated their experiences with the health system.

Overall, Jacobson (2001) points out "recovery is a process of integrating illness into the self-concept" and when viewed in the process of storytelling it can reveal the unique ways people manage their identities and make-sense of their experiences in view of other discourses. This speaks to the ways personal narratives have influenced the ways recovery is thought about in society—as less emphasis is placed on being *recovered*, and we now speak of being *in recovery*. As this study indicates when viewed as a resource and a process, personal narratives about mental illness are influenced by other discourses, but more significantly they influence discourse by the ways they re-inform or re-define traditional concepts such as recovery in new ways.

Schneider (2003) highlights the skillful ways people construct their identity in order to manage the consequences of being categorized as someone with mental illness. According to

Schneider (2003) it is challenging for people to construct a positive identity outside of or away from the category of mental illness once they are diagnosed. She explains denial of mental illness is a “dangerous option” and if people “are to mitigate the negative consequences of membership in the category, they must accomplish this with the utmost delicacy” (Schneider, 2003, p. 185). To construct a positive identity people use three strategies including “distancing”, “rejecting”, and “normalizing” (Schneider, 2003). Distancing refers to the ways people deny association with the category by indicating they do not have characteristics defined by the category, or do not have the same characteristics as other people in the category (Schneider, 2003). Rejecting occurs when people deny their behaviour in particular circumstances is due to or a result of mental illness (Schneider, 2003). With the strategy of normalizing people point out that certain characteristics defined as part of mental illness are also present in people who are not identified as having mental illness (Schneider, 2003). Employing these strategies people manage their identity in ways that reduce the negative consequences of being characterized by membership in the medical category of mental illness (Schneider, 2003). This study of narratives exemplifies the manner in which narratives are active practices in discourse. Drawn on as a resource, the narratives Schneider (2003) analyzes are situated accounts with representative types of content and structure, but more significantly they are followed as resourcefully developed discursive practices aimed at managing negative consequences in order to accomplish a positive identity.

The assessment of narratives as resource and practice is present in a study by Cardano (2010) who followed the development of four personal stories to see how people use narrative to make sense of their experiences of mental illness. She refers to the “identity reconstruction process” as a balance between two contrasting points: “stigma” and “charisma” (Cardano, 2010, p. 269). There is notable diversity between the four narratives being analyzed the process by which the

people made sense of their experiences and reconstructed their identity is similar.

Carless and Douglas (2008) look at the ways other discourses can provide new opportunities for constructing identity in positive ways. Their analysis demonstrates how men who experience serious mental illness can construct positive identities when asked to talk about their experiences with sport and exercise. In their narratives the men constructed a positive identity that integrated mental illness experience and sport experience. The stories were characterized into three narrative types including “an action narrative”, “an achievement narrative”, and “a relationship narrative” (Carless & Douglas, 2008). This study indicates people draw on various narrative and discursive resources as they tell their stories, and more significantly it suggests that sharing a story about madness involves artfully managing a number of discourses.

Estroff et al. (1991) explore the relationship between general discourses about mental illness and the construction of personal narratives about mental illness. They point out as people draw on social and medical discourse about mental illness to self-label they also work to normalize their identity in their narratives. They explain the “analysis of illness-identity and normalizing talk has revealed a wide array of individual strategies and experiences that persons diagnosed with psychiatric disorders invoke from numerous domains to account for their symptoms, hospitalization, and diagnosis” (Estroff et al., 1991, p. 361). These findings on identity work encourage a closer look at what strategies are in play as people manage discourse in other areas, how this works and what implications it has for bridging experiential and medical knowledge.

Venhaus (2009) examines personal narratives as a resource for understanding how the stigma of mental illness influences the identity and sense-of-self of people living in rural areas. She describes how people in rural settings attribute experiences to childhood trauma rather than genetics and brain chemistry. The study indicates the stigma of mental illness overshadows the

sense of identity of members of a rural community and this is reflected in their narratives.

In their work on institutional identities, Gubrium and Holstein (2001) point out that the postmodern self is continuously navigating the demands of a deprivatised life across a “striking panorama of discursive environments” (p. 13). The social science literature on personal narratives and mental illness includes studies that examine strategies in discourse that are specific to particular circumstances and contexts. One area of study looks at narratives as resources in health and social care organizations and institutions and what is involved when people face demands of these facilities to receive assistance (M. Chase, Zinken, Costall, Watts, & Priebe, 2010; Nelson, Lord, & Ochocka, 2001; Schneider, 2010). These studies show how personal narratives are involved, integrated and managed to fit organizational discourses and policies in order to facilitate acceptance into, or rejection from an organization. In these studies, the focus is on the discourse of particular settings and forms of talk that have direct implications and consequences. These studies indicate narratives are invoked and shaped when organizational imperatives are in play, and indicate narratives are used as resources to bridge and connect personal experience and medical perspectives in institutional discourse.

Marvasti (2002) describes how service-users and intake officers at a homeless shelter co-construct “organizationally useful accounts of homelessness” to facilitate the process of accepting people into the shelter (p. 616). Employing Holstein and Gubrium’s (2000) concept of “narrative editing” Marvasti (2002) analyzes the ways staff and clients engage in discourse. Personal narratives are shaped through “collaborative editing”, “directive editing”, “confrontational editing”, and “dismissive editing” into “locally sensible” and “organizationally useful” accounts (Marvasti, 2002). Showing how narrative encounters involve co-construction of meaningful and consequential circumstances the study signals the importance of understanding

narrative strategies people use to manage demands of medical and social care systems.

### *Narrative Context and Construction*

Narrative construction and narrative context are less developed in studies of personal narratives about madness but Hornstein (2002) points out “narratives show us how the context of mental illness can be as important as any “defect” or disease” category (p. B7). Generally, the literature about narrative construction examines the ways stories are structured and how they are organized such that their development, along a particular plotline, is recognizable as a story. Stories develop in keeping with social and cultural norms of storytelling. Analyses of narrative construction examine how people draw upon broad social and cultural discourses to inform the content and the development of their stories. Whereas studies of narrative context focus on the influence that social situations and discourses have on stories.

What seems to be a paucity of studies on the construction and contexts of mental illness stories may be due to the position and claims that people are trying to make with their stories. Considerable focus on the content of mental illness narratives has the immediate effect of giving voice to problematic situations in mental health care and social attitudes. Addressing these issues is of primary concern. Presenting alternative characterizations of mental illness can be accomplished by looking at story content and the way it represents shared experiences, such as trauma and mental illness. Narrative content can be studied in order to identify new approaches and ideas about mental illness, and narrative content can be drawn upon to challenge negative situations. Social sciences literature that explores the construction and context of narratives goes beneath the content to find out what influences the way stories are told in relation to broader discourses. As Johnstone (2004) explains exploring the “uses of narrative in human life, we are



paying increasing attention to the political effects of narrative, seeing storytelling not only as a way of creating community but as a resource for dominating others, for expressing solidarity, for resistance and conflict; a resource, that is, in the continuing negotiation through which humans create language and society and self as they talk and act (Johnstone, 2004). In social sciences literature personal narratives are a resource that can be drawn upon for directing attention to what stories tell us, and more significantly to why that content is presented in the manner it is.

The influence of context on story construction is neatly developed in a narrative study of Gulf War Syndrome (GWS). Cohn, Dyson, and Wessely (2008) describe how upon returning from the Gulf War in the 1990s, military personnel began to describe physical and psychological suffering such as “fatigue, muscle pain, memory loss, headaches and insomnia” (p. 1642). At first, cases were reported only in the USA and the UK, and these were eventually followed by cases arising in Canada, Denmark, Australia and France (Cohn et al., 2008). The medical community recognized GWS as an illness and defined it as a psychological disorder, a type of Post Traumatic Stress Disorder (PTSD). The lay community however, attributed the aetiology of GWS to a variety of causes including exposure chemicals, toxins, vaccinations and various environmental factors during the conflict. Increasingly, people who served during the Gulf War began to fear this “possible health threat” and “perceive their own health and body differently” (Cohn et al., 2008, p. 1642). Discussing how illness narratives develop, Bury (2001) points out “patients would frequently discuss the onset of the condition with respect to the possible effects of events occurring at the time of onset, yet leave themselves open to more strictly medical explanations as well” (p. 269).

The discourse about causes of GWS became a complex mix of rumour, medical explanation, and personal experience. According to Cohn et al. (2008) fear and rumour became a

“significant causal agent and vector for its transmission” (p. 1642). The lack of clarity regarding the aetiology of GWS became linked to a broader uncertainty regarding how military personnel interpreted their role in the conflict. The secrecy and obfuscation historically inherent in military hierarchy and authority plus the uncertainty of illness experiences became intertwined and are evident in the illness narratives told about GWS (Cohn et al., 2008). In time, it was suggested that GWS was part of a conspiracy and “all ‘official’ medical research that fails to confirm a biological basis must also be part of the cover-up” (Cohn et al., 2008, p. 1642). Studying the development of stories about GWS demonstrates how influential context can be on construction of narratives, particularly when there are no clear medical explanations. “The constant flow of rumours and anxieties, provided not merely the context out of which individual narratives would eventually transpire, but actually shaped the way they would be constituted and the meaning they would contain” (Cohn et al., 2008, p. 1642). Narrative studies of construction and context show “how active, constructive, and selective is the process of making sense of illness, in which ideas from a variety of sources are drawn upon and reworked” (Fitzpatrick, 1989, p. 261). Following the context and construction of personal narratives between the lay community and the medical community may offer explanations about the development of certain experiences.

Narrative studies that include discussion of a substantive topic and its relations to construction or context show just how influential context can be on personal narratives. Garro and Mattingly (2000) remind us “narrative realities are vulnerable to social influence” (p. 264). For example, Harden (2005) explores the context of parenting with relation to the themes that emerge in the stories told by parents whose children were experiencing “mental health problems” (p. 351). “Three dimensions of responsibility” emerged in the study. These dimensions include “moral,” “causal,” and “for self” (Harden, 2005, p. 351). The themes are explored as more than

representative content. They are considered in terms of the influence of context on “dimensions of responsibility” (Harden, 2005). The most influential context is represented in the role expectations of parents as the ultimate care providers for their children. Concern for the mental health of their children, these parents invoked broader social discourses about parenting and judged themselves according to normative constructions of what it means to be good parents.

Harden (2005) discusses the challenges that this creates.

Parents describe the difficulties they faced in attending to this responsibility in relation to their lack of knowledge and experience; the shared responsibility of care with healthcare professionals; the pressures of their extended parenting role on their own health and wellbeing; and the pressures on their relationships. (Harden, 2005, p. 367).

Taking responsibility is complicated by a child’s illness, where a normative social expectation of parenting is troubled by the medical contexts in which they must participate. The study concludes with a call to recognize the importance of the contexts in studies about mental illness. Narrative studies that attend to contexts and “problematize intersections between individual life stories and larger historical dynamics offer the most significant contributions” for developing relationships between the lay community and the medical community (Maynes, Pierce, & Laslett, 2008, p. 45).

Understanding cultural differences in stories, perceptions and responses to mental illness have been studied for some time (Kleinman, 1988d, 2009; Mattingly & Garro, 2000). These studies consider the value of incorporating and learning from other cultures. However, there is growing concern that cultural approaches and ideas about mental illness are increasingly influenced by North American (Western) approaches (Kleinman, 1988d; Watters, 2010). A unique narrative study about early intervention in psychosis shows just how influential the

Western approach to mental illness can be. The study followed the life narrative of a young woman who had immigrated to the United States. She was well educated and had a career as a computer scientist. Over the course of five years she had experienced symptoms of mental illness, but had not sought out psychiatric care until many years after her initial experiences. Her story offered a unique opportunity for a clinical exploration of a rather lengthy “duration of untreated psychosis” (Tranulis, Park, Delano, & Good, 2009). Current clinical approaches to mental illness encourage early intervention as a factor that influences better prognosis.

Over the course of the interviews with clinical staff, Kuna and her husband learn to take up the medically defined version of her experiences. The interviews tell the story of how Kuna struggles to accept her experiences as illness, and her husband’s concern, shame and guilt for not having acted sooner to get her treatment. With medication Kuna got better. Soon after starting medication she and her husband were interviewed. One particular excerpt stands out as a turning point where contexts and construction collide. Kuna’s husband recalls,

“...she would take me to Starbucks and tell all these strange stories, and I’d been accustomed to the stories now for what, five years, and now I, you know, a part of me says when I go home, “What happened to all the stories?”

Tranulis et al. (2009) explain,

What was most evident in Kuna’s narrative, and also her husband’s, is the emotional significance and, in fact, the critical role that the literal space of the Starbucks and the figurative, shared space of the “storytelling” played in maintaining a stable and communicative marriage. (Tranulis et al., 2009, p. 620)

Kuna and her husband are central characters in a constellation of contexts. The challenge is to reconstruct their narrative to include new and familiar social contexts that may be at odds. Learning to talk about mental illness experiences in the context of Western medicine and receive

clinical care has helpful and harmful effects for the couple.

Stories of mental illness are compelling and narrators draw us in requesting recognition and seeking solace, but if stories are held apart from the contexts in which they are lived and told, their significance as calls for action or as discursive opportunities for personal change are lessened. Giving exclusive “attention to narrative means neglect of other crucially important features of cultural life and human experience” (Garro & Mattingly, 2000, p. 265). Zilber, Tuval-Mashiach, and Lieblich (2008) suggest analysis of narratives in context should involve close attention to three interrelated spheres including inter-subjective relations, the social field, and meta-narratives. The literature on narrative construction and narrative contexts supports (in principle) the idea that narratives bridge meaning between personal experience and discourse about mental illness. As the above studies show personal stories are often the first place where meanings about madness are negotiated, and where people come in contact dominant discourse and the meanings it ascribes to the experience of madness. With regard to viewing narratives as a bridge the literature on narrative context and construction highlights the ways connections are made between everyday narratives and broad social discourse. This literature offers insight into how social, historical, and cultural influences saturate and multiply the possible ways that personal stories of mental illness are told, and yet consideration of how meaning is bridged or what takes place in order for narratives to influence medicalization has not been addressed.

### *Narrative Types and Themes*

The idea of narrative types is drawn from the extensive literature on illness narratives in the area of chronic illness (Bury, 2001; Charmaz, 1983; M. Crossley, 1998; Frank, 1995; Haidet, Kroll, & Sharf, 2006; Harter, Japp, & Beck, 2005; Hyden, 1997; Hyden & Brockmeier, 2008;

Kleinman, 1988a, 1988d; Mattingly & Garro, 2000; Riessman, 1990, 1993; Sharf, 2009). In studies about chronic illness, particular types of stories are identified across groups of people who share similar illness experiences, such as cancer (Mathieson & Stam, 1995). The stories have similar content and structure and as such they become narrative resources that help others story their experiences. Studies of illness narratives contribute to understanding personal experience in context. They “humanise the practice of clinicians, and even society as a whole, by looking beyond the disease or the narrowly constructed clinical case to see the “patient as person”, one who experiences disease and inhabits a complex world” (Mattingly, 2004, p. 73).

Narrative types offer frameworks for defining and analyzing what stories are about and how this relates various contexts. Narratives described as performances or “healing dramas” play an essential role in health care (Mattingly, 2004). Examining the relationship between narratives and illness demonstrates what stories accomplish. Narratives may be explored “as illness,” and “about illness,” or can be redefined as “illness as narrative” (Hyden, 1997, p. 48). Narrative types describe how a person reflects on and develops his or her story. Bury (2001) framework includes “contingent narratives” that explain direct physical experiences, “moral narratives” that are evaluative, and core narratives that “account for events” and “give shape” to stories (p. 263). The most noted characterizations of types of illness narratives was developed by Frank (1995) whose work on “restitution, chaos, and quest narratives” continues to inform narrative approaches to research across disciplines including mental illness. Rutledge (2005) points out these types are helpful, but applying them directly to narratives about mental illness is challenging and requires consideration of the broader contextual models for understanding mental illness.

Studies of mental illness draw on the idea of narrative types to see if there are representative themes across personal accounts. Adame and Hornstein (2006) considered

whether “first-person accounts of emotional distress” had similarities to stories about physical illness or if they “constituted a new form” of narrative (p. 139). The study included ten published autobiographical accounts written between 1908 through 1995, which were analyzed in terms of “structure, voice, and purpose” (Adame & Hornstein, 2006, p. 143). From the analysis three narrative types were identified: “traumatic interruption,” “revelation/purposeful suffering,” and “continuity” experiences” (Adame & Hornstein, 2006, p. 143). The authors discuss potential directions for new research in light of their study. They suggest a sociolinguistic study that examines the detailed structure of language used, a comparison between mental and physical illness narratives, such as cancer or AIDS, and a cultural study of narratives of mental illness across various countries. Extending this list, it would also be important to examine narratives for the influence of social contexts and the position and interpretation of these narratives as historically situated with consideration to changing social, economic, and political climates. Additionally, it would be of interest to consider ways relationships between the consumer-survivors and the medical community is constructed in personal narratives, and further how the identification of types of mental illness narratives influence the way the two communities meet discursively regarding specific topics.

Exploring thematic content in personal narratives contributes to knowledge about the common qualities and character of experience and can highlight new views about mental illness. In a study that reviewed published and unpublished literature about first-person narratives Ridgway (2001) searched for narratives about recovery in mental illness. Using Mishler’s (1986) seminal approach to narrative analysis, Ridgway (2001) identifies a core theme in the area of recovery and describes eight common ways that it is expressed in personal stories. She explains recovery is storied as a real and positive possibility, which is in contrast to long-held beliefs

about mental illness as a chronic and life long illness requiring on-going medical treatment and custodial care. This conception of recovery is now a real consideration in discourse about mental illness and is re-informing approaches to mental illness. As Ridgway (2001) points out analysis of themes in personal narratives can “provide the mental health field with another means to respectfully listen to and learn from consumers” (p. 341). With further study the analysis of personal narratives may indicate how the medical community is taking up or responding to the theme of recovery in mental illness and how consumer-survivors are using these ideas to construct new views of mental illness.

Social science literature includes analysis of narrative themes pertaining to social care issues as well as medical ones. In a study of homelessness, Kirkpatrick and Byrne (2009) used Clandinin and Connelly’s (2000) concept of “metaphorical narrative inquiry space” to explore how people who had experienced mental illness, and who had been homeless talked about “moving on” and how they conceptualized the idea of “place”. The participants all shared the common experience of being part of a social program called HOMES (Kirkpatrick & Byrne, 2009). The objective of the study was to provide information and insight to nurses assisting people in the HOMES program. The narratives had a variety of plotlines but shared thematic similarity across a number of dimensions. The central theme was the importance of “place” and additional themes included “loss”, “moving on”, “on the move while homeless”, “the door as a metaphor for control”, and “getting the message out” to help others (Kirkpatrick & Byrne, 2009, p. 73). The identification of narrative themes in this study connects personal, social and medical aspects of homeless experience to enhance understanding between consumer-survivors using the service and the medical professionals managing the service.

In social science research, studying narratives for thematic qualities has led to the



development of conceptual frameworks. For example, the themes present across personal narratives are used as a resource to evaluate consumer-run organizations. Brown (2009) applied a pre-developed conceptual model to analyze the stories of seven members of a consumer-run organization in order to gauge how well the organization supported its membership. Using participant observation and semi-structured interviews life history narratives were constructed for seven members of the organization. “The interviews were minimally structured so informants could tell their stories in their own words and according to their own understanding of the experience” (Brown, 2009, p. 247). However, using collected observational and interview data the researcher not the participants constructed the life history narratives. The “principles of journalistic feature writing” guided the construction of the stories, which were developed chronologically, in a problem-and-solution framework, and story development was similar to a “narrative arc” in fictional stories (Brown, 2009, p. 248). Interview quotes were included as examples of an “insider’s” point-of-view and the participants were given an opportunity to review and edit the life history narrative (that had been created for them) for “accuracy of the narratives and theoretical conclusions” (Brown, 2009, p. 248). The fact that the researcher constructed the final versions of the consumer’s life story narratives is troubling.

An article by Baldwin (2005) addresses issues of ethics when researchers are “entrusted to be the co-authors of a person’s story” (p. 1024). He recommends that researchers be mindful of maintaining narrative continuity in stories, that they ensure people as much narrative agency in the process as possible, and be aware of “disabling master narratives” and encourage counter narratives. His final point is a reminder to pay close attention to the small, everyday stories people tell and not just focus on constructing broad life stories. Focusing on the content and construction of everyday, small stories may be more meaningful for people whose experiences

have been fragmented by illness experiences (Baldwin, 2005). He suggests research on life story narratives is focused on coherence, continuity and authenticity across a storyline, whereas researching small stories present in everyday text and talk involves attention to “fleeting and fragmented” presentations of experience. He asserts,

The skill required, therefore is the ability to recognize these small stories, in all their complexity, collecting them in different times and settings so that we can learn to understand how they contribute to the development and maintenance of the Self. (Baldwin, 2005, p. 1027)

Studies of narrative types and themes contribute much to understanding relationships between people and the organizations they interact with, and when considered together with studies of narrative contexts and construction, and the literature about narrative identity, recovery, and sense-making (as discussed above), a more comprehensive picture of how narratives work as a bridge begins to develop. In the next section I conclude the review of social science literature with a look at studies of narrative and mental distress presented by people who have been labelled with psychiatric disabilities and identify as ex-patients, consumers and psychiatric survivors. The experiential insights described in these narrative studies are also described as a connection of bridge for better understanding madness experience, but the focus is on identifying how stories can re-inform perceptions of madness from a consumer, survivor, or ex-patient perspective.

#### *Narrative and Consumer-Survivor-Ex-Patients*

Increasingly social science scholars and mental health professionals who have experienced being diagnosed and treated for mental illness are sharing their personal stories and exploring the ways they can re-inform knowledge and perceptions of madness (Bassman, 2001; Beresford,

2005; Church, 1995; Frese & Davis, 1997; Kottsieper, 2009; Perkins, 2007; A. C. Schiff, 2004). This is significant because it adds a unique perspective to understanding relationships between personal narratives and discourse about mental illness. Bassman (1997) notes there is much to be learned from consumers, survivors, and ex-patients who have professional expertise as psychologists, psychiatrists or in other allied health professions. He describes this as having “experiences from both sides of the locked doors”— that is, as both a patient and a professional in the mental health system (Bassman, 1997, p. 238). The study of narratives by people in this position brings a unique perspective to the study of narratives and discourse about mental illness. The quote alludes to the idea that although separated by locked doors on the wards of institutions there are opportunities for resolving the obstacles (physical and discursive) between patients and health care providers.

As a psychologist and a consumer/survivor, Bassman (1997) suggests personal stories are valuable on two levels including an individual level, and a social, relational, ideological level. First, he notes on an individual level “consumer/survivors are finding validation in narrative approaches that seek to understand life experiences as constructed stories” (Bassman, 1997, p. 240). In this regard stories are examined for what they offer to either medical or consumer-survivor perspectives in terms of new knowledge and interpretations of personal experience. Secondly, Bassman (1997) describes the value of narratives on a social or ideological level and he suggests narratives of “marginalized groups provide rich expansive interpretations to a history that is subjectively controlled by the dominant ideology” of medicine (Bassman, 1997, p. 241). In both regards personal narratives of patients, consumers, survivors, and ex-patients are valued as a resource useful for re-informing and challenging established ideas about madness and mental illness.

Kottsieper (2009) discusses the place of a clinician's experiential knowledge in therapy and describes how disclosing her experience with depression has influenced her practice as a psychologist. She considers the value of stories as contributors to curriculum in clinical psychology and suggests more study is needed to explore the benefits and challenges of incorporating experiential knowledge into mental health practices. Drawing on her experience as psychologist and as a patient she suggests increasing efforts to study mental illness and rationalize the experience in therapy obfuscate personal meaning. She explains, "I am a scientist-practitioner who thinks that maybe we have gotten a bit too far away from what we set out to study: the person, not the disorder" (Kottsieper, 2009, p. 189). This suggests that as a communicative connection, narratives offer a way to reconnect and in a sense bridge meaning between personal experiences and rationalized, medicalized discourses. People who have firsthand experience as patients and medical knowledge as practitioners have an important perspective to bring to understanding mental illness, that represents a lived expression of the way meaning is bridged between personal experience and discourse about mental illness.

As an activist and consumer-survivor, Morrison (2006) draws on her experiences to examine narratives within the consumer/survivor/ex-patient movement. Morrison (2006) examination and analysis of the literature of the movement, as well as other personal stories about madness, presents a new framing of the experience of mental illness. She identifies an overarching narrative type called the "heroic survivor narrative" and develops a framework to describe the phases of acceptance and resistance experienced by consumer-survivors (Morrison, 2006). The heroic survivor narrative enacts the positive and active discourse of survivorship that is established in personal stories about chronic illnesses such as Cancer and AIDS, but includes an

activist dimension as people negotiate and negate medicalization. Morrison (2006) explains that as people become part of the mental health system they experience five phases including “entry into system, disregard by system, resistant response, solidarity, politicization” (Morrison, 2005). Each phase of the heroic survivor narrative demonstrates that people use stories to actively convey consumer-survivor experiences and support an activist consumer-survivor community. As Mishler (2005c) explains “narratives of resistance” are a way people have challenged and moved away from medical definitions of their experiences.

It is clear from the literature that activists and advocates use personal narratives as resources for challenging and re-informing established medical discourse about madness. Cohen (2005), a “leader in the international consumer/survivor/ex-patient (c/s/x) movement” analyzed thirty-six personal stories collected in 2001 for the MindFreedom Oral History Project (p. 333). Using qualitative and quantitative analysis Cohen (2005) identifies common themes in narratives about recovery that call for more “progressive mental health policy”, and he outlines a number of points to inform new perspectives on how to regard mental illness. Cohen (2005) analysis indicates there is “no magic bullet” for treating mental illness rather the best approaches include “multiple recovery methods”, “one-on-one therapy”, a focus on “empowerment, and strong support from family and friends (p. 343). Studies such as this bring to light alternatives for treatment and care in mental illness, however, concerns over the cooptation of consumer-survivor narratives have also been raised in the literature.

The literature on personal narratives in this area is critical and cautionary. For instance, Costa et al. (2012) describe the ways personal stories have been co-opted by the “psychiatric system to bolster, research, education, and fundraising interests” (p. 85). They point out that consumer/survivor narratives are transformed from claims of individual agency and voice used to

serve the consumer/survivor/ex-patient movement into versions of “disability tourism” and “patient porn” (Costa et al., 2012, p. 93). Speed (2006, 2011) cautions that although re-conceptualizing and differentiating peoples’ experiences in discourse as patients, consumers, and survivors provides a typology for closer analytic examination it also creates new categories of subjectivity that bring new sets of challenges and expectations. As an activist and consumer/survivor, Beresford (2005) points out the potential for learning from individual accounts of madness such as autobiographies and memoirs is unlimited and available in “a massive body of unrecorded and hidden service user knowledge, which remains alive in the memories of service users” (p. 39). From my review of this body of literature I find support for the idea that medicalization is managed in personal narratives as people bridge meaning between their experiences and dominant discourse about mental illness. In the next section I turn my attention to medical literature about personal narratives and mental illness, and discuss how this literature attends to narratives as a resource for improving and enhancing clinical care.

### **Medical Literature and Personal Narratives about Mental Illness**

#### *Improving psychiatry and psychology with patient narratives*

The development of psychiatric approaches to madness in the mid-1800s paralleled growing interest and expression of madness in literature setting up a connection between medicine and literature that still exists today (Feder, 1980; Sonne, 1985). Literature and psychiatry are “so intimately related that this may be one of the reasons why so many psychoanalysts, linguists, and literary scholars find it not only fruitful, but also necessary to talk to one another and even work together” (Sonne, 1985, p. 223). As Sonne (1985) points out literary analyses of autobiographies and memoirs often integrates the work of early psychiatrists, such as Freud or R. D. Laing in

order to inform the analysis of a narrative. According to Feder (1980) “In the study of madness literature, psychoanalytic and psychological theory provides but one discipline that, along with others—especially literary, religious, and social history—helps to elucidate the various symbolic forms into which the human mind transforms experience” (p. xiii). Following from Freud’s psychoanalytic approaches concerted effort was made to bring autobiographical accounts of madness under the medical microscope. There was interest in how patients expressed themselves narratively and whether this might offer insight into madness if the stories were empirically observed and analyzed. Today fictional and autobiographical accounts are used as a resource to strengthen medical efforts to understand and treat madness. More specifically, personal narratives are used to enhance medical understanding of mental illness, to supplement medical education, and to improve therapeutic approaches to mental illness.

Initially only historically published narratives were drawn on as evidence to support new theories about how mental illness developed and how physicians could help patients resolve it (Kaplan, 1964). Using autobiographical accounts from literary sources physicians and psychiatrists began to identify and define a medically recognizable (and definable) experiential voice of mental illness. Physicians and psychiatrists reviewed literary works by famous philosophers and authors who, in writing about their lives included descriptions and reflections on experiences of madness. Narratives were gathered from the writings of famous and infamous persons such as William Cowper, Friedrich Nietzsche, and Vincent van Gogh (Alvarez, 1961); Leo Tolstoy, Jean-Paul Sartre, and Vaslav Nijinsky (Kaplan, 1964). Excerpts from these literary accounts were organized and presented in collections. The narratives were accompanied by brief introductions and interpretations of what the stories meant and how they could be used to inform medical approaches. Editorial commentary included criticisms of hospital care and

recommendations for improving it (Scull, 1979; Shorter, 1997). Autobiographical accounts were discussed in terms of research developments in brain chemistry, and were used to point out the difficulties of including patients in treatment decisions (Alvarez, 1961). But Alvarez (1961) notes that personal stories were also viewed as a “word of hope” for re-informing medical approaches and the inclusion of personal narratives was viewed as a new untapped source of information for re-energizing medical perspectives (p. 15). According to Kaplan (1964) personal narratives were a way to discover or create a direct connection with personal experience of madness.

Here, perhaps to a greater extent than any other data, we can come into intimate contact with the reality of mental illness itself, not only to find out “what it was like,” but also seek the kernel of purposefulness and intentionality around which it is organised. (Kaplan, 1964)

Kaplan (1964) does not suggest that stories have a direct role in this transformation, but sees them as examples for the medical community to draw on as they guide patients through the process of treatment. The medical community is positioned as the only viable witness to mental illness stories, and this discounts the experiential views of patients as capable of interpreting their own stories and contributing to a dialogue about the best directions for improving their situations. Still, as Ingram (1991) explains medical perspectives were divided about whether madness was a condition that could be valued or ignored, suppressed or endorsed.

If like whooping cough or gout, it was simply something to get through or die of, the experience itself was worthless, a hiatus in a normal life. If, however, madness was saying something about normal life, and was also a commentary upon itself, then the mad could offer important clues for the understanding both of themselves and of the world of the sane. (Ingram, 1991, p. 18)

This uncertainty rather than inspiring other possible explanations and shifting madness away



from medicine led to calls for greater inclusion of personal narrative in medical discourse. These developments encouraged new approaches to studying mental illness, which shaped and informed the role of medicine in madness. Thus autobiographies and patient narratives became a new form of data to be taken up, translated and co-opted by medicine. The task of translating personal narratives into medical discourse ensured that madness would remain a medical concern.

Medical interpretations of narratives included ideas about madness as a social response, placing less emphasis on the physical nature of mental illness. For example, Kaplan (1964) interpreted and translated narratives about madness as an act of social rebellion and not wholly as an illness. He explains madness manifests as an active choice of “rebellion or rejection of expectations regarding social participation” and “the major value orientations of western society” (Kaplan, 1964, p. xi). In his view madness was a response to a “difficult or unrewarding life situation” when a patient turned away from social responsibility, choosing not to participate or to behave in ways that opposed socially acceptable conduct. This aligns with the view of Parsons (1951), who suggested people who experience illness take on a “sick role” where they are unable to participate productively in society, and it was their role to comply with doctors’ directives until such time as they were well enough to work again. Over time narratives were increasingly interpreted using medical language, which was and is, viewed as a way to help patients resolve (and redefine) difficult situations and move on to new solutions (Kaplan, 1964).

The use of narratives as a resource to support approaches in psychology and other allied medical fields has been great but stories remain distinctly framed and directed by medical perspectives. As Casey and Long (2003) point out as patient stories are re-defined and develop structure personal meaning can be lost to the influence of dominant medical and cultural

explanations. Still, as narratives are used to help patients manage or re-story their experiences the influence of social, cultural and medical forces is being considered. For instance, McLeod (2006) describes the value of narrative approaches in psychotherapy and refers broadly to the way stories connect personal experience with social systems of discourse. He explains, “the concept of narrative provides a bridge between the stories told by specific persons, and the dominant discourses and narratives within which we all collectively live our lives” (McLeod, 2006, p. 207). Westerhof and Bohlmeijer (2012) advocate that personal narratives are valuable throughout psychological care and can be usefully incorporated during diagnosis and intake phases, and in reporting client progress and evaluation of outcomes. According to B. Schiff (2006) narratives support better theoretical understanding of behaviour and “they help us to tie together interpretations with relationships, interactions, cultural systems of belief and personal dispositions” (p. 25). The expectations of what narratives can provide are great, however they are viewed as something to be incorporated into medical discourse, therefore understanding the implications of the ways medical discourse is managed by stories is overlooked. To counter this are studies that aim to centralize patient experiences in clinical care.

Bradby, Hargreaves, and Robson (2009) note there is a sense of urgency in therapeutic and theoretical circles to include personal narratives as part of health and social care decision-making. They note that even as medical approaches are attending to patient narratives, there is now a call for health care practitioners to attend to patient perspectives (Bradby et al., 2009). They suggest narrative approaches are valuable in the traditional sense of professionals helping patients reconstruct experiences and attitudes, but more significantly stories can provide insight into how approaches to treatment can be improved. However, they point out that traditional approaches for including narratives as resources for improving health care have been less than

stellar, when calls for patient-centred medicine and the use of narratives merely serves to support rhetoric and tokenism (Bradby et al., 2009). Bradby et al. (2009) caution that using personal narratives as resources for making medical approaches more efficient or “to present stories as nuggets of evidence requiring de-coding is to seriously under-estimate their value” (p. 335). The use of narratives as medical resources will undoubtedly continue as there are merits to this approach, however, increasingly peoples’ stories include medical knowledge and conceptualize madness as illness further strengthening medical perspectives, and reducing the impetus of alternative conceptions of madness.

Roberts (2000) points out after the initial rush of appreciation for including narrative accounts in medicine narrative approaches have already shifted to a lower level on the medical hierarchy of knowledge. He outlines the benefits and difficulties of fitting anecdotal evidence provided by narratives together with evidence-based medicine asserting that “they are necessary and complementary companions” (p. 432). In his discussion Roberts (2000) describes how scholars recognize “an “enormous gap” between our empirical knowledge base and the information that patients need and want” (p. 432), and that “it is clinicians who need to bridge the gap” (p. 440). Similarly Bensing (2000) points out there are gaps between evidence-based medicine and patient-centred medicine that require bridging despite efforts to bring the two closer together with the inclusion of patient narratives. One approach to closing this gap has been to use autobiographies as a teaching resource in medical education.

### *Supplementing medical education*

According to the Madness and Literature Network, “literary research has become a key resource for the advancement of medical and health professionals' education, affording broader

perspectives, critical thinking skills and promoting an emotionally receptive or empathic climate for clinical practice” (Madness and Literature Network, 2014). Over the past few decades, literary scholars have provided assessments and contributed research regarding autobiographies about madness demonstrating they can be used to inform better understandings of mental illness. As Crawford and Baker (2009) point out “psychiatry studies the human mind within an increasingly biological, medicalised paradigm, yet it focuses on the same concerns as literature—human experience, reactions to events, emotions, behaviour and affect” (p. 237). Reaume (2006) asserts the inclusion of madness narratives is a way to re-inform the traditionally medicalized history of madness with stories of those who experienced madness in various historical and social contexts. And teaching in the social sciences has also benefited from the inclusion of autobiographies about madness. Lewis (2004) used a book club style approach to present personal narratives about madness to students in a sociology course. Sakalys (2000) comments the study of literary works in nursing practice has added a political and cultural dimension to learning about relationships between patient and care provider. Today autobiographies are integrated into traditional medical school teaching in classes designed to broaden the scope of medical curriculum, increase interdisciplinary, and better prepare medical residents. Ideally these accounts are a way to connect medical students with patient experiences but there is a risk that these accounts become more greatly assumed into medical discourse.

Flood and Farkas (2011) explain the inclusion of personal accounts of madness encourages greater interest in medical humanities and expands “the career-specific focus of the curriculum (which) can create a kind of professional “silo”, a monocultural approach” in medicine (p. 129). For instance, while traditionally students have engaged in reading cases for diagnostic and treatment purposes, the addition of studies in madness literature provides medical students

opportunities to develop greater insight into personal values and perceptions as future healthcare providers (Flood & Farkas, 2011). Through critical readings of madness literature medical students gain improved narrative competence and greater insight into aspects of mental illness they may not otherwise have experienced. The use of autobiographies in medical education opens up possibilities for understanding madness as a medical subject and as a rhetorical strategy that enables people to manage the contradictions and challenges that come with living with madness (Flood & Farkas, 2011). As well, narratives about madness offer “the possibility of drawing inferences not only about individual experiences but also of institutional and societal relationships” (Flood & Farkas, 2011, p. 132). However, regarding narratives in a medical context automatically positions them as a resource to be drawn upon and translated or interpreted into medical language, and does not bring to light the ways these relationships are managed by the narratives.

A number of frameworks for analyzing narratives are presented in the literature making the use of autobiographical accounts in medical education much more formal. These frameworks are proposed as ways to support more effective clinical treatment by doctors and nurses, but they also emphasize stories as resources to be translated in medical contexts. Kirkpatrick (2008) develops a “narrative framework for understanding stories” that is presented as a way to facilitate better relationships between patients and nurses and “ensure a firm foundation for the relationship and shared decision making” (Kirkpatrick, 2008, p. 65). The framework draws upon the narrative work of Rappaport (2000), which describes three levels of narrative—personal, community, and dominant cultural or master narratives. Kirkpatrick (2008) discusses how listening for and understanding the relationships between the various narrative levels, as they are presented by patients, enhances nursing practice by increasing shared understanding, and

providing opportunities for linking or partnering with patients. The approach is intended to help nurses recognize the everyday contexts and conditions people with severe mental illness talk about and to relate this to their clinical practice. Kirkpatrick (2008) points out that the framework is not intended to be a script for clinical treatment or intervention, but should be considered as a guide for strengthening clinical relationships, and in this way it serves to bridge personal and medical knowledge about mental illness.

Donohue-Smith (2011) presents a conceptual model to address concerns that the study of mental illness memoirs in medical education is different than what clinicians may encounter in their practice with patients. The model is intended to help clinicians analyze autobiographical accounts and consequently become more “empathetic and effective” when providing treatment (Donohue-Smith, 2011, p. 140). Acknowledging that “memoirs speak from a distinctive perspective, one that has too frequently gone unheard” and that they are “rich in detail” and “emotionally compelling” Donohue-Smith (2011) notes there are a number of challenges when addressing actual patient narratives in clinical practice. For example patients modify their stories to fit the expectations of a medical context, and the content of stories is a selective rather than historical accounting of experience. She proposes “clinicians must have a clinically valid and reliable strategy for creating their own meta-narrative, one that deconstructs and reinterprets the story told by the client without distorting or disregarding the client’s voice” (Donohue-Smith, 2011, p. 140). To do this involves using a model that provides a “systematic approach to extracting and organizing the “data” provided by the narrator” (Donohue-Smith, 2011, p. 141). Stories are resourced as data for the construction of patient “portrait” that includes a variety of personal, familial, cultural and community contexts.

Certainly, using personal narratives as a resource for medical education and subsequently as a resource in clinical practice has enhanced approaches to mental illness in medicine. However, while using personal narratives medical interests co-opt and integrate personal stories, reframing them to support the advancement of future medical approaches. Returning for a moment to the bridge metaphor, personal narratives are not merely a bridge but a gateway to a cache of narratives as data to be interpreted, thereby ensuring the continued development of medical discourse.

Woods (2011) described two recent autobiographies for the ways they support and encourage the diagnostic criteria and labelling of mental illness. The article highlights how literary autobiographies provide compelling and important insights into the phenomenological and psychosocial aspects of mental illness (Woods, 2011). By the same token, the article describes how valuable medical discourse is as a way for people to structure and frame the course of their experience. Woods (2011) points out that acceptance of medical diagnosis is the pivotal moment for the author's of these autobiographies and their stories represent a form of "recovery writing" that should not be confused with (and is not part of) activist or survivor literature that counters medical perspectives (p. 104). In this way autobiographical accounts become not only resources for analysis but also resources for supporting medical views and approaches to mental illness. When personal narratives are resources for medical education and used as data for greater insight into mental illness, and when they are deconstructed to support medical criteria then opportunities are lost for understanding how personal stories bridge meaning between experience and discourse, and how this manages the course of medicalization.

## **Literary Studies and Personal Narratives about Madness**

### *Connecting historical, societal, cultural, and medical views of madness*

The presence of personal accounts of madness in literature harkens back centuries, but over the last few decades much greater attention has been paid to exploring and analyzing these stories (Feder, 1980). This body of literature broadly considers madness as a literary motif or genre and a symbolic expression of human experience (Feder, 1980). In literary studies autobiographical accounts of madness are examined for the ways people are situated socially, historically, and culturally as they share their stories. According to Feder (1980) literary approaches highlight and examine stories as “an aesthetic construct of the psychic, historical, and social forces which together determine the intricate mental processes of human beings” (Feder, 1980, p. 28). As Jones (1997) points out some of the earliest autobiographical accounts of madness, in works such as *The Book of Margery Kempe* (circa 1436) reflect spiritual and religious interpretations of the time while current day narratives are representative of today’s socially and medically constructed meanings of madness (see also Castagna, 2011). Literary studies of personal accounts of madness highlight the various social and historical forces that influence understandings of madness at different times in history, and position stories as a resource and a site for viewing how various social, historical, medical and cultural forces meet in human experience.

Literary studies look to stories to demonstrate the socially constructed nature of madness by locating and examining madness at the crux of various discursive forces. Thiher (2004) takes a historical phenomenological position to examine how literature informs approaches to madness and alternately how theories about madness influence literature. He asserts, “Literature can bridge the gap between the medical mind and the insane mind because the literary imagination



has historically shared certain features with the insane imagination, as well as traits with the medical imagination that has tried to explain madness” (Thiher, 2004, p. 2). The interconnections between literature, philosophy, psychology, history, and medicine are of key importance because they are the language games through which madness is articulated and recognizable (Thiher, 2004).

Hacking (1998) proposes madness is a socially and historically “transient state” which thrives at the intersection of four social vectors including medical (taxonomy of illness), cultural polarity (ranging from virtuous to criminal), observability (visible suffering), and illness as social release (p. 1). The metaphorical meeting place of these vectors is an ideal “ecological niche” for the conception of new configurations of madness. Of interest to Hacking (1998) is the way “some types of mental illness and some arrangement of symptoms are central at some times and places and absent in others, even in the history of one fairly continuous culture” (Hacking, 1998, p. 13). In his text Hacking (1998) recounts the story of Albert, a citizen of the late-1800s, in order to demonstrate how the four vectors contribute to the development of “fugue epidemic of the 1890s” (Hacking, 1998, p. 12). Albert’s madness is defined by his inexplicable, random wandering from town to town. Hacking (1998) follows Albert’s story in parallel with the development of social, medical and historical knowledge of fugue-states. He points out how historically there continues to be confusion and contestation surrounding many mental illnesses where the view is that “symptoms are both nurtured and natural, both moral and neurological” (Hacking, 1998, p. 8). Albert’s story is a literary resource for observing, analyzing and understanding how medical, cultural, social, and historical vectors or forces come together to construct mental illness. Literary accounts like Albert’s are analyzed as a way to follow the

intersections and interplay between social, cultural, medical and historic discourses and understand how they influence ideas about madness.

### *Challenging traditional views of madness*

Feder (1980) suggests critical examination of literary interpretations shows they influence how madness has been understood at various times in history and how traditional understandings of madness are challenged with new interpretations. For instance, Weiss (2000) points out that feminist analyses of autobiographical accounts of madness generally present one of two views. One, that conceptions of madness have historically been used to subdue and silence women, and two, that acts of madness are a “form of subversive power” that have enable women to “disrupt patriarchal discourses” (Weiss, 2000, p. 1). Both views influence how women and madness are understood today. Weiss (2000) indicates literary studies of personal narratives emphasize particular theoretical perceptions and perspectives, explaining madness in terms of other issues—such as gender wherein madness is viewed as either empowering or silencing. Weiss (2000) contends that examining autobiographies from the standpoint of the authors re-informs opposing views, and in this example, indicating empowerment and subjectivity are both evident in women’s narratives about madness. She explains, “by writing about and retelling their experiences, these women put themselves in an ultimate position of control over their experience. They were able to decide what parts of the experience to reveal and how to reveal each particular incident” (Weiss, 2000, p. 69). Analyzed with the author’s perspective in mind emphasizes and demonstrates how people actively manage the meaning and development of their stories.

In another literary study, Smith (2000) looks at autobiographical accounts and challenges assumptions about social and historic understandings of women and madness in a review of four autobiographies. Smith (2000) contends autobiographical accounts demonstrate new representations of women and madness as people represent themselves and their experiences in new ways by “manipulating autobiographical conventions to represent experience that has historically been unrepresentable” (p. iii).

A study by Hubert (2002) highlights the connections between autobiographical accounts as informants of and as influenced by social, historical, and medical views. The analysis indicates autobiographies written in the late-nineteenth century resist medical tradition and call for institutional reforms, whereas mid-twentieth century autobiographies demonstrate women’s acceptance and internalisation of psychiatric diagnoses (Hubert, 2002). Some more recent narratives challenge psychiatry and the idea of mental illness, while other narratives integrate a writer’s artistic abilities, political views and individual experiences to confront the historic and social contexts in which their experiences take place. Autobiographies demonstrate the similarities and highlight the relationships between people who have experienced madness and the social, cultural and historical contexts in which they live out their experiences. In the epilogue Hubert (2002) states “madness narratives can create bridges that are difficult to build in ordinary conversations” (p. 144). Formality and structure of narrative is essential to autobiographical writing and allows for the story to be drawn out and analyzed for the ways it meets or resists hegemonic discourses about madness. These literary studies of narratives about madness support my interest in showing how narratives manage medicalization. They point to the value of an analysis that takes up the author’s perspective to reveal, not only the ways

dominant discourses come into play in people's stories, but also how people themselves manage and bridge meaning between their experience and discourses available to explain that experience.

Focusing on the social construction of madness, Young (2009) describes the ways narratives "challenge and change the dominant cultural discourse about mental illness" (p. 52). Young (2009) reviews four autobiographies and describes four common thematic plotlines, including symptoms, diagnosis, treatment and acceptance. She suggests in the act of writing an autobiography people face up to and confront hegemonic perspectives and discourses that inform social, cultural and historical definitions of mental illness. According to Young (2009) writing about symptoms, diagnoses, and treatments helps people resolve conflicts between personal experience and medical knowledge, which leads to acceptance of diagnosis and treatment options that writer's "need to live the self-determined lives they seek" (Young, 2009, p. 61). Writing engages readers in ways that normalize mental illnesses, while also offering authors a way to "publicly refute and correct the social construction of mental illness" when it does not fit with their personal experiences (Young, 2009, p. 66). Young's (2009) analysis demonstrates the significance and influence of autobiographical writing for people who experience "mental illness"—it is seen as a way to connect with a public audience, and correct or re-inform perceptions and ideas in discourse about mental illness.

However, in drawing on personal narratives of madness this study privileges medical perspectives of madness as mental illness by emphasizing and encouraging medical conceptions of madness (such as symptoms, diagnosis and treatments). The study does not question how medical concepts are also social constructions, and suggests alternative constructions of madness outside of medical concepts are limited. For instance, Young (2009) is critical of one author's efforts to re-claim madness from medical discourse and reads this effort as an indication that the

author is proposing “that our society should deconstruct the entire construction of mental illness” (p. 62). According to Young (2009) the writer presents “a beautiful and stirring invocation of the potential of the human mind” but fails to account for human suffering in the process (p. 62). There is a missed opportunity here to engage the idea that madness could possibly be considered (or constructed) outside of a medically explained experience.

As White (2008) points out autobiographical accounts “challenge notions of a universal subject, and function as tools for resistance” (p. 6) and “can therefore function as a means for those suffering from traumatic events to lay claim to the experiences” (p. 7), which is something that Young (2009) does not explore in her analysis. White (2008) applies feminist scholar Sidonie Smith’s (1991) idea of the “autobiographical manifesto” in her review of three autobiographies about madness. She describes how writers resist hegemonic discourse in their stories by making statements about their identity, by making their unique experiences public, by recognizing their roles in a marginalized community, by describing ideals about their future and expressing calls for social change. The extent of these goals suggests that personal narratives play a central role in managing meaning in discourse. More than just storied representations of people’s experience, narratives are viewed as contributors to discourse, nonetheless there remain opportunities for explaining just how this is accomplished and what implications it has for individuals and medicalization of madness.

### *Metaphor in autobiographies as resource for understanding madness*

Although the presence of personal narratives dates back centuries the popularity, professionalization, and profitability of autobiographical accounts as a genre of popular culture literature is fairly recent (Wolfe & Wolfe, 1976). Previously viewed as a sub-genre of psychiatric

literature the rise in popular interest since the mid-twentieth century has encouraged literary scholars to examine autobiographical accounts and the ways metaphors are used to express experiences of madness. Metaphors in fictional literature are tools for structuring plot and defining characters, which help authors manage the confusion of madness for readers.

Instability of meaning ripples outward in its narrative expression, from the mind of the character, to the structure and meaning of the text itself, allowing the author to make maximal use of figurative and metaphorical language – to describe the illness, and often, to use the illness itself as metaphor for achieving other rhetorical aims. (Flood & Farkas, 2011, p. 131)

The same can be said for autobiographical accounts. Metaphors offer a reference point for the construction of shared, meaningful connections between writer and reader, whether the accounts are fictional or not. The intent of a story is to construct shared meaning.

In autobiographies the meanings of madness are rooted in real experiences, which are initially interpreted by the person who has had the experience. In the case of medical or clinical approaches these metaphors are taken up and re-interpreted in ways that fit empirical and rationalized explanations for madness. Whereas literary approaches take up and extend personal interpretations to deepen understanding of the significance of the metaphor for the individual and the contexts in which they live their experiences. To do so literary analysis of personal narratives examines the form and development of stories to determine why and how narratives about madness are so compelling.

Examining the characteristics of this genre and exploring the literary reasons for its popularity Wolfe and Wolfe (1976) note that autobiographical accounts have “evolved recognizable formulaic elements in structure and imagery” (p. 895). They explore the genre in terms of “imagery and metaphor, structure, point of view, and characterization” (Wolfe & Wolfe,

1976, p. 898). They suggest the use of metaphor in autobiographical accounts is unique because “the power of metaphor becomes the central link between the experience of the reader and the experience described by the author in an autobiographical work. On the most basic level, it represents an attempt at communicating the incommunicable” (Wolfe & Wolfe, 1976, p. 898).

They describe four main characteristics evident in autobiographies about madness. First, they point out autobiographies about madness include deliberate and patterned use of a “controlling metaphor” that sets the tone and provides a “central link” for the story (Wolfe & Wolfe, 1976, p. 898). Secondly, metaphors in autobiographical accounts of madness are described as a way for the author to share the “emotional quality of the illness, but to some extent its structure as well” (Wolfe & Wolfe, 1976, p. 899). A metaphoric structure sets the tone of a narrative making the experience of madness interpretable and understandable to others, for example descriptions of caves, labyrinths and tunnels convey feelings of fear, isolation, and confusion, and in doing so (Wolfe & Wolfe, 1976).

The third characteristic of autobiographical accounts of madness is their reliance on only one or two narrated points of view, these being almost solely from the perspective of the “narrating patient or doctor” (Wolfe & Wolfe, 1976, p. 900). Highlighting this characteristic suggests personal accounts provide a connection that is particularly focused on bridging the medical-experiential relationship. Wolfe and Wolfe (1976) point out the genre’s popularity may be due to this didactic nature of stories as autobiographies about madness tend to centre on therapeutic experiences specific to the relationship between the author (as a patient) and their doctor, as it plays out within medically guided practices of therapy. The way the protagonist manages chaotic experiences with madness within the institutional confines and control of a hegemonic medical system makes the story compelling to readers. The protagonist is considered

as someone other than a patient complying with medical directives. What is unclear from these assessments is how autobiographical accounts and the metaphors they include, reflect or integrate or manage social and medical discourses.

The fourth common characteristic of autobiographies about madness is the similarity in character development (Wolfe & Wolfe, 1976). The popularity of the genre resonates with its (mostly) female readership because (most) stories involve a central female character storied as “highly intelligent, witty, articulate (within the bounds of their illness), and yet vulnerable and perhaps above all, passive” (Wolfe & Wolfe, 1976, p. 900). As “a creative intelligent woman victimized by the roles she is forced into” readers identify with the main character as someone facing issues that parallel and reflect broad social issues, such as gender inequality (Wolfe & Wolfe, 1976, p. 900). For example, Wolfe and Wolfe (1976) point out that protagonists such as Hannah Green in “I Never Promised You a Rose Garden” (Greenberg, 1964) or Mary Jane Ward in “The Snake Pit” (Ward, 1946) use wit as a form of “psychotic defense” (p. 900). Here are the beginnings of an assessment of how narratives manage medical discourse, and it raises the question of how people narrate their stories in order to identify with a reader or have the reader identify with them. By examining metaphoric structure and tone, didactic narrated points of view, and the writer’s ability to identify with readers literary studies demonstrate in narratives we can see the ways people manage madness and the dominant discourses that inform it.

Literary studies examine stories and demonstrate how writers structure their accounts and use metaphors to construct meaningful connections between their experience and the medical and social world in which their personal experience takes place. However, in a review of literary and philosophical discussions of madness and autobiography, Stone (2004) points out that discussions of madness literature often do not go far enough in considering how the act of



shaping the raw experiences of madness into a coherent and sequential narrative can “do violence to the speaker and their experience” (p. 23). Writers who construct a narrative for structuring their experience leave behind the chaos and catatonia of madness, only to return armed with narrative “tools” and “mechanisms” for ordering their experience. Sometimes the tools are artful descriptions in storied form, and other times they are guided by biomedical concepts and discourse. Stone (2004) suggests the act of composing a narrative or memoir reduces understanding of what madness experience truly is—that it is different from reason. But bridging personal experience and medical knowledge requires that reason be present in narratives in some form so that meaningful approaches in care can be provided when needed. Stone (2004) explains that although applying narrative form to madness experience is deemed positive in therapy as a sense-making device, there is a risk that the new rendition could “completely subsume the alterity of madness” (p. 19) or alternatively “dramatize the very echoes and reverberations of distress” (p. 20). He asserts that a narrative approach that “only explains, connects and concludes will at best fail to signify its object” and at worst it will reproduce forms of historic and hegemonic control (Stone, 2004, p. 24). To break away from the limiting expectations of traditional autobiographical narrative analysis, autobiographical accounts should be analyzed for metaphoric, poetic, dialogic, active, agentic, and reader-directed qualities, rather than for how well they produce madness in a chronological, linear and structured form (Stone, 2004).

VanDongen (2003) does just that when suggesting that narratives be viewed as performance rather than in textual form. She explores “walking stories”—stories that are embodied, everyday expressions of what Sarbin (1998) calls “believed-in imaginings”. In madness, walking stories seem to have little coherence and make little sense to those watching,

but VanDongen (2003) points out there is reason in this expression of madness and translating it into a symptom or a literary device reduces its meaning. Recognizing the performative ways people live their life stories is a better indication of the metaphoric meaning than trying to apply medical or even literary concepts even though these are the main ways narratives have been addressed. Stories can be recognised as symbolic rather than symptomatic. VanDongen (2003) states her studies indicate that people use symbols in a “very personal way” and that over time personal stories often “never changed and were consistent, but not recognised as ‘true’” (p. 209). Additionally, drawing on Goffman (1961) she notes that judging by the ways madness narratives and behaviours challenge norms, even in the most confusing narratives people indicate they are aware of social rules and expectations.

As Feder (1980) suggests although it is not always evident whether or how some stories provide a bridge to reason, “both autobiographical accounts and imaginative representations of madness provide evidence that such bizarre constructions cannot be viewed merely as signs of withdrawal from reality” (p. 26). Metaphors in autobiographies reveal sophisticated narrative strategies and practices at work in stories that can offer ideas about how madness is structured and how it is managed within social, historical and cultural expectations. Literary analysis of madness in autobiography has a long history of drawing on stories as resources for understanding social, cultural and historic influences on madness, but the emphasis is most often on how these forces culminate in mad experiences or how they influence the development of stories, rather than on the ways these forces are managed and influenced by personal narratives.

### **Summary of Literature Review**

In order to situate this thesis in the literature about personal narratives and madness this

review covered three main scholarly disciplines in which storied accounts have been studied. The review began with discussion of the social sciences literature, which most directly guides and informs this thesis. This body of literature examines stories for the ways people use narrative to manage identity, recovery, and make sense of their experiences. It includes analyses of narrative contexts and the construction of narratives, which maintain that social and cultural influences direct and shape meaning in personal narratives. Social science literature includes analyses of themes and types of narratives, which characterizes narratives and identifies shared themes in stories in order to better understand individual experiences of madness. Included in this section is a review of literature by people who have experience as mental health professionals and as consumer, survivors, and ex-patients. This literature indicates narratives play an important role in challenging medical discourse and approaches to madness.

The second section in the chapter describes medical literature about personal narratives and describes how narratives provide support for medical and psychiatric explanations of mental illness. This body of literature discusses how personal narratives are useful for enhancing medical education programs. My review indicates personal narratives are integrated and co-opted into medical discourse as data to improve and enhance psychiatric theory and treatment approaches, and to supplement resources in medical education.

The final section in the chapter outlined the ways autobiographies about madness are regarded as a literary genre and how stories are analyzed for the ways social, historical, cultural and medical influences come together in the expression of madness. Literary studies of women and madness were presented to indicate how the addition of feminist perspectives re-informs traditional views about madness. A description of metaphors indicates there are differing views regarding whether autobiographies of madness should be analyzed using narrative structuring or

whether a more fluid and reflexive approach to metaphor in madness narratives is better.

Following the three bodies of literature it is apparent there is a common underlying analogy that describes personal narratives as a bridge that helps connect various understandings about madness, however none of the areas of literature includes a clear empirical study of what narratives bridge or how this works. The social science literature comes closest to realizing how this is possible because it includes assessments of how narratives accomplish things in discourse and what implications this has for individuals (such as making sense of madness, or re-storying identity); however, what influence this has on dominant discourse and how this influence happens remains a question. Medical literature is informative but rather than look at how narratives bridge the use of narrative content and form is translated and integrated to support medical discourse. Literary studies offer important commentary regarding the ways personal narratives reflect the influences of social, cultural and historic forces, which come together as storied structured expressions of human experience.

From my review of the literature it is apparent there is an opportunity to examine how personal narratives about madness manage medicalization. I suggest this happens as people make meaningful connections between their experiences and the dominant discourses that shape and rationalize these experiences. I call this *narrative bridging*. I use this concept to refer to the overall practice where people work to make sense of their experiences (for themselves and others) by connecting their experiences to broad socially dominant discourses. In my analysis I identify three strategies of narrative bridging, which are resisting, re-informing, and reinforcing dominant discourses. I suggest with these strategies people bridge meaning thereby influencing discourse about mental illness, and in this way personal narratives manage the medicalization of madness. To most thoroughly develop these ideas requires a comprehensive theoretical

framework that regards communication as central to social change, and is flexible enough to cover the broad influence of discourse and connect it to the everyday discursive actions of individuals in various contexts. In the next chapter I discuss two theories that centralize communication and provide explanations for how discourse is an influence in society and a catalyst for action. The next chapter includes a discussion of Habermas's (1987) Theory of Communicative Action and Fairclough's (1992) Social Theory of Discourse.

## CHAPTER 3 THEORY

### Introduction

The previous chapter reviewed how personal narratives are studied as resources and practices in literary, medical and social science literature. The review highlights a common idea across these three scholarly areas that is, that personal narratives are a communicative bridge—a way to bridge meaning between personal experience and dominant medical and social discourse about madness. The review brings to light that although narrative is talked about as a bridge for meaning and it is studied for how this can be a benefit or support literary, medical and social science interest in madness, there is limited discussion of how narratives work to bridge meaning. Following from the literature review my idea in this thesis is that people who experience distress and trauma labelled as or associated with mental illness accomplish the work of bridging meaning everyday using narrative strategies to manage the expectations and contradictions they encounter in dominant discourse about madness. Therefore it is of interest to identify and follow how they do this in the personal stories they share about their experiences. To support my idea that people use narrative bridging strategies to accomplish things in discourse I look to two theories, which centralize communication and conceptualize discourse and narrative as social practices. These two theories are described in this chapter. I discuss Habermas's (1987) Theory of Communicative Action and Fairclough's (1992) Social Theory of Discourse because they best conceptualize how language and discourse work in society as a communicative connection that conveys meaning and initiates social action.

## **Habermas's Theory of Communicative Action**

One of the most widely discussed and influential theorists of the 20<sup>th</sup> century, Jürgen Habermas has developed a theory that most comprehensively addresses the relationships between individuals and social systems. The appeal of this theory for such a task is the way it centralizes communication as the shared, active, and ongoing practice that relates individuals and social systems in ways that produce meaningful interaction, which contributes to social action. According to Habermas (2003) “fundamental to the paradigm of mutual understanding, is rather, the performative attitude of participants in interaction, who coordinate their plans for action by coming to an understanding about something in the world” (p. 577). Broadly speaking, the Theory of Communicative Action relates the development and workings of systems and structures of society with the efforts and intentions of individuals who manage and participate in those systems (Habermas, 1987).

The theory directs attention to the practice of communication as it arises in everyday lived experience, and it conceptualizes it as a practice of working toward understanding and social connection. It is a theory that views social action in relation to conditions of possibility that arise from the use of language and the ways individuals work toward understanding what needs to be said, and more importantly the best ways to convey their experiences in order to achieve understanding (Habermas, 1987). Fultner (2010) explains “Habermas’s entire theoretical edifice stands on the foundation of his account of human communication, more specifically, of how we use language in order to reach mutual understanding with one another” (Fultner, 2010, p. 54).

The theory of communicative action offers a central perspective from which to consider broad social processes and individual efforts by focusing on language and attending to

communicative acts in the construction of meaning, understanding and social relationships. Habermas (1987) demonstrates differences in the way language is used to accomplish “mutual understanding, social integration and socialization” and he outlines how the communicative work involved in these functions influences and guides social interaction (Habermas, 1987, p. 5).

Pensky (2010) describes Habermas’s project as:

...a theory of communicative reason that encompassed both the “micrological” level of the actual epistemic foundations for differentiated modes of human knowing and acting, and the “macrological” level of the rise of social modernity, with its suite of new institutions and practices that embody, in various forms, these foundations. (Pensky, 2010, p. 25)

With consideration given to the relationship between micro and macro processes of communication the theory is helpful for understanding the ways individuals manage hegemonic discourse as they negotiate the ongoing complexity of social systems and the consequent rationalization of their personal experiences. Three overarching sets of concepts provide a framework for considering how communicative action guides and shapes society including lifeworld, system, and colonization, the public sphere and ideal speech situations, and communicative action and validity claims.

### *Lifeworld, System and Colonization*

The theory of communicative action is founded on the premise that the backdrop for the development of society is everyday life experience. Habermas’s use of the lifeworld and system distinction follows the philosophical phenomenological approach of Husserl who posited that all understanding of the world be rooted first and foremost in human experience (Cahoone, 2003).



Mitrovic (1999) explains,

Habermas distinguishes the social environment or “the world of life” (in which man leads his everyday life by establishing more or less direct relationships with others) from the social systems (economic, political, legal-normative) as specifically structured and institutionalized interaction patterns among people. In the history of human society, social systems grew out of the world of life” (Mitrovic, 1999, p. 220) (Emphasis in original).

Making distinctions between lifeworld and system Habermas (1987) constructs a theoretical approach that includes everyday experience as lived and how that experience is organized socially. The distinctions between lifeworld and system are evident throughout Habermas’s (1987) work, which explains differences in how each addresses and relates to communication. This includes the goals of social action (communicative or instrumental), how action is coordinated (orientation or consequence), what is involved in directing action (everyday language or steering media—such as money), and how action is understood (interpretive or objective) (Heath, 2010).

Generally lifeworld exists as a background to systems and structures that guide social life and it is where communicative action begins. Lifeworld is described as the “nexus of meaning that makes it possible for speakers to talk about the same thing” (Johnson, 2006, p. 53). In lifeworld meaning is taken-for-granted and communicative action is oriented toward consensus and shared ideals and morals (Habermas, 1987). Through everyday language the lifeworld is the foundation of all social and cultural knowledge and the “medium or symbolic space within which culture, social integration and personality are sustained and reproduced” (Scambler, 2002, p. 45). Habermas (1987) explains how social action is understood through interpretive means where “every new situation appears in a lifeworld composed of a cultural stock of knowledge that is ‘always already’ familiar” and individuals readily draw from this stock of knowledge to act and

communicate in society (p. 125). However, as the complexity of lifeworld experiences encourages a search for shared meaning that is not be satisfied by this available stock of knowledge, efforts are made to increasingly objectify and instrumentalize the experience.

Habermas (1987) explains it is not possible to stand outside of lifeworld to critically reflect upon it because it is the backdrop upon which society continually exists. “In his usage, the lifeworld is that prereflective web of background assumptions, expectations, and life relations that serve as a source of what goes into explicit communication while always itself remaining implicit” (Roderick, 1986, p. 155). In order to critically assess lifeworld experiences they must be defined thematically, in order to make them “subject to argument as the participants attempt to re-establish their mutual definition of the situation, a pre-requisite for successful cooperation” (Scambler, 2002, p. 45). As specific themes are brought into view the meanings associated with them become the basis for negotiation, and the consequence of negotiation is the development of increasingly rationalized and systematized explanations.

According to Habermas (1987) system is situated within and reliant upon lifeworld. System arises as a result of demands for greater explanation and organization of lifeworld experience. Where the focus of lifeworld is communicative action oriented to understanding and shared meaning accomplished through language, system is driven by instrumental action coordinated on the basis of social consequences and the influence of mediums such as money. Instrumental action is strategic and works toward goals that support rationalized and purposive structures of society that are directed by money (economy and market) and power (state, institution, administrative) (Habermas, 1987). As non-linguistic forms of influence money and power do not necessarily invoke consensus and the social values of lifeworld (Habermas, 1987). As individuals, acting in accordance with system imperatives such as these, become aware of the

consequences of the strategic and purposive nature of their communication and how it undermines lifeworld values there is a shift back to the stock of knowledge provided by lifeworld with its emphasis on consensus and values.

The distinct actions and orientations of lifeworld and system make them supportive of and detrimental to each other (Finlayson, 2005). The interdependent relationship ensures that each provides what the other cannot produce (Scambler, 2002). When social and personal contexts of lifeworld do not provide satisfactory accountings of lived experience or become problematic there is a desire for rational explanations. But the strength and performance of system is dependent upon, maintained and produced within lifeworld, and as such it is reliant upon lifeworld for providing foundational, communicatively shared meanings and patterns of consensus in order to legitimate its role and function. Consequently, the emphasis on rationalization of lifeworld increases the complexity of system and its influence and power over everyday lived experience while reducing the moral values and consensus required for system to operate. The result is a crisis of legitimation in system that arises because of system's colonization of lifeworld.

Over time, increased rationalization of lifeworld results in colonization as system expands within lifeworld to the point where it colonizes, or takes over, key areas of lived experience (Habermas, 1987). But it is not as simple as suggesting lifeworld becomes dependent upon increasing system complexity because while lifeworld seeks increased rationalization to account for unexplainable experiences, the basis for greater understanding provided by system must always be grounded in lifeworld itself (Habermas, 1987). System and lifeworld are not representative of two equal or dichotomous parts of society rather system is embedded within or

emerges from lifeworld. Kelleher (2001) explains how each is important but also susceptible to a loss of meaning.

In the theory of Habermas the lifeworld is an important part of society; it is also important that system and lifeworld remain integrated, for the mechanisms of the system, such as free market economy and the legal system, need to be anchored in the values of the lifeworld. As the system becomes more differentiated and the lifeworld more rationalized, there is a risk of ‘uncoupling’.  
(Kelleher, 2001, p. 129)

Uncoupling produces a loss of meaning that threatens lifeworld and system. As system gains influence the lifeworld is increasingly held under the sway of consumerist and commodified values and the public sphere becomes a place where administrative powers interject bureaucratic influence (Habermas, 1987). This makes it easier for system, via non-linguistic media such as money and power, to redirect interests and redefine issues in terms of the economy, politics or bureaucratization. Public and private interests are redirected from questions about morality, justice or human rights, thereby impoverishing social values intrinsic to lifeworld. Consequently, an impoverished lifeworld no longer provides moral values required by system.

Habermas (1975a) explains how this leads to inflexible systems that no longer operate under meaningful conditions. “The definitive limits of procuring legitimation are inflexible normative structures that no longer provide the economic-political system with ideological resources, but instead confront it with exorbitant demands” (Habermas, 1975a, p. 93). Facing greater demands system is called upon to provide value in terms of much more narrowly defined and reduced lifeworld. Eventually, these limited values no longer satisfy and a crisis of meaning occurs. A crisis is evident when it appears that system is responding and addressing lifeworld demands for rationality, but in actuality system does not have adequate explanatory control. This is the case when lifeworld demands exceed system’s ability to provide meaningful structure and

rationalization. Ironically, this raises doubts with the public and leads to distrust of system, yet it continues to fuel public interest and reliance on consumerist values (Habermas, 1987).

For example, in health and illness colonization and a crisis of meaning have occurred. Meanings of health and illness are increasingly tied to values of economy, technology and politics and defined in terms of consumerist values such as wait times and service user satisfaction. Arguably this has benefits but increasingly the health care system is unable to meet growing expectations and address public concerns about health and social care. Even as consumer expectations place strain on administrative, economic and political systems and there is greater demand for system to provide meaningful, value-laden approaches to health and illness issues. System values, and the strategic and instrumental actions required to sustain them, no longer provide an adequate or meaningful accounting of lifeworld experiences of health and illness, and meanings of health and illness are no longer wholly satisfied by either lifeworld or system. And so thematized meanings of health and illness become the focus of discursive negotiations brought on by the colonization process and crisis of legitimation.

The next step is not to examine differences or judge the value of various meanings, but rather to explore how lifeworld and system are linked in discursive negotiation of meaning. According to Habermas (1975a) “both paradigms, life-world and system, are important. The problem is to demonstrate their interconnection” by focusing on interaction, how meanings are negotiated, and what this accomplishes (p. 4). He does this by centralizing communication as a formal-pragmatic practice that takes place in theoretically ideal speech situations in the public sphere (Habermas, 1987).

### *The Public Sphere and Ideal Speech Situations*

Habermas's (1987) conception of the relationship between lifeworld and system works well as a framework for considering relationships between everyday lived realities and the way those realities are systematized and rationalized, but it is in the concepts of the public sphere and ideal speech situation where understandings of communicative interactions is explained. Habermas (1987) contends that opportunities for personal expression, which resist or reinforce hegemonic perspectives arising with the development of rational social systems, occur in the public sphere. This concept fits with the tradition of critical social theories intent on recognizing and describing the workings of society (Crespi, 2004).

With the conception of the public sphere the theory of communicative action recognizes formal and direct political struggles and the multivalent efforts of marginalized groups. Dahlberg's (2005) close reading of Habermas (1987) conception of the public sphere points out that it includes various forms of discourse (including everyday discourse), it considers positive and negative forms of power, and it emphasizes deliberation as a process rather than an end-goal. These points are significant because they indicate that Habermas's (1987) theory is not only applicable in more formal deliberative engagements, but it also offers conceptual frames for following the process of deliberation that individuals engage in while managing in day-to-day discourse as it relates to influences from broader social discourses. Pensky (2010) provides a succinct definition of the public sphere that describes it not only as a space for deliberation but also as a place where individual agency can be articulated and contribute to discourse.

The public sphere is the space that participatory modern politics opens up between the everyday lived world of shared particular experiences and attitudes, on the one side, and the hierarchical, bureaucratic institutions of modern governance, on the other. This narrow and fragile space constitutes the arena where subjects, as

citizens, exercise their rational agency by participating in informal discourses on matters of shared interest. (Pensky, 2010, p. 23)

Additionally, Dahlberg (2005) points out Habermas's (1987) development of the concept of the public sphere addresses more than a broad general public, it also includes all those disparate and "complex networks of multiple and overlapping publics constituted through the critical discourse of individuals, community groups, civic associations, social movements, and media organizations" (p. 6). Brady (2004) asserts there are agonistic qualities in Habermas's (1987) approach to the public sphere that have been missed or misread by critics who emphasize the consensual and normative qualities of his work. And Flynn (2014) adds Habermas's (1987) theoretical development of the concepts of system and lifeworld is "a formidable way of articulating realistic possibilities for mobilized public spheres" in the form of social movements (p. 213).

Habermas (1987) develops his concept of the public sphere from the perspective of what would be most ideal, not from the perspective of a negative assessment of society. He indicates there are opportunities for open and democratic deliberation of ideas within the public sphere. These opportunities are defined in part by what Habermas (1987) calls the ideal speech situation, which he notes is a theoretical ideal that is not usually achieved in real world contexts (Finlayson, 2005; Habermas, 1987; Outhwaite, 1994). According to Outhwaite (1994) the ideal speech situation like the public sphere is conceptually intended to provide an extension of what is possible, providing a virtual possibility of what society could aspire to, but also as an important "constitutive condition" for making rational communication possible (p. 45). As Finlayson (2005) explains "the concept of the public sphere is both an idea and an ideology" and it is theoretically "an inclusive and egalitarian vision of society worthy of pursuit, but never fully

realized” (p. 12). Habermas (1987) recognizes the imperfections, variety and complexity of real world discourse, and suggests that in order to communicate in view of these complexities, a level of shared understanding must exist (Fultner, 2010). In this regard Habermas (1987) explains that conceptualizing a public sphere and ideal speech situation must include an explanation of the way language is used as individuals strive to connect with others and achieve shared understanding and the meanings they wish to convey. This is particularly pertinent when considering communicative actions aimed at resisting or reinforcing hegemonic perspectives arising with the development of rationalized lifeworld experiences.

### *Communicative Action and Validity Claims*

As a social theorist, Habermas (1987) initiates a paradigmatic shift in critical theory, which looks at language use and the production of meaning as a necessary way to understand human society (Fultner, 2010; Habermas, 1975d; Mitrovic, 1999). To do this he draws attention away from a philosophy of consciousness, which he describes in the opening of Volume 2 of TCA as having already been deposed early in the 20<sup>th</sup> century by language based philosophies and psychological theories based on behaviourism (Habermas, 1987). The theory of communicative action emphasizes a “paradigm of mutual understanding between subjects capable of speech and action” (Habermas, 2003, p. 576). The theory is helpful for framing the relationships between individuals and social systems based not on material, economic or political grounds but on the basis of the action of communication in public sphere where individuals strive for ideal speech situations. The theory sets out a formal-pragmatic conceptualization of communication, which explains how language is used to convey meaning and how it coordinates social interaction (Fultner, 2010).



According to Finlayson (2005) the theory of communicative action “is pragmatic because it focuses not on what language says, but on what the language does; it is a theory of language (in) use” (p. 32). Drawing on speech act theory Habermas describes how communication serves a mediating function in society that involves three linguistic components—propositional, illocutionary and expressive—which provide formal structure for speech acts and are related to social interaction through cognition, obligation and expression (Habermas, 1987). Communicative acts are formalized in grammar as mutually accepted structures of language, and communicative acts become pragmatic when language is used to coordinate action. The theory of communicative action articulates formal-pragmatic elements of communicative action that contribute to the development of universal principles that guide social systems.

Communicative action is described as an “ambitious concept” that “attempt(s) to fuse hermeneutic and functionalist approaches in social theory” (Jütten, 2011, p. 701). It begins in the lifeworld as individuals draw on lived experience and existing discursive resources provided by both lifeworld and system. “Our formal-pragmatic description of the general structure of speech acts has to draw on the pretheoretical knowledge of speakers who belong to a modern and--in a sense still to be explained more precisely—rationalized lifeworld” (Habermas, 1987, p. 77).

Three claims made in discourse regarding the validity of speech in any given situation form the basis for communicative action. Habermas (2001) explains that as a linguistically meaningful endeavor the general goals of communication are outlined as claims of validity between speakers. With regard to a speaker’s implicit motivation, he proposes that communication is driven by attention to truth (that the claims made are as factual as possible), sincerity (that the claims made align with assured intentions), and rightness (that claims made communicate socially normative understandings) (Habermas, 1987). Fultner (2010) explains, “in

communicating, we represent facts about the world, we express our subjective states and we interact with others; and these three functions correspond to the three validity claims of truth, sincerity, and rightness that formal pragmatics analyzes” (p. xxiii). Outlined at linguistic and discursive levels, language functions to provide meaning and meaning can be negotiated based upon shared or contested claims to validity.

In providing a formal-pragmatic approach that focuses on what communication accomplishes, Habermas (1987) defines distinct goals, strategies and motivations for lifeworld and system. While validity claims demonstrate foundational commonalities of communicative endeavors, it is the disparate strategies and motivations of lifeworld and system that contribute to shifts in communicative--and therefore social action. Habermas (1987) takes the distinction between lifeworld and system approaches to social action (outlined above) to a more focused level when he outlines three functional aspects unique to communicative action.

Under the functional aspect of *mutual understanding*, communicative action serves to transmit and renew cultural knowledge; under the aspect of *coordinating action*, it serves social integration and the establishment of solidarity; finally, under the aspect of *socialization*, communicative action serves the formation of personal identities. (Habermas, 1987, p. 137) (emphasis in original).

The outline of these three functional aspects of communicative action explains how meaning is managed along individual, relational and societal lines.

The functional aspects of communicative action construct meaning that is negotiated based upon shared or contested claims about the perceived validity of communication (Habermas, 1987, 2001). Communicative action is implicitly motivated by the three validity claims. First, there is a desire for “truth” where communication is based on claims that are as factual as possible. Second, the desire for “sincerity” which involves some assurance that claims

and intentions are aligned. Third, when claims are made that fit socially normative understandings this satisfies the desire for the “rightness” of communication (Habermas, 1987).

As individuals use language to express the uniquely variable circumstances of their experiences their perspectives and ideas must be presented to some degree based upon a shared understanding of what makes socially acceptable discourse. On one hand this ensures a level of communicative purchase, no matter how confusing, random or oppositional the expressions might be. On the other hand, the use of language also situates and positions individuals in relationships with others, and how language is used helps them to secure and manage those relationships. Communicative acts involve argumentation and justification based upon idealized conceptions about what makes a good argument and believable truths which lead to acceptance or challenges to meaning based on lifeworld experience.

In the theory of communicative action Habermas (1987) provides a broad conception of how language works to create and maintain relationships in society and to convey meaning based upon shared values (Fultner, 2010; Habermas, 1987). It puts emphasis on “the rational and consensual elements operative in everyday speech and normative discourse” (Brady, 2004, p. 344) in order to explain how challenges to these elements influence and instigate social action. My discussion of Habermas’s (1987) theory of communicative action describes three main conceptual areas that account for how lived experience relates to social systems via communication. The distinction between lifeworld and system demonstrates how communicative acts shape and inform the rationalization of personal experiences and how this leads to a colonization of lifeworld by system. With this conception we can consider the ways lived experiences that are unexplained come to be part of systems and structures of society, but also how the search for rational explanations can go so far as to lose sight of morals and values.

Efforts to address this happen in the public sphere, which ideally includes opportunities for all stakeholders in an issue to have a fair say. Habermas (1987) notes this is not always the case but the idea of the ideal speech situation can show how conditions that are not ideal can be challenged when people seeking some consensus regarding their needs and points of view are able to question the validity of the communication of others. Habermas's (1987) theory is a macro and micro level conception of the role of communication in producing shared understanding with a view to how this constructs social systems. In the next section I outline Norman Fairclough's (1992) Social Theory of Discourse which takes a more focused approach to how language and everyday discourse work and what they accomplish in society.

### **Fairclough's Social Theory of Discourse**

Fairclough's (1992) Social Theory of Discourse explains how language functions in society to produce meaning and social change. It draws on numerous theoretical approaches including discourse analysis, linguistic studies and social theory and includes the work of Foucault, Habermas, Giddens and Althusser (Fairclough, 1992). It is a form of critical discourse analysis and addresses what Fairclough (1992) views as the missing elements of Foucault's discourse analysis which focuses on hegemony in historic and cultural discourse, and the close analysis of language such as that in conversation analysis. Fairclough (1992) has written extensively on critical discourse analysis, applied it to many settings, discussed its' key characteristics, and explored and explained ways to improve its use in the social analysis of discourse (Fairclough, 1985, 1993, 2010). However, in this chapter I focus specifically on his social theory of discourse as it fits best to consider the ways people manage dominant discourse in their personal narratives. The outline of the theory is particularly interesting as it addresses

three levels of language in society and accounts for the way discourse as practice has constructive and constitutive effects for individuals, relationally, and has an overall influence on social views.

In the social theory of discourse the main premise is that “changes in language use are an important part of wider social and cultural changes” (Fairclough, 1992, p. 5). The theory conceptualizes how language use in discourse influences social action at individual, relational and societal levels and identifies three “constructive effects of discourse” (Fairclough, 1992, p. 64). According to Fairclough (1992) discourse is involved in the construction of social identity, social relationships, and “systems of knowledge and belief” (p. 64). He explains most succinctly that language has three main functions which correspond to these discursive effects.

The identify function relates to the ways in which social identities are set up in discourse, the relational function to how social relationships between discourse participants are enacted and negotiated, the ideational function to ways in which texts signify the world, its processes, entities and relations. (Fairclough, 1992, p. 64).

Fairclough’s (1992) social theory of discourse is broad enough to account for social change yet provides a conception of language that is focused enough to discuss what goes on in language and relate this to what goes on in society for individuals, relationally and socially. With this theory Fairclough’s (1992) objectives are to connect linguistic and discourse analysis with social analysis and critical analysis of society to explore and analyze social change. To accomplish this he develops a theoretical framework comprised of a three-dimensional analysis of discourse which defines discourse as text, as discursive practice, and as social practice.

### *Three Dimensional Analysis of Discourse*

Fairclough (1992) regards discourse as a resource and as social practice. He highlights “a dialectical relationship between discourse and social structure” where discourse is influenced by the structure of social systems, but it also influences the development of social structures (p. 64). The central focus of Fairclough’s (2001) theory is social practice to which he attributes a great amount of action and influence in regards to social change. Focusing on the dialectical nature of discourse he explains how it plays a role in everyday practices of language use, how it is representational because it includes and “recontextualizes” other social practices, and how it is used to constitute identity and as such becomes a “way of being” (Fairclough, 2001, p. 2). Each of these roles is described as a dimension that contributes to and influences society.

Together the overall effect of the three roles or dimensions of discourse as a social practice is referred to by Fairclough (2001) as “orders of discourse”—these are the broad social structures or systems that are constituted in discourse as social practice (p. 2). Fairclough (2001) explains “orders of discourse” are ordered and networked social practices, which are characteristically dominant and hegemonic, they are described as the shared genres in which social life is enacted (p. 2). He points out “discourses include representations of how things are and have been, as well as imaginaries—representations of how things might or could be or should be” (Fairclough, 2001, p. 3). The representational and imaginary quality of discourse as social practice makes change possible through a process of “inculcation” which occurs when people take up and position themselves within orders of discourse (Fairclough, 2001). What is most significant is that in discourse people challenge and identify with particular orders of discourse in ways that resist them or reinforce them. They strategically manage discourse to suit calls for change and to support the status quo. According to Fairclough (2001) this involves

“rhetorical deployment: people may learn new discourses and use them for certain purposes while at the same time self-consciously keeping a distance from them” (p. 3). He adds that over time this leads to people being positioned in (subject to) orders of discourse without realizing it. To study the ways this may come about and interpret the implications this has for individuals and society Fairclough (1992) describes three dimensions of discourse including discourse as text, discursive practice, and discourse as social practice.

First, discourse as text is most clearly defined as instances of talk and/or written or recorded communication such as narratives that can be analyzed for structure and content. In the Social Theory of Discourse an analysis of text involves examining vocabulary, grammar, cohesion and structure (Fairclough, 1992). These move the analysis from a specific focus on words through to sentences, then to how sentences are structured and how the overall text is put together to create meaning (Fairclough, 1992). Further, attention can be given to the types of speech acts evident in a text, for example request or threat, and the ways the texts relate to other texts, intertextuality (Fairclough, 1992, p. 75). Fairclough (1992) points out an analysis of text generally includes some level of interpretation of the meanings in a text, and this overlaps with the second dimension.

The second dimension in the social theory of discourse is discursive practice. With discursive practice Fairclough (1992) is referring to the ways texts are produced, distributed and consumed in social interaction (p. 78). Analysis of discursive practice focuses on the way text is used to convey meaning. Although closely linked to text analysis, discursive practice focuses not on what is produced but how it is produced, that is, under what circumstances. Analyzing discursive practice involves interpreting how narratives are produced, situated and taken up in various contexts (Fairclough, 1992). This is done with the awareness that discursive practices

respond to and reflect the particular instances in which discourse happens. According to Fairclough (1992) discursive practices are influenced in two ways: 1) by what and how much a person knows about a topic or how well they are able to speak about it, and 2) they are limited by the social expectations (norms, conventions, orders of discourse) of a particular situation (p. 80). These elements and influences all come together to influence the interpretation of texts and talk in social interactions. Fairclough (1992) points out it is the ways these influences and interpretations work that is of most significance in the Social Theory of Discourse. He explains,

The major feature of the three-dimensional framework for discourse analysis is that it attempts to explore these constraints, especially the second – to make explanatory connections between the nature of the discourse processes in particular instances, and the nature of the social practices they are part of. (Fairclough, 1992, p. 80)

This theoretical framing is most pertinent when considering how people manage dominant discourses in personal narratives because it highlights the importance of analysis of text as a practice in the process of communication and meaning production that is influenced by other discourse and by circumstances.

The third dimension of discourse is discourse as social practice and this dimension refers to discourse at broad social levels. It turns analytic attention away from the significance of text and contexts of production to look more broadly at the hegemonic and ideological influences of discourse (Fairclough, 1992). According to Fairclough (1992) ideologies are broad “significations/constructions of reality” that frame understandings of social relations and identity, that are evident in and guide construction of texts and discursive practices, and that inform, direct, advance or alter “relations of domination” (p. 87). Ideologies are part of



discursive structure and part of social action, which Fairclough (1992) notes is best viewed in a dialectical and fluid relationship.

The key to the third dimension of discourse as social practice is hegemony. For Fairclough (1992) the concept of hegemony points the way to possibilities for social change. It is the social power expressed by dominant groups that lead in areas of politics, economics, and culture, but (like Habermas's (1987) system) it is also vulnerable to change, instability, and challenge. Fairclough (1992) describes hegemony opportunistically, "Hegemony is about constructing alliances, and integrating rather than simply dominating subordinate classes, through concessions or through ideological means, to win their consent" (p. 92). He adds hegemony involves struggle, instability, and the construction or destruction of social relations on a broad social scale (Fairclough, 1992). In Habermas's (1987) terms this may be considered like the negotiation of meaning between lifeworld and system, where the "spread of conversational discourse from the private domain of the lifeworld into institutional domains" resists or reinforces hegemony (Fairclough, 1992, p. 98). With the concept hegemony Fairclough (1992) stakes a claim that brings together the idea that theorizing discourse as text, discursive practice and social practice highlights how discourse is specifically and broadly influential in social change.

### **Summary of Theory**

In this chapter I described conceptual elements of Habermas's (1987) Theory of Communicative Action and Fairclough's (1992) Social Theory of Discourse. Due to the comprehensive and extensive nature of the work of both theorists concepts in the theoretical frameworks that most resonate with this thesis were described. First, Habermas (1987)

centralizes communication in a theory that addresses the relationships between lived experience and societal structures that organize and direct experience. He begins with a phenomenological view that roots communication in lifeworld and explains how the need to rationalize some lived experiences leads to the development of system. When the increasing rationalization of experience prompts a call for a return to moral and ethical values, system responds by colonizing more of lifeworld experience. He suggests that calls for change come through the public sphere where ideally people have opportunities to participate as people speak out about their needs. He indicates that in striving for ideal speech situations people make claims about the validity of other peoples' efforts in discourse, and suggests challenges to these efforts lead to change.

The second theory I outlined was Fairclough's (1992) Social Theory of Discourse which attends to how language use in society has influential effects. He describes discourse as social practice and outlines three functions of language that correspond to three dimensions of discourse. Language constructs social identities, it builds and informs the construction of social relations, and it influences and constructs beliefs and knowledge about how the world and society function. From this Fairclough (1992) describes a theoretical framework that attends to three dimensions of discourse 1) discourse as text, which includes analysis of language form and content, 2) discursive practice, which refers to the ways discourse is produced and shared in relations to contexts and circumstances in which the discourse takes place and 3) discourse as social practice, wherein the concept of ideology is viewed as both a structuring of society and a part of social processes, and hegemony which is essential because it is in the discursive struggles over power and meaning where opportunities for social change are most likely to happen.

In the next chapter I follow these conceptualizations of discourse as influential social practice to a more specific methodological level in a discussion of Gubrium and Holstein's

(2009) approach to Narrative Inquiry called Narrative Ethnography. I discuss the theoretical foundations and describe the key methodological concepts of their methodology. Habermas's (1987) Theory of Communicative Action, Fairclough's (1992) Social Theory of Discourse, and Gubrium and Holstein's (2009) Narrative Ethnography move the theoretical and methodological thinking for this thesis from a broad understanding of discourse as social practice with influence on social action, through to focused attention on how to analyze personal narratives. They provide a comprehensive theoretical and methodological framework for my analysis of personal narratives about mental illness online, and my explanations for how narrative strategies are used in these stories as people manage the expectations and contradictions of medicalized discourse.

## CHAPTER 4 METHODOLOGY

Reviewing the literature in chapter two I described how studies of personal narratives about madness attend to the content and form of stories and highlight themes and categories for analysis, but have given limited attention to analyzing the work that goes on in narratives as people manage various discourses in light of their experiences. In chapter three I described the Theory of Communicative Action (Habermas, 1987) and the Social Theory of Discourse (Fairclough, 1992). I draw on these theories to inform my conception of the central role of communication in expressing lived experiences within social systems, for describing narratives as a discursive practice, and for recognizing how language influences social identity, social relations, and societal knowledge and beliefs. From this I understand personal narratives as active practices of meaning making in discourse, rather than only as products of experience.

In this chapter I describe Gubrium and Holstein's (2009) method of narrative ethnography. This methodology allows me to attend to how meaning is accomplished in discourse by alternating between an analysis of the work and the contexts of narrative practice. Narrative ethnography is an analytic guide that helps to with interpretation of the interplay between personal narratives and dominant discourses. This approach works well for my analysis of personal narratives about madness online and my interpretation of the narrative strategies used to manage dominant discourses.

### **Narrative Inquiry**

Narrative inquiry is comprised of various methodological approaches that appreciate and attend to narratives as a rich source of insight about lived experiences. It encompasses anything and everything to do with stories in everyday talk and text. According to Chase (2008)

“contemporary narrative inquiry can be characterized as an amalgam of interdisciplinary analytic lenses, diverse disciplinary approaches, and both traditional and innovative methods—all revolving around an interest in biographical particulars as narrated by the one who lives them” (p. 58). All together the possible methodological approaches for doing narrative inquiry present a tangle of analytic possibilities for studying all forms of stories about all manner of substantive topics making it challenging to determine whether or how, a particular methodology best fits for a critical study of narrative. Holstein and Gubrium (2012) suggest securing the “integrity of the research process” involves careful deliberation about the analytic goals of the research, consideration of the substantive nature of the stories being studied, and alignment of theoretical perspectives, methodology, and analytic goals. They add when researchers recognize the “theoretical sensibilities that shape their procedural choices” the selection of a methodological approach is strengthened (Holstein & Gubrium, 2012, p. 6).

To sort out the complicated field of narrative inquiry Holstein and Gubrium (2012) frame it according to “how researchers from various disciplines deal with narrative data” (p.4). They explain the analytic focus of the research process, by virtue of the strategies and tactics used to address narrative data, helps to distinguish between various approaches in narrative inquiry. Holstein and Gubrium (2012) identify three possible categories of narrative inquiry based upon analytic focus. First, a narrative analysis may focus on the *content and form of stories*. Second, a narrative analysis may focus on *interactions between storytellers and the production of storytelling*. Third, a narrative analysis may focus on *stories in society*—how they come to be and what they accomplish (Holstein & Gubrium, 2012). As evidenced by the wide array of narrative methodologies these three perspectives overlap and intermix, but the degree of

emphasis placed on each (or one) area characterizes the narrative inquiry. The analytic emphasis of this thesis is *stories in society*, and the methodology I use is called Narrative Ethnography.

Gubrium and Holstein's (2009) methodology—Narrative Ethnography—provides theoretical foundations and methodological guidelines that support my examination of the narrative strategies people use in personal stories to manage dominant discourse about madness. This methodology supports my exploration of the ways narratives strategies are used in personal stories to resist, reinform and reinforce dominant discourses about madness, and more broadly for discerning how personal stories contribute to discourse that supports or refutes broad social constructions such as medicalization. The methodology provides guidelines for analyzing stories at the level of everyday discourse and then, using analytic bracketing, it outlines how to analyze discourse at broad social levels. Narratives are analyzed as a social practice for what they accomplish in discourse. In this thesis narrative ethnography helps me identify and explain the narrative strategies people use in their stories as they manage contradictions and expectations of dominant discourse about madness. Narrative ethnography helps bring to light the way stories work as they bridge meaning between personal experience and social and medical perspectives about madness.

### **Narrative Ethnography**

Narrative ethnography is the critical assessment of the contexts and practices of discourse in text and talk. Narrative ethnography involves an analysis of the narrative practices that happen as a story develops, the narrative contexts that relate to how a story develops, and an interpretation of the relationships between them. Recognition of narrative themes and story forms that are relevant to personal experiences expressed in the stories also contribute to the

analysis. These methodological characteristics and the theoretical traditions that support them align with the analytic goals of this thesis, which are to analyze the narratives strategies used in personal stories posted online to discern how they resist, re-inform, and reinforce dominant medicalized constructions of madness, and for how these stories work at bridging meaning in discourse.

Narrative ethnography is a methodology that supports a critical analysis of narratives. Exploration of how narrative circumstances and processes of storytelling are related in the social construction of meaning reduces epistemological tendencies to embrace the narratives uncritically. Atkinson and Delamont (2006) caution that the ideals researchers share about the inherent value of narratives can compromise the critical potential of research when personal stories are privileged as more authentic than other forms of discourse, when analysis disregards context, and when narratives are studied as products rather than processes in social interaction. If a narrative inquiry merely celebrates the emancipatory value of stories in the struggle for meaning without some critical level of analysis, the results and conclusions are compromised (Atkinson & Delamont, 2006). For example, when an inherent value is placed upon the authenticity of personal stories their truth as a form of experiential knowledge goes unquestioned among other forms of discourses. This elevates narratives above other forms of discourse without consideration for how they relate to other discourses or what makes them more or less important. Consequently, interpretations regarding what is valuable about a story are based upon content and character rather than relationships to other discourses, to narrative contexts, and to the ways stories are constructed in practice. Additionally, when efforts to tell a personal story are interpreted as an act of agency or voice without reference to the contexts and conditions of storytelling there is a missed opportunity to explore why and how the story, and the act of

storytelling are liberating. Narrative ethnography resolves these issues because stories are analyzed as ongoing social practices influenced by and taking place in relation to a variety of contexts and discourses and with reference to how they highlight possibilities for social action (Gubrium & Holstein, 2000).

*Theoretical Traditions: Taking up a position on the “analytic catbird seat”*

Narrative ethnography is theoretically positioned to view the interconnections between everyday discourse and dominant societal discourses. This view helps to highlight the consequences of discursive relationships. Situated at the “crossroads of narrative, social interaction, culture, and institutional life” Holstein and Gubrium (2000, p. 96) take up a theoretical position they describe as “an analytic catbird seat” (Gubrium & Holstein, 1998, p. 416). Rooted in social constructionism, the vision for an inherently critical approach to narrative inquiry was crafted from a collaboration of three theoretical traditions.

Narrative ethnography draws together theoretical constructs from social phenomenology, Foucauldian discourse analysis, and ethnomethodology. These three traditions have a common interest in the empirical value of lived experience (epistemologically-knowledge and/or ontologically-existence). They centralize discourse and power, and have advanced theoretical discussions aimed at uncovering and following the construction of meaning in and through discourse. However, each advances a different methodological focus when it comes to analyzing discourse. In social phenomenology, the primary focus for understanding the world begins with the study of everyday experience and discourse is just one part of that experience. Ethnomethodology examines discourse as it occurs in everyday interactions between people in order to analyze how experience and knowledge of the world is produced. Foucauldian discourse



analysis follows how relationships between discourse, power and knowledge position people as subjects in society.

Narrative ethnography emphasizes the complementary characteristics of these theoretical traditions (Gubrium & Holstein, 2009). The unique perspectives of each approach are not set against each other as conceptual competitors, nor are they merged together to form a theoretical amalgam (Denzin, 1998; Dingwall, 1998; Gubrium & Holstein, 1997). According to Denzin (1998) “in a stunning sequence of theoretical moves, the authors create a space for dialogue between and across” theoretical traditions (p. 406). The use of these theoretical traditions is intended to make narrative ethnography inherently critical—to give it a “critical consciousness ” making it distinct from other methodologies (Holstein & Gubrium, 2005, p. 499).

In our view, what is required is a new hybridized analytics of reality construction at the crossroads of institutions, culture and social interaction—an analytics that “misreads” and co-opts useful insights from established traditions in order to appreciate the possible complementarity of analytic idioms, without losing sight of their distinctive utilities, limitations, and contributions. (Holstein & Gubrium, 2005, p. 492)

In narrative ethnography the theoretical perspectives and analytic strategies of social phenomenology, Foucauldian discourse analysis, and ethnomethodology are adapted and alternately applied throughout the research process. It is “a strategy of playing one conceptual source against another to gain analytic leverage on the complex process of social construction” (Gubrium & Holstein, 2012, p. 348). The objective in bringing them together is to gain insight into the practices and circumstances involved in discursive interaction. Analysis of everyday discourse in relation to dominant discourse constructs a comprehensive view of how meaning is constructed. The result is a methodology that concentrates on how narratives come together in light of local and societal circumstances (Gubrium & Holstein, 2009). Scholars interested in

narrative inquiry welcome the emphasis on positive interconnections between theoretical traditions and the flexibility of shifting analytic focus between local and societal discourse. With narrative ethnography researchers can take up a central and active position for analysis of what goes on between big and small stories. According to Smith and Sparkes (2009),

That is, it allows us to maintain a focus on the interactional accomplishment of local realities in terms of, for example, the ways in which stories about experience are presented, structured, and made to cohere, while also allowing us to maintain an awareness of the institutional and cultural conditions that shape this accomplishment. (Smith and Sparkes, 2002, p. 145)

Using narrative ethnography involves analysis that alternately focuses on personal stories and dominant discourses to interpret how they support or refute dominant social constructions of experience, such as medicalization. For instance, this thesis benefits from reflexive attention to the ways discourse is used to make claims about madness, which brings to light how medical and social perspectives about madness are influenced by and influence personal accounts, while helping to highlight what is accomplished in the discursive relationships between the two. An analysis using narrative ethnography highlights what is meaningful about discourses about madness, how it is meaningful, and what is accomplished by particular stories about particular circumstances as they work to advance or agonize medicalization. Gubrium and Holstein (2009) explain narrative ethnography facilitates critical “interest in both the internal and external organization of accounts, especially how the two relate in practice to produce situationally adequate stories” (Gubrium & Holstein, 2009, p. 17). Theoretically narrative ethnography builds conceptual tools and processes for analyzing narrative reality as people participate in discourse.

### *Interpretive Practice*

Narrative ethnography is more than a staid framework or theoretical curriculum it is an active methodology for analyzing the practices of narrative production. Gubrium and Holstein (2009) provide “analytic guidelines and procedural suggestions” that move methodologically from considerations of how stories are socially constructed to what circumstances influence and inform that construction (p. 124). This is achieved using a method of analysis called “interpretive practice” (Gubrium & Holstein, 2009; Holstein & Gubrium, 2000). The objective of interpretive practice is to discern how meaning is accomplished in discourse by alternating between an analysis of how everyday discourse is produced and an analysis of the broad social and discursive conditions in which this production occurs. The goal throughout the research process is to map and interpret the circumstances and the production of everyday narratives in view of dominant discourses by analyzing what is involved in telling a story and how contexts influence the telling. According to Holstein and Gubrium (2012)

If one views stories as taking shape and being reshaped in the process of presenting accounts in the context of cultural particulars — then it is eminently sensible to employ a form of analysis that does not focus exclusively on personal accounts but traces how accounts unfold in social interaction. (Holstein & Gubrium, 2012, p. 6)

Using interpretive practice the analysis shifts between analysis of the work of producing narrative, with analysis of the contexts or circumstances of production. In interpretive practice how the stories are produced and presented and the consequences of their presence is of greater interest than the correctness of the substantive narrative content or the narrative structure of a story though this does have bearing on the analysis. Overall the interpretive practice is a method that attends to how narratives develop, under what circumstances, and with what effect.

Interpretive practice gives analytic attention to two essential areas including narrative context and narrative practice in order to view possibilities or opportunities for social action and “potential for change” (Holstein & Gubrium, 2005, p. 500). With interpretive practice narrative accounts are conceptualized as ongoing processes of meaning-making where personal experience is socially constructed and in ways that may reflect shared understanding of the social conventions for how a story should be told in a particular setting, at a particular time, to a particular audience. In this regard narrative accounts are analyzed as discursive practices in communicative action that participate in discourse by responding to and including relevant and related circumstances. In the analytic process this ensures that attention is given to what matters in personal accounts, while giving equal attention to what is emphasized as popular or important in dominant discourse.

With an analysis of the how stories come together and what contexts influence their development, differences and similarities in language use become visible. Interpreting how and why particular language is used helps in discerning what is accomplished in discourse, and what could be accomplished. Differences and similarities in language use are analyzed for the ways they are invoked in dominant discourse and everyday narratives, and for what meaning this produces. However, interpretive practice looks beyond the structural nature or thematic content of stories. It resists generalization of individual experiences into broad social categories based on ideal types of stories by emphasizing discursive relationships in view of the contexts and practices of storytelling. Narrative ethnography resolves criticisms that face other approaches in narrative inquiry by analyzing narrative “as a form of social action, with its indigenous, socially shared, forms of organization” (Atkinson & Delamont, 2006, p. 170). Like other narrative approaches there is interest in the content and organization of storied accounts, but connecting

the analysis of content with an analysis of the circumstances of story construction is unique to narrative ethnography. While a focus on the content of a story (themes, issues) and how it is organized in specific instances (interviews, testimonies) draws out the emancipatory potential of a story as a product of social interaction, the use of interpretive practice resists privileging and generalizing individual experiences into broad categories. For to consider stories solely as descriptive accounts of personal experience negates their role and value as agents of change working in discourse.

Interpretive practice provides a method of analysis that highlights how narratives engage with and manage dominant discourses. It helps to uncover how and what narrative accounts contribute or can contribute to social action as participants in discourse, whether they aim to support or refute hegemonic constructions of experience such as medicalization. Holstein and Gubrium (2005) explain,

Putting it in ethnomethodological terms, the aim of an analytics of interpretive practice is to document the interplay between the practical reasoning and interactive machinery entailed in constructing a sense of everyday reality, on one hand, and the institutional conditions, resources, and related discourses that substantively nourish and interpretively mediate interaction, on the other. (Holstein & Gubrium, 2005, p. 493)

Interpretive practice encourages critical and reflexive analysis on two fronts. First, it asks how practices of storytelling come into play to construct meaning in discourse. Second, it asks what circumstances or contexts influence storytelling practices and what influence this has on directing meaning. The inclusion of both brings to light social realities where “diverse articulations of discourse intersect, collide, and work against the construction of common or uniform subjects, agents, and social realities” (Holstein & Gubrium, 2005, p. 498). These diverse articulations are managed methodologically through a process called “analytic bracketing” which

details how to alternate between dominant discourse and everyday narrative, and how to account for the practices and contexts that influence their relationship and development.

### *Analytic Bracketing*

In interpretive practice, analytic bracketing is the essential methodological tool used throughout the research process. The objective of analytic bracketing is to be inclusive of everyday narratives and dominant discourses in order to reveal how they engage in meaning construction. Analytic bracketing involves alternating analyses between everyday discourse and dominant discourses focusing on one at a time and setting aside or bracketing the other. It is a form of “critical bracketing” that makes “visible the constructive fluidity and malleability of social forms” and works to “reveal a potential for change” (Holstein & Gubrium, 2005, p. 500). Using analytic bracketing to follow the interplay between discourses-in-practice and discursive practices highlights the ways personal stories participate in the “practical accomplishment of meaning and its relation to social action” (Holstein & Gubrium, 2005, p. 483).

Analytic bracketing involves four analytic concepts. The first two dimensions represent the levels of discourse that come under analysis. These are dominant discourses, which are defined as *discourses-in-practice*; and everyday discourses, which include personal narratives, and are defined as *discursive practices*. The other two concepts frame the analysis of *how* narratives come to be and under *what* circumstances they develop. These are referred to as *narrative work* and *narrative environment* (Gubrium & Holstein, 2009). The concepts are used in analytic bracketing.

## Discourses-in-Practice

Drawn from the theoretical perspectives of Foucauldian discourse analysis, *discourses-in-practice* are the broad social, historical and cultural discourses in which experience and meaning take place. Discourse at this level is recognized as a form of, and a vehicle for the expression of power. In his extensive accounting of madness for example, Foucault (1965) demonstrates the way historical and cultural discourses define madness and create subjectivities controlled via discursive norms and expectations. In narrative ethnography when the analytic focus is on discourses-in-practice it explores what is happening discursively at historical and cultural levels and sets aside consideration of individual accounts (Gubrium & Holstein, 2009; Holstein & Gubrium, 2000). The objective is to identify the way dominant discourses advance or restrain social constructions of experience. For example, the way social discourse invokes and advances the medicalization of madness. An analysis of discourses-in-practice aims to identify controlling discourses and establish their role in producing or contributing to discourse in everyday circumstances. The analysis also aims to discern the consequences of these constructions and what happens when people take up or contest discursive subjectivities, such as medicalization. Analysis of discourses-in-practice highlights “grounds for problematizing or politicizing the sum and substance of what otherwise can be too facilely viewed as arbitrary or individualistically constructed, managed, and sustained” (Holstein & Gubrium, 2005, p. 499). After identifying influential characteristics of dominant historical and cultural discourses, the analysis shifts to focus on discursive practices with the aim of uncovering how discourses-in-practice are taken up and managed in the everyday interactions.

## Discursive Practice

*Discursive practice* is most simply defined as everyday talk and text. Ethnomethodologically it is viewed as an interactional accomplishment where meaning is constructed via the discourse of everyday conversational practices and in particular contexts. Analytic bracketing is used to focus on discursive practices and demonstrate how and under what circumstances, identity and other individual social constructions of meaning are produced. Setting aside discourses-in-practice, an analysis of discursive practices emphasizes how meaning is negotiated in everyday situations. This does not mean however that the broader implications of discourses-in-practice are completely forgotten, rather they are set aside as the focus is on the individual production of narrative accounts. For example,

Social realities such as crime and mental illness are not taken for granted; instead, belief in them is suspended temporarily in order to make visible how they become realities for those concerned. This brings into view the ordinary constitutive work that produces the locally unchallenged appearance of stable realities. This policy vigorously resists judgmental characterizations of the correctness of members' activities. Holstein and Gubrium (2005, p. 486)

By bracketing discourses-in-practice, the analysis discerns how individuals in everyday situations manage and express their personal experiences in discourse as it relates to their circumstances and to the practices of storytelling relevant to them at a particular time and place. The methodology is notably critical as the analysis foregrounds the narrative efforts of people who experience the consequences of dominant discourses-in-practice. Analysis of discursive practice brings to light the reasons why dominant discourses are (and need to be) managed and challenged (Holstein & Gubrium, 2005).

For example, dominant historical and cultural constructions of madness in everyday discourse are not merely recognized, they are broadly accepted as the correct way to refer to and



talk about madness—as mental illness. Discursive practices (the everyday constructions of madness experience) are looked to as examples of these hegemonic views, however, they are also influential participants and critical informants of how social constructions of madness are formed and managed. An analysis of discursive practices opens up considerations for why, where, and how taken-for-granted perspectives and definitions of madness can change. Analytic attention results in more than recognition, inclusion and acceptance of personal discourse as a contributor to discourse about madness. It helps to highlight what is meaningful, how it may have become meaningful, and what is accomplished by particular stories in particular circumstances (Holstein & Gubrium, 2000).

Understanding the relationships between personal narratives and dominant discourses involves analysis of the ways stories are practiced, under what circumstances they evolve, how they are present (and presented) in discourse (Gubrium & Holstein, 2009; Holstein & Gubrium, 2000). As analytic bracketing brings into view either discursive practices or discourses-in-practice, analysis is applied to how narratives are practiced and in what contexts. Now, with either discursive practices or discourses-in-practice in view the analysis explores the processes and circumstances relating to narrative participation in discourse. Attention is given to the practices by which everyday discourses come to be constructed—the *narrative work*—and to the relevant contexts in which narrative work takes place—the *narrative environment* (Gubrium & Holstein, 2009; Holstein & Gubrium, 2000). This dual analysis is an essential part of interpretive practice. A focus on *narrative work* and *narrative environment* provides the opportunity to identify possible connections between discursive practices and discourses-in-practice, and interpret how they develop and what they achieve (Gubrium & Holstein, 2009). According to Gubrium and Holstein (2012), “The reflexivity of the artfully methodical and the substantive

sides of reality construction is a key to our program. Discursive activity, on the one hand, and discursive resources and conditions, on the other, are mutually constitutive” (p. 344). Analytically bringing to light the contexts and practices of narrative construction at everyday and societal levels of discourse points the way to “alternative constructions” of meaning (Holstein & Gubrium, 2005, p. 500).

### *Narrative Context*

Stories and storytelling have consequences in society. Storytellers make choices about what to include or leave out of their accounts. They do so for particular reasons that may or may not be clearly evident. Using narrative ethnography the relevance of the narratives as contributors to social action is made apparent when accounts are analyzed in relation to the contexts in which they take place. In narrative ethnography, stories are viewed as “discursive ways of doing or accomplishing something” and therefore are analyzed as ongoing practices in relation to context (Holstein & Gubrium, 2012, p. 7). In this thesis exploring and mapping the ways meanings about madness are managed at the intersection between personal stories and dominant discourses benefits from an analysis of context. Using narrative ethnography, the consequences of what contexts stories draw on, work through, and reproduce to convey meaning about madness are recognized as meaningfully consequential. To accomplish this involves thinking about how narratives are situated in social discourse. Gubrium and Holstein (2009) explain,

Concern with the production and reception of stories in society requires that we step outside of the narrative texts and consider questions such as who produces particular kinds of stories, where are they likely to be encountered, what are their purposes and consequences, who are the listeners, under what circumstances are

particular narratives more or less accountable, how do they gain acceptance, and how are they challenged? (Gubrium & Holstein, 2009, p. 23)

The knowledge gained from analyzing narratives in context expands possibilities for understanding just why and how certain discourses (dominant and individual) come to be, while bringing to light social and cultural assumptions, as well as what these assumptions achieve and for whom.

Narrative ethnography is theoretically guided by an interest in how people socially construct experience. The method for analyzing context draws on the phenomenological view that reality and experience of the world are “actively constituted” through human consciousness and social interactions (Gubrium & Holstein, 2000; Holstein & Gubrium, 2000, p. 86; 2005). In narrative ethnography context is viewed as it is constructed and defined in the text and talk of discursive practice. Therefore analysis of narrative as socially constructed reality necessarily begins with the assertion that context is constructed and presented in narrative accounts. In narrative ethnography context is integral to the analysis and recognized as essential to the practice of meaning making.

Advancing a critical perspective, narrative ethnography displaces notions of context that define it simply as the physical or social space in which stories happen (Fairclough, 1992; Gubrium & Holstein, 2009; Kupferberg & Green, 2005). In narrative ethnography context is analyzed as discursively constructed reality made meaningful via the process of narrative construction in particular circumstances. It is “not a social situation but a subjective mental model that participants construct of the relevant properties of the social situation” (vanDijk, 2003). According to Kupferberg and Green (2005) people “constantly construct and co-construct the cultural, social, psychological, and historical contextual resources that are relevant to them

during the interaction in the “workshop room” of problem discourse sites” (p. 19). Attending to context and how storied accounts are constructed in practice increases the critical nature of narrative inquiry (Atkinson, 1997).

However, Holstein and Gubrium (2004) point out although context is an essential and influential part of narrative practice it is not always attended to in narrative inquiry. They explain, “context can come into interpretive play in seemingly endless ways. It is essential to any understanding of social behaviour, yet it is not uniformly consulted or used in social analysis” (Holstein & Gubrium, 2004, p. 299). In narrative research, context is included inconsistently. It is openly referred to in analyses of collections of stories or it is subtly mentioned as background in discussions of narrative and social behaviour. Narratives are analyzed away from or out of context in order to get at the linguistic structure of a story or its thematic content (Atkinson & Delamont, 2006). The context of stories is either taken-for-granted or left undisturbed. When narrative content and organization are the sole focus of analysis context is obfuscated.

Examining narrative accounts independently of context leads to assumptions about why a story is told, why it is told in a particular way, why it is meaningful, and what consequences this has for storyteller and society. These assumptions may or may not be in keeping with the constitutive influences and original contexts of the narrative. Further, assumptions or oversight about contexts encourage the expansion of dominant views and discourses that have either lost efficacy or that favour interpretations of experience that have negative consequences for marginalized groups. For instance, discourse about madness has been practiced across a wide variety of contexts. Medicalized constructions consistently and considerably influence this discourse. Narrative studies discuss how the inclusion of personal perspectives via stories has shifted what was once a solely medical frame. Analysis of narrative content and structure has

brought to light particular topics of concern and highlighted how discourse is used to encourage the use of medicalized language or construct unequal subject relationships. An analysis that includes contexts aims to highlight how subject relationships, use of language, and topical issues are advanced because they are discursively connected to one another. Such an analysis indicates how even as it resists medicalization, madness discourse remains rooted in it. Understanding how the medicalization of madness is managed requires more than an analysis of narrative content or structure. A close look at the various contexts in which meanings about madness are constituted is required if the workings of these discursive relationships are to be unraveled.

Isolating narratives and studying them without consideration of the contexts they are constructed in limits how much can be understood about their value and meaning or how they participate in constructing meaning in society. To consider the content or form of a narrative without consideration of when, where or how it came to be reduces or removes essential points of reference for understanding its' meaning. Stories have value because of the ways they relay and construct meaning in particular contexts. As narratives are constructed and expressed they convey and create meaning in and about lived experiences. Analyzing narratives with close attention to the contexts in which they are practiced strengthens how well they can be understood and creates discursive space for new renderings of experience.

### Narrative Environment

Narrative ethnography encourages flexibility and the acceptance of a plurality of lived experiences as they are constituted in full view of the multitude of social contexts that influence narrative practices. In narrative ethnography contexts are conceptually referred to as *narrative environments* and are defined as the contextual and circumstantial settings where stories take

place (Gubrium & Holstein, 2009). They are the spaces in which storytellers are positioned to tell their stories. Narrative environments are represented as physical spaces such as workplaces, schools, or the local grocery store. They include metaphorical, emotional and psychological spaces in which social life is experienced such as in families, friendships, and culture (Gubrium & Holstein, 2009). Narrative environments also include discursively constructed social positions such as status, agency and influence (Gubrium & Holstein, 2009). Analysis of narrative environment identifies circumstances in which struggles for meaning take place, and demonstrates how contexts are implicated in that struggle.

Narratives take place across a myriad of contexts for various reasons and depending on the narrative environment a storied account may be told in a variety of ways. As variations of a story are constructed to accomplish different goals in different circumstances the struggle for shared meaning increases. For example, narratives about madness told in hospitals and courtrooms are constructed in different ways to accomplish different ends—either clinical treatment or incarceration (Holstein, 1988; Holstein & Gubrium, 2004). Riessman (1993) points out “narrators speak in terms that seem natural, but we can analyze how culturally and historically contingent these terms are” by considering the narrative environments in which they speak (p. 5).

Although the number of narrative environments in “storytelling are endless” the analysis of narratives in context need not be a never-ending or impractical task (Gubrium & Holstein, 2009, p. 123). Narrative ethnography offers five analytic guidelines that facilitate critical and pragmatic analysis of context. First, because there are so many possible narrative environments or contexts it is essential to set clear boundaries that mark out the most relevant contexts for analysis (Holstein & Gubrium, 2004). The boundaries are not necessarily a reflection of or the

result of a predetermined set of theoretical themes. In narrative ethnography contextual boundaries may be based upon an initial review of narratives, which highlights the most relevant and referenced narrative environments in storied accounts. Gubrium and Holstein (2009) indicate there are broadly identifiable narrative environments that may be considered, including but not limited to close relationships, local culture, status, jobs, organizations, and intertextuality.

Analysis of narrative environment is a way to follow the influence of context on storied accounts to see not just what is said, but how what is said comes about in view of contextual influences. Phoenix and Howe (2010) describe how analysis of narratives in view of narrative environments is a way to get at the process of meaning making as it occurs in various settings.

What we aim to achieve here is a methodological illustration regarding how we might analyze data in such a way that takes into account the role of context across social settings and subsequently allows a consideration of how context is brought to bear on the experiences of everyday life; that is, how context can shape and frame the process of meaning-making. (Phoenix and Howe, 2010, p. 142)

To facilitate the analysis of narrative context involves discussion of how the narrative environments under consideration in the narratives are relevant for the analysis (Holstein & Gubrium, 2004). This is the second guideline, and it ensures the analysis accounts for how the context and the meanings of the narratives are connected. To analyze how narrative environments are related to the meanings put forth in a story the consequences of storytelling in or about that environment must be clarified. The analysis takes up narrative environments as more than background context for a story. Rather narrative environments are analyzed as an influential part of the meaning making process in order “demonstrate empirically the linkage between action and contextual effects” (Holstein & Gubrium, 2004, p. 308).

The third analytic guideline suggests a narrative environment should be “described and analyzed as it is more or less recognized by, or related to member and their activities” (Holstein & Gubrium, 2004, p. 309). Throughout their fieldwork Gubrium and Holstein (2009) emphasize the ways contexts are “extremely consequential” for both storytellers and society (Holstein & Gubrium, 2004, p. 302). Including narrative environments requires an analysis of how storytellers view themselves in particular contexts. It involves analysis of, if and how storytellers recognize their role in taking up a position in these narrative environments, how they convey and interpret their positions, and whether they recognize options and alternatives for how these narrative environments construct subjectivities.

The fourth guideline is cautionary. It warns against analyzing narratives in order to determine cause-and-effect implications between narratives and narrative environments. Analysis requires a focus on relationships between discourse and context, not causes-and-effects. To achieve this narratives and narrative environments are viewed from more than one perspective. Drawing on ethnomethodological and discourse analytic practices, narrative ethnography takes a top-down/bottom-up approach to analysis (Holstein & Gubrium, 2004). Analysis of narratives is accomplished in view of both discourses-in-practice (dominant discourses) and in reference to discursive practices (everyday discourse) in order to interpret analytic connections between narratives and narrative environments. For example, Foucault’s (1965; 2009) analysis of historical and societal perspectives on madness demonstrates complex relationships between discourse, power, and subjectivity. An analysis of narratives and narrative environments at a broad societal level uncovers “sociohistorically variable ‘discursive formations’ (sometimes referred to as ‘discourses’), systems of rules which make it possible for certain statements but not others to occur at particular times, places and institutional locations”



(Fairclough, 1992, p. 40). However, to explore how these systems of rules are managed in daily conversation requires a close analysis of narratives and narrative environments at the level of everyday discourse. This brings to light what is involved in resisting or reinforcing the rules and what consequences this has on discourse and eventually on lived experience. Analyses that include both top-down and bottom-up perspectives indicate how context is influential in determining individual meaning of experience as well as social responses to it (Holstein & Gubrium, 2004). Narratives and narrative environments are recognized as relationally consequential in “conversational and cultural manifestations” (Holstein & Gubrium, 2004, p. 304).

A fifth guideline for analyzing narratives and narrative environments emphasizes how context is important for the construction of meaning in discourse because it provides discursive positioning needed for stories to make sense to storyteller and audience (Holstein & Gubrium, 2004). Analysis of the various contextual perspectives expressed in narratives reveals the implications and consequences of narratives in particular narrative environments (Holstein & Gubrium, 2004). It may also reveal opportunities for alternative meanings. To accomplish this the analysis relies upon analytic bracketing to move between discourse in everyday contexts and discourse in broad societal contexts. Analytic reflexivity encourages awareness of the relationships between various contextual dimensions of narrated experience, thereby reducing the risk of overlooking consequential narrative relationships. Analyzing narratives and narrative environments is further developed and complemented with the additional analysis of narratives in practice, which provides interpretation of how storied accounts come to be.

### *Narrative Practice*

Stories and storytelling involve communicative practices that often go unnoticed, unrecognized and under-appreciated (Gubrium & Holstein, 2009). Narrative ethnography draws upon theoretical perspectives and methodological approaches that are ethnomethodological in character to formulate an approach that includes analysis of narratives as active practices (Gubrium & Holstein, 2009). Shifting analytic sensibilities from an examination of narratives as products of interaction, narrative ethnography is interested in the active processes of story construction as they play out in narratives. Narrative ethnography is a methodology that can be used to analyze textual accounts where the interactional accomplishments of storied practices may not be readily in view. Narrative practices are discerned via analysis of narrative environments apparent in stories, and in the contexts in which stories are presented. This involves interpretation of the way contexts shape the presence and presentation of the stories.

Narrative ethnography involves analysis of the ways stories actively come together. Now attention is given to the practices storytellers use to socially construct their experiences in narrative form. Analyzing narrative practices, also referred to as narratives in practice, centralizes storytellers' "constitutive agency" and acknowledges stories as active "discursive ways of doing or accomplishing something" (Holstein & Gubrium, 2012, p. 7). Narrative ethnography offers a way to take a close reading of how personal stories manage and engage with dominant discourse by including analysis of narrative practices involved in the production and presentation of storied accounts. This involves specific accounting of how stories are pulled together from the myriad of discursive possibilities offered by discourses-in-practice and discursive practices. It involves a look at how influential characteristics of narrative environments and contexts come into play as a story is worked up in discourse and requires

interpretation of how types of narrative practice work to construct meaning in discourse (Gubrium & Holstein, 2009). Analysis of narrative practice highlights how narrative efforts and intentions are expressed in the development of a story and this highlights narrative strategies that go into producing and presenting accounts as they are constructed for particular audiences in various venues on certain occasions.

For this thesis, narrative ethnography provides a way to explore how personal stories manage and engage with dominant discourse about madness. Analysis of narrative practice helps in discerning how, and with what effort, stories come together and resist, re-inform, or reinforce medicalized conceptions of madness across a variety of contexts. In some instances narrative practices are readily apparent as people openly express their intentions to trouble or support medicalization or its effects. The analysis attends to such clearly stated intentions as they are evident in the content or form of a story while keeping an analytic watch for subtle or unintended consequences that result from these practices.

Narrative ethnography follows narratives as social practices that accomplish meaning in discourse rather than sorting them into representative categories or types of experience. This involves setting aside or bracketing what narratives say and how they are structured in order to trace out how and under what conditions narrative accounts are pulled together. This requires that narratives and the narrative practices that bring them to life be followed as they exist or develop in among other forms of discourse. This reduces the penchant in a narrative inquiry to privilege personal stories as more authentic expressions of experience and knowledge (Atkinson & Delamont, 2006). A focus on only the content and form of stories encourages the privileging of personal stories as more authentic, moral or revealing than other forms of discourse (Atkinson & Delamont, 2006). This happens in two ways. First, as particular types of stories are privileged

over other types of stories; and second, as personal stories are privileged over other forms of discourse. In the first instance, various versions of experience are combined to create an ideal or representative narrative. Preferred narratives are generally encouraged and shaped by the expectations of dominant discourses and this has the effect of reducing opportunities for other versions of the same experience to be emphasized or valued. And yet, this contributes to contestation in discourse. Challenges are made to displace or reconstitute privileged narratives. These challenges signal that narratives have emancipatory value. They represent voice for the marginalized. They encourage agency within structured social systems. However, when efforts to capitalize on the value of these counter-narratives remain fixed on their content and form, the analytic cycle of privileging certain narrative accounts is not reduced but expanded. New narrative ideals are constructed in keeping with the discursive preferences of a particular historic or cultural moment. Therefore, where narrative inquiries aim to be emancipatory it would be advantageous to emphasize how personal narratives are practiced interactively in discourse, rather than highlight content and form in isolation thereby privileging narrative accounts as having something better to say.

In the second instance, social science research that essentializes the value of personal narratives or positions personal stories as more important or more informative than other forms of discourse negate their value as active contributors in discourse. If personal narratives are believed to hold more insightful knowledge than other discursive forms then the work of interpreting their meaning begins by discounting the influence of other discourses. This inhibits and undermines consideration of how narratives work within broader constructions of experience such as medicalization, in order to manage its consequences. By extension analyzing narratives independently of other discourses removes contextual cues that highlight how discursive

relationships work. When greater attention is given to the value of narrative content alone there is reduced insight into how narratives participate in the discursive construction of subjectivities or how they work to expand or resist hegemonic perspectives. Ironically, this obscures how narratives direct or facilitate social action and what they accomplish as participants in discourse.

### Narrative Work

Mapping the *narrative work* that goes into the social construction of a story contributes to a more transparent understanding of how meaning is constructed in discourse. The aim of an analysis of narrative work is to discern how discursive relationships are activated in the telling or presentation of a story. The constructionist sensibilities of narrative ethnography asserts that storytelling is an ongoing process of meaning making with no clear beginnings or endings (Gubrium & Holstein, 2009). Stories emerge from already encountered discourses and are shaped and informed by personal experiences, historical and cultural discourses, and all manner of individual and societal interpretations. Although time and page limits may bind them narratives in practice are part of ongoing discourse.

Gubrium and Holstein (2009) describe six forms of narrative work that can be applied in narrative analysis. The first methodological concept is *activation* (Gubrium & Holstein, 2009). It marks a starting point for the analysis of narrative practices and analysis of activation addresses what and how a narrative is initiated. Discerning the origins of a narrative in progress requires assessing interactional and productive starts and stops in discourses-in-practice and discursive practices. Analysis involves identifying how a storied account was called for or set in motion. This may include formal directives such as the case in a court of law, a professional meeting, an appointment, or in an interview, or a story may be called for casually in everyday conversation

with family, friends or acquaintances, and stories may be activated by verbal or written request. Identifying the ways stories are activated provides an analytic starting line for discerning how and who participates in the construction of the narrative. An analysis of activation indicates what and why a storied account is meaningful in particular settings and times.

Where activation looks at how stories are called up in everyday discourse, *linkage* refers to the way the meaning making process begins (Gubrium & Holstein, 2009). Linkages are defined as the elements of a story that connect it to other contexts and discourses. These linkages or connections provide contextual clues that make a story relevant or meaningful for both storyteller and audience. Linkages proffer socially shared references that make a story easier to understand. In discourse, linkages in a story may include references to shared experiences on a broad social scale such as family life or they might be specific instances shared only by members of an individual family. Linkages form a web of discursive connections upon which a story is generated.

As storied accounts are produced in view of narrative contexts and with reference to socially shared circumstances they are made distinct as expressions of experience through a process called *composition* (Gubrium & Holstein, 2009). Composition is an active practice in narrative work that makes each narrative distinct. It entails the engagement of linkages and contexts with a storytellers personal experiences and interpretations of their experience. Literary composition involves the formal development of a connected plot or thematic elements in a story. In narrative work, composition refers to the unique and subtle ways storytellers bring together their experiences in their story. For example, though storied accounts of depression share similarities in content and form, the emphases, details and nuances a storyteller uses to express their particular experience will contrast with other accounts.

With the concept of *performance*, personal narratives are analyzed as artful constructions of experience made to relate to and engage in discourse (Gubrium & Holstein, 2009). The analysis attends to how personal stories are presented for social consumption. It involves taking a close look at how a story is presented in particular contexts, and how descriptions of characters and their roles in a story are made to relate to, or made relevant in terms of, recognizable social references. An analysis of narrative performance follows how familiar social constructions are made unique or problematized in storied discourse and how this supports the effect or intent of the story. For example, people may present themselves in the role of a patient in order to support a medicalized version of madness, or to resist and counter medicalization by explaining how their experience as a patient was in contradiction to social values about how patients should be treated. Analysis of performance involves tracing out “how performative particulars, such as roles, purposes, audiences, modes of expression, and emphases, reflexively shape stories over and above their texts” (Gubrium & Holstein, 2009, p. 85). The intentions and efforts made to story accounts are oriented to as if the story were a performance. This involves examining how the telling of a story relates to its immediate contexts and to the constellation of contexts from which and in which it develops. Analysis of narrative performance highlights how stories do the work of conveying meaning about social situations and relationships.

The social nature of narrative work is extended in the narrative practice of *collaboration* (Gubrium & Holstein, 2009). Collaboration refers to ways that storytellers and audiences interact to encourage, facilitate or direct the development of their stories. It is readily recognizable in formal interviews but occurs in all settings where storytellers are encouraged by verbal and nonverbal “response tokens” to ‘go on’ with their story (Gubrium & Holstein, 2009, p. 93). Questions and comments made by a listener or interviewer offer “consequential incitements” for

a storyteller to share more of their story—‘and then what happened’... ‘I can’t believe it’ (Gubrium & Holstein, 2009). These cues and the work of collaborating have consequences for how a story and its meaning develop, and for what is made relevant and what is left out. Analysis of collaboration highlights how a story is socially constructed in ways that include or reflect the perspectives of both storyteller and audience.

Story construction and meaning are vulnerable to a variety of influences including the activation of a story, the linkages made between accounts, the compositional interpretations provided, the story’s performative characteristics, and the collaborative practices of storytelling. In narrative ethnography these elements of narrative work are rounded out with analysis of *control* (Gubrium & Holstein, 2009). Control includes the “normative expectations” and the “objectives and strategic preferences” expressed subtly or overtly as a story is told (Gubrium & Holstein, 2009, p. 109). An analysis of narrative control involves an assessment of how dominant discourses advance socially constructed subjectivities by controlling and directing meaning in everyday discourse. Status, entitlement, and hierarchical social arrangements advance which versions of a story and whose versions of a story are notable and meaningful. However, “control can seldom be unilaterally asserted, even as matters of status, hierarchy, and entitlement may lurk in the background” (Gubrium & Holstein, 2009, p. 109). People control or guide how their stories and meaning develop in discourse. They resist, re-inform, or reinforce discourses that help with interpretations of their stories as required for managing and promoting their intentions to others.



## **Summary of Narrative Ethnography**

Gubrium and Holstein's (2009) narrative ethnography is an active and critical methodology that attends to the ways stories are practiced in context. It draws from phenomenology, ethnomethodology, and Foucauldian discourse analysis. With narrative ethnography the objective is to discern how narrative environments and narrative work are related and what consequences this has for the construction of meaning in discourse. The analysis involves a process called interpretive practice, which distinguishes between discourses-in-practice (dominant societal discourses) and discursive practices (every talk and text). Through the process of analytic bracketing the analysis alternates between everyday discourse and dominant societal discourse. The alternating focus is an analytic checkpoint for the researcher, ensuring the narrative work involved in the practice of storying accounts remains in view of the narrative environments in which they are practiced and vice versa. Interpretation of the ways each shapes the other provides insight into meaning making and highlights opportunities for social action. Narrative ethnography attends to narratives as both a resource and a social practice in discourse, more significantly it emphasizes how and what is involved as people story their experience in view of broad social discourse. Narrative ethnography is an ideal methodology for this thesis. The concepts of narrative environment and narrative practice, and the alternating analysis of discourses-in-practice and discursive practice (using analytic bracketing and interpretive practice), are a guide for taking up a central perspective from which to analyze the narrative strategies people use in their stories as they manage dominant medical and social discourse about madness.

In the next section of this chapter I describe how I collected and coded the narratives researched for this thesis. I begin with a brief discussion about the internet as a site for

researching personal narratives. I then describe how I selected the eleven websites for the research, how stories were collected, and my approach to coding and analyzing the stories.

## **Method**

### *The Internet as a Site for Researching Personal Narratives*

Inspired by a culture of self-disclosure and personal testimony, personal stories now appear as almost essential content on the Internet. The inclusion of personal narratives in medical discourse and the increased presence of personal narratives on the internet is encouraging consumer-survivors to publicly share stories about madness. These narratives are influential participants in discourse, due in part to changes in political and social inclinations that now celebrate inclusiveness and value polysemy. Additionally, the shift from patient to consumer centred health care encourages people to share stories as a way to call for improvements to medical and social care. The Internet is encouraging and expanding political, economic and social participation in the public sphere.

The Internet as a communicative space supports greater individual agency and active citizenship. Members of various communities find an ideal place for making claims and raising issues, and communities that have been marginalized in the past now have opportunities and places to express ideas, concerns, interests and experience. The presence and the ease with which stories are accessed online indicate an increased valuation and acceptance of experiential evidence about madness. Generally speaking, communicating openly on the Internet about personal health and illness experience is promoted as liberating for individuals and marginalised communities. Stories provide online peer support and promote alternative ideas and attitudes about care and treatment, while authorship and the expression of personal stories facilitates the

formation of community support groups and social movements (N. Crossley, 2002, 2006; Davis; Polletta, 2009).

As a research site the Internet has been the centre of attention for the past two decades. It garners attention in popular culture and in academic research where it is embraced as a democratizing utopian ideal or demonized as a site filled with dystopian motivations and intentions (Loader & Dutton, 2012). Research interests explore how the Internet is used, theorize about its potentials and possibilities for social change while speculating about its challenges as a free and open discursive space (Markham, 2008). Research efforts focus on collecting and analyzing the content and structure of online texts, examine the differences and similarities between the presentation of online and offline narratives, and assess the value and quality of peer support groups and online health information (S. Jones, 1999c; Rice & Katz, 2001; Sharf, 1997). This research provides insight into specific issues, but there are opportunities to explore the dynamics of discursive arrangements involved in the construction of meaning online.

As Markham (2008) notes the challenge of “observing and interviewing in these (virtual) contexts is that our expectations remain rooted in embodied ways of collecting, analyzing and interpreting information” (p. 278). Traditional methodologies assess online texts in terms of topics, themes, accuracy and value, which advances post-positivist ideas concerned with developing theory, upholding empirical credibility, and producing generalizable research findings (Denzin, 1999). Seale (2005) suggests internet research be characterized in three ways.

Most existing studies fall into one of the following areas: the relationship of people to health information on the internet, the dynamics of virtual communities in web-hosted discussion groups and support groups, and the narrowly defined issue of accuracy or quality of information as defined by medical interests. (Seale, 2005, p. 516)

Within these three areas traditional methods assess online phenomena in terms of topics, themes, and accuracy of information. Denzin (1999) points out this encourages research that advances post-positivist ideas concerned with developing theory, upholding empirical credibility, and producing generalizable research findings.

To open up the tripartite focus requires a shift in thinking about potential methodological opportunities in Internet research. According to Seale (2005) a critical approach to researching Internet communication involves highlighting “relations of production that lead to particular representations becoming prominent” (p. 537). A common thread in the literature is the idea that there is a need to advance research beyond thematic, structural and content oriented analysis. Enriquez (2009) suggests when the sole concern of an analysis is evaluating the content and structure of online communication the values and expectations of the real world are automatically transposed onto the virtual data and the real opportunity for learning about the Internet and the topic at hand are overlooked. The remedy to this is an analysis that follows the text as active discourse to uncover how it relates to other discursive interactions on and off-line. Jones (1999a) suggests a critical approach to Internet research emphasizes questions regarding practices of communication and processes of meaning-making, which are the focus of this thesis.

A critical methodology advances an interpretive, subjective and relational view of the Internet and includes analysis of online communication as practice in discourse that can bring to light how meaning—online and off— is constructed, organized and related (Jones, 1999a). This involves identifying what is being said in discourse, how it is said, what influences the discourse, and what implications this has for relevant stakeholders and society generally. To approach internet research with a critical perspective inquiries should be made regarding practices of internet communication and processes of meaning-making. According to Kitchin (2007)

studying the internet “holds enormous potential for social scientists (and others) who have an interest in understanding the ways in which humans create and negotiate meaning, and the ways in which those negotiations give rise to constructions of reality” (p. 14). To do this involves recognizing narratives on the Internet as discursive practices and as participants in the construction of meaning.

The internet is an ideal communicative site for examining how people manage dominant discourses in their stories about madness and mental illness. The compelling number of personal stories online and the increasing relevance attributed to stories as influential in discourse about madness makes the internet an ideal choice for researching how dominant discourses about madness is managed in personal narratives. Researching narratives online aligns with theory and methodology of this thesis on two counts: personal narratives are situated within broader discourse on websites, and narratives are prevalent and publicly accessible.

First, the internet serves as a theoretically productive site for watching negotiations of meaning in discourse because narratives can be collected and analyzed as they are situated in broad social discourse (discourses-in-practice) about madness. Jones (2005) explains narratives on the internet form “a distinct class of life documents, deriving its class distinctiveness from a unique “situatedness” at the fluid private/public boundary” (p. 297). Described in this way narratives are like “situated performances” in internet discourse (Jones, 2005, p. 300). Situated in discourse on a website, which is positioned in a larger network of websites on the Internet, personal narratives can be analyzed for the ways they are used to manage dominant discourses about madness, and as participants in the negotiation of meaning.

Second, the prevalence and accessibility of narratives on the internet make it a compelling site for analysing personal narratives. In this thesis I take a naturalistic approach to

collecting narratives. I make the assumption that these days when someone is experiencing mental distress or is confused or worried about their behaviour or the behaviour of a loved, the first thing we do is search online for information. It was important to me to follow available links to find a variety of websites and storied accounts. Denzin (1999) suggests naturally occurring narratives work well for showing how meaning is constructed as part of “an instance of the system in action”—that is, narratives can be followed as practices in discourse or as part of a system of discursive exchange. In this thesis the Internet is flexible enough to accommodate analysis of narratives as practices, and to interpret the relationships between discourses-in-practice and discursive practices is at both local and global levels of discourse in order to demonstrate narrative strategies used in the management and negotiation of meaning about madness.

### Ethics

This research analyzes stories available in the public domain. The University of Calgary, Conjoint Faculties Research Ethics Board initially expressed concern about researching personal stories about mental illness on the internet. To satisfy these concerns it was clarified that only existing stories already openly available to the public would be collected. Stories were present and posted prior to the research and were not influenced by the researcher. As such, personal narratives were considered to have met with current definitions of public domain. Citation of material reproduced from the websites would be included in the final thesis. The names of websites and links to home pages would be included. However, when drawing excerpts from the narratives names of individuals who had written the stories would not be included in the project, pseudonyms would be used. The Board granted approval for the research.

## Website Selection

To reflect and respect the need for a naturalistic inquiry of how personal narratives appeared on the internet a simple search of key words was conducted using the internet search engine, Google ([www.google.ca](http://www.google.ca)). Broad descriptive terms were used to search for personal stories. Key search terms included: personal stories, mental illness, mental health, madness, consumer/survivor/ex-patient, consumer/survivor/ex-patient movement. These terms were combined in various ways in order to get as many lists of websites as possible, and to see whether the changes in terms would result in different websites appearing on the search lists. The key words were entered into the Google search box randomly over the course of a week. Again this was done to determine if the search engine would provide alternative websites at different times. Generally, the same list of websites appeared over the week, with the only change being in the order in which they appeared. To manage the tens of thousands of pages listed after each search, only the first two screen pages were reviewed for potential websites.

Potential websites were defined as sites where stories were posted on the main, public pages of the site and/or where stories could be accessed with less than five links to click. Websites that required registration or involved accessing a message/discussion board or chat room were not used in this research. This did not pose any difficulties as many websites openly included personal stories on their home page or included a link to stories on the homepage tabs or menus. Over the course of a week a number of potential websites were reviewed. Websites that included first-person narratives were bookmarked on the computer. A short list of possible websites was determined by two main criteria: whether the website appeared on the first pages of all the searches and whether the stories on the website were in first-person. Once a short list of

potential websites was decided upon inquiries were sent to the website administrator and/or the head of the website's sponsoring organization requesting permission to include the site and the personal stories it presented in the research. The email request is include here in Table 1.

**Table 1. Requesting Permission to Research Online Personal Narratives:  
The email message sent to organization administrators**

Dear,

My name is Monique Solomon. I am writing to ask permission to include the (website name) in my graduate research. I am studying how personal stories contribute to social change. It is my belief that when personal stories are shared publicly they help change the way care is provided in society. This has been the case for people diagnosed with cancer, aids, and multiple sclerosis, but not many studies have looked at how personal stories contribute to better understandings of mental illness. By following the stories and topics on your website I hope to create awareness about mental illness issues and highlight how important it is to listen to the ideas and concerns of people who have experienced it. Below is an explanation of how the research will be conducted, and the formal request for your permission.

With your permission I would like to keep track of the topics, ideas and stories on the main pages of the website over the next two months. I will be taking notes and may include samples from the website in my written research. The website will be publicly cited and identified in the final report. The research will be used to inform my doctoral project and may also be submitted for further publication or presentation. Information collected will be stored confidentially and securely on one personal computer. The research material will be destroyed after a period of ten years.

Your agreement to have the website included in the study is voluntary. At any time during the research period (dates given) you may withdraw permission to have the website included in the study. Only the material collected up to the point of withdrawal will be referred to in the research.

I will provide you with a message that can be posted to let people visiting the site know about my research. I will not be looking at stories told in the member sections. I will not solicit information or conduct surveys.

My research project has been approved by the University of Calgary, Conjoint Faculties Research Ethics Board. You may contact the Ethics Resource Officer if you have concerns or comments, at [rburrows@ucalgary.ca](mailto:rburrows@ucalgary.ca), 403-220-3782. Please reply to this email at [solomonm@ucalgary.ca](mailto:solomonm@ucalgary.ca) to let me know if you consent to having the website be part of my research.

Thank you.  
Monique



Positive responses were received from eleven websites. The list of websites from which personal narratives were collected is included here in Table 2.

<b>Table 2. The websites from which personal narratives were collected</b>
Beyond Meds <a href="http://beyondmeds.com">http://beyondmeds.com</a>
Freedom Center <a href="http://www.freedom-center.org">http://www.freedom-center.org</a>
Here to Help <a href="http://www.heretohelp.bc.ca">http://www.heretohelp.bc.ca</a>
HOPE (Harvesting Our Personal Efforts) <a href="http://www.mhrecovery.com/index.htm">http://www.mhrecovery.com/index.htm</a>
MindFreedom International <a href="http://www.mindfreedom.org">http://www.mindfreedom.org</a>
National Alliance on Mental Illness (NAMI) <a href="http://www.nami.org">http://www.nami.org</a>
National Council for Community Behavioral Health <a href="http://www.thenationalcouncil.org">http://www.thenationalcouncil.org</a>
National Empowerment Center (NEC) <a href="http://www.power2u.org">http://www.power2u.org</a>
White Wreath Inc. <a href="http://www.whitewreath.com/index.php">http://www.whitewreath.com/index.php</a>
World Fellowship for Schizophrenia and Allied Disorders <a href="http://www.world-schizophrenia.org/stories/index.html">http://www.world-schizophrenia.org/stories/index.html</a>
World Health Organization – Europe (WHO-Europe) <a href="http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/personal-stories">http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/personal-stories</a>

Website administrators expressed no hesitation about their website being used for research particularly when it was made clear that only storied accounts that were openly available and accessible would be part of the study. A few administrators extended invitations for me to contact them directly by telephone. Once email contact was established a

conversational tone was used in any further emails to answer questions about the research. Participating websites were offered a short description of the research to post on their website announcing the research. Only one website administrator agreed to include the description. Others decided that such a posting would not be necessary, because the stories on their websites had been posted with permission given to the websites to use as desired. Additionally, it was noted that the stories were already always accessible to anyone without need for permission.

A review of the eleven websites took place over nine months, between May 2011 and January 2012. Information from the websites was collected along with the personal stories to construct a view of the contexts in which the stories were presented. Information was collected from the main pages of the websites. Organizational information that appeared on the website's home page tabs, such as mission and vision, or 'about us' was collected in the form of web-archives, screen shots, webpage links, and copies of webpage text.

In total 407 personal narratives were collected and read. The number of personal stories on each website varied from 6 to 174. Stories were between 74 words (shortest) and 9,385 words (longest). Stories were collected and organized according to the websites on which they appeared.

The information for each website was collected and stored using a software program called Scrivener (Literature&Latte, 2005-2014). Scrivener is a software program for writers working on large, complex works such as dissertations, manuscripts, or screenplays. The program allows for large quantities of textual and graphic data to be collected and arranged, as it appears online. Written text is constructed in what is referred to as the project binder. The program is flexible enough for a writer to view and edit between and across chapters, sections and data. It includes options for coding meta-data and frames for searchable detailed side notes.

The program was used to organize all the material collected from the websites. Each website was assigned a separate folder in the program. Personal stories that appeared on a website were collected in individual documents within folders for each website. Stories were listed in the same order in which they appeared on the website. Hard copies of all stories were printed. Stories were collected 'as is'. No edits, corrections or changes were made to the content of the stories. The font of the text was standardized using Times New Roman for purposes of coding and analysis.

Prior to coding consideration was given to how narratives were presented on the websites. The content of the websites was reviewed to identify the discursive contexts in which the narratives were situated. The presence of personal narratives on the website indicated stories were considered a valuable discursive resource for contributing to meaning about madness. Comparison of the websites indicated that narratives were presented in similar ways across all websites regardless of the mandate of the sponsoring organization or individual. And stories were posted with little explicit commentary or discussion. Brief introductions presented the stories as positive and helpful.

### Coding and Analysis

To code and analyze the stories I use interpretive practice and analytic bracketing described above in my discussion of narrative ethnography (Gubrium & Holstein, 2009). The narratives were coded in twice. Initial coding involved recognizing thematic patterns in stories from each website. First the most frequent and most emphasized contexts and experiences were defined for individual websites. Second, the narratives from all the website were coded together. Coding from the individual websites and coding from all the website together produced fourteen narrative headings made up of the most emphasized contexts and experiences of madness. These

included job/work, education/school, the system, society, medication, treatment, diagnosis, a full story, experience/perspective, recovery, housing, advice/advocacy, and alternatives. To facilitate analysis and discussion the fourteen narrative headings were reviewed and reduced to three experiential areas made up of medical experience, social experience, and consumer/survivor experience.

The coded narratives were analyzed using interpretive practice. This involved alternately analyzing the narrative work and narrative environments that were evident in the text of the stories. A set of charts was developed to provide a visual template for the analysis of each experiential area. The charts were used to map how stories were practiced and what circumstances influenced their production. The practices and circumstances were analyzed for the ways they related to each other and to the main experiential areas. This brought into view key tensions and contradictions that signified a struggle for meaning in discourse. Analysis of the narratives demonstrated how the contradictions were described and what this accomplished in discourse and meaning about madness.

### Presentation of Narrative Excerpts

In the following three analysis chapters I present and discuss a number of narrative excerpts which are drawn from the websites I reviewed for this research. I decided early in the research process not to use the real names of the people whose stories are discussed in my analysis. Although all the narratives appear openly and publicly on the websites, and I received permission from the website administrators to study the stories, I chose not to include real names but to use pseudonyms. My decision to use pseudonyms supports the requirements of my ethics application. As a result there are no direct identifiers, except the stories themselves, to indicate

authorship or which website the stories appear on. The narratives are all presented here using the same text and formatting although many appear online using various fonts and other visual designs. Grammar and spelling in the narratives are as they appear on the websites. The narratives are not presented as single blocks of text in one paragraph. I have separated the lines of each narrative into “units of discourse” or “spurts of language” to create emphasis and highlight the points people make in their stories (Gee, 1985; Chafe, 1980; Reissman, 2008). Additionally, I have changed any references to places or to specific names of psychiatric drugs or hospitals and in their place I use (ABC drug) or (ABC hospital). This note about the presentation of narrative excerpts in the thesis applies to all three analysis chapters.

### **Summary of Method**

To collect the stories from the websites I took a naturalistic and straightforward approach using a general search engine (Google) to search for information about mental illness and personal stories about madness. I did this intentionally to find out what possible websites would come up for someone looking for information about mental illness. The stories used in this research are all in the public domain. The stories were posted prior to the research, with some being online the web for a number of years and others being more recently posted. I did not activate memberships or join chat groups to access any stories.

The stories were collected and organized in a software program called Scrivener, which allowed me to collect the stories and other material from each website (including screen shots of homepages, mission/vision pages, about us pages, and the pages on which the personal stories were posted for example). Stories were also printed in hard copy. The narratives were initially collected and organized according to the organization they were posted by, and then stories were

reviewed and coded according to most prevalent narratives contexts and narrative environments. Stories from all the websites were then compiled according to the narrative context groupings.

In the next three chapters I present my analysis of the personal narratives collected from the websites. The stories are analyzed using interpretive practice and analytic bracketing from the methodology discussed above: narrative ethnography (Gubrium & Holstein, 2009). I examine and discuss personal narratives from across all the websites and describe the narratives strategies evident in the stories and how people use these strategies to make meaningful connections between their experience and discourse about mental illness.

## CHAPTER 5 ANALYSIS: WHAT IT'S LIKE BEING A PATIENT

### Introduction

Over the next three chapters I examine personal narratives posted on eleven websites that provide personal, social and medical support and information about mental illness and psychiatric survivorship. In this thesis I argue that medicalization is managed in personal narratives through a practice I call *narrative bridging*. I propose narrative bridging takes place as people make meaningful connections between their experiences and discourse about mental illness. In order to do this I suggest people use three narrative strategies, which are: resisting, re-informing, and reinforcing discourse about mental illness. In the chapters that follow I examine the narratives to see what connections are made between personal experience and discourse about mental illness and consider how these narrative strategies play out.

In this chapter, I describe and discuss how narrative strategies are evident in stories about what it's like being a patient. In Chapter 6 I describe how the narrative strategies of resisting, re-informing and reinforcing discourse happen in stories about relationships, and in Chapter 7 I consider the ways these strategies are apparent in stories about recovery. Overall, my examination and analysis indicate that through narrative bridging medicalization is managed in personal narratives because various meanings about mental illness that circulate in discourse are resisted, re-informed, and reinforced. The personal experiences people share in their stories are more than general historical accounts of their experience, rather they are selected experiences shared in particular ways, which support personal claims about mental illness. These analyses are significant because they demonstrate how discourse about mental illness is interpreted and made meaningful in stories, and more significantly how discourse is imbued with personal meaning. From this I suggest that personal narratives play an important role in managing and influencing

medicalization because the meanings people give their personal experiences are storied in view of dominant discourse about mental illness.

In this chapter I examine personal narratives about *what it's like being a patient*. The chapter explores the narrative strategies evident in stories about what it's like being diagnosed with mental illness, what it's like taking psychiatric medications, and what it's like being in hospital treatment. Examining narratives about diagnosis, medications, and treatment indicates people make meaningful connections between their experiences and discourse about mental illness by questioning and describing negative consequences of medical practices and approaches in treating mental illness. The narratives analyzed in this chapter show that in order to do this people invoke the role or status of being a patient, and while this helps them make their case against medical practices and inserts personal views and meaning into discourse about mental illness, it also holds people (and the discourse they use) within a medical frame or gaze thereby reinforcing medicalization.

### **Personal Narratives about What It's Like Being Diagnosed with Mental Illness**

Narratives about diagnosis manage medicalization by explaining the negative effects of psychiatric labels, by including descriptions of life events with diagnosis, and by questioning psychiatric diagnostic practices and the bio-chemical basis of mental illness. My analysis of these narratives indicates there is a desire to name the madness experience, which at this time only medical discourse provides. In this section I examine personal narratives about what it is like being diagnosed and the excerpts on this topic are thematically arranged to reflect key issues apparent in the majority of the stories.



In the first of three sub-sections I examine personal narratives that describe the negative consequences of diagnostic or psychiatric labels. The narratives in this section indicate although psychiatric labels provide more negative than positive consequences people place value on having ways to refer to their experiences. The next sub-section demonstrates how people resist and re-inform approaches to diagnosis by providing biographical details about their lives and aligning diagnosis with life events, and questioning why contextual and relational factors are left out of diagnostic practices. The narratives in this section indicate people emphasize things that medical discourse leaves out in order to make diagnosis meaningful. In the third sub-section I examine personal narratives that directly contest medicalization by calling into question the basis of diagnostic practices. In this section people bridge meaning by invoking the patient role in ways that position them as lay-experts, and as such they criticize medical discourse that defines mental illness as a bio-chemical imbalance or brain disease by describing information researched from scientific literature that criticizes medical approaches.

*Narratives explaining what it's like to be labelled with mental illness*

In personal narratives about what it is like being a patient, medical diagnosis is storied as a key life event, which indicates a change in status constructed in and by medical discourse. Although people talk about being aware of having a lifetime of experiences that are different from others, it is the direct application of a diagnostic label of mental illness, as applied and endorsed by the professional expert language of medical discourse, that activates and orients the direction of their stories. Stories about diagnosis highlight contradictions and expectations in dominant discourse and show the ways people connect their experiences to these discourses by describing the long-term negative consequences of varying practices and processes of medical

diagnosis. The stories make meaningful connections in discourse by giving specific accounts of where and how diagnosis is far from stable or helpful, and although (generally speaking) the stigma of diagnosis is quite recognizable and acknowledged in society, the stories provide detailed accounts that point to areas for improvement. Taking up medical discourse and asserting experiential knowledge the stories highlight three contradictions about diagnosis. First, stories describe the long-term consequences psychiatric labels have on how people are perceived by others, and the effects this has on their sense of self. Second, the stories emphasize the importance of life events as relevant to the diagnostic process, and people question the lack of effort made to include these events in diagnosis. Third, the narratives directly question medical assertions about the biochemical basis of mental illness as a so-called brain disease.

The following narratives show how diagnosis and the application of medical labels all but erase personal identity outside of a medicalized one. The stories indicate that from an experiential point-of-view the challenge is not necessarily with specific labels but with the broad label of mental illness. In their stories people use analogies to make meaningful connections in discourse, they reference the views of others, they include descriptions of the long term consequences of being diagnosed with a mental illness, and they indicate how diagnosis while helpful for framing experiences changes perceptions of self and identity.

Describing what it is like to be labelled with a mental illness, “Alex” creates a visual image using an analogy to support his feelings of being weighed down by a system that values labels as a way to categorize and define people and their experiences.

Sometimes I feel like one of those big suitcases in the old black-and-white movies with labels plastered all over them from every place the person had visited that you can't see the suitcase itself anymore? The weight of the system's labels is dragging us down as much as the disorder or illness itself is.

When he describes feeling like a “big suitcase in the old black-and-white movies” the analogy conveys meaning regarding the transient nature of medical labelling and suggests that with each journey in the medical system new labels take precedence over the old labels making them, in a sense, meaningless. With reference to “old movies” he invokes stereotypical ideas about what it is like to be a patient labelled with psychiatric diagnoses. The narrative creates connection rather than distance thereby bridging meaning between his experience and discourse about mental illness.

In personal narratives about what it is like being diagnosed with mental illness people also directly resist discourse about mental illness, while reinforcing it at the same time. The contradiction that is created is what makes the connection between experience and mental illness discourse more meaningful. In the following narrative “Lara” describes the consequences of psychiatric labels by both acknowledging their value and criticizing the all-encompassing effects they have to “shut down understanding”.

I have gotten feedback from many people that when they got a psychiatric label it was a relief because it gave a name to what they had been experiencing.

I don't discount the importance of having a framework with which to make sense of our experiences, but does it really have to take a psychiatric diagnosis to validate your life path?

Who wants to be defined by a so-called illness? How empowering is that?

These labels shut down understanding.

They reduce the mystery and complexity of our experiences into a

diagnostic category that impedes healing.

These terms colonize us, and foster dependency on a system to “fix” us. After all, if it is an “illness,” we have no control over its course, and must hand our power over to others who do.

In this narrative “Lara” begins by showing she is knowledgeable about the views of a general community of peers—“many people” who have also experienced being diagnosed with mental illness. Aligning with this community supports her initial claims about the value of diagnosis as a “relief” and a “framework” for making sense of experiences. By acknowledging the views of other people, and the potential value of diagnosis she makes a meaningful connection by demonstrating her openness to general discourse about mental illness. From this positive position “Lara” then expresses her frustration about diagnostic labels in the form of rhetorical questions—and her acknowledgement of other peoples’ views at the beginning of the narrative makes it seem reasonable to expect that we (readers) might take a more open and accepting view of her perspectives and criticisms. Using rhetorical questions “Lara” presents personal reflections about diagnosis without providing specific details about her own experiences. Instead of describing particular instances she eloquently answers the questions on a broad scale explaining that psychiatric labels reduce the “mystery and complexity” of personal experience, “impede healing”, “colonize”, and “foster dependency” on the medical system. In this narrative discourse about mental illness is resisted and re-informed with broad points about what labels do, while it is also reinforced as having some potential to help “many people” give structure to their experiences.

In the next narrative “Darla” begins with a reference to what “many people” think about labels but rather than describe broad social consequences of diagnostic labels she follows with a specific example from her own experience. After describing how “many people” “hate” and

“object” to psychiatric labels she makes a claim about the way labels work to overshadow the way people are perceived. She points out that after diagnosis people are “seen through the filter of their labels” and to support this claim she describes her own experience of this.

Many people who have been diagnosed as mentally ill hate labels and object strongly when people are called schizophrenic, bipolar, or borderline.

After people are diagnosed, everything that happens to them is seen through the filter of their labels.

A couple of years ago I was admitted to a hospital on an emergency basis. The next morning I called my office to say I wouldn't be in because I was in the hospital.

At the time I worked in a very progressive agency with several people who themselves had psychiatric disabilities.

My colleagues assumed I was in a psychiatric unit. These same colleagues called every psychiatric unit in the Boston area trying to find me.

In reality, I had been admitted to the hospital because of a respiratory infection. They had assumed that if I was in the hospital on an emergency basis of course I was having a psychiatric emergency.

To support the claim that diagnosis is a “filter” for all experiences “Darla” points out that even in a “progressive” workplace with co-workers who have also experienced “psychiatric disabilities themselves” social assumptions about mental illness are pervasive. By explaining her absence was due to an infection not mental illness, “Darla” resists and re-informs discourse that assumes people who have been diagnosed with mental illness will be less productive or have more disruptions to their work or jobs. Her narrative demonstrates that although her co-workers have firsthand experience with mental illness and know her well, a diagnosis of mental illness overshadows other possible reasons for her stay in hospital. This narrative both resists and reinforces medical discourse. When “Darla” describes two peer communities that share her

experience of being diagnosed—“people who have been diagnosed” and “colleagues”—diagnosis becomes a rallying point that can be contested, as such it is resisted for what it does but reinforced as a meaningful connection. The narrative demonstrates how difficult it is to raise concerns about other personal health issues or life events once a diagnosis of mental illness is made, and indicates how psychiatric labels exclude other life events and circumstances.

The following narrative describes the all-encompassing consequences of diagnosis showing how being labelled with mental illness not only takes over how a person is viewed in social situations, but also how diagnostic labelling socializes people into seeing themselves as “a mental patient”. As “Liam” recalls his feelings of “humiliation” he uses terminology that today is viewed as politically incorrect, that is, to reference a person as “schizophrenic” implies that their diagnosis is their identity. The shift in discourse about mental illness now precludes such references and instead the emphasis is not on the character traits of an individual, but rather on a state that they experience or have acquired—someone is said to have schizophrenia or to be diagnosed with mental illness, rather than called mentally ill. The changes in meaning associated with phrases about mental illness have come about in part because of the ways people have storied their experiences as something externally applied rather than as something inherent to them. “Liam” emphasizes this point when he includes description of the various settings he participates in and when he suggests these setting were a catalyst for enforcing external assessments of his diagnosis, but also as powerful contexts within which his own sense of self was consistently and frequently reminded of his diagnosis. Analysis of this narrative indicates there is a contradiction between applications of diagnostic labels, how they are socially reinforced, and how although discourse has changed, certain meanings and associated phrases still play out in particular contexts.

The humiliation of being labeled schizophrenic threatened to become a self-fulfilling prophecy: in the hospital, shelters, group homes and programs I was put in I was being socialized into being a mental patient.

I was encouraged to see myself as a broken invalid, to forget my strengths and instead focus on my weaknesses and vulnerabilities as evidence of being a defective human being.

I learned to fear what was inside me as signs of my ‘disorder,’ and to turn over authority of my mind and experience to doctors and therapists.

Everything became a symptom.

I remember telling my hospital psychiatrist I was reading existentialism and Marxist philosophy, and later I found out he had put this down in my medical record as a form of bizarre behavior.

My ‘treatment plan’ instructed me to give up my passion for activism and organizing.

When I tried to talk about my sexuality and being bisexual, they told me that my feelings were part of my disorder.

This narrative is interesting for the way it develops. “Liam” begins with descriptions of external contexts and forces, directing attention to the social and relational sites where expectations of being a patient lead to being “socialized into being a mental patient”, and brings attention back to his personal experience by describing the harm this caused to how he saw himself. The clear statement about how “everything became a symptom” works as a transition point. Before this statement “Liam” conveys a passive patient role that is overshadowed by medical discourse, but after this statement he asserts individuality and a more active tone to make statements that question medicalization of his experiences. Additionally, his use of scare quotes around the words ‘disorder’ and ‘treatment plan’, signals his questioning of the use and value of medical discourse to name and address his experiences. “Liam’s” assessment and experience of how “being labelled threatened to become a self-fulfilling prophecy” and then how “everything

became a symptom” is supported with examples that are in contrast to his so-called identity as “schizophrenic”. He describes his feelings regarding intimate relationships, his contributions to society as an activist, and his intellectual interests are made part of his “medical record”. The assumption being that without a psychiatric label these would not be viewed as “bizarre behavior” and symptoms of mental illness, but would be viewed as unique and interesting aspects of his identity.

In the narrative that follows “Lara” describes her experiences with a look back at how she struggled to make sense of medical labels and the medicalization of her experiences over her lifetime. This excerpt is a good example of the ways diagnostic labels take hold and have consequences for people over their lifetime. In this narrative there are no mentions of “many people” sharing the same experience, nor are there descriptions of relationships with colleagues, or medical contexts that contribute to patient identity, instead “Lara” uses metaphor to describe her personal struggles with diagnosis. She describes how she “alternately fought and reluctantly accepted” not just a label, but like “Liam”, a medically ascribed identity in which she viewed herself as “sick” and “disordered”.

From childhood, I had alternately fought and reluctantly accepted a view of myself as “sick” and “disordered.” The acceptance was winning.

I hated the labels but identified with them at the same time. I didn’t see a way out from the box they imprisoned me in.

By the time I was eighteen, I was well on my way to becoming a perpetual “patient.”

I had no tools, no frameworks, with which to redraw the maps in my mind. This is the power of psychiatric brainwash.



This narrative shows resistance through language such as “psychiatric brainwash”, which has greater impact when contrasted with the initial descriptions of childhood. Connecting the ideas of childhood vulnerability with socially loaded terms such as “brainwash” and “imprisoned” the story becomes meaningful because it invokes a sense of sympathy. At the same time the struggle “Lara” has to reject and also “identify with” the labels indicates there is something necessary about having a medical frame of reference for her experiences. Her narrative suggests that once labelled with a diagnosis a person’s life experiences and personal meanings are overshadowed and the constricting definitional nature of psychiatric diagnosis has no room for life experiences and events.

The personal stories in this section describe what it was like being diagnosed with mental illness. By connecting their experiences with discourse about mental illness people assess the value of diagnostic labels. They resist and re-inform discourse by explaining that labels overshadow all other parts of their lives creating negative long-term consequences for how others see them and how they see themselves. The narratives explain that although people openly resist labels there are no alternatives for naming their experiences, therefore diagnostic labels are still used.

#### *Narratives including and aligning life events with diagnosis*

The stories in this section show how people connect their experience with broader discourse when they recount their diagnosis experience and include life events and biographical details that medical practices of diagnosis leave out. In narratives about diagnosis people question why these details are left out, by describing how external events become medicalized as mental illness, and by describing how their life experiences had different personal meaning

before being translated into mental illness. These narratives re-inform discourse about mental illness by bringing attention to, and questioning why and how life events that have personal relevance are deemed less relevant in the process of being diagnosed.

In this narrative the isolation of the experience of madness is further compounded by isolation created by diagnosis. To convey this “Wynona” uses the term “twilight zone” to describe her sense of this isolation. The term conveys meaning because it is drawn from a popular 1950s television show where each episode told a story of a character experiencing dark unexplained and unexpected events. The term “twilight zone” is also meaningful as an expression that has been used in past to describe people who have been diagnosed with mental illness because it connotes a sense that someone is not completely paying attention or aware of what is going on around them. In this narrative “Wynona” uses the term to preface her feelings of being out of touch with what was happening to her. More significantly, I read this as a way to also convey meaning about what it is like being diagnosed, according to “Wynona” her diagnosis was done without reference to her other life experiences as evidenced in the second line when she say “nobody ever inquired what had happened to me” or asked “what drove you mad”. She follows these points by explaining that she was “observed, diagnosed, and treated like a disturbed person” and restates her point that “no one ever looked at the association with my life history”.

In psychiatry, my twilight zone was extended. A distortion of reality was forced on me once more.

Nobody ever inquired what had happened to me, or asked: “What was it that drove you mad?”

I was observed, diagnosed and treated as a disturbed person, but no one ever looked at the association with my life history.

“Wynona’s” narrative bridges meaning between her experience and discourse because she uses the “twilight zone” reference to describe how psychiatry “extended” her negative experiences, but it also applies to how psychiatry and the diagnostic process are out-of-touch with the reality of her experiences by leaving out important contexts of her “life history” that, according to “Wynona” are important keys to “what drove me mad”.

In narratives about what it was like being diagnosed people almost invariably included a short reference or long narrative about what was going on in their lives before and during diagnosis. The next two narrative examples question either directly or indirectly the viability of diagnostic practices in psychiatry that leave out life events and personal history. In the following narrative “Shelley” bridges meaning by providing a clear description of the way her “serious car accident over 20 years ago” becomes the catalyst and cause of her diagnosis. Her story provides a clear account of how diagnosis of mental illness is predominantly based upon a person’s behaviours regardless of the emotional, physical and even biological factors that may also be involved. “Shelley” refers to the “medical profession” not a specific doctor when she explains how her “severe neck and upper body injury” are “dismissed” as “whiplash”. As she builds the details of her account, “Shelley” describes how she was “frantic for sleep—some relief from the injury pain” and in “desperation” went to a psychiatrist looking for a way to improve her sleep. This sense of urgency created in the narrative is contrasted in the next line when “Shelley” explains the psychiatrist was “nice” and “we chatted”.

I had a serious car accident over 20 years ago causing severe neck and upper body injury, which the medical profession dismissed it as “whiplash”.

I started crying at work, at home and all the time from pain and not sleeping. I was frantic for sleep-some relief from the injury pain

and in desperation went to psychiatrist thinking he could help me.

The psychiatrist was nice-we chatted and he gave a prescription. I wasn't getting better so the psych doctor gave me more drugs and suggested I go into a psychiatric hospital for a needed rest.

I had no idea of how "being a psychiatric patient" would cause other physicians to deter any medical treatment I needed for years to come.

After following up on advice to "go into a psychiatric hospital for a needed rest", "Shelley" explains how this event changed how she was treated by "other physicians". She asserts using quotations that "being a psychiatric patient" changed how she was perceived and it resulted in a lack of proper care and treatment for what had initially begun as serious physical injury. From "Shelley's" perspective her diagnosis as a "psychiatric patient" is clearly connected to the car accident she was injured in. Her narrative builds convincingly and supports the idea that diagnosis of mental illness either leaves out essential life details, or integrates them and translates them into something medicalized. The story is an example of what Ivan Illich (1976) calls the "the sick-making powers of diagnosis and therapy" (p. 3). Whereas narratives like "Shelley's" bridge meaning between experience and discourse by re-informing perceptions that diagnosis involves a full and rigorous application of testing or assessments, there are other stories that describe how being diagnosed re-defines and changes how people see themselves and their character and abilities.

"Ella's" story describes how diagnosis led to her reframing and reinterpreting things she perceived of as her "ups and downs". In this narrative past experiences and behaviours are questioned and re-storied as symptoms of impaired biology rather than as a unique expression of personal character and experience. "Ella" recalls how she "always had ups and downs" and how before diagnosis she looked upon these as part of who she was in childhood, and now who she is

in adulthood, as a writer being both “very anxious and very creative”. Her description conveys a sense of acceptance that she experiences “intense writing highs” followed by “intense creative lows where my mind seemed mired in muck”.

I’d always had ups and downs. As a child, I’d been very anxious and very creative.

As a writer I’d experienced intense writing highs when I could write for hours at a time and get by with very little sleep, and I’d also experienced intense creative lows where my mind seemed to be mired in muck and I couldn’t eke out a single sentence for weeks on end.

It never occurred to me to medicalize or pathologize that behavior...it was just part of me and who I was and how I operated.

Her story demonstrates how easily diagnosis shifts perceptions of behaviour from something personal, unique and even valuable, to something medical. In “Ella’s” narrative she clearly states that she never considered attributing her experiences to mental illness, but rather she explains these behaviours are “just part of me and who I was and how I operated”. The significant impact of diagnosis for “Ella’s” change in self-perception is clear by the way she refers to thinking that was the way she “was”, and not the way she still is today.

Narratives about diagnosis more often than not include some description of what was happening when a person was diagnosed. “Uma’s” story presented below is one example of the way people list the events and experiences in their lives that they believe to have an impact on their being diagnosed with mental illness. And like others, “Uma” lists events, but then follows this with a reflection on whether diagnosis of mental illness was really relevant or helpful. Perhaps as “Uma” points out the criteria for diagnosis are never truly met.

During this time I got married, entered the tiring and wonderful world of parenthood, completed my Ph.D., and purchased a home.

Withdrawal added significantly to this life stress, and still I was fine.

I began to wonder what relevance my diagnosis had to my current life, and to have doubts about the circumstances of its application. Not long before I was diagnosed, I was bitterly rejected by my family due to my lesbianism and partially as a result, had dropped out of college (though I had no trouble holding a job).

I am no longer convinced I ever truly met the criteria for diagnosis, though it is difficult to discern such a subjective “truth” from a decade away. It is certainly true that I was alone, angry and profoundly sad.

Narratives like “Uma’s” include detailed descriptions of life events, and reflections on how these events aligned with their feelings at the time of diagnosis. Narratives such as these show people often look to past experiences to make sense of diagnosis, and this prompts them to question its relevancy and applicability in various circumstances. These recollections and reflections re-inform and resist the ideas in discourse that diagnosis is securely based on medical science and empirically gathered evidence.

For the final narrative in this section, “Uma” continues her story and reinforces the overall sense that diagnosis does not just give a name to an experience or behaviour, but becomes an active way for people to describe and question a life time of experiences. The inclusion and emphasis of life events in peoples’ stories about diagnosis suggests it is a variable practice that while it provides a framework for understanding mental illness, has little substance beyond its consequences and effects on people lives. As “Uma” explains having a discursive “framework” for understanding emotional crises is important, but the consequences of applying that framework and who controls its meaning has lasting influence on peoples’ lives.

My diagnosis provided a framework in which all of my emotional experiences were pathologized, by doctors, by those around me, but most painfully, by myself. For almost a decade, I was never

sad; I was depressed. I was never happy; I was manic.  
A good day was a day on which I felt nothing.

When people describe their experiences with diagnosis they include important events and circumstances and create meaning that bridges their experience with discourse because the diagnosis is given context that is understandable by others.

### *Narratives challenging diagnostic practices*

Personal narratives directly and indirectly question the validity of biological and biochemical basis of mental illness. This is significant as a form of resistance to medical discourse because it essentially resists the idea that madness is illness—in the biological or genetic sense of the term. In their stories people call into question why, if madness is biological or chemical, diagnostic conclusions are made based upon circumstantial evidence and self-reported symptoms. To make a point about questionable diagnostic practices stories include references to scientific research, and expert commentary. Interestingly, in their narratives people rarely (if at all) described any form of empirical or scientific testing when they were diagnosed. In her personal narrative, “Ardene” simply describes the process she encountered when she was diagnosed. Her experience raises questions about practices of diagnosis and shows how narratives very simply can resist and re-inform discourse.

I was told my mental illness was caused by a chemical imbalance  
in my brain.

I was told I had a brain disease.

I asked how they knew this. Did they take any tests to determine  
this? I didn't remember my blood being tested for any such thing.

I was never given any answer.

“Ardene’s” narrative directly questions diagnostic practices and the scientific presumption that mental illness has a biological basis. The point she makes is not whether this may or may not be true but more simply from her experience that we cannot know whether it is, because diagnosis is not based on empirical tests, but rather on the application of terminology based upon a taxonomy of disorders that are defined and determined based upon overt behavioural symptoms and self-report.

In the narrative below "Stefan" offers a longer explanation for how he came to question the biological basis of mental illness when he learned that people “significantly recover over time” – a claim which overturns a long held assertion in medicine that mental illness is incurable. He provides support for his view by adding that studies show “alternative treatment models” “produce better results than treatment-as-usual”. In the remainder of the narrative he uses rhetorical questions to resist and re-inform discourse about mental illness as a “brain problem”.

I found that nearly all long-term studies indicate that the majority of people diagnosed with major mental illness significantly recover over time. That was news.

Furthermore, I learned that medications are ineffective and even harmful to a large minority of people with major diagnoses, and that some alternative treatment models, which use little or no medications have produced better results than treatment-as-usual. That was news, too.

But if mental illness is a brain problem, and if people who experience mental illness can recover significantly, what happens to their brain problem? Is it fixed? Was mine fixed?

At this juncture I stumbled onto neuroplasticity. In science, neuroplasticity refers to the brain’s natural ability to change, adapt, and heal across the lifespan. I learned that the brain was highly malleable, changing its structure and chemistry in response to both internal and external stimuli – from thinking positively to experiencing trauma.

Most importantly, I learned that utilizing the brain’s natural



potential to heal, people were recovering from massive strokes, head traumas, overcoming learning disabilities, rewiring obsessive-compulsive behavior, erasing the pain of phantom limbs, restoring memory acuity, enhancing cognitive processing during old age, learning to see without eyesight, strengthening muscles just by thinking about them, using meditation to create lower-stress neurological states, and on and on.

If people could train their brains to overcome these problems, why not major mental illness?

To demonstrate his knowledge and his efforts to learn about brain function “Stefan” describes the science of “neuroplasticity”. He explains how the brain has been shown to repair and adapt over a lifespan, but including this reference reinforces the idea that mental illness is related to brain functions. In effect this counters his resistance to discourse about mental illness as a biological disease and reinforces a medicalized view that suggests mental illness *is* a brain disorder.

In “Thom’s” narrative the lack of empirically informed medical practices for diagnosis is evident in the way he describes the casual nature of his many diagnoses over just one year. His narrative highlights a contradiction between the simplistic and casual way he is diagnosed and the complex long-term effects of being labelled with a mental illness. In his narrative, “Thom” recreates a conversation he has with an emergency room psychiatrist, and then includes his reflections on the consequences of diagnosis.

“The auditory hallucinations you have been experiencing are symptoms of schizophrenia. This may have changed your sense of reality, and it explains the delusions and suspiciousness. You have a chemical imbalance in your brain, and I can prescribe you medication that will make you better.”

There isn’t much time to discuss the diagnosis. This on-call psychiatrist had other patients to see. He rises and shakes my hand. I’ve given him the right answers to get me discharged.

I had no way of knowing then that this doctor’s diagnosis would

start a year-long journey into the mental health system and the depths of hell. It would feature seven different diagnoses, 13 different mind-altering drugs, more than a dozen psychiatrists and psychologists, hundreds of hours of therapy, drug overdoses, self-mutilation, a suicide attempt, a weight gain of 140 pounds and being committed by the state of (XYZ) for four months into three separate mental institutions.

Stories like “Thom’s” express frustration about the lack of clear diagnostic processes and the random and changeable nature of diagnostic labelling. To make a meaningful connection in discourse, narratives such as the one that “Rainey” tells below, indicate people use their knowledge and understanding of psychiatric labels to demonstrate how the variable and changeable practices of psychiatric labels makes them meaningless. “Rainey” explains how her diagnoses have “nothing to do with the symptoms I describe” and how the practices of naming disorders are perpetuated as she is drawn further into the medical system.

The actual diagnoses vary, depending on the psychiatrist, and some of them include Major Depression, Dissociative Identity Disorder, Generalized Anxiety Disorder, Social Anxiety Disorder, PTSD, and the list goes on.

I’ve also been diagnosed with illnesses that have nothing to do with the symptoms I described.

You see, once I got into the system, I developed other behaviors simply from the side effects from the medications I was given or from trying to survive in a psychiatric hospital or day program.

These added behaviors were diagnosed with things like Chronic Undifferentiated Schizophrenia, Borderline Personality Disorder, Schizo Affective Disorder, and the list goes on.

These are the reasons I do not believe in the existence of mental illness. The system simply can’t get it right, most likely due to the fact that there are no scientific tests for any mental illness.

Psychiatrists — and (ABC organization) — will tell you that brain scans show differences in the brain chemistry of people with these illnesses, but hey, they failed to stop the medications before

scanning the brains. Those scans are of chemically-altered brains!

Other explanations are possible, too, like childhood trauma, which is the most prevalent occurrence in people who have been diagnosed with a mental illness.

Adding to this challenge, and making it more difficult to manage medical experiences are the ways diagnoses change for patients depending on the time in their lives or the doctors they spoke to. Stories demonstrate patient proficiency with psychiatric labels and how sarcasm and other rhetorical tools are used to describe contradictions in diagnostic practices. Below “Thom” recalls an instance and a conversation that explains the way he responds to constantly changing diagnostic labels, and indicating they lose meaning.

While in therapy, the psychiatrist changes my diagnosis. I am so used to this that I don’t even pay attention to the new illness.

This doctor says I don’t have schizophrenia or Schizoaffective Disorder, or Bipolar Disorder or any other psychotic illness. Now I have Borderline Personality Disorder, an emotional dysregulation featuring extreme sensitivity and a short fuse.

The doctor says most people with BPD were abused. Were you abused?

“I already told you. No.”

The doctor says the diagnosis is unusual for a young man and calls me unique. By way of explanation, he tells me I have built an “invalidated environment” where I have not learned to care for myself emotionally. Then he drones on about my emotions.

“OK.”

He is mildly surprised that I have no interest in his pontifications on my illness and his perceptions on my life. I’m done humoring these people. I want to go back to my room and read.

The stories in this sub-section show how the diagnostic process discounts or ignores what is going on biographically for people when they are diagnosed. More importantly, it indicates how

relevant it is for these biographical events to be recognized and connected to the discourse used to describe mental illness.

*Section Summary: What it's like being diagnosed with mental illness*

Psychiatric labels are easily produced and reproduced in discourse about mental illness. The narratives in this section indicate that the desire to receive some form of help or treatment during crises encourages people to accept the labels and the stigma that accompanies diagnosis. The narratives show people re-inform and bridge meaning between their experience and discourse about mental illness by resisting the practices of diagnosis, by describing the long-term consequences of psychiatric labels, by including and aligning life events with diagnosis, and by directly questioning the biological basis of mental illness. These narratives indicate a sense of futility as people try to move out from under, or away from, psychiatric labels, but also suggest that there is little (or no) other way to frame mental illness experience. People make connections between their experiences and discourse about mental illness by resisting, re-informing and reinforcing discourse about diagnosis. The stories in this section indicate people struggle to manage the lack of alternatives and the variable and confusing nature of their diagnoses, and do so by highlighting issues and specific challenges, which re-inform discourse and direct attention to what needs to change. The medical profession responds with increasing efforts to label and name people's experiences, which is evidenced by the continued use and expansion of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM). Medicalization is reinforced and expands as the medical profession continually adjusts and alters labels and explanations in order to maintain control of the power to name mental illness (Foucault, 1965). In effect, the medical profession keeps 'moving the goal line' (so to speak), and people remain in

the system as psychiatric labels change, and as a consequence less attention is paid to naming mental illness (madness) based on non-medical discourse or lifeworld experience.

### **Personal Narratives about What it's Like Taking Psychiatric Medications**

This section focuses on personal narratives about what it is like taking psychiatric medications. The analysis examines the ways people manage medicalization by making meaningful connections between their experiences with medications and discourse that suggests taking medication is beneficial. Analysis of these narratives indicates people resist and re-inform meaning in discourse by describing the debilitating effects of psychiatric medication, by highlighting the lack of controls in practices of prescribing medications, and describing social pressure to take medication. The stories also highlight contradictions between personal experience and discourse regarding the perceived value, efficacy, and levels of knowledge that purportedly accompany practices of prescribing and monitoring medications. They also indicate that the uncertainty of mental illness necessarily involves some form of treatment or management, whether that means medications or alternatives. In these narratives patient status is invoked to resist, but also reinforces the need for medical care. Examining these narratives it is apparent that there is a vast disconnection between what people experience when taking medication and how medications are monitored, suggesting there is a lack of integration of experiential knowledge into the medical discourse.

#### *Narratives explaining the experience and effects of psychiatric medication*

Even more than diagnosis, narratives about what it's like taking psychiatric medication describe the traumatic psychological and physical control psychiatric drugs exert over people and

the power this has to threaten their identity and health. Stories resist and re-inform medical discourse by including detailed information about the immediate short-term effects of medication and its long-term effects. The narratives give a sense of how people saw themselves during the time they took medication and these descriptions align with and therefore reinforce historical images of heavily medicated, nonresponsive patients. The stories most resist discourse about mental illness by demonstrating the iatrogenic force of medicalization (Illich, 1976). The narratives describe how psychiatric medications create effects that are more challenging than mental illness. Interestingly few narratives describe medications in a positive way or indicate that they are helpful for long-term use. Some people suggest that medications are helpful in crisis situations or for short-term interventions. Narratives about what it's like taking psychiatric medications provide an important, though overlooked source of information about medication effects and prescribing practices. By including specific details in their stories people re-inform discourse about mental illness in ways that go beyond what medical records and reports can provide.

The stories re-inform discourse about mental illness by explaining that it is often the effects of medications that lead to behaviours usually attributed to madness. Rather than indicate a positive change in identity these stories suggest that medication is an assault on the self. In the first narrative in this section "Liam" describes how he looked in photos "of that time, positioning his experience with medications in a past that seems disconnected to his present state. He is clear from the outset of the narrative that the medications made him "a different person" and "basically a zombie". "Liam" points out that with medication he "was being docile so they considered it recovery". His reference to how "they considered it recovery", suggests that the term "recovery" has different meanings, which in recent years is the case as more and more

people define recovery as an ongoing process, rather than an end-state with a full return to so-called normal functioning and the complete absence of illness.

I have photos of that time, and the look in my eyes is totally different, not me, a different person.

I was basically a zombie, but I was being docile so they considered it recovery.

Today I worry that I might have some lingering side effects from the (ABC drug), and other drugs I took, including twitching in my body, memory disturbances, and worsened panic. There could be other long-term damage that I may never be able to sort out and recognize.

“Liam’s” narrative resists discourse that suggests medication is helpful, and also that medication can lead to complete and full recovery, as is the case with an acute physical illness such as cold or flu. His description of what happened to him as a result of taking psychiatric medication re-informs discourse about mental illness by indicating it is often medication that causes the so-called symptoms, or overt behaviours, that have come to be associated with people who are diagnosed with mental illness. “Liam’s” narrative and others like it bring to light the taken-for-granted idea that medication is by definition deemed to be positive and helpful, something that is increasingly contested.

The narratives examined for this thesis indicate people do not say much about what their medications are supposed to treat exactly. The narratives do not readily include descriptions of what symptoms or problems the medications are treating or how they are supposed to work. As noted in the previous section diagnosis does not involve any readily practiced empirical testing for mental illness, rather mental illness is determined by self-report, by a show of some behaviour deemed a symptom of mental illness, or determined by psychiatric observation. Therefore the prescribing of medications is and how well or poorly they work can be assumed to

be based on the same things—self-report, psychiatric observation, or changes in behaviour. The narratives include few descriptions of what medications are supposed to do *for* them, but they include many descriptions of what these psychiatric medications do *to* them. Below “Ardene” describes how the medications she was on “made me sleep too much” and “drool”, and she explains she “had the (ABC drug) shuffle” and her “tongue stuck out from time to time”.

I was put on (ABC drug). (ABC drug) made me sleep too much and slowly my will was being destroyed. I felt flat and empty inside.

Besides, I had the (ABC drug) shuffle when I walked; I drooled and my tongue stuck out from time to time.

It was very embarrassing.

I didn’t know these were side effects to the medication. No one had told me this.

I thought I was much more mentally ill than I was. I was overmedicated from 19-- to the end of 19--.

I seemed to be a zombie on (ABC drug).

Aside from physical effects “Ardene” explains how these things made her “embarrassed” and that “no one had told me this”—raising the question: If people taking medications are not told of these effects, how is the public to be made aware that these effects are due to medication not mental illness? “Ardene’s” narrative does more than give perspective to negative effects of medication it also indicates how not knowing these effects could occur made her feel as if she “was much more mentally ill than I was”. “Ardene” describes how this impacted her sense of reality and ability to connect with others, she says she “felt flat and empty”. All of these descriptions are meaningful because they are things that others can understand regardless of whether they have been diagnosed with mental illness or taken medications. The narratives



bridge meaning by resisting and re-informing discourse about mental illness that encourages medications as the so called best way to treat mental illness.

Discursive self-portraits such as “Kelly’s” (in the next example) provide insight into what medicalization of madness costs people in terms of their health and lifestyle in the future. “Kelly’s” narrative explains the medication did reduce some symptoms, but “they immobilized me with side effects”, which created other problems.

I went through a variety of medications, always in very high doses.

Although they reduced the severity of my symptoms, they immobilized me with side effects. I was a walking Zombie.

Walking was stiff—I'm told my face was expressionless and I drooled.

Wouldn't that scare anyone?

Her description is a telling example of the ways medications do not help but rather compound or shift attention to other issues, including the inability to engage socially. Whereas “Ardene” describes her interpretation of photos of herself, “Kelly” explains how others saw her “I’m told my face was expressionless” and she adds “wouldn’t that scare anyone?”.

Stories describe instances where people refuse or complain about the effects of one medication only to be given another medication. The narratives suggest the stronger the refutations to medication the more medical practices assert this type of control. These stories indicate how calls for improving knowledge about drug interactions and side effects are discounted. For instance, rather than address the unwanted effects of medication, more medication is prescribed to counter the effects or ineffectiveness of prior medication. Narratives about the effects of medication include descriptions of how the significance of medically induced problems is ignored or obscured as more medication is prescribed. Ironically, while long lists of

negative effects accompany prescriptions attempts to address or reduce these consequences are limited to giving more medication.

In the next narrative “Liam” describes “spending several months taking a very powerful ‘anti-psychotic’ tranquilizer” and includes personal experience and the experience of others to construct a story that exposes how side effects from medications can have fatal consequences. The narrative does not reference medical journals or empirical testing, but a clear connection is made based on experiential knowledge about the effects of medication. It is a descriptive story that references an event and indicates parallels between characters sharing the same residence and the same types of medication. The narrative constructs an image of characters in care and under watch, but unprotected. They are vulnerable to the effects of medication prescribed to control, not create, negative experiences.

I spent several months taking a very powerful 'anti-psychotic' tranquilizer drug called (ABC drug), used to treat schizophrenia.

It completely changed my personality and denied me the most basic sense of who I was; it made me stupider, slower, fatter, and also, because of the side effects, at times more desperate and suicidal.

At one residential facility I was at, a man had killed himself right before I arrived. A patient who was his friend told me why: he was having severe side effects from his meds and no one was listening to him. The meds were why he jumped off the roof and killed himself, not mental illness.

When I was on medication it was impossible to know how much of my pain was the medication, not the problems I had to begin with.

“Liam’s” narrative also highlights long-standing social and cultural beliefs about madness as unpredictable behaviour, but rather than situate the unpredictability in a person, the narrative emphasizes that the greater threat is the unpredictable effects of medication. Narratives

explaining the effects of taking psychiatric medications suggest like mental illness, the medication used to treat mental illness also makes life and behaviour unpredictable.

### *Narratives describing problems with prescribing practices*

The desire for medications to work is a prevalent theme in stories about what it's like taking psychiatric medications, and this is often the reason people stay on medications and try new medications despite the negative effects. Notable in these narratives are references to seemingly over-zealous prescribing practices and a lack of monitoring drug tolerance or drug interactions beyond general indications listed by pharmaceutical companies. Narratives counter and give meaning to these lists, however, peoples' narratives describe a distinct lack of communication with regard to how people are told about the effects of the drugs. These narratives resist medical discourse by explaining how taking medications is a hollow promise for a so called normal life, and yet, often people have no other immediate resources to help them cope with their experiences of mental illness.

“Shelley’s” story reads like a list of “side effects” that might be included with a prescription, however, with the inclusion of her personal experience the list bridges meaning between discourse about medication and “Shelley’s” personal experience. She begins by situating her experience temporally, which indicates she has a long history of experience with medications. Her initial reference to “the kind psychiatrist” is immediately countered by the description of how the “new neuroleptics” “literally tore me to shreds”. “Shelley’s” narrative builds in intensity as she describes dramatic and frightening changes in her body functions and behaviour, and she explains how the doctor dismisses her claims about the effects of the medications. She explains how her efforts to inform the doctor of the issues she was having were

dismissed because the doctor “had never heard of the drugs causing them”. Like “Kelly” in the narrative above, “Shelley’s” lack of knowledge about the drug effects, led her to believe she “must truly be crazy” because she had “no idea they were the real culprit causing all my trouble”. The narrative bridges meaning as she connects her experience to discourse in ways that resist and re-inform what is known or assumed about the efficacy and safety of medications. “Shelley’s” narrative suggests greater communication with patients about medications is certainly warranted. She continues with the medications despite the effects with the hope “I’d be myself again”.

In 1999 the kind psychiatrist put me on the new neuroleptics:  
(ABC drug) and (ABC drug). They literally tore me into shreds.  
All the above-mentioned problems became worse.

My body twisted in agony from the spasms they caused. I drooled  
and shook. I couldn’t wake up and wet my pants from the drug-  
induced stupors.

Every time I told my doctor what problems I was having he said  
he’d never heard of the drugs causing them. I thought I must truly  
be crazy to be feeling like this.

I stayed on the drugs having no idea they were the real culprit  
causing all my trouble.

The doctor kept promising me one of these drugs would work-I’d  
be myself again.

I believed him.

To him I was a psyche patient-give her more drugs and see how  
she does.

All this time I was driving a car.

With the simple line at the end of her story, “Shelley” offers a dry twist of humour that points to the contradictions and ironies of medication-induced normalcy. After explaining and describing her experience she brings attention back to the reality of everyday life when she states simply, “All this time I was driving a car”. The implication being the dangers of mental illness as a threat

in society are treated as more extreme than the dangers of her driving while under the influence of prescribed medications. “Shelley’s” experience challenges and re-informs discourse that suggests medications are helpful, but more significantly her point at the end of the narrative indicates prescribing practices and monitoring of medications is limited. In her narrative “Shelley” describes how she followed the doctor’s directions and believed when he “kept promising me one of these drugs would work”. Her compliance to continue taking the medications despite the effects is indicative of how the desire for medications to “work” and the need to “believe” the doctor hold people within a medicalized state requiring them to be good patients.

Narratives like “Shelley’s are further evidence of the ways stories resist and re-inform discourse about mental illness. “Shelley” explains how she “trusted my psychiatrist completely” her faith in the medical community is evident as she comments “after all he was a physician and thought he knew what he was doing”. This narrative re-informs, but also reinforces discourse about whether medical approaches and the medical community generally have all the answers. “Shelley’s” narrative like the other narratives above demonstrates there is a lack of complete information provided to patients regarding what or how medications will affect them. The narrative indicates regardless of whether the information people receive is listed to them there is some disconnect between what they are told to expect and what actually happens. As a result people describe a loss of faith and trust in the medical professionals they turn to for help.

I trusted my psychiatrist completely after all he was a physician and thought he knew what he was doing.

I had no idea at all what these drugs were doing to my body, my mind and my whole life. How they affected my behavior and caused me to act so completely different from how I really was.

I now realize that these drugs were indeed extremely dangerous and to question what ever any doctor tells me.

According to “Shelley” she “had no idea what these drugs were doing to my body, my mind, and my whole life” and with this expression of her experience she draws the impact of medicalization into her “whole life”. Her narrative indicates that she has better understanding of the drugs as “extremely dangerous”, and as a result she has changed her behaviour so that she knows to “question what ever any doctor tells me”. “Shelley’s” experience makes a meaningful connection by addressing traditional discourse that suggests being a good patient means following doctors’ orders. However, “Shelley” still implies a need for medical assistance, but now she will “question” what she is told.

Compliance was storied socially as a way to get well. In the next narrative the realization of the risks involved in being a good patient are described in hindsight, as “Annette” explains how following doctor’s orders led to serious physical illness due to the prescription of strong medications that were not monitored properly by a physician.

I took 1500 mg. of (ABC drug) every day for seven years, plus an antidepressant and such other drugs as (Dr. ABC) ordered.

When it reached the point that I was getting up four or five times a night to urinate, I insisted “against (Dr. ABC’s) wishes” that she refer me to another psychiatrist for evaluation. He recommended that she do the kidney tests that she should have been doing every six months, but had never done.

I was diagnosed with nephrogenic diabetes insipidus, a rare incurable kidney disease that is usually caused by bad doctors prescribing (ABC drug). Nephrogenic diabetes insipidus causes urine output to increase “in my case” the increase was five times normal.

I quit the doctor and the ABC drug.

The treatment for nephrogenic diabetes insipidus is (DEF drug), which costs \$10,000 a year, and (GHI drug), which causes

potassium depletion, so I took (them) and got hypokalemia.  
Potassium supplements were added to complete the drug package.

The narrative explains detailed consequences as a result of “Annette” taking the medications and having limited or no follow up on the effects she was reporting. The narrative reinforces discourse that challenges the over use of medication, but more significantly it also indicates “Annette’s” level of understanding and knowledge which runs contrary to much discourse about mental illness that suggests it is something that reduces a person’s cognitive abilities. This positions people as “lay-experts”, a term described by Epstein (1996) in his comprehensive analysis of the AIDS epidemic. He states, “the intervention of laypeople in the proclamation and evaluation of scientific claims have helped shape what is believed to be known about AIDS” (p. 3). In this thesis Epstein’s (1996) discussion of AIDS patients as “lay-experts” is a helpful example for considering how people, as patients, are also taking a lead in the development of knowledge about mental illness. However, the application and strength of their challenges to scientific claims about mental illness have not yet reached the same level of influence.

#### *Narratives describing the pressures to take psychiatric medication*

In this subsection I examine one last prevalent theme about what it’s like taking psychiatric medication, that is, I look at narratives that describe social pressure to take medications and the struggles people have to resist or even withdraw from medication. On the websites reviewed for this thesis there are many narratives about what it is like to withdraw from medications. These narratives are presented as warnings, guides, and advice to others about the dangers of stopping medication too quickly or without support, and they include information and

insight explaining how people have to negotiate negative social responses and an unsupportive medical community.

“Uma” re-informs discourse about mental illness by describing her experience and providing details about the “long and gruelling” process of withdrawing from medication. “Uma’s” narrative is in some respects quite similar to the narratives about the effects of medication described in the previous subsection. The effects of withdrawal she reports include “tremors that made it difficult to even to hold a fork to eat”, “headaches so profound” she had to work less and “could barely speak”. The narrative includes no mention of the kind of support given by a physician or psychiatrist, so it is unknown whether “Uma” stopped taking medication by her own choice or upon the advice of a doctor. It is more likely that it was her decision to stop taking medication, and to support this she describes how the results were noticeable and positive.

The process of withdrawing from these drugs was long and gruelling.

When I withdrew from (ABC drug) I experienced tremors that made it difficult to work or even to hold a fork to eat. Fortunately, the tremors were not permanent and finally abated 6 months after my final dose.

While withdrawing from (ABC drug), after the slightest drop in dose I experienced weeks of headaches so profound I could work for only a few hours a day and could barely speak or do anything other than sleep in the evenings.

Despite the difficulty, my wife and I both noticed that once each withdrawal period had passed, each time I dropped another drug from my regimen, I became healthier and more resilient.

I wasn’t getting sicker. I was getting better.

The narrative begins with a description of the terrible effects of withdrawal and then moves to a happier conclusion, which “Uma” explains “despite the difficulty” she and her wife noticed over time as she slowly reduced the medication she “became healthier and more resilient”. This is



meaningful as it indicates to others that withdrawal is possible and can have positive results, however, the narrative suggests that in order to withdraw people need their own support systems because the health system provides little assistance once compliance to take medication is violated. Adding to the difficulty of trying to withdraw is discourse about mental illness that encourages compliance based upon a social beliefs that medications provide relief and/or reduce experiences of mental illness.

In the next narrative “Laurel” explains how expectations of compliance for taking medication are subscribed to and encouraged by family and friends making it difficult to resist medications even when personal experience indicates they are harmful. In “Laurel’s” narrative, she describes how friends assume she would be better with medication, however, she replies “when I was on medication I gashed myself up a hundred times worse than I ever did off of it”. In support of her experience she follows this with reference to a “book” that describes “aggression linked to medication”, and then states, “I feel so much better now that I am off of it”. “Laurel’s” narrative connects her experience in a meaningful way to broader discourse about the efficacy of medication. With the inclusion of her points about a book that supports her view, and then with her own assertion that she is better without medication.

And a lot of my friends who have gone through the same thing will say, Well, maybe you wouldn't cut yourself so much if you were on medication.

Let me tell you something. When I was on medication I gashed myself up a hundred times worse than I ever did off of it. That (ABC book) tells you all about aggression linked to medication.

I feel so much better now that I am off of it.

And I feel a lot more empowered now that I am out of the system, and knowing that I can exist out of hospitals is something that I never thought I would be able to do.

As “Laurel’s” narrative suggests resisting these calls for compliance can result in relief and a greater sense of identity outside of being a patient defined by medical discourse. Generally, discourse endorses the use of medication as the best way of treating mental illness as a biochemical imbalance in the brain. In “Laurel’s” narrative she explains how moving away from the “system” makes her feel “a lot more empowered” and has given her personal insight that she is “able to exist out of hospitals”. The narrative bridges meaning with strategies of resisting and re-informing discourse about the possibilities of people moving away from the medical system successfully.

In some instances narratives describe how people are compelled to stay on medication due to unspoken and internalized social pressures to comply. “Stefan’s” narrative describes the impact of pervasive beliefs about mental illness and how discourse about compliance is translated into how people see themselves as being a good or bad patient. (This theme is even more evident in the next section of this chapter, which focuses on narratives about hospital treatment.) “Stefan” explains he “began openly expressing to others that I was taking ‘my meds’” and he comments this was the way he could look like a “good patient”. He describes his efforts as a way to earn the respect of others and to be “worthy of inclusion and accolades”. His is a telling narrative that bridges meaning between experience and discourse on a number of dimensions including identity, relational and ideological. Specifically he brings together discourse about the efficacy of medication, the influence of relationships, the oversight of the medical system, and the overshadowing influence of pharmaceutical companies. “Stefan” connects these various discourses and personalizes compliance by storying the conflict he feels as a result of his “emergence into a walking advertisement for the pharmaceutical companies”. He tried to view mental illness like a medical disease, “like diabetes”, but explains he was unable

to accept this because the medication, “the pills, never quit instilling within me their unlisted side effects of shame, unnaturalness, isolation and dependency”. “Stefan” does not give details about the physical effects of the medications rather he describes the effects in a more profound and personal way. This is apparent in the last line of this narrative when he uses colloquial language to describe what it feels like to have to take medications for mental illness.

I even began openly expressing to others that I was taking ‘my meds,’ as if the choice made me a ‘good patient’ worthy of inclusion and accolades.

However, my emergence into a walking advertisement for the pharmaceutical companies came at the price of repressing internal conflicts.

Indeed, no matter how much support and validation people offered, no matter how many times I reminded myself mine was a medical disease ‘like diabetes’ which required medical solutions, the pills never quit instilling within me their unlisted side effects of shame, unnaturalness, isolation, and dependency.

It is simply impossible to forget you are crazy when you eat from five bottles of pills every day.

After drawing together other discourses to make a meaningful connection between his experience and discourse, “Stefan” brings attention back to a reflection on his personal experiences when he explains how challenging it is to “forget you are crazy when you eat from five bottles of pills every day”. With this line he brings attention back to situation localizing and personalizing the experience. In “Stefan’s” story discourse about medications is resisted as it indicates the difficulty of accepting that mental illness is like any other “medical disease” requiring medical treatment.

The websites reviewed for this thesis include stories that describe broad social pressures to continue taking medication. In “Stefan’s” narrative he explains that he became “terrified of discontinuing medications” because of prevalent discourse that emphasizes Bipolar as an

“incurable chemical imbalance in the brain”. He follows this advice because of his belief that it is based upon “hard science” and because it is strong in the Bipolar community where “advice orbits around one unshakeable core” that is “NEVER quit your meds, or else...”

...I became terrified of discontinuing medications ever again. And there were plenty of people to confirm the wisdom of my fear.

In fact, I soon discovered that all Bipolar advice orbits around one unshakeable core: Whatever you do, no matter how good or stable you feel, NEVER quit your meds, or else...

This way of thinking is justified by the belief that Bipolar is an incurable chemical imbalance in the brain which medications help restore.

Given the overwhelming presence of this theory in the media, medical texts, and amongst professionals and peers, I presumed it was backed by hard science and became invested in taking pills for the rest of my life.

The narratives above indicate there is pressure to take medication in all areas of discourse, medical, social, peer groups, and even personally as people try to follow what they believe will be the best approach for helping them. The narratives highlight how assumptions are made and developed in discourse about mental illness. The inclusion of personal knowledge gives context to the pressures around compliance and this resists and re-informs discourse and directs attention to contradictions and incorrect assumptions.

In personal narratives about medication people resist discourse by describing successful instances where people stop taking medication. These narratives offer testimony about what happens when people stop taking medication. “Stefan” described his initial trepidation of living without medications, and the uncertain sense that he might experience dramatic changes in his intellectual abilities or sense of reality, which he refers to as “mental slippage to indulge in existential contemplation”. However, after “a few months” he was “clearer and even relatively

grounded” so much so that he questions the science behind the idea of a “chemical imbalance in my brain.”

At first I was too occupied with watching for signs of mental slippage to indulge in existential contemplation. But after a few months, as I realized I was clearer and even relatively grounded, the question inevitably arose: What happened to the chemical imbalance in my brain?

To find answers I started researching heavily. Instead of relying – as I had in the past – on government agencies, major organizations, professionals, and bestselling books for explanations of mental illness, I went straight to the source: to the scientific journals that provide empirical evidence to support or refute psychiatric theories.

To answer his question, “Stefan” avoids popular literature or information provided by social care agencies, suggesting he is aware that many are directly informed by science that looks at mental illness as a brain disease and instead he looks to “scientific journals”. His narrative demonstrates an interest in developing knowledge as a lay-expert, and suggests that having information to refute or support the idea of mental illness as a physical illness from a scientific source positions people outside of being a patient.

In some cases people describe accepting medications as a short-term approach in a crisis, which can be challenging given that most psychiatric medications take four to six weeks to show any effect, and then another few months to determine whether they are having the desired effect. These narratives describe how there are situations where use of medication is justified or acceptable, citing its value in certain circumstances. Accepting medications for use in the short-term, “Brian” explains he is not “anti-psychiatry nor am I anti-med” and that medications “were created for, short-term crisis intervention”. In this narrative although he does not describe personal experience with medications, he outlines experience with a form of therapy suggesting

it helped “me to see and change negative patterns in my thinking”. As explanation for needing or using both approaches he describes grieving after his father died from suicide, and then includes points about his family and friends wanting him to return to his job. “Brian” constructs meaning around these events and connects them to discourse about what medications are suited for, and then he returns attention to his part in the process suggesting he “is partly to blame”, “wanted a quick fix”, and “wanted the pain to go away”. He places responsibility for taking medications on himself explaining he “filled that first prescription, no one held me down and administered it”.

Not that I am anti-psychiatry nor am I anti-med. I believe that there is a time and a place for psych meds. They are fine for what they were created for, short-term crisis intervention.

Talk therapy can be wonderful and I credit (ABC therapy) for helping me to see and change the negative patterns in my thinking.

I was seriously depressed when I originally sought help, but I was appropriately depressed. My father had killed himself in a rather violent way and I was understandably upset.

Everyone was so concerned about getting me back to work as quick as possible rather than allowing me to have the necessary time to grieve.

I am partly to blame. I wanted the quick fix. I wanted the pain to go away. I filled that first prescription, no one held me down and administered it.

“Brian’s” narrative and others like it direct attention to possibilities for including medications in treatment alongside other psychiatric interventions. The narratives hold people in the medical gaze as patients, even with the inclusion of other approaches that do not use medication. These narratives bridge meaning by connecting experience and discourse in ways that incorporate and accept medical approaches, but resist the ways medical approaches are administered.

This subsection shows the pressure to take psychiatric medication is asserted in many ways including through relationships, beliefs in scientific discourse, pressure from family,

friends, peer communities, and medical professionals. In personal narratives people bridge meaning as they resist and re-inform discourse by connecting it in meaningful ways to their experience of medications. In the final narrative for this section “Thom” recollects a conversation with his father about his decision to stop taking medications. The narrative does not include descriptions of effects or changes in identity, social beliefs in discourse about medication, or the truthfulness whether mental illness is or is not a disease. Instead it creates imagery and has a more positive tone as “Thom” asserts his decision about medications to his father who is a pharmacist.

I call my dad the pharmacist the next day. I tell him I am done with the pills. He tries to talk me out of it.

“I’m done with them.” My voice is strong, and my resolve is absolute.

“If you feel that strongly about it, we have to support you,” he says. “As a pharmacist though, I am hesitant. I think it is a big mistake.”

“I understand.”

“You’re going to need a refill of your (ABC drug),” he says. It is my (ABC medication).

“I’m done with them,” I repeat.

“(Son), you have to at least be on that. You’ve been on it for five years.”

“Dad, I’m done with the pills. All of them. End of discussion.”

He is taken off guard. But he sees a son who is finally taking back control.

The clouds lift in the next few weeks. I see the sun. I have friends again.

I am smiling.

“Thom’s” narrative stands in contrast to the first narrative examples presented in this section describing narratives about what it’s like taking psychiatric medications. In the earlier narratives people described the effects of medications, that made them feel and look like “zombies”, they describe not only the personal effects and pressures they feel to take medication, but make their experiences meaningful by linking them to broader discourse about medications. “Thom’s” narrative is included here to demonstrate that not only does he discover and appreciate the physical and psychological liberty of not being on medications, but more significantly his narrative indicates how important that people have opportunities to assert their will and that this can be done in a positive manner. In the narrative he describes how his father tries to convince him he needs medications, and highlights how his father “is taken off guard” as he “sees a son who is finally taking back control”. Evoking meanings and contexts of father-son relationships “Thom” makes a meaningful connection that conveys a scene reminiscent of a movie with a happy ending. “Thom’s” narrative implies that he comes-of-age by asserting his will and as such he makes his own happy ending by resisting and ultimately re-informing discourse about the value or need for medication. He makes a meaningful connection that asserts a positive outcome which re-informs discourse and medicalization.

*Section Summary: What it’s like taking psychiatric medication*

Personal stories about experiences with medications describe contradictions regarding the psychological and physical impact of medications on personal identity. Having succumbed, by choice or by force to take medication, people describe dramatic changes medication causes in their lives. As these stories indicate medications prescribed to treat and help reduce the challenges of mental illness merely add more complications. In these narratives, it is not



experiences of mental illness that are described as challenging but rather the effects of medications prescribed with limited knowledge of how individuals may react to the drugs, and limited monitoring of peoples' physical and psychological health when they take them.

The prevalence and detailed manner in which narratives about the effects of medications and random prescribing and monitoring practices strongly indicates increased attention is needed to better discern the effects of medication, but this attention needs to focus beyond what is listed on a pharmaceutical pamphlets or what appears in medical records. If there is to be better understanding of medications a concerted effort must be made to integrate and involve the knowledge and experience of people who have experienced being prescribed and taking medications. The narratives in this section indicate that when experience and discourse are connected in narratives there are opportunities for influencing and directing medicalization, and yet, as long as there is an increased availability and desire for medications to treat mental illness medicalization will continue to expand as personal experience becomes part of the medical discourse.

### **Personal Narratives about Being in Hospital**

Similar in tone and language, narratives about what it's like being in hospital are reminiscent of historical accounts of madness presented in autobiographies and memoirs. In this section my examination of the personal narratives suggests people manage medicalization by making meaningful connections between their experiences as hospital patients and discourse about what it is like in so called mental institutions or asylums. Examining these narratives indicates that in their stories people both resist and reinforce meaning in discourse as they describe hospital and therapy settings, by explaining what it is like being treated in hospital, and

by explaining how being a good ‘*bad*’ patient is required if better treatment or reduced hospital treatment is desired. My definition of a good bad patient is someone who outwardly behaves in ways that follow the status quo in order to help them manage the effects of medicalization.

My analysis of these narratives indicates that with descriptions of hospital settings and narratives about negative treatment people reinforce stereotypical views of what it is like to be a patient in hospital being treated for mental illness. The narratives include descriptions of outward shows of resistance, which reinforce (and are reinforced by) popular media in movies and on television creating imagery about the stereotypical ‘bad mental patient’ who requires constant supervision and restraint. Ironically, while these narratives are composed as a way to directly resist medical approaches, the portrayal of traumatic hospital treatment in popular culture and media indicates society is aware of the negatives thereby reducing the so-called shock value of the stories, and perhaps lessening their impact.

#### *Narratives describing hospital and clinical settings*

Detailed descriptions of hospital environments and therapy settings reinforce discourse about mental illness that suggests these contexts are far from helpful or supportive to people in need of care. The narratives are critical and exaggerated characterisations of treatment facilities that emphasize status differences between patients and doctors, and descriptions of hospital environments match those produced in fictional movies or on television. In his narrative “Liam” contrasts his “fragile emotional state” with the “chaos and violence” of the hospital, which was “like a prison”. The narrative resists mainstream ideas about hospitals as safe and calm places where people, as patients, are take to get well. It resists these ideas by emphasizing other

discourse about what a hospital is like for people experiencing mental illness, and this ironically reinforces fictional accounts that describe so called mental institutions as chaotic and dangerous.

When I arrived at the hospital, it was like a prison. The chaos and violence, the crowding and screams were terrifying. Throughout the night police brought in anyone fitting the ‘mental’ description and dumped us all together.

In my vulnerable and fragile emotional state the impact of this pandemonium was devastating. I was in shock from fear.

Using just a few lines “Liam” distances himself from the other people at the hospital when he explains “the night police brought in anyone fitting the ‘mental’ description and dumped us all together”. His description connects experience and discourse by both resisting and reinforcing assumptions about the differences between what a hospital is like for people diagnosed with mental illness and those who are brought to general hospital for some other care. In “Travis’s” narrative the distinction is apparent in a short description of how he becomes aware of being “under a high surveillance regime”.

I once managed to obtain my medical records from one of the clinics I was in, and when I saw how the smallest thing I had done or said had been noted down, I realized that I was under a high surveillance regime.

These two narratives indicate that when describing experiences in hospital people manage discourse that is contradictory. As people tell their stories they reinforce popular media accounts and discourse that portrays hospital and mental illness experience negatively, but their narratives are also aimed at resisting mainstream ideas that hospital experience is positive. The two actually work together as a way to re-inform how people are treated in hospital.

The following is narrative describes “Cathleen’s” experience at a therapist’s office not a hospital. “Cathleen’s” narrative reads like a richly detailed novel. The narrative is a uniquely

storied description of a therapist's office and it is effective as a way of resisting discourse because of the way "Cathleen" alternates between detailed points about the look of the office she was in and much broader references to psychiatry, professional and academic credibility of psychiatrists, and family relationships. She uses descriptive imagery to draw these various discourses about mental illness together in a meaningful way to suggest that she is aware of the influence the office environment has and how this is used as a way to establish power and status differences between doctor and patient.

I remember therapy. I remember the array of their tasteful, decorative little offices, all the little tchotchkes that were supposed to demarcate the small variations among their bourgeois personalities.

Were they a sensitive New Age therapist was the office bedecked in fuchsia quilts and crystal and all those other oh-so-spiritual consumer products?

Were they a neo-Freudian therapist, with that imposing bookshelf of fat leatherbounds in perfect unread condition "Father Daughter Incest" was the unfortunate title always directly in my view in one worthy's office with all the delightful mental images it called up.

Were they the savior surrogate parent type, with all the testaments to that loving transference, ostentatious displays of the patients' artwork slavishly dedicated to them all over the room?

And the constants the imposing therapist's chair, more like a throne, really, from which they peered down at the little "manic depressive" teenaged me, the "client", in my perch near some luxurious houseplant. This seating plan never varied no matter what breed of therapist I encountered in my career as a patient.

I remember the walls covered with their various degrees and awards, seemingly just to emphasize the difference between the accomplished professional and the decompensating mental patient in their care.

Later, during my academic theory days, nobody had to explain the concepts of "asymmetry" and "hierarchy" to me twice.

The narrative “Cathleen” composes characterizes the unspoken power structure and hierarchy of status that traditionally accompanies discourse about the settings of psychiatrist’s offices. She artfully manages this discourse in descriptions of office settings that befit the various types of therapists she has encountered using references such as “sensitive New Age therapist”, “neo-Freudian”, and “savior-surrogate parent type”. In contrast to these typologies of therapists, “Cathleen” offers a characterization of herself seated below the “imposing therapist’s chair, more like a throne”, and she successfully conveys her feelings during these encounters with sarcastic insight into the dynamics that she, as “little ‘manic depressive’ teenaged me, the ‘client’, in my perch near some luxurious houseplant”, is aware of her role and identity as a patient. With this description of her experience “Cathleen” connects her experience to discourse about psychiatric therapy that is reminiscent of traditional hierarchies in medical settings.

In narratives about hospitals and therapist’s offices people explain that they recognize how their experiences of isolation are a way the medical staff, particularly in hospitals, maintain control. Narratives include descriptions of how people are unable to connect with others in hospitals or share experiences in any way other than that prescribed or directed by hospital staff. The following narrative indicates how isolation in hospital effectively imposes control and convinces people of their status as patients within the hospital. Interestingly, in some narratives people describe having to take part in group therapy as a way to support their treatment, and yet, this approach to socializing patients is controlling and contrived, whereas naturally developing relationships in hospital settings are discouraged. Additionally, as noted above in narratives about medication, the effects of medication discourage social contact. Generally the narratives examined here are critical of how treatment in hospital discourages community building and peer support thereby producing isolation, which exacerbates mental illness.

In the following narrative “Lara” reflects on her experience of isolation and describes how relationships may have provided additional support for people in hospital. Her explanation of how hospital staff respond when they “got wind that we were getting too close to someone or (gasp!) starting to love another ‘patient’” is conveyed with a sense of sarcasm. “Lara” connects her experience with discourse that assumes people in hospital treatment for mental illness should or cannot enjoy meaningful relationships. She explains having close relationships with others may “have been of great support”.

I contrast these experiences to being in the hospital – we could have been of great support to one another, but we were isolated by the oppressive structures that were always monitoring us.

There was the ever-present threat of being put on restriction if staff got wind that we were getting too close to someone or (gasp!) starting to love another “patient.”

Most conversations were regulated and moderated by the keepers of the ward.

Conditioned by psychiatry, I learned not to let anyone in, and I remained isolated and ashamed.

Narratives such as “Lara’s” echo stories throughout the analysis, which indicate that isolation is an influential form of medicalized power that is evident not only in hospital settings, but is also part of peoples’ experiences generally, for example isolation may include separation from family, bureaucratic isolation due to health system demands for compliance, and in “Lara’s” example, isolation from others in hospital. The narratives in this subsection make a connection using discourse that describes hospital and clinical settings as isolating and as places that are similar to fictionalized accounts in popular culture. People descriptions of settings reinforce popular discourse about so-called mental hospitals, but these negative descriptions are intended to re-inform discourse that suggests hospitals are places of care and safety where people can get

well. Examining narratives about hospital settings indicates that people negotiate contradictory discourses about expectations for hospital care by reinforcing popularly accepted fictionalized accounts of what hospital care is like in the case of mental illness.

*Narratives describing what it was like being treated in hospital*

Discourse about hospital treatment for mental illness today is tarnished with the dark residue of past institutional transgressions, and my analysis of the following narratives indicates in some ways this has not changed. My examination of narratives about treatment experiences in hospital shows people use references to popular culture as examples to connect their experience to discourse and support their claims about negative and traumatic treatment in hospital. The following narrative integrates a literary example with personal experience, which reinforces discourse that suggests electroshock is dangerous and can be fatal, even though it continues to be deemed helpful in clinical terms. In his narrative “Liam” explains how “they had tried all the different medications they could think of” and was then told “if nothing else helps, electroshock is needed”. “Liam” explains he “desperately wanted to get better” and “considered” the electroshock therapy, thereby indicating he is following the directions of his doctors and being a good patient. Following this he connects his experience to that of two influential male figures with a story about how his father “keeps a quote” of Hemingway in his office as a reminder of “bad experience with electroshock”. “Liam” contrasts his father’s and Hemingway’s bad experiences with what the hospital says about electroshock being “completely safe and effective and had no side effects”.

After more than two months locked up the doctors said they had tried everything.

What they meant was they had tried all the different medications they could think of.

They said that when nothing else helps, electroshock is needed. I desperately wanted to get better, so I considered agreeing to go ahead with it.

My father had told me of his bad experience with electroshock and how it harmed his memory: he keeps a quote from the author Ernest Hemingway above his desk, and I knew that Hemingway had killed himself after receiving electroshock.

At the hospital they told me it was completely safe and effective and had no negative side effects.

To convey his experience regarding whether to choose electroshock therapy or not, “Liam” connects his experience with those of his father and Hemingway and he makes a valid case for not trying it, even though he is assured it is safe by the hospital staff.

In the following narrative “Anton” describes his experience in hospital when the medications he was given caused him to have a painful reaction. Whereas “Liam” drew on outside contexts and relationships to give meaning to his experience and connect his experience to discourse about being in hospital, “Anton” gives a detailed account of his experience. He describes how he was “tortured for periods of time” in hospital because he was “having to take a lot of drugs” and they caused him “extreme pain”. The narrative is made meaningful as a result of the ways the language he uses create imagery that is a reminder of the ways people were treated historically in hospital. For instance, he describes “being tortured” and explains hospital staff “apparently didn’t care about the pain”. He places quotes around the words “doctors” and “nurses” signifying a lack of respect for professionals who are charged with helping people but in “Anton’s” experience cause more harm.

While I was in the "hospital" I reacted in a certain way to the anti-depressant, so I was told by people there that I was a "manic depressive" and that from time to time in my life, I would have



mental breakdowns and have to be locked up during those times.

This was the hospitalization where I was tortured for periods of time, usually a day or two, by having to take a lot of drugs.

The drugs interacted and there were "side effects" of extreme pain in my neck.

Even so, when I expressed the fact that I was being tortured, the "doctors" and "nurses" apparently didn't care about the pain.

This was one of the first times that I realized that "doctors" and "nurses" in a psychiatric "hospital" don't really care if they torture someone.

Narratives like “Anton’s” and “Liam’s” highlight what Illich (1976) calls the iatrogenic problems caused by medicalization. The significant thing in these narratives is that in order to convey experience and make claims that are deemed valid, people in hospital are recalling their experiences and connecting them to language and to discourse that reflects historic and popular culture works about madness in institutions. These narratives extend and expand medicalization by using imagery and terms that fit already established discourses about the power of medical institutions.

The next narrative begins with a concrete statement that establishes “Vicky’s” account as a form of testimony. As evidence she describes her experience from a much broader perspective than “Anton” in that she describes it in terms of her vulnerability within the health system as a whole. “Vicky” provides background as evidence to support negative descriptions of being in hospital and part of the health care system. Building on her statements, she includes a discursively powerful expression of violation—“raped by the system”—which links her experience to other victims of crime. Her description emphasizes her status as weak and furtive, in contrast to the faceless, powerful health system that is “shielded” by other systems of control (justice, legal).

I was the victim of involuntary psychiatric hospitalization on (mmddyyyy).

No history of mental illness, no criminal history, no history of violence.

Believing that this was some sort of administrative or legal blunder, I futilely sought assistance.

Dozens of disappointments later, I realized that I had been raped by a system that assumed guilt in the absence of a crime. No rape shield law existed to protect me.

Hiding my humiliation by withdrawing into the shadows was the only balm for my defilement.

I poked my head out many times, preferring to believe that justice would eventually prevail. To my dismay I learned that my rapists were shielded behind nebulous laws designed to give them carte blanche over my life.

My determination to fight has overcome my pain, and David is determined to face Goliath. My sling is the pen, my stone is the truth, and vindication is my catharsis. Therefore, I must either write or lose my integrity once again in the shadows of my shame. There are no other options.

With only one mention of psychiatric experience at the outset, “Vicky” contextualizes her experience with the inclusion of the Biblical story of David and Goliath, which creates imagery that supports her sense of being overshadowed and over powered by the health system and in hospital. However, the use of this story also indicates that “Vicky” is taking up a stand the health system as represented by Goliath. This narrative is reminiscent of autobiographical writers such as Lara Jefferson (1974) and Joanne Greenberg (1964) who describe a great desire and necessity to write about personal experiences in order to make them meaningful and connect to others.

In addition to narratives about negative hospital experience, people also included descriptions in their narratives of how they directly expressed resistance to hospital treatment. The following two narratives are included here as brief examples of how people story events

about behaviours where they openly express their resistance in hospital. First, “Anton” states he has an “infinite hatred for psychiatry” and describes how he rebelled in hospital by eating an orange—“the peel and the orange at the same time”.

One time to prove my infinite hatred for psychiatry, I started to eat an orange, while in the hospital.

I ate the peel and the orange at the same time. I chewed many times because I was sure the peel was hard to digest.

A psychiatric “nurse” who was there said to me, “It’s going to be hard to break you”.

I appreciate this short narrative as it includes “Anton’s” comment that he “chewed many times because I was sure the peel was hard to digest”. This suggests the moment of resistance was not merely a rash expression of mental illness, but that “Anton” was intent on making a point about his disdain for the treatment he receives in hospital. The comment is made all the more pointed when followed by “Anton’s” recollection of the nurse’s comment, “it’s going to be hard to break you”. Narratives that recalled direct resistance by people when they were in hospital were more prevalent than I expected in the narratives on the websites, but as expected they appeared on activist websites that support moving away from medical approaches to madness.

In “Anton’s” narrative the imagery is layered to include his experience in “solitary confinement at the ‘hospital’”, but in his narrative a connection is made to contexts outside of the hospital. He describes how when “allowed into a room that had a toilet” he would “flush the toilet at least 20 or 30 times” until someone brought him back in solitary confinement.

Often I was in solitary confinement at the “hospital.”

When I was given a little more freedom, and allowed into a room that had a toilet, I would flush the toilet at least 20 or 30 times, as much as I could, to protest the violation of rights.

First the authorities would say, “That’s just more money your

insurance has to pay us.”

Finally, a few minutes later, as I was flushing the toilet, a more powerful guy, an orderly, would come to the room, and I would be forced back into solitary confinement.

When “Anton” recalls that “the authorities” would tell him “that’s just more money your insurance has to pay us” he makes a connection to discourse outside of hospital contexts and reminds us of the links between how he is treated and the consequences of this on society even when he is in hospital. The imagery created in these two narratives reinforces discourse about hospital treatment that fits with historic and popular representations and shows people give meaning to their experiences by connecting to discourse in other contexts.

#### *Narratives explaining experiences of being a good ‘bad’ patient*

The narrative in this subsection indicates how resisting medical control or negative treatment in hospital requires a show of outward compliance with medical staff and practices. In narratives people explain how behaving as a good patient is a way to reduce the need for additional treatment in hospital, and they are able to leave hospital sooner. In narratives such as this what it means to be a good patient is questioned as the people describe the difference between how patients are treated if they are in hospital for a physical illness and how patients are treated if in hospital for treatment of mental illness.

In this subsection “Julie’s” narrative captures the ways people manage and negotiate experiences in hospital, and her narrative is an example of narrative bridging as she resists and re-informs discourse about mental illness. “Julie” details the difference in how she is treated for “chronic lung disease” and how “psychiatric patients” are treated. She explains how with physical illness she is “a full partner in my own treatment and recovery” and she explains this

involves being “consulted, listened to, and given information to make informed choices”. She adds there are times she and her physicians “disagree” and she chooses to “take their advice, while other times I don’t”. The detail of the narrative indicate “Julie” is knowledgeable and articulate about this, and demonstrates people connect experiences as “psychiatric patients” with other patient related experiences and are cognizant of the differences in treatment they receive.

Here is the key difference between what happens to psychiatric patients and what happens to people with physical illnesses.

With my rheumatologist, and with my lung doctor (I also have a chronic lung disease). I am a full partner in my own treatment and recovery. I am consulted, listened to, and given the information I need to make informed choices.

I acknowledge that the doctors have expertise that I lack, and they, in turn, acknowledge that I have information about the workings of my own body that they need to guide them in their recommendations.

Sometimes, we disagree. Then we talk about it. Sometimes I take their advice, while other times I don't.

Psychiatric patients, on the other hand, are usually assumed not to know what is best for us, and to need supervision and control.

We are often assumed to be talking in code; only so-called "experts" can figure out what we really mean.

A patient who refuses psychiatric drugs may have very good reasons - the risk of tardive dyskinesia, for example, or the experience of too many undesirable negative effects.

But professionals often assume that we are expressing a symbolic rebellion of some sort when we try to give a straightforward explanation of what we want, and what we don't want.

I'm sure you've all heard the many psychiatrist jokes that feature the punch line, "Hmm, I wonder what he means by that?" Well, doctor, I want to tell you, we usually mean just what we are saying. In the slogan of the women's movement: "What part of no don't you understand?"

“Julie’s” description of how “psychiatric patients” are “usually assumed not to know what is best for us” is followed by reasoning about why people might resist treatment, and he explains that this is interpreted as a “code” that only “so-called “experts” can figure out what we really mean”. The addition of the “psychiatric joke” at the end of the narrative references the “women’s movement” adding further context and impetus to the narrative. This is significant because it aligns psychiatric patient experiences with the oppression and subjectivity experienced in other socially marginalized groups, and situates patients within a larger frame of reference often as part of a social movement.

In “Julie’s” narrative she explains what she calls “the dilemma of the “good patient”. She describes the “good patient” as someone who is “compliant, who does what he or she is told, who doesn’t make trouble”, which on the surface would seem to indicate that a person is getting better. However, compliance is then interpreted by “professionals” as an indication that their “clients” are “too sick, too disabled, too unmotivated” to participate in their recovery. “Julie” adds that “good patient” is one who has “internalized the staff’s very limited vision” and that a “good patient” “doesn’t ever really get better”. The dilemma “Julie” brings to light is a meaningful way to connect experience and discourse, and although she does not include specific personal experience, her insight and reflection on the topic indicate she has first hand experience.

I often hear professionals say that, while they support the ideas of recovery and empowerment in principle, it just won't work for their clients, who are too sick, too disabled, too unmotivated. Whenever I hear these objections, I want to know more about what kinds of programs these professionals work in, and what goes on there.

I know that the professionals who knew me as their patient thought the same things about me. That's the dilemma of the "good patient."

A good patient is one who is compliant, who does what he or she is told, who doesn't make trouble, but who also doesn't ever really get better. A "good patient" is often someone who has given up hope and who has internalized the staff's very limited vision of his or her potential.

This narrative does more than resist and re-inform discourse about mental illness. It offers analysis of the situation people are in when they are in hospital and in the health system. It connects to discourse about what makes a good patient, which traditionally involves following directions, but the dilemma "Julie" brings to light indicates that even following directions and going along is deemed a sign of mental illness, and in this way people are held within a medical gaze. In this case medicalization has an insidious quality creates a situation that is seemingly inescapable as people try to be "good patients" but must also assert some level of initiative in order to be deemed getting better.

The final narrative for this section most poignantly and effectively describes the dilemma of the good 'bad' patient. I have separated it into stanzas for ease of reading. In this narrative "Julie" conveys her experiences and the challenges she has behaving outwardly as a good patient, while inwardly she wishes to behave like a bad patient. In the first stanza "Julie" explains how she knew what would befall a bad patient and how she "gritted" her teeth and went along with the hospital staff, even thanking them for their efforts. The second paragraph is "Julie's" explanation of what being a "good-bad patient" involved and the efforts she went through to keep her true feelings in check. Considering the circumstances of being in hospital and the almost complete lack of control over her situation, "Julie's" narrative indicates she had a strong and clear sense of the dynamics of her situation and how to manage this complete medicalization of her experiences.

I tried hard to be a good patient. I saw what happened to bad patients: they were the ones in the seclusion rooms, the ones who got sent to the worst wards, the ones who had been in the hospital for years, or who had come back again and again. I was determined not to be like them. So I gritted my teeth and told the staff what they wanted to hear. I told them I appreciated their help. I told them I was glad to be in the safe environment of the hospital. I said that I knew I was sick, and that I wanted to get better.

In short, I lied. I didn't cry and scream and tell them that I hated them and their hospital and their drugs and their diagnoses, even though that was what I was really feeling. I'd learned where that kind of thing got me - that's how I ended up in the state hospital in the first place. I'd been a bad patient, and this was where it had gotten me. My diagnosis was chronic schizophrenia, my prognosis was that I'd spend my life going in and out of hospitals.

I learned to hide my feelings, especially negative ones. The very first day in the state hospital, I received a valuable piece of advice. Feeling frightened, abandoned, and alone, I started to cry in the day room. Another patient came and sat beside me, leaned over and whispered, "Don't do that. They'll think you're depressed." So I learned to cry only at night, in my bed, under the covers without making a sound.

My only aim during my two-month stay in the state hospital (probably the longest two months of my life) was to get out. If that meant being a good patient, if that meant playing the game, telling them what they wanted to hear, then so be it.

At the same time, I was consumed with the clear conviction that there was something fundamentally wrong here. Who were these people that had taken such total control of our lives? Why were they the experts on what we should do, how we should live? Why was the ugliness, and even the brutality, of what was happening to us overlooked and ignored? Why had the world turned its back on us?

So I became a good patient outwardly, while inside I nurtured a secret rebellion that was no less real for being hidden. I used to imagine a future in which an army of former patients marched on the hospital, emptied it of patients and staff, and then burned all the buildings to the ground. In my fantasy, we joined hands and danced around this bonfire of oppression. You see, in my heart I was already a very, very bad patient!



Halfway through the narrative “Julie” describes her objective in being a good-bad patient when she states “ my only aim during my two month stay in the state hospital...was to get out”. She describes how others helped her understand what she needed to do to make this happen: “I learned to cry at night, in my bed, under the covers without making a sound”, and her narrative indicates she was adept at “playing the game”. Just past the midway point in the narrative “Julie” shifts attention to a broader view to reflect on why and how the transgressions and trauma carry on in hospitals even though there is awareness in society.

In the final verse “Julie” returns to her own interpretation of the situation and describes how she would like to openly express her “secret rebellion that was no less real for being hidden”. In this final stanza she uses a phrase that recalls an event in history (circa 1490s) known as the “bonfire of the vanities” in which religious leaders burned objects deemed sinful. The phrase and the ideas have since been recreated and adapted for use in popular culture film and books. In this narrative, “Julie” uses the phrase “bonfire of oppression” suggesting she wishes to clear the oppression of the hospital (and health system). It is interesting to note that despite her anger “Julie” makes a point of noting that the hospital would be “emptied of patients and staff” before being burned “to the ground”. In her final phrase “Julie” counters her opening statement indicating that although she “tried hard to be a good patient” but she says, “in my heart I was already a very, very, bad patient”. In this narrative, and in others throughout the chapter, it is evident that people connect their experiences as patients to broader discourse about mental illness, using narratives strategies of resisting and re-informing discourse. As people accomplish the everyday work of sharing a personal story, their narratives bridge meaning between lifeworld and system discourse and thereby influence medicalization of madness, whether to expand or direct or shape its course.

*Section Summary: What it's like being in hospital*

Generally the narratives in this section describe hospital treatment as “just like in the movies”. The stories recreate scenes, sets and characters reminiscent of popular movies. The inclusion and presentation of dramatic language and details in the narratives suggests that popular culture discourse is drawn on to emphasize and to strengthen claims about the tragic conditions and treatment people receive in hospital. The narratives reflect these socially and culturally shared meanings in performative ways to convey drama and to bolster peoples’ explanations about what it was like in hospital. However, although composing a detailed and dramatic narrative creates the possibility of gaining attention and presents an informative and truthful account of traumatic experience, it may reduce the potential impact of the narrative to resist discourse, because its meaning aligns with popular social beliefs that are built upon fictional accounts.

These narratives bridge meaning by highlighting similarities between personal experience and popular discourse about what hospital treatment is like, but this also reinforces ideas about the need for coercion and physical control in extreme instances for people who are diagnosed with mental illness. Like narratives about medication discussed above, these stories suggest there is an uncertainty inherent in mental illness that necessarily requires some form of treatment or management. However, as people do the work of storying their experience they also reflect on what it means to be a good or bad patient and this indicates people have a clear understanding of the nuances of negotiating medicalization as it plays in purely medical contexts. Additionally, it highlights how people adeptly connect their experiences in these medical settings and

circumstances with discourse about mental illness arising in other contexts (such as media) to bridge meaning.

## **Chapter 5 Summary Discussion**

This chapter examined stories about what it is like being a patient. It provided a starting point for examining narratives about mental illness experiences posted on websites that provide medical, social, activist and peer support to people interested in, or diagnosed with mental illness. Stories about what it is like being a patient were the most prevalent across the websites with most conveying disappointment and frustration with the medical system. This is not surprising. In the absence of an alternative discursive framework mental illness continues to be a medically formed and informed experience. The narratives indicate that to manage medicalization people draw on their roles as patients and this gives validity to their claims about being diagnosed, taking psychiatric medications, and being treated in hospital. However, although invoking the role or status of being a patient helps people make claims about medical practices it also has the effect of extending medicalization by reinforcing medical discourse.

The examination of narratives in this chapter highlighted the dichotomies of being a patient labelled and treated for mental illness and showed that by describing and explaining personal experience and including reflections on their treatment people asserted experiential authority to communicate about and negotiate the negative aspects of medicalization. The stories are practiced as valid “forms of public testimony” used to challenge medical discourse (Everett, 2000, p. 5). Stories about medical experience resisted and re-informed discourse about mental illness in ways that added to the legitimacy of their efforts to criticize its effects. According to

Miah and Rich (2008) “medical language is paradoxically drawn upon to frame the experience and gain legitimacy, albeit to challenge biomedical constructions” (p. 67).

The most prevalent topics in narratives about what its like being a patient included three main themes discussed over the three section of the chapter. These included narratives about what it’s like being diagnosed with mental illness. These narratives re-inform and resist diagnostic labels by describing the consequences of labels, by including life events along with diagnosis experience, and by challenging the biochemical basis of mental illness and its use in diagnostic practices. The narratives about diagnosis indicated people draw on their status or role as patients to make claims about the value of medical diagnosis, and in this way they remain in a medicalized frame of meaning, but efforts to resist and re-inform discourse about diagnosis negotiate and manage medicalization.

Narratives about what it’s like taking psychiatric medications focused on the effects of medications, problems with prescribing and monitoring of psychiatric medications, and social pressures to comply and take medication. These narratives indicate that people connect their experience of taking medication with discourse by resisting and re-informing discourse about the detrimental effects of medication. And yet, the uncertainty of mental illness and the desire to reduce personal distress indicate that there is a continued interest and call for medications that can help to alleviate issues of mental illness. Narratives about what it’s like taking medications have a wealth of experiential information and knowledge that would vastly improve understanding about medication from a lifeworld perspective.

In the third section in the chapter I examined narratives about what it’s like being in hospital for treatment of mental illness. Narratives about being in hospital indicate people are adept at recognizing the hierarchies of power built into the physical settings and environments of

therapy offices and hospitals, and they are artful in the ways they negotiate meaning in discourse. Examining these narratives showed that people make connections between their hospital experiences and discourse in popular culture about how people are treated in so-called mental institutions. The narratives highlight an interesting dichotomy facing people in hospital, one that requires them to comply with medical authority in hospital to avoid further treatment, but compliance can also be interpreted by medical professionals as an indication that a person is not able to take responsibility for themselves and is therefore still in need of medical treatment. In their narratives people describe these contradictions and the consequences they create, and they indicate that to manage these things they take on (what I call) a good-bad patient role, where they outwardly present some level of compliant behaviour in order to avoid increased treatments, but they still hold distrust and anger about how they are treated and so will look for other ways to express their negative thoughts and feelings. There are narratives that describe instances where people are outwardly resistant and in these cases the stereotypical idea of bad patients is confirmed, and this has the effect of extending medicalization as it seem mental illness is viewed as an inherently uncertain experience.

In this chapter I examined narratives and identified and discussed the ways people use narrative strategies of resisting and re-informing discourse to make meaningful connections between their experience and discourse about mental illness. From my analysis it is evident that people assert their role as patients to support claims about medical experiences and in doing so inadvertently reinforce medical conceptions of mental illness which extend medicalization. My examination of the narratives also indicated personal narratives manage medicalization as people bridge meaning between their experience and discourse about mental illness.

## CHAPTER 6 ANALYSIS: HOW RELATIONSHIPS MATTER

### Introduction

In this chapter I continue my examination of personal narratives with a look at how people use narrative strategies in stories about their relationships with family and friends, relationships in the workplace, and relationships with the health system. Analyzing these stories indicates people use narrative strategies of resisting, re-informing and reinforcing discourse about mental illness in ways that relate to their experiences outside of medical contexts. In these narratives, like the stories about being a patient discussed in Chapter 5, people include medical experiences and use medical discourse but less directly. The narratives in this chapter shift attention away from medical discourse as the only way to understand mental illness, and instead direct attention to the various ways relationships matter and how they contribute to meanings in discourse about mental illness. In their stories people describe relationships outside of medical situations and construct meaning about mental illness in ways that re-contextualize it in terms of supports and challenges of family, workplace, and health system relationships.

When it comes to managing medicalization narratives about relationships shift attention away from madness as a clinically defined illness, and direct attention to what Szasz (1961) calls “problems of living”. By storying experiences in terms of social circumstances and relationships people make mental illness more understandable and relatable for others. As Briggs (1996) points out “by weaving dominant social formations into the texture of descriptions of conflictual events, narrators can naturalize discursive and social hierarchies” (p. 29). The examination of narratives in this chapter suggests people make their experiences more relatable when they resist, re-inform, and reinforce discourse about mental illness as it relates to their relationships in dominant social spheres such as family, work, and the health system. Additionally, the narratives

work to secure social belonging and community acceptance, and work as a way for people to create meaningful connections based on shared social values about relationships. Overall, this chapter aims to show how narratives about relationships highlight the ways people invoke other contexts and social roles as they make connections between their experience and discourse about mental illness. The personal narratives examined in this chapter indicate people describe the experiences they have outside of medical contexts, but to do this they invoke social roles that may be challenging to fulfill without some form of medical or social support. The narratives show people manage medicalization by resisting, re-informing, and reinforcing discourse about mental illness as they connect this discourse to their experiences with family, in the workplace, and in relation to the health system.

### **Personal Narratives about Relationships with Family and Friends**

Narratives about family and friends normalize medicalized conceptions of madness by shifting the focus from specifics about diagnosis, medication and hospital treatment to socially shared discourses about positive and negative relationships with family and friends, and the desire and need for support. Contextualizing their experiences in terms of relationships with family and friends people resist and re-inform discourse about mental illness by shifting attention to social roles they have in common with others. My analysis of narratives about relationships with family and friends shows people describe and explain the ways their relationships influence their experiences of mental illness, and how they resist and re-inform discourse that is contradictory. People describe instances that emphasize problems that arise or result from their relationships with family and friends, and their narratives indicate how they make sense of or

challenge these relationships and what they mean in light of personal experiences of mental illness.

Three prevalent sub-themes are evident in the narratives including stories about contradictions between the support and lack of support from family and friends; I refer to this contradiction as *tough love* or *tough life*.<sup>1</sup> In the stories people make connections between experience and mental illness discourse by invoking ideas about social expectations, for instance, expectations that family and friends will be supportive when someone they know is experiencing illness or distress. The narratives suggest there is a continued lack of clear information and support for family caregivers, and the lack of alternatives encourages family to either turn to medical approaches when help is needed, or to be absent. The lack of alternatives for providing support translates into an extension of medicalization. The second sub-theme in this section is comprised of narratives wherein people explain mental illness as a result of family life or their biological or genetic heritage. The narratives explain that people had challenging relationships and life circumstances that caused their mental illness, or they describe how they are predisposed to mental illness because their family members had also been diagnosed. I refer to the narratives in this section as nature versus nurture stories. In the third sub-section I review stories that emphasize the importance of family support. These storied accounts are more positive as people describe how they are able to move on (and through) crisis with the help of supportive relationships. Generally telling stories about relationships with family and friends is a legitimate way to shift attention away from medical contexts to explain personal experiences and provide

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<sup>1</sup> I give credit to one of the narratives I review below. The author recounts how she is treated by family and interprets the experience with reference to “tough love”.



reasons or justification for mental illness. It has the effect of positioning people in an acceptable discourse that is socially and culturally familiar and in this way secures a sense of belonging in society.

*Narratives explaining the contradictions of care in relationships with family*

People describe the sadness and frustration they and their family members experience as a result of a lack of understanding about mental illness, which is brought about by rhetoric that suggests there is support. For instance general public sentiments in discourse about mental illness, which are informed by public health campaigns, suggest there is increased awareness about mental illness issues. However, the narratives indicate this is not the case and by connecting experience to discourse people aim to address this lack of insight. The narratives in this section demonstrate an interweaving of meaning that mixes together the medical meanings with social expectations. They suggest the way to manage this is to increase family involvement, educate and support families, and develop individual and specific care plans that provide solutions in specific everyday situations.

Narratives do more than describe relationships with family they offer interpretations of the quality and influence of relationships. Stories describe how family and friends often do not understand what is happening or know how to help. Stories like “Max’s” describe the ways this lack of knowledge manifests in relationships with family. In the following narrative “Max” talks about how lack of understanding of family and friends can “make recovery more difficult” and he uses common colloquial phrases such as “just snap out of it” and “pull yourself up by the bootstraps”. These common phrases are understood and apply in various contexts, which makes them relatable to readers of the narrative.

Friends and family can also make recovery more difficult.

Because they don't understand the illness, they may think they are helping their loved one by telling them “Just snap out of it,” or “Pull yourself up by the bootstraps.”

Mental illness is more complicated than that, and such words are hurtful and often lead to guilt feelings.

Those feelings can lead to more stress, which leads to more depression or other symptoms.

In this short narrative excerpt “Max” gives a straightforward explanation for why these common phrases are not helpful when he says mental illness is “more complicated”, words such as these are “hurtful”, and can “lead to guilt feelings” and “more stress”. Although the narrative is not unique or overly dramatic, it works because it simply makes a point about the need for better education and understanding about mental illness.

Narratives about family also describe more direct ways family intervenes, and how this is interpreted as a negative or positive thing. The next narrative describes how a lack of understanding is compounded when family and friends are a contributing factor to the onset of mental illness. In the narrative below, “Anton” begins with a broad reference to psychiatry as an intervening factor where family relationships are concerned. He outlines the connections between psychiatry and the law, which gives context to his relationships with his family. The narrative links together two system discourses (medicine and law) with the lifeworld experience of family relationships.

Psychiatry often intervenes in people's lives when they are having a problem with relatives.

The relatives call the police, and if the person has a psychiatric history of problems, then the police feel justified in getting the person locked up.

To this day I have a form of hatred for all of my relatives, and I

would like within 5 or 10 years, to live in a location where my relatives don't live.

I guess my hatred transforms itself into infinite politeness. I try to be totally polite and loving to all of my relatives.

But I trust them not at all.

The narrative begins in third person and the tone is somewhat formal as an explanation of what happens when relatives call in authorities to deal with family issues. The narrative reinforces discourse about the ways families are reliant upon system authorities to manage mental illness issues. However, the inclusion of “Anton’s” perspective and the ways he tries to manage the situation positively by being “totally polite” is in contrast to behaviours that psychiatry, the police and relatives deem disruptive enough making “the police feel justified in getting the person locked up”. After describing the situation “Anton” explains how he manages his “hatred” of his relatives with “infinite politeness” and explains how in future he would like to live away from them, which implies at the current time he is still bound to them for some form of familial support. Ironically, both “Anton” and his relatives are working to the same end, that is, being away from each as a way to manage the issues that arise from mental illness. The narrative bridging in this account suggests that having no other alternatives medicalization continues with the help of the legal system.

Personal narratives about relationships with family are not all completely negative, but rather highlight how challenging it is to reconcile the need for some type of formal care with social expectations around the value of family care. The stories indicate there are few options in-between. In the next narrative “Serena” recreates a conversation she has with her father about where she might stay after she is released from hospital “into my father’s care”. “Serena’s”

narrative conveys a sense of futility, from her perspective and her father's point of view, regarding her options after hospital treatment. She interprets his response as "tough love".

After six weeks of medication, recreation, and psychotherapy I was released to my father's care but he wouldn't let me live with him. I was reduced to begging on the phone.

"Daddy, please talk to me. Please let me stay in your house for just a little while."

The phone was silent on the other end.

Then, after a long silence....."Serena" I'm sorry you can't live with me....you see it just won't work. You are too.....unpredictable."

Tough love seemed to me an unbearable cruelty. My family didn't know how to deal with me, my closest friends began failing me, and all I felt I wanted was love, some understanding, and a bit of competent compassionate treatment.

The narrative headlines her efforts to follow hospital treatments including "medication, recreation, and psychotherapy", and implies these things are still not enough to have made a difference to her father's view of her possible future behaviour. This re-informs discourse about mental illness, suggesting that these approaches are not as viable as they are perceived to be for helping people. The narrative highlights problems with medicalized care practices, one that assumes a person's family is willing and able to provide ongoing care once the professional medical institution has determined hospitalization is no longer necessary. Ironically, the narrative bridges meaning by highlighting a gap in care practices. It shows how different criteria, requirements, and expectations about what a person needs manifest in "Serena's" life.

This next story emphasizes expectations regarding family values and support, and provides another example of what might be considered tough love. In just a few short lines "Thom" creates a dramatic contrast between so-called average family events on a summer day

and the particular day when he experienced involuntary hospitalization. The content and contexts referred to (suicide and involuntary hospitalization) demonstrate that medicalization is ineffective and leads to greater stressors for people and their families. We can assume “Thom” is struggling because he is at a psychiatrist’s office on a “bright sunny day” in summer. Upon initially reading this narrative there is a sense that the question that “Thom” is asked by the psychiatrist is rather inane—that is, when asked whether he will report his “suicidal thoughts” to his parents, “Thom” answers “No”, after all, discourse about mental illness would indicate that if he really felt that way why would he tell them about it. But it is the contrast “Thom” creates when he explains what happens next that works to resist, re-inform and reinforce discourse about mental illness.

Three weeks later, on a bright sunny day in early July, we have a family session with the psychiatrist. On this day, like most, I am agitated. I don’t want to be here.

“Thom”, if you have suicidal thoughts, will you alert your father?” she asks.

I stare at her and don’t respond.

“If you have suicidal thoughts, will you tell your father?”

“No.”

“Then I have no choice; you must be hospitalized.”

Like hell I do, I think, as I run from the room and then the building. It is the last act of freedom I will have for four months.

My dad catches me down the road. He urges me to go back, but I refuse. As we talk, a squad car pulls up beside us, and two armed officers jump out. One grabs my arm and puts me in the back of the car. I see my mom staring at me as we drive past the psychiatrist’s office.

“Thom’s” narrative is of interest because of the way he composes his account by starting with the image of a sunny summer day, then describes in a more dramatic how he responds to the psychiatrist’s statement that he “must be hospitalized”. The text is energized with his present tense description of how he escaped the situation “I run from the room and then from the building”. It creates imagery and connotes a sense of fear, or a fight-or-flight response, that is in contrast to the “bright sunny day”. His “last act of freedom” is thwarted by his father who tries to “urge me to go back” which implies his father made efforts to express familial care, but “two armed officers” interrupt and “Thom” is forced back to hospital. But “Thom” does not leave his story at this point, but reinforces the contrast between medical and familial care when he describes his mother’s response “I see my mom staring at me as we drive past”. The line bookends his perspective of how his parents also have little recourse, and once part of the system, they are resigned to accept whatever help it can provide even if it means watching their son being taken away because they are seemingly unable to provide the support he needs. The contradictions between medicalized care and familial care are evident in this narrative, as are the expectations that familial care should but does not or can not draw on resources that will help to manage mental illness.

The narratives examined in this section are significant for pointing out that contradictions in discourse about mental illness and family support extend medicalization because responses to mental illness by family members often involve system authorities. As people explain and describe their relationships with family they show contradictions between their experience and social expectations of family values of support and care. Medicalization is extended as people and their families have limited or no alternatives in long-term and crisis situations, but it is managed because of the ways people bring to light issues and gaps in social care.

### *Narratives emphasizing mental illness as a result of family life*

This subsection demonstrates how medicalization is managed as people resist, re-inform and reinforce discourse in stories that describe how they view life circumstances and/or their heritage or genetic background being a cause or catalyst for mental illness. Prevalent in the narratives are attempts to integrate both, which suggests that even though there is a shift to a more widely accepted medicalized view of mental illness as a so-called brain disorder, people still include and align this with their life experiences. This is similar to the analysis of narratives about diagnosis in Chapter 5, where people include life events and question the biological basis of mental illness in narratives about psychiatric diagnosis and the effects of labelling.

Although the old psychiatric trend of framing or blaming mental illness on parental lineage or irresponsible parenting has been displaced by medicalized ideas about madness as mental illness, the effects of home life are still a big part of narratives about family relationships. The stories include recollections of traumatic abuses in childhood, and root the aetiology of mental illness in home life and experiences of early childhood or adolescence, which counters medical discourse about mental illness as a brain disease. Additionally, in some cases there are descriptions of abuse and negative influences of health providers, teachers, and even social agencies as correlates for causing mental illness.

One of the most distressing narratives describes how the interplay between home life and assumed genetic predisposition to mental illness led to a life completely defined by mental illness. In “Ward’s” story he describes his entrance into the medicalized world of mental illness as something that began “before I was born”. His narrative is one that stands out as a clear example of the failure of medical and social systems to provide support and make a positive

difference. Even with no direct mention of biological causes or direct abuses “Ward’s” narrative re-informs discourse simply by describing his family life. In this narrative “Ward” demonstrates he has reflected on what happened in his life and had opportunities to compose his narrative in a way that indirectly resists and re-informs discourse about mental illness. The first line draws attention to the discursive power of the medical and social care systems to superficially decide who has mental illness, and what criteria are needed to make this decision. “Ward” explains how his “natural mother had been locked up” and how this was ostensibly how he came to be viewed as a “mental patient” even before he was born because of his “mother was peculiar”. The description of his “natural mother’s” plight of “being locked up” before and “again soon after” his birth is followed by a description of how the system extended its reach into his home life with foster parents.

The description emphasizes how his foster “mommy and daddy” were drawn into following the directions of the social worker “Miss B”. The narrative is not constructed in a way that places blame on the foster parents, but rather “Ward’s” references to “Miss B” suggest she personifies the power and dominance of the medical system. For instance, “Miss B” had his parents “looking for symptoms”, she would arrive monthly to “discuss my ‘problems’”, his parents “were supposed to encourage” him to explore, they were talked to at length about “curbing my ‘hostile’ impulses”. Each point throughout the narrative is storied in the context of everyday childhood activities, which “Ward” highlights as normal in contrast to how they are interpreted by “Miss B” and the health system.

Psychiatrists and social workers had already decided before I was born that I was going to be a mental patient.

My natural mother had been locked up just before she gave birth to



me and was locked up again soon after.

The social worker from the (ABC) Hospital told my foster parents that my mother was "peculiar," and Miss B soon had them looking for symptoms in me, too.

Every month Miss B would come and discuss my "problems" with my foster parents.

If I only wanted to stay in the back yard with my sister and make mud pies, this was a sign that I was too passive and withdrawn, and my mommy and daddy were supposed to encourage me to explore the neighborhood more.

When I started to wander around the neighborhood, I went to a neighbor's garden and picked some flowers. The neighbor complained, and Miss B held a long session with my parents about curbing my "hostile" impulses.

When Miss B had discovered enough "symptoms," I was sent to the (ABC) children's psychiatric ward, to be officially diagnosed and to be made an experimental animal for Doctor C.

I was one of the first children to be "treated" with electric shock.

I was six years old.

Like "Thom" in a narrative in the last section, "Ward" constructs meaning using contrast to contextualize his relationships with family and the system. In this narrative resisting and re-informing discourse is accomplished indirectly as "Ward's" descriptions of innocent childhood activities are transformed (translated) into symptoms of mental illness. The culmination of all of "Miss B's" observations is diagnosis of mental illness, and the degree of seriousness of such a diagnosis is emphasized greatly when "Ward" concludes he was "made an experimental animal" for a doctor, and he "was one of the first children to be treated with electric shock" at "six years old". "Ward's" narrative bridges meaning in discourse by connecting and contrasting everyday moments in childhood with discourse about being observed for symptoms and eventually being

diagnosed as “mentally ill”. The imagery of “making mud pies” and “picking flowers” is contrasted with the medicalization of “Ward’s” childhood.

Stories about family neglect and abuse reinforce discourse about mental illness that suggests it arises as a result of problems people have in relationships. These stories suggest that mental illness is very much connected to social issues that impact family life, and construct and reinforce ideas in discourse about mental illness being strongly correlated to family crises. The next two narratives describe traumatic events in childhood. In the first narrative “Lora” provides great detail about her family life to support the claim she makes about the “cause-effect hypothesis” that suggests that “people abused as children often develop depression as adolescents and adults”. Her statement indicates she recognizes that she is basing this on “opinion” she has heard “in general and with regard to myself personally” which has the effect of positioning her comments as being balanced and based on more than her personal experience.

“Lora” makes the statement and then follows this with specific descriptions of what happened to her in relationships with her father, grandfather, and half-brother. She comments she “got the guts up to move in with my mom”, and mentions at the end of the narrative that her grandmother “practically admitted” she knew about the abuse, indicating even her maternal relationships are far from positive. As “Lora” sketches out the key people and relationships that she views as having contributed to her depression this connects to discourse about mental illness as a result of family issues and abuse.

I’ve heard the opinion, in general and with regard to myself personally, that people abused as children often develop depression as adolescents or adults. I don’t argue with that theory at all, but I think my ideas about depression fit in perfectly with this cause-effect hypothesis.

The fact that my grandfather... and my father (sexually abused me)

until I got the guts up to move in with my mom—these events pretty well tore those rose-coloured glasses off me and allowed me to see the real world, early on. My dad still strongly denies that he abused me.

I got a letter from my half-brother saying he wanted to help however he could; he wanted to be my big brother. He couldn't make the choice of whose story to believe, but he feels for how I've suffered, and he says his relationship with our father has been strained for the last five years.

My father makes it hard not to believe him, my half-brother says. I can imagine; he's a natural arguer. It's good to know that my half-brother is supportive of me anyway.

But it still boggles my mind how most of that family is trying to ignore the issue. Grandma practically admitted to me in her letters that she is aware of what happened.

But no one will hold my dad responsible for what he's done. It's me, not him, who's left the family circle.

“Lora’s” story, like many I read for this research, includes personal events as precursors to mental illness. These stories connect by describing circumstances that people can relate to because they have knowledge of their own relationships. These narratives are also meaningful because they frame mental illness in contrast to medical perspectives, with medical approaches being about order and biological evidence for illness, and troubled relationships being pieced together recollections of events prior to mental illness onset or diagnosis. The stories bridge meaning by reinforcing discourse as “Lora” describes her “opinion”, but this also is a way to resist a completely medical focus on mental illness. The consequences of such narratives is they point out that mental illness is the medicalized name for consequences of relational abuse, and not as in this case, a biologically based brain disorder. However, the need to explain and rationalize the events and the consequences of the abuse means medicine and medical discourse are used and this thereby expands medicalization into social relationships.

In personal stories social and cultural values about ideal family relationships are invoked producing narratives that contrast with expectations about supportive, safe, caring family environments. “Tamara’s” narrative shows that even without specific details about circumstances and events relationships and home life are easily translated into medical issues. In just a few lines “Tamara” indicates her life growing up in a “house filled with suppressed tension and secrets” transformed her feelings “of unpredictability” into behaviours such as “avoidance” and loss of “confidence” and “control” which become part of her story about mental illness.

I now understand, for example, that growing up in a house filled with suppressed tension and secrets created in me an ever-present feeling that my world was about to collapse. (My parents at last divorced when I was 15.)

That feeling of unpredictability made me avoid or fear things I couldn’t possibly control, such as the weather or bad drivers or the whims of political leaders.

Over time, I lost my confidence in being able to “control” or trust my own self—my academic abilities, my relationships, my gut instincts.

As people like “Tamara”, “Lora” and “Ward” share their stories it is easy to make meaningful connections between their experience and discourse about mental illness because the stories are relatable. The narratives recollect family stresses and relationship challenges that other people may have some experience with, though perhaps to a much lesser degree. Additionally, while mental illness is increasingly defined in public discourse as a chemical imbalance in the brain, these narratives suggest there are many other factors that play a role. This raises questions about the complete efficacy of medical approaches to manage mental illness, even as Szasz’s (1961) “problems of living” continue in peoples’ lives. The narratives resist discourse that suggests

mental illness is solely biological by re-informing discourse about the correlations between personal trauma in families and the onset of development of mental illness.

*Narrative describing the importance of support from family and friends*

The personal narratives in this section are in contrast to the stories examined in the last two-subsections. In this section the stories provide clear evidence of the value and need for positive support in close relationships. In the stories people express gratefulness and appreciation for the patience, care and sacrifices made by their family and friends to help them in times of crisis and over the long-term. The analysis of these narratives suggests people benefit greatly from medical interventions where needed, but most significantly when medical approaches are limited and specific, and do not constitute the overall or only approach to mental illness. This is significant because once again it indicates that although mental illness is defined in biological terms people credit the support of family and friends as the reasons for their recovery. The inclusion of positive descriptions of the help of family resists the idea that only medical practices provide complete intervention, and ironically in contrast to the negative narratives, these stories reinforce discourse that suggests that family support is needed as a corollary to medical interventions.

In contrast to the narratives in the last sub-section, the stories below include descriptions of extreme situations of care and tremendous gratitude. As described by “Gracie” in the following narrative, having positive and consistent support from close relations is a “privileged position to be in”. She does not directly mention any medical interventions, but rather focuses on the things that helped her to stay “housed and fed and, if possible, occupied”. “Gracie” describes how the “unconditional and unwavering love” of parents and friends and community healed her

“mental distress” because everyone was “tolerant” of the challenges posed by her expressions of distress.

The things that healed my mental distress were the unconditional and unwavering love of my mother, my family and friends and the community I lived in. I was kept safe by this body of people.

I am blessed with a tolerant and very loving family and a tolerant and loving community, something which to this day I do not take for granted.

I now recognise this as a privileged position to be in.

My mother and my step-father, (and three key friends) being a few of my hands-on 24/7 team, taking it in shifts to be responsible for me, keeping me housed and fed and, if possible, occupied.

Positive narratives like “Gracie’s” create meaningful connections between experience and discourse about mental illness that align with cultural discourse that indicate family support should be encouraged where possible. Her descriptions of a “tolerant and loving community” signal the necessity for broader social support in mental illness. Additionally, “Gracie’s” emphasis on family and community support and the points she makes about having her basic needs, suggest the best approach to mental illness remains a socially supportive environment—something which is clear in the next chapter on recovery.

In “Gracie’s” narrative she describes having a community of caring to support her. She describes the way her mother provided help in order to “keep me out of hospital and off medication”. “Gracie” describes her mother’s home as “an acute crisis centre” and acknowledges the “major disruption” this caused to the “quiet routine” of family life. She suggests that “ideally” there should be more places available for people to go where medication is not required, and places where people would have the choice to “prevent the medicalisation of what is essentially a human experience”. The narrative connects her experience to discourse

about the importance of familial care, and although she asserts a need for non-medical interventions, she recognizes that without medication “round-the-clock attention” creates an “enormous work-load” for caregivers.

My mother wanted to keep me out of hospital and off medication.

The reality of this is her home became an acute crisis centre and I was a major disruption to the quiet routine of their lives.

Obviously, this is not an ideal situation and it would be wonderful if there were places people could go that did not force medication on you if you didn't want to take it to prevent the medicalisation of what is essentially a human experience.

In the beginning I needed round-the-clock attention as is the case with anyone in an acute crisis and when this experience is not blocked or suppressed with drugs it is an enormous work-load for those involved.

“Gracie’s” point about medicalization resists and re-informs discourse that suggests only medical interventions are helpful and successful for people experiencing mental illness, though she notes that “when this experience is not blocked or suppressed with drugs” it is challenging to manage. By explaining how her mother was able to provide support for her, “Ken” constructs a narrative based on the idea that family support is perhaps most essential and helpful despite the challenges of mental illness. In this narrative emphasis is placed on responses to mental illness outside of medical contexts because the experience was managed and treated with family care. And although instances like “Gracie’s” seem to be rare, her narrative suggests greater focus on family care in mental illness can re-inform community and social care practices, which would further resist and re-inform discourse about mental illness. The narratives in this subsection indicate how family care is more than an added comfort in moments of crisis, rather they describe how community and family support can provide an alternative to medical approaches.

*Section Summary: Relationships with Family and Friends*

Stories about family and friends invoke norms about the value of supportive relationships and the challenge of unsupportive ones, and describe contradictions and similarities between experience and discourse about the value of relationships to help people experiencing mental illness. People describe how a lack of family concern accompanied by a lack of understanding about mental illness and limited resources (or access to resources) to help caregivers, results in a loss of trust between family members, compounds negative experiences of mental illness, and creates a sense of despondency about family relations. These narratives resist and re-inform discourse about mental illness because they counter public beliefs about the availability of social support, but because social support is still greatly directed and controlled by medical approaches, efforts to improve situations still begins with the medical system.

In their narratives people describe a desire for greater family involvement, but recognize a lack of education and knowledge about the challenges of particular mental illnesses and of the health system results in more issues and problems. The narratives describe specific scenarios where no one involved understood what was happening, and explain how people lose friends and family because of a lack of understanding about mental illness. Alternately, there are narratives that express the opposite and these narratives connect experience and discourse about family support in ways that indicate it is and could be much more effective with additional resources. Narratives in this section include descriptions of events and re-create conversations, which assess the quality of family relationships. Examining narratives about relationships with family and friends indicates social expectations of family care are not often met, but when they are they are desired over medical approaches. However, the necessity for care in crisis and also for chronic experiences and the variability in family and community support indicate that medicalization will



continue, but with the addition of family interventions and knowledge gained from this, it can be shaped and directed to develop a more ideal situation.

### **Personal Narratives about Relationships in the Workplace**

Personal narratives about work indicate how taken-for-granted and expected it is to be seen as successful and productive in society. The personal narratives examined in this section resist and re-inform negative perceptions about the unproductive character of people who are diagnosed, labelled, or identified as having psychiatric disabilities. My examination of narratives in this section indicates people connect their experiences to discourse about mental illness in ways that emphasize how they are similar to others and have shared values about being successful and productive in society. Narratives about relationships in the workplace re-inform negative perceptions by describing how people experience job loss and how they value their work, by describing the influence of relationships with supportive and unsupportive employers and coworkers, and by explaining the challenges of asking for and accepting assistance. The stories resist and re-inform discourse by indicating people want to work and make efforts to maintain positive relations in the workplace. However, the narratives also indicate there is a real need to consider how workplaces and job requirements may be adapted to help employees who need assistance due to psychiatric disability. It is this need for assistance that encourages the expansion of medicalization into workplace contexts as other system discourses, such as social aid and insurance benefits, draw on medical discourse to inform policy. People legitimate claims that resist and re-inform discourse about mental illness that suggests people are unwilling or unable to work productively by describing and explaining their desires and efforts to stay in the work force.

*Narratives describing job loss and what “I was...” before mental illness*

Most noticeable in narratives about relationships and experiences in the workplace are the ways people frame their experience of work and mental illness in terms of loss. In their narratives people describe the consequences of losing or having to quit a job by explaining what their profession was, how successful they had been, and what they lost as a result of their mental illness experience. People often begin narratives about the workplace with statements that recall their successful days and high-level achievements. These statements situate people in a positive and socially acceptable, and possible enviable position. The narratives examined in this subsection do not directly reference relationships in the workplace, but include assertions about how people relate to their work. The narratives indicate people recognize how their experiences of mental illness impact their ability to be successful and that this has influence on relationships within and outside of the workplace.

In the following narrative “Cyndi” uses the phrase “I was...” to construct her experience of mental illness in relation to past performance and success as an athlete. As noted above, I refer to these narratives as *“I was...” stories*. This phrase is found often as people begin a narrative about how their experience of mental illness began. That is, they situate their experience not in a family relationship, but relate it to a workplace setting and context thereby shifting attention outside of medical contexts.

In the 19--s I was a nationally ranked track athlete and rower.

Following my first hospitalization in 19-- for suicidal depression, I was prescribed (ABC drug), an 'old-style' tricyclic antidepressant.

As a result of taking this medication, I landed back in hospital with tachycardia (heart irregularities), petechiae (rupturing of blood

vessels), and high blood pressure.

Exercise was definitely out of the question.

In this narrative “Cyndi” creates contrasting imagery when she states her success and then follows with a statement about her “first hospitalization”. Without discussing or explaining the circumstances she makes a connection that is memorable by giving a chronological account of being successful, being in hospital for “suicidal depression, then back in hospital for “tachycardia”, and then being unable to exercise. Although the narrative contains no direct resistance to discourse about mental illness and problems with success, “Cyndi” composes a narrative that indicates the use of medication and her experiences in hospital for depression contributed to her loss of identity as a successful athlete. She makes a meaningful connection between her experience and discourse by initially asserting an image of a driven, hard working person now limited due to mental illness and medical experiences.

In “Hillary’s” narrative below there is a similar structure in the composition, and it reads like a timeline describing her successes, as measured by her high income, education, opportunities for leisure. After describing these successes “Hillary” transitions with a statement wherein she recognizes that she was outwardly successful, but explains this was not fulfilling, and she shifts attention to her feelings of shame about her “secret” of mental illness.

I was a career woman, making a six-figure income by the time I was thirty years old.

I had a professional degree.

I traveled the world with the freedom to come and go at my leisure.

Yet with everything I always thought I wanted, I was the loneliest, most unhappy soul.

I sabotaged my personal life for fear that if anyone got close

enough, they would discover my shame.

The shame was that my life centered on a deep and out-of-control secret. My secret had my time and attention 24 hours a day.

“Hillary” does not directly resist or re-inform discourse that suggests people are less productive or successful due to mental illness, but describing her loss in status and finally her loss of confidence reinforces ideas about the challenges of working while experiencing crisis or chronic mental illness.

In the next narrative “Martin”, like “Cyndi” and “Hillary”, starts with an “I was...” statement and he also makes points about his success on the job. And like “Hillary”, he explains the value of the job when he refers to it as “the kind of job everyone considers, these days, very secure”, but he adds that even having “security” and “benefits” was not enough to help him in his situation.

I was working for a large chemical waste company as a plant foreman and an on-site union representative.

I had worked there for about seven years and had climbed the ladder well.

It was the kind of job that everyone considers, these days, very secure.

It paid well, I was a senior man and I had security, benefits, pension - the whole bit - but in the end, none of it helped.

These three narratives indicate how the experience of mental illness is storied as an interruption to the working self, as well as reducing status and esteem that comes from having a good job. Of interest is the way these narratives reinforce how discourse about work is such a meaningful and essential part of peoples’ identity and how it influences the perceptions of social status. Examining these narratives indicates as people talk about their experience of mental illness they make connections to discourse about work as a way to establish recognition of their efforts and

abilities as productive members of society. The narratives describe the frustration people experience when facing job loss or negative responses from employers due to mental illness. By describing successes in the workplace people characterize themselves in a positive way, which has the effect of offsetting negative discourse about mental illness and people's ability and efforts to work. They explain that mental illness experiences disrupt their achievements and give some indication of the continued desire to work and be productive.

In some narratives, people indicate they are willing to work but the circumstances of their mental illness make this difficult. In one such story "Angie" describes the loss she experiences when unable to fulfill or even pursue educational or career goals because of her diagnosis of schizophrenia. This narrative is an example of how a variety of discourses are brought together, shifting attention away from medical discourse per se, and onto other contexts and circumstances. "Angie" explains how she is open about her diagnosis and this makes it "difficult to get a job". She notes she also has difficulty staying in college and this has limited her job options.

I've had a few odd jobs and at one point I worked in a protected workplace, but since I always let the employer know that I have schizophrenia, it's difficult to get a job.

I haven't been able to stay at college long enough to finish a semester, so I don't have an education.

There is no way that I can get a job that I would really enjoy without one, so I've had to watch my dreams go by without being able to do anything about them.

It's been very bad for my self-esteem, and I have often felt that I was no more than a worthless piece of garbage.

After explaining the challenges of getting a job "Angie" reflects on how she has to "watch my dreams go by" with little ability to "do anything about them". "Angie's" loss of self-esteem is

obvious when she describes feeling like “no more than a worthless piece of garbage”. The narrative is more than an example of the challenges of getting or keeping a job. As “Angie” describes her efforts, explains her intentions, and expresses her disappointment, she responds to discourse that suggests people who are diagnosed with mental illness are unwilling to work. She resists and re-informs this idea by offering testimony about her efforts to improve her education to secure a job. She stories her desire for work alongside her feelings of self-worth demonstrating how just impactful the circumstance of not working is on her wellbeing. The connection made in this narrative highlights the need for making workplace situations adaptable and assisting people in finding work that is achievable and fulfilling.

“Ardene” explains how she made efforts to find work and how she found support among colleagues who were aware she was “mentally ill”. In this narrative she explains how having the support of people in the workplace makes a great deal of difference, and how this allows her to carry on even after being “embarrassed by a breakdown”. “Ardene’s” narrative indicates people can find the support they need in relationships in the workplace so that they might resist and re-inform discourse that suggests mental illness reduces a person’s ability to work.

I went out and I found jobs and I worked.

My employers and fellow employees knew I was mentally ill, but they supported me in my desire to work and they encouraged me to keep on trying.

When I broke down, they were there for me.

I felt humiliated and embarrassed after a breakdown, but they never reminded me of the embarrassing things I did. They only told me how happy they were that I survived and that I was getting stronger and better every day.

In contrast to the narratives at the beginning of this subsection, “Ardene’s” narrative does not begin with the words “*I was...*” but rather she states “*I worked*” indicating that although there

are many difficulties there are opportunities for people to work. The narratives in this subsection show people make meaningful connections between their experiences and discourse about mental illness in the workplace. The narratives describe the losses people experience and their reactions to these losses, and in effect resist and re-inform discourse that suggest mental illness reduces peoples' desire and ability to be successful at work. The narratives convey that people recognize the importance of having a job, and that storying their experiences in the workplace in ways that show their desire and efforts is a way to respond to negative perceptions of mental illness and work. For instance, whereas "*I was...*" stories describe previous success, statements such as "I went out and I found jobs and I worked" draw attention away from negative perceptions of mental illness as causing a lack of effort or avoidance of work, and instead highlight efforts and accomplishment.

#### *Narratives describing relationships with employers and co-workers*

Personal narratives about expectations at work and difficulty in relationships indicate how identity, ability and circumstances are tied together in discourse about mental illness in the workplace. In these narratives people draw on a variety of contexts as they connect their experiences to discourse and about mental illness and work. As may expected these narratives indicate there are instance where people find greater support at work, and others where the workplace situation adds to the challenges of mental illness.

In "Jack's" narrative he recalls comments and experiences with his employer and how these experiences influenced his perceptions of himself. It is interesting that "Jack" does not disparage his employer, rather he asserts that "no boss tolerates incompetence lightly" and he supports the idea that even when "this guy mumbles orders" he should "get it right". This fits

with the narratives above that indicate people make efforts to succeed regardless of the circumstances. This narrative is interesting because of the way “Jack” also includes references to the competence of race, for instance “like a white man [should]”; although it is not clear from the story whether he is recollecting a phrase his boss uses, or if it is just a locally popular phrases he uses to express his situation. He follows this with a bracketed comment suggesting if he was not “white” his situation may have been worse. In either case the reference indicates “Jack’s” awareness of his subordinate position as an employee and that he must get the job done right. “Jack” explains he “diplomatically” explained that he “was having a bit of trouble understanding” his boss, and then he vaguely makes a point about hindsight not being helpful. Rather than explain the context or circumstances further, “Jack” draws attention back to his personal experiences and his perception of himself as “the mostly incompetent type”. But he brings us around to see that this personal assessment is based on his idea that he is “prone to self-fulfilling prophecies”, something he mentions after describing how his difficulties at work are “probably due to my low self-confidence, low self-esteem, and mental illness”.

No boss tolerates incompetence lightly, but when this guy mumbled orders to me, he expected me to get it right, “like a white man [should].” (Now that think of it, perhaps matters would have been worse for me if I hadn’t been white . . .)

And, yes, I should have told him diplomatically that I was having a bit of trouble understanding him; however, hindsight is just that—hindsight.

I was, and likely still am, the mostly incompetent type.

This is probably due to my low self-confidence, low self-esteem and mental illness—though I wasn’t diagnosed and ‘certified’ until the next calendar year, 19---. (My main challenges are depression and obsessive-compulsive thinking; treatment with antipsychotics has been the most helpful.)

Also, I was prone to self-fulfilling prophecies. For example, when



my boss told me to do something, I was convinced I'd get it wrong. Thinking this, it was hard not to screw up. Then, when I did, it only heightened the probability that I'd screw up again the next time he gave me an order. It was a vicious Catch-22.

“Jack’s” narrative includes many intertwined references to context and meanings he directly and indirectly experiences, such as, being an employee seen as “incompetent”, being unable to understand mumbled instructions, needing to “get it right” “like a white man [should]”, being “diplomatic”, having “low self confidence”, and being diagnosed with mental illness. Drawing the meanings of these points together he composes a storied account that connects his experience to discourse about mental illness in a myriad of ways. In the final sentence he places responsibility for his circumstances back on himself, and even suggests that similar situations will happen again. By explaining his relationship with his boss “Jack” demonstrates he is competent and able to understand and reflect on what it means to be an employee, he also shows he knows what is expected of him in the workplace. However, his comments about being “convinced I’d get it wrong” reduce his abilities to something less significant, and as such his boss’s expectations, and more significantly his own expectations of himself, align with perceptions of people with mental illness being ineffective in the workplace. This narrative demonstrates all three narrative strategies as “Jack” resists, re-informs, and reinforces discourse about mental illness and the workplace.

“Gina’s” narrative presents a situation that contrasts with “Jack’s” because although she is concerned about the reaction of her employer and co-workers she finds they are supportive. In this narrative “Gina” describes how she “struggled with my work situation” and reinforces discourse that suggests mental illness causes people to be less productive. She explains she “couldn’t get anything done; any attempts were half-hearted and lacklustre”, even so her

concerns and desire to work are also storied into the account. She describes how she “needed a serious break from work” and to “get some healing time”. “Gina” describes the difficulty she has making the decision to talk with her employer saying “I was risking a lot talking to him about my sickness” and “afraid it would tarnish his image of me”. When “Gina” describes telling her “supervisor” she refers to her “sickness” and “illness”, terms which reinforce the idea of her distress as an illness requiring medical attention. By talking about her situation as “sickness” “Gina” frames her situation in a way that is acceptable and understood in the workplace regardless of the outcome. However, to her “great relief” her employer is “sympathetic” because he has a family member who “had suffered from” the same “illness”.

I still struggled with my work situation, though. I couldn’t get anything done; any attempts were half-hearted and lacklustre.

I asked for two weeks off—and received it—but these few days weren’t going to help. I needed a serious break from work in order to recover. I didn’t know what to do.

We couldn’t afford to live without my income—yet, I was in great danger of losing my job if I didn’t get some healing time. After much despair, I approached my supervisor in person, explaining my situation.

It was difficult to do; I felt I was risking a lot by talking to him about my sickness. I was afraid it would tarnish his image of me—and that I might lose my job.

To my great relief, my supervisor was sympathetic; his mother-in-law had suffered from (ABC mental illness) and he was well aware of the various issues associated with the illness.

He talked with our human resources (HR) person, and they and my doctor applied to get me on short-term disability. This would stabilize my financial situation while I worked to recover.

“Gina” finds support in her workplace because she is able to frame her experience in a way that is socially acceptable, as “illness”, and this is further enhanced because of the personal

experience her supervisor has with the “illness” in his family. The point here is not to judge whether they are talking about something that is a true “illness”, but to emphasize how the meanings ascribed to the experience “Gina” has connect with socially acceptable discourse about mental illness, and also make an additional connection via a shared personal experience. “Gina’s” story finds meaning connecting with discourse, and connecting with the personal narrative that her supervisor shares.

My examination of this narrative indicates to me that the connections made between experience and discourse are what continually shape discourse about mental illness and expand medicalization. The continual reference to mental or emotional distress (or madness) as an “illness”, makes the word “illness” a social code word that is imbued with a myriad of meanings, not the least of which is that a person needs assistance that is made legitimate by medical discourse. When mental illness is acknowledged and used to refer to personal experience it enables people to access assistance as long as their “illness” meets medical criteria.

The final narrative in this subsection describes “Martin’s” assessment of how people saw him when he wanted to take leave from work. He explains it is “ironic” that people thought he was trying to “scam” the system to “get time off”, whereas as he points out “who wants to be labelled with mental illness”. “Martin” connects his experience to discourse by describing the responses of co-workers using the workplace context to draw attention to his employed position in society. But as he implies the consequences of being defined with a label of “mental illness” while not positive, need to be accepted if he is to be supported in his request for leave from work.

Some of my co-workers were somewhat standoffish,  
some were supportive,  
others looked at me and thought that it was just a scam; that I was  
just trying to get time off –  
ironic since who wants to be labelled with mental illness?

As these personal narratives indicate relationships in the workplace can have a negative and positive influence depending on the expectations and perceptions of employers and co-workers. It is the connection to medical discourse that both helps people get support, but it also results in reinforced perceptions of mental illness being a limitation in the workplace. The narratives demonstrate how it is virtually necessary for people to assert a patient role if they are to be helped, and by drawing this into workplace contexts the ideas of medicalization are expanded. But with all due respect to people who desire and make efforts to return to work, taking up this position also affords them opportunities for highlighting where and perhaps how workplaces might better assist people with mental illness, thereby shaping or directing the expansion of medicalization.

*Narratives explaining the challenges of getting assistance and returning to work*

Whether stories about the workplace and the relationships people have with employers and colleagues are positive or negative these narratives draw discourse about mental illness away from medical contexts, however, this shift in focus is short lived. Narratives about leaving the workplace or adjusting benefits indicate people return to medicalized discourse, because of connections between medical discourse and other system discourses, such as disability support, government aid, or health leave. These systems impose bureaucratic controls that are connected to and draw on medicalized conceptions of mental illness to support decisions about peoples'

eligibility for benefits or social programs. The result is a return to medical discourse as a frame for madness. However, as Estroff (1981) points out the vagaries around the connections between work and medical discourse construct a dichotomy where “not working is seen as both symptom and proof of *their* disabilities and deficits” (Estroff, 1981, p. 168, emphasis in original).

In the following narrative, “Martin” describes how his efforts to secure support early in his working career were refused due to his diagnosis of mental illness. Years later when he requests support and time off, his earlier diagnosis is redefined and labelled “stress” not mental illness, thereby relieving the organization of any need to follow through on his claim and provide support.

I had never before submitted a claim to the insurer. Frankly, I didn't think that there would be any question as far as being covered.

I had been diagnosed a decade or two before, and they had actually denied me group life insurance through the company because of my illness.

And yet, when I had to go off of work, the same company denied my claim saying that I didn't have an illness; that it was just work-related stress.

So it's ironic that the same company is telling me two different things.

What angers me the most about it is that I just wanted to get back to work. That's all I wanted to do. I wasn't trying to scam anybody. All I wanted was help to get back on my feet.

In workplace scenarios such as this, definitions of mental illness are evidently fluid and changeable based on medical discourse. As “Martin” indicates, making disability claims and negotiating the practical and emotional stresses of requesting assistance is a contradictory process that calls into question the way medical discourse influences insurance and social assistance programs. Stories such as “Martin’s” in effect show how people are denied an identity

as a patient or as an employee. At the end of the narrative “Martin” explains he is angry because he “just wanted to get back to work” and was looking for “help to get back on my feet”, these comments address and resist the idea that people who are diagnosed, labelled, or identified as having psychiatric disabilities do not want to work. His narrative draws attention away from medical aspects of mental illness and frames his experience in terms of his experience of trying to get back to work.

In the next narrative “Ardene” includes many personal details when she describes her situation of wanting to work and be independent following her divorce, but her desire to work is discouraged by her therapist. She resists and re-informs discourse about mental illness by explaining her desire to work, and also by describing her family situation and her responsibilities as a single parent. Using these other contexts and circumstances to frame her experience she makes a meaningful connection between her experience and discourse about mental illness that is not solely informed by direct medical experiences. In doing this she draws attention away from a direct discussion of her medical experiences, only referring to her strong “desire to be healthy again”. For the most part the narrative describes social programs and the risks her therapist states will befall her if she does not succumb to expectations around how she should behave in order to maintain custody of her children. And yet, similar to “Martin” in the previous narrative, “Ardene” expressly states “I wanted to work” and she adds her “conscience told me I had to work”, which clearly indicates her concerns about being a provider and being productive. At the end of the narrative “Ardene” conveys the clear idea that maintaining a job will help her to “get better”, and she explains wanting to “find a doctor and therapist who would support my desire to be healthy again”.

December 19--, my husband decided to divorce me and left me with two young children. I wanted to work. My conscience told me I had to work. I had to face reality if I wanted to get well again.

My therapist tried to convince me to go on welfare; to get food stamps; to get housing assistance; to get aid for families with dependent children.

I told her that, in good conscience, I couldn't do that. I wanted to get better.

She told me, "You can't make it without welfare. You will fail and you will lose your children."

We argued about this on several visits, until finally I told her I couldn't see her any longer because she was trying to force me to go against my conscience.

I knew what I had to do to get better. What I wanted was to find a doctor and therapist who would support my desire to be healthy again.

In both preceding narratives, "Martin" and "Ardene" explain the circumstances of their experiences in terms of work and systems of support that are in place to provide assistance. For "Martin" it is the "insurer" of the company he works for, while in "Ardene's" case it is the therapist assigned to provide support. In both cases there are clear issues with regard to how people are viewed once labelled with mental illness and it seems mental illness is not only perceived as limiting peoples' abilities in the workplace, but also that claiming mental illness is viewed as a "scam" or way to be relieved of work responsibility. These personal narratives resist and re-inform discourse that makes these assumptions about mental illness and the workplace.

In the next narrative "Tanya" describes concerns about returning to work after having been on a disability claim. Her narrative also suggests there is a need for greater support and guidance when someone returns to the workforce. Unlike the challenges of negotiating a claim, this story includes insights into the ways returning to the workplace are possible. It constructs a

positive outcome, indicates possibilities for success at work, and demonstrates how “Tanya” manages perceptions and discourse about mental illness in the workplace. The narrative begins with a context and circumstance familiar to many, that is trying to maintain a steady income, but as “Tanya” explains the choice to “come off disability” and become “financially independent” is challenging and the results are “unknown to me”.

It was a very scary step to take to come off disability.

Being on disability pension is safe and comfortable. The jump from being supported financially to being financially independent was an unknown for me.

From high school, I knew what it was to be a student; but I’d never really had a job. I had fears: Will my illness get in the way? Will I get too stressed? Will I lose my job?

But I did it. I did it slowly and with care, making sure I stayed well along the way. It took a lot of goal-setting in small steps and getting as much support from doctors and family as I could. I was lucky to have a great boss who cared about my well-being.

I was honest about my situation and showed that I was eager to face my fears and move forward with my life. And, I had settled into the work well over the two years I had been there part-time, so I was already at home with the work.

In this narrative “Tanya” describes her success at transitioning between disability benefits and returning to work as a slow process that she moves through with great awareness of the potential challenges that may happen in future, she wonders “Will my illness get in the way?” She explains her success to date is due to “a lot of goal-setting in “small steps”, as well as maintaining a support system of family and doctors, and she attributes part of her success to her “great boss who cared about my well-being”. “Tanya’s” narrative gives meaning to her experience of mental illness that suggests it is a transitional circumstance and she bridges that circumstance by re-informing discourse in ways that indicate success at work is possible. Many



narratives like “Tanya’s” were evident on the websites reviewed for this thesis suggesting the workplace context is a powerful one, which people draw on to give meaning to their experiences in ways that do not fully focus on medical aspects.

One final narrative included in this subsection indicates just how meaningful work is as a context for re-informing and countering negative discourse about mental illness. “Caterina” explains the benefits of positive work environments where she participates as employee and contributing citizen.

I have a great job that I love. It doesn’t provide many luxuries, but I do my job well and what it gives me in positive strokes I cannot even put a price on.

I have incredible co-workers who know my story and who give me positive feedback all the time, my relationship with my boss is strong, and I feel completely valued at work.

These gifts mean the difference between life and death—the ultimate price!

“Caterina’s” narrative is characteristic of expressions of relief and happiness shared by people who had return to work or maintain some connection to their workplace. She explains how she “has a great job I love” though it “doesn’t provide many luxuries”, but it is the “positive feedback” and relationships she values most. In narratives about getting assistance and returning to work people connect their experiences to a social context that is understood by most people.

#### *Section Summary: Relationships in the workplace*

Success and achievement are driving forces in society. The ways people connect their experiences of mental illness to discourse in relation to work is reflective of the ideology this sentiment constructs. The narratives indicate mental illness interrupts the ability to remain

consistently productive and this creates problems and issues, adding to peoples' stress. However, individual experiences are storied with specific explanations that describe how people had been successful in their jobs before their experiences of mental illness, they describe the positive and negative influence of relationships with employers and co-workers, and describe the desire and effort it takes to return to work. By describing their experiences in terms of work place contexts people draw their experience away from medical contexts thereby lessening the focus on their experience as illness. The narratives resist and re-inform perceptions about mental illness that suggest it reduces the desire and ability to work, and they highlight the ways people make efforts to return to work. However, as indicated in the narratives people have to accept definitions of their experiences as "illness" and be labelled with a mental illness in order to receive assistance in times of crisis making it difficult to come out from under a medicalized framework. And although this draws medicalization into the workplace, peoples' narratives also bring focus to personal efforts to continue working, and highlight issues and opportunities for changing how people might continue to work while managing mental illness.

### **Personal Narratives about Relationships with the Health System**

The examination of narratives in this chapter has so far aimed to show that as people story their experience of mental illness in terms of relationships with family and friends, and in relationships in the workplace, they make meaningful connections that resist and re-inform discourse about mental illness. In this final section I examine the narratives people share on websites about their relationship with the health system. The health system rationalizes and manages mental illness in society and therefore carries a lot of weight when it comes to influencing how people with mental illness are perceived and responded to. In these narratives

people work at managing the expectations and consequences that arise from their involvement with systems of health and social care that require them to compromise and comply in broader societal and bureaucratic regards. People describe instances and situations that draw attention to how the health system disempowers them by reducing them to categories of mental illness. They draw on personal experiences to explain how their relationship with the health system influences other contexts and circumstance in their lives. Narratives about the health system negate ideas about the positive value of medicalizing madness by highlighting how the system re-victimizes people, by describing what it is like trying to manage in life outside the system, and by explaining the challenges of deciding whether to publicly disclose mental illness.

*Narratives describing how the health system re-victimizes people*

Narratives about the health system emphasize how people navigate a system full of contradictions. The stories call attention to how the health system works at cross-purposes with people and raise questions about the social and personal costs of accepting assistance. The narratives highlight a broad contradiction facing people who are diagnosed, labelled, or identified as having psychiatric disabilities, that is, they rely on a system of care that is based on a taxonomy that aims to control what their experiences mean and how they are to be managed. People describe the power of the health system to control and direct not only their experiences of mental illness, but also how this impacts other aspects of their lives. In the narratives the health system is described as an overpowering entity that expands medical control into everyday lives with little regard for long-term impact or consequences. As the following narrative illustrates the influence of the health system discounts individual identity and personal interpretations of experience. “Wynona” explains entry into the health system virtually erases any sense of

individuality as people are categorized according to their mental illness. Her story echoes the narratives in other areas discussed throughout the analysis.

If you enter the psychiatric business as a patient, you run a high risk of being reduced to the mental disorder you came with, or to a disturbed object. Only what is significant for the diagnostic examination is seen and heard. Patients are examined but not really seen; listened to but not really heard.

Other narratives about the health system support “Wynona’s” description and suggest that within the system the experience of mental illness is generalized using medical discourse. “Wynona” makes her points succinctly as she states people are “examined but not really seen; listened to but not really heard”. Her narrative raises a question about what value diagnosis has, and as the narratives in the previous chapter indicate, what are the consequences of being diagnosed? Although the negative consequences are clear as per the discussion of diagnosis in Chapter 5, it is unclear how or what a diagnosis provides for people in a positive way, notwithstanding the use of labels to categorize and position people within the medical system.

Examining narratives about the health system indicates people resist the medicalization of their experience by constructing their narratives using a variety of relatable discourses that are part of other social care discourses. In the following narrative “Alex” uses discourse from the generally well-known social support group Alcoholics Anonymous (AA) to frame his resistance and critique of the health system. He references the 12-step program, thereby creating an image of people in a support group meeting using the standard, and now popular, narrative framework of these meetings. He cites the “usual procedure” for introductions at these meetings and uses it to show how psychiatric labels are part of a larger system of control and categorization. He then refers to a “numerical code from a thick book” and describes how it is used to “classify us as a disorder or illness, not a person”. Through the first part of the narrative “Alex” addresses the

health system directly, but then he shifts attention using a reference to popular music to make a point about how people are treated in the health system. He cites popular musician Bob Seger and takes a line from one of Seger's songs, effectively connecting his experience with the health system in a way that can be understood by people who have no idea about what it is like to be part of the health system. "Alex" recalls the lyrics and emphasizes a line from the chorus when he explains that Seger's song "ends with the cry, "I'm not a number." With this he effectively conveys the emotion and passion with which he feels the health system disregards people—as people.

At support group meetings, the usual procedure is for a person to stand up and say, "Hi, I'm Bill (or Beth) and I'm a \_\_\_\_\_ (Fill in the blank with any label you choose: depressive, manic depressive, alcoholic, cocaine addict, codependent, unipolar, schizophrenic, etc.)."

To the government, doctors, insurance companies, and others making up "the system," we are no longer a person. We are a disorder.

The government will give us disability, (health assistance), and other benefits only if we have been properly diagnosed and categorized as having this or that disorder.

To doctors and insurance companies, not only are we a disorder, we are also a number.

They use a numerical code from a thick book known as the International Classification of Diseases (ICD) to classify us as a disorder or illness, not a person.

In one of his songs, Bob Seeger sings about how he feels "like a number," and ends with the cry, "I'm not a number."

And neither are we a number, no more than we are a diagnosis, disorder, or illness.

We are people.

In this narrative the point is made that once labelled by psychiatric diagnosis it is near impossible to avoid the consequence of being within and outside the health system. “Alex’s” narrative accomplishes resistance to discourse about mental illness and the controls of the government, doctors, insurance companies and other system bureaucracies by including references to popular social care agency discourse (AA), and a reference to popular music. In his final point he calls upon phrasing that is reminiscent of social movement discourse when he states, “neither are we a number, no more than we are a diagnosis, disorder, or illness. We are people”. In this narrative “Alex” does not use a specific personal experience, but rather connects his general experience with discourse about mental illness as part of a controlling health system. “Alex” artfully links a variety of discursive contexts to construct and convey his interpretation of the health system and give them meaning that can be more widely understood. These connections give meaning to what it is like to experience the power of the health system as a form of control in personal life.

In the following narrative “Terri” describes her experience relating to others in the health system. Her experience demonstrates how community rather than isolation should be a focus of the health system. The narrative is similar in topic to those in the previous chapter that describe peoples’ experiences as patients in hospital. “Terri” makes three points about how the health system re-victimizes people drawing on her experience with others in the system. First, she notes the health system re-victimizes people by using their psychiatric diagnosis as a predetermined assessment of their situation, and in some instances disregarding the social circumstances they experience. Second, she describes how people “become more agitated when triggered by the system’s hurtful and negative treatment” and to this she adds how her experience providing support to others results in “peace and healing”. Third, “Terri” explains the system “frequently harms people by forcing them to define themselves as ill and unworthy of being taken seriously”.

Through this narrative “Terri” provides an assessment of the system using her experience, and she draws more specifically on the experience of others to provide examples, such as in the case of “survivors of domestic violence”.

Over the last several months, I have met so many people who have talked about their oppression and re-victimization by the mental health system.

I have heard repeated stories about survivors of domestic violence not being believed because they had a mental health diagnosis and therefore could not possibly be telling the truth.

I have witnessed them become more agitated when being triggered by the system's hurtful and negative treatment and I have seen them experience peace and healing when I told them I believed them and would help in whatever way I could.

I truly believe that the mental health system frequently harms people by forcing them to define themselves as ill and unworthy of being taken seriously.

I think that often reactions to abuse and trauma are mistaken for symptoms of mental illness. This can allow staff to feel justified in performing harmful practices such as overmedicating and labeling, which can bring about feelings of blame, guilt and worthlessness.

“Terri’s” narrative offers a meaningful evaluation of the health system based upon her experience and assessment of what happens to other people she has met, and from her evaluation she suggests the isolating characteristics of health system are a result of the ease with which psychiatric labels “allow staff to feel justified in performing harmful practices”. This indicates with the continued expansion of medical discourse as a way to explain social issues there are increased risks that people will not be treated in ways that reduce problems, but rather in ways that increase problems and re-victimize people.

In narratives about the health system it is evident that people are well aware of the way the health system is structured and how this re-victimizes and isolates people giving them little

opportunity to move away from medicalization. “Darla’s” narrative below explains her view of the “old patriarchal system of treatment and culture of disease” and emphasizes the “professional distance” it encourages.

This old patriarchal system of treatment and culture of disease is characterized by a hierarchical arrangement of power, a mechanistic view of the mind, causality due to organic forces outside the person’s self, an emphasis on a person’s deficits, and treatment administered by an expert—always at a professional distance.

Did they think they might catch it? Why were they all so careful to maintain that professional distance? For years I felt trapped because I knew no other way to look at myself and my process.

Following “Darla’s” description of how the health system is “characterized” she shifts to a more personal tone and questions the isolating practices of the health system asking “did they think they might catch it?” With these questions the narrative highlights a contrast between the calculating professional discourse that is assumedly aimed at providing support for people, but which leaves little room for people to connect to their personal experience. For this thesis, the point supports the idea that it is with personal narratives that people are able to give meaning to their experiences—meaning that can be conveyed and understood by people who have not had the experience of mental illness. The narratives in this subsection indicate people reinforce discourse about mental illness that suggests there are grave inadequacies and contradictions in how the health system works to help as well as control mental illness.

#### *Narratives describing experiences in and out of the system*

The impact of negative experiences in the health system and the isolating patterns of treatment are also notable in narratives about what it’s like moving in and out of the system. In



many narratives people describe their wishes to be out of the system and explain how the system does not prepare them so they can manage in society. People speak of the practical realities of trying to maintain housing or establish relationships, and far from suggesting they are better or are free of experiences of mental illness, people explain they continue to struggle with experiences of mental illness.

In “Laurel’s” narrative she explains she did “not know how to exist outside” of the system, and how she struggled to socialize because she did not know what was “socially appropriate” and defines her inability to “read people” as a disadvantage. “Laurel” clearly defines her awareness of the difficulties she has and attributes them to being “confused” by “medication”, fatigue, or anxiety, which she refers to as “spazzed out”, and to all of this she adds that her “sense of direction was horrible”. The meaning and feeling the narrative conveys builds as each point is added. The intensity with which “Laurel” stories this short narrative indicates her sense of frustration at having been transitioned “in and out of the system” and then she abruptly ends the list of points, as if exhausted, when she simply states she had to “learn how to exist” and “just how to have a conversation”.

And I was getting to a point where, after 2 years in and out of the system, I really didn't know how to exist outside of it.

I didn't know how to socialize, I didn't know socially appropriate things like I didn't know how to read people, I was so confused, the medication made my head so screwed up, that I was either tired or spazzed out, my sense of direction was horrible, it was just all of these things that I couldn't explain and I didn't know why and I really had to learn how to exist, just day to day life. Just how to have a conversation.

“Laurel’s” narrative reinforces discourse about mental illness that suggests people are unable to socialize and have troubles managing without intercession of the health system, though she

resists discourse that says the health system is the best choice for helping people to learn to manage in society. She bridges meaning between her experience and discourse by reinforcing what is perceived to be the state of mind of someone struggling with mental illness, but also resists discourse by indicating medical practices used by the health system create greater problems—as is the instance where she mentions “the medication made my head so screwed up”.

Whereas “Laurel” describes her difficulties in a personalized manner, “Sandy” provides an explanation that draws on other social contexts in order to give meaning to and explain how she moves in and out of the health system. In recollecting and storying her experiences “Sandy” demonstrates how she is a central vector where a variety of system discourses come together, and she makes sense of these experiences by reinforcing discourse that suggests the health system is one of many controlling social agencies that manage mental illness. The central point she makes is that because she can no longer “pay the bills in private hospitals” her disruptive behaviour is handled “not by the men in white coats but by police officers”. Her reference to being “transported” to “state mental hospital” is clear and her use of the popular reference “men in white coats” connects to popular culture and indicates disdain for the mental health system. This has become a popular reference describing psychiatric attendants who in the past wore white lab coats when taking someone to a psychiatric institution.

By virtue of “Sandy’s” personal experience she connects a number of system discourses that have different perspectives on mental illness. For instance, “Sandy” recalls her “episodes of loud music and delusions were interrupted not by men in white coats but by police officers”, who were presumably notified about the disruptive behaviour by a neighbour. The point here is “Sandy’s” narrative implicates and integrates discourse about mental illness from the perspectives of law enforcement, community neighbours, and the health system, as well as

mentioning the economic consequences of mental illness. Her narrative demonstrates she is adept at understanding and navigating the subtle connections and differences between the many meanings that arise in various specific discourses about mental illness.

I could no longer pay the bills in private hospitals, so my episodes of loud music and delusions were interrupted not by men in white coats but by police officers, who transported me to the state mental hospital.

There I would wander the silent halls and take my (ABC drug) for a week or so until I came down from the manic high and reestablished myself as a non-person just getting through life as unobtrusively as possible.

“Sandy” includes a line describing how she would “wander the silent halls” of the hospital and take medication until she “came down from the manic high”. The line contrasts with her initial description of “loud music” and being “transported” to hospital by police. In the first instance it conveys and reinforces meaning about mental illness as something that needs to be controlled, and in the second it indicates that once controlled “Sandy” loses something of her identity. Poetically, the references to “loud music” and “silent halls” might be considered a way to convey a sense of freedom in one instance (“episodes of loud music”) versus the limited freedom and control within hospital (“wandering silent halls”). “Sandy’s” narrative indicates how continual transitions in and out of the health system perpetuate her economic situation, ensuring that she live her life “as unobtrusively as possible”. In this narrative “Sandy” draws attention to other circumstances and contexts and effectively conveys meaning about her experience without having to explain in detail the influence of each system discourse. In fact each area could be examined in much more detail for the ways these discourses influence her experience.

“Julie’s” narrative directly addresses the health system and the problems it causes for people when they wish to become independent or move away from a relationship with the health

system. She explains people are asked to comply with certain protocols in order to receive help and in this way the health system re-exerts influence over peoples' lives, and consequently medicalization expands to encompass social programs. "Julie" explains she "was able to escape the role of chronic patient" because she "left the surveillance and control of the mental health system" but attributes this to "falling through the cracks"—a colloquial reference to having been forgotten by a social agency when perhaps assistance was still needed or desired. In her narrative there is a sense of relief as she writes about having avoided the complications of social housing programs with their "unwanted strings" and conditional support.

One of the reasons I believe I was able to escape the role of chronic patient that had been predicted for me was that I was able to leave the surveillance and control of the mental health system when I left the state hospital.

Today, that's called "falling through the cracks." While I agree that it's important to help people avoid hunger and homelessness, such help must not come at too high a price.

Help that comes with unwanted strings - "We'll give you housing if you take medication," "We'll sign your SSI papers if you go to the day program" -is help that is paid for in imprisoned spirits and stifled dreams.

We should not be surprised that some people won't sell their souls so cheaply.

From the first line of this narrative "Julie" demonstrates her understanding of what it means to have the "role of chronic patient" and she adds this was a role that was "predicted for me". Unlike the narratives of "Laurel" and "Sandy" who describe being in and out of the system, "Julie" makes claims about the system from the perspective of someone who has been part of it, but who has also moved away from its direct control. She demonstrates knowledge of the protocols and expectations of the health system as a regulatory body that bases provision of service on compliance not on individual need. Her critique and resistance of the way the health

system operates is evident when she explains that assistance comes at “too high a price” and explains it “is paid for in imprisoned spirits and stifled dreams”. Similar to many narratives examined on the websites, “Julie’s” narrative makes connections between her experience and discourse about mental illness using different circumstances to create contrast that compels imagery. In her narrative she “agrees” that people should be helped with the necessities of life to keep them from “hunger and homelessness” but she points out these “must not come at too high a price”. After providing realistic examples of how people have to comply, “Julie” contrasts this with examples that are not as measurable but equally compelling by asserting, “people won’t sell their souls so cheaply”. The narratives in this subsection describe the influence of the contradictory circumstances created in relationships with the health system. It is evident that people are aware of these dynamics and their narratives highlight how system discourse about mental illness does not cleanly reconcile with the personal experiences people have in relationships with the health system. This is significant because it demonstrates discrepancies between what people value and what the health system can (and is willing to) provide, and indicates how the control of the system subsumes efforts to provide care regardless of the personal costs.

#### *Narratives explaining the challenges of public disclosure*

In many of the narratives on the websites people include some mention or reference to how difficult it is to decide whether to publicly disclose their diagnosis or tell others about their mental illness experiences. Many narratives reviewed on the websites include descriptions of social stigma, as well as “self stigma”, but there are also a number of narratives where people take an assertive stand to be open about their experiences with mental illness. People describe the

consequences of coming out and some people give reasons for why they keep their experiences private. Notably, people frame their experiences of disclosure with some reference to how the health system via public health campaigns is making efforts to address the stigma of mental illness, but point out these campaigns have little or no success.

The experiences storied in these narratives anecdotally supports literature that indicates public health campaigns have limited success because they are based upon medicalized conceptions of mental illness. As Blackman (2007) explains public health campaigns that aim to reduce stigma of mental illness fall short because they are constructed and emerge from a medical framework. The campaigns promote medical meanings of mental illness as a way to “normalize psychopathology in order to help lessen and reduce stigma” (Blackman, 2007, p. 2). However emphasis on biological determinants is seen to increase public perceptions about the prevalence and unpredictability of mental illness. Blackman (2007) states that campaigns that invoke medical discourse are a “catastrophic failure, with the resulting finding that they often increase public fear and prejudice, confirming societal phobias that mental ill-health is a random biological event that is beyond one’s control” (p. 2). My examination of the personal stories on websites indicates this is the case, and shows people are adept at recognizing and managing the consequences of these perceptions, whether or not they choose to disclose their mental illness experiences.

In their narratives people explain how they encounter the continued existence of social stigma despite the efforts of campaigns and public education programs, and they describe being the target of stigma in their communities. In the following narrative “Ellen” describes instances that are reminiscent of historic scenes of a judgmental and ignorant public targeting individuals without provocation. “Ellen” begins with her assessment of the problem of stigma suggesting it

is “caused mainly by ignorance and bad publicity”. She then describes being made fun of while waiting for a ride to a meeting near a local hospital that she “was in for four years” and explains “people may gesture towards me, putting their fingers to their head and shouting insults”. She then describes her experiences applying for jobs and explains how “workplaces have reservations about employing somebody who has had mental health problems”. Following the description of her personal experiences “Ellen” gives her definition of mental illness, which aligns with discourse used in public health campaigns that suggests “depression is an illness just like any other”. She explains that she has “been on the radio talking about the subject” and offers a statement of her credibility when she points out she has “two books of poems published on this and other matters”.

There is a lot of stigma attached to mental health problems, caused mainly by ignorance and bad publicity.

I live near the hospital that I was in for four years, and sometimes when I am waiting to get a lift to one of my meetings people may gesture towards me, putting their fingers to their head and shouting insults.

When I have applied for a job I have experienced that many workplaces have reservations about employing somebody who has had mental health problems.

The way I see it, depression is an illness just like any other, and no one ought to feel ashamed about it.

I have been on the radio talking about the subject, and have had two books of poems published, on this and other matters. I had great reactions to it, and a lot of people came to talk to me afterwards. I have also spoken about my experiences at a conference on mental health in (ABC major city), in front of 300 people.

“Ellen’s” efforts to openly discuss her personal experiences and the stigma of mental illness are well received and she explains “a lot of people came to talk to me afterwards”. The narrative

demonstrates that with her acceptance of medical discourse, “Ellen” is able to position herself as a “lay-expert” who can speak on the topic of mental illness and stigma. The narrative reinforces the idea that mental illness is “an illness just like any other”, but the inclusion of “Ellen’s” references to her publications and public presentations on the topic resists discourse that suggests mental illness is a completely disabling experience. In the narrative “Ellen” gives descriptions of her social experiences of mental illness and thereby shifts attention from a medical-clinical framework of mental illness to a social framework based on medicalized conceptions of “depression”.

Whereas “Ellen” openly shares her experience there are many who choose to keep their experiences with mental illness private. In narratives like “Pete’s” below, people describe the need and desire to “hide ourselves from the general public” to lessen the risk of being “recognized as having a disability”. “Pete” expressly speaks for himself and others when he describes how “we don’t other people to know that we’re not ‘normal’”. Most interesting to me about “Pete’s” narrative is the confidence with which he asserts that he and others like him are skilled and experienced at hiding their mental illness experiences. One line in particular is a significant reference to how people manage the medicalization of their experiences. He explains, “we have worn masks throughout our lives, and know which face to put on in which circumstances”. With this line “Pete” addresses discourse about mental illness on a number of levels, but what meaning it is given depends on what perspectives is taken. If expressed in a conversation with a medical professional in the context of the health system an assertion such as this would indicate a need for clinical care. However, this is less likely the case in instances where people are explaining that they are avoiding social stigma not medical treatment.



Many of us who are afflicted with mental illness try very hard to hide ourselves from the general public, so that we are not recognized as having a disability.

We don't want other people to know that we're not 'normal.'

We have worn masks throughout our lives, and know which face to put on in which circumstances.

We are so clever that our deception is usually never detected.

Our illness and struggle is kept secret.

The narrative reinforces discourse about mental illness that indicates there are continued issues with social stigma in society, and that suggests the health system is unable to address these adequately. “Pete” adds, “we are so clever that our deception is usually never detected” suggesting that the health system and society are unaware of many instances where people a) avoid the health system regardless of challenges that might be considered mental illness, or b) having been diagnosed are able to manage well enough outside the health system and medicalized conceptions of mental illness that they and their “illness and struggle is kept secret”.

As strongly as some people advocate for keeping their experiences hidden there are many people who describe shifting their views. In the following narrative “Sarah” describes how initially she was fearful of being “stigmatized by others” and stigmatized herself, but she explains she has “thrown off the yoke of stigma’s straw man and have ‘come out’ about my illness. The short sentence blends a number of metaphors and analogies suggesting “Sarah” recognizes the full extent of her choice to be open about her experience of mental illness.

Most importantly, however, I no longer stigmatize myself, or fear being stigmatized by others.

I’ve thrown off the yoke of stigma’s straw man and have ‘come out’ about my illness.

I’ve learned to tell people that having a mental illness isn’t any

different from other obstacles life throws in people's way from time to time.

Like "Ellen" in a previous narrative, "Sarah" invokes the definition of mental illness that has been constructed based on medical discourse, but extends this to include all difficult experiences—that is, she explains mental illness "isn't any different from other obstacles life throws in people's way from time to time". And similar to narratives about what it is like to be a patient (discussed in Chapter 5) "Bailey" presents her narrative as one that represents other people who have experiences of mental illness as she describes how "more and more survivors are choosing to be open".

Thus fortified, many survivors choose to stand up to stigma. We take advantage of 'educational moments' to talk about the suicide that has impacted us.

More and more survivors are choosing to be open and are met with compassion and understanding, empowering others to also be open.

As often as not, people respond with stories of suicide in their own circle. The silence is breaking.

To support her claims "Bailey" uses the language of survivorship and indicates that increased acceptance in society is comprised of "compassion and understanding" which is "empowering others to also be open". The narrative reinforces a survivor discourse that is usually in opposition to medical discourse about mental illness, however, in this narrative "Bailey" brings the two together when she describes taking advantage of "educational moments" to talk about the impact of mental illness.

As the narratives in this subsection indicate, keeping mental illness private is not the choice made by everyone. In a number of narratives people explain how they selectively choose whether or not to disclose their mental illness experiences. What is evident is that a tremendous

amount of energy and effort goes into either hiding mental illness or openly expressing it, indicating that socially mental illness has not yet reached a stage where it is readily accepted. Even when it is acknowledged and defined as being like any other illness or negative experience, mental illness remains under the domain of the health system.

*Section Summary: Relationships with the health system*

Like narratives about relationships with family and friends, and relationships at work, the narratives in this section indicate people manage medicalization by discussing their experiences outside of specifically clinical contexts. However, in talking about relationships with the health system on this broader scale, people invariably call up contexts that are medical, thereby reinforcing discourse about mental illness that includes medicalized concepts and perspectives. Narratives about the health system demonstrate how people navigate contradictions between what is expected and what is desired in the way of support. The narratives bring attention to how the health system works at cross-purposes with people, and raise questions about the social and personal costs of accepting assistance. In stories about their relationships with the health system people make efforts to reconcile negative assumptions and public perceptions about mental illness that are prevalent in public discourse, but often it comes down to a choice of whether or not to publicly disclose personal experiences of mental illness. Narratives about the health system show that although these stories keep people in a medical frame of reference, the health system provides a social and relational point for connecting experience and discourse and potentially moving away from medical discourse.

The narratives in this subsection show people are adept at communicating how the health system defines them and at describing how it is a struggle to negotiate the powerful discursive

constructions that extend their identity as a patient or a person with mental illness in society. Narratives about people's relationships with the health system extend medical discourse by integrating it into social discourse, but the ways people manage various issues, such as whether to disclose mental illness, indicates that it is in narratives where meaning is negotiated. This negotiation shows alternative meanings about mental illness come about through resistance, re-informing and reinforcing medical discourse. However, in order to manage the medicalization of madness in these ways, people reconstitute identity from the perspective of subject within a broader social system of health.

### **Chapter 6 Summary Discussion**

In this chapter I examined and analyzed the personal narratives people tell about their relationships in three broad social contexts, including family and friends, the workplace, and the health system. Personal narratives about family and friends normalize medicalized conceptions of madness by shifting the focus from medical contexts to socially shared circumstances about positive and negative relationships with family and friends, and the desire and need for positive support. In personal narratives about relationships in the work place people address negative perceptions about the unproductive character of mental illness by describing the personal effects of job loss on identity and self-esteem, by describing relationships with employers and co-workers as supportive and unsupportive in the work environment, and by explaining some of the challenges of getting and accepting assistance. In the third section I examined narratives about peoples' relationships with the health system, which indicated that people make concerted efforts to manage stigma and this often means taking up definitions that align with medicalized conceptions of mental illness. Narratives about the health system also indicate medicalized

versions of mental illness contribute to uncertainty in society, and that people take seriously the challenges of whether or not to disclose their experience of mental illness publicly.

Overall, the narratives examined in this chapter indicate as people describe various relationships outside of medical contexts they re-inform discourse about mental illness in society. The narratives address ideas about the availability of support for families, and raise questions about the influence of family heritage and heredity on instances of mental illness in families. Personal narratives about relationships in the work place resist and re-inform discourse that suggests mental illness is characterized by a lack of interest, effort or ability to succeed on the job. And although narratives about the health system address stigma and the challenges of being part of the health system, these narratives also reinforce discourse that says mental illness is like any other illness or social problem.

None of the stories reviewed for this thesis are completely without some relational or contextual reference, that is, the narratives are not purely descriptions of a medical nature. As this chapter has aimed to show personal narratives about how relationships matter are meaningful because they include details and circumstances of peoples' experiences—of lifeworld. And yet, in order to make sense of situations and communicate meaning to others about these contexts and relationships they are also connected in meaningful ways to medical discourse. Personal narratives about relationships manage medicalization by adding context and alternate meanings that are used to translate mental illness into something more than a medical experience.

## CHAPTER 7 ANALYSIS: WHY RECOVERY IS PERSONAL

### Introduction

Throughout this thesis I examine personal narratives to see how medicalization is managed. Specifically I look at the ways people bridge meaning between their experiences and discourse about mental illness. In the previous two chapters I analyzed personal narratives about *what it's like being a patient* (Chapter 5), and personal narratives about *how relationships matter* in mental illness outside of medical contexts (Chapter 6). I have aimed to show that in their stories people use narrative strategies of resisting, re-informing, and reinforcing dominant discourses about mental illness in ways that make their experiences meaningful to themselves and others. My analysis thus far has described a variety of narrative examples about medical and non-medical contexts indicating that as people use these narrative strategies they bridge meaning between personal experience and discourses about mental illness, a practice that I refer to as narrative bridging. In this chapter I continue my analysis of narratives collected from websites with an examination of narratives people tell about their experiences of recovery.<sup>2</sup>

From my examination of narratives about recovery I suggest people actively reclaim discourse about mental illness and redefine it in ways that demonstrate *why recovery is personal* (and for this reason I use this phrase as the title for this chapter). My analysis aims to show that as people story their accounts they talk about recovery not as a final solution to be achieved, but rather as an ongoing personal life practice. Storying their experiences of recovery as something ongoing and personal people manage medicalization by purposefully reflecting upon their lived

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<sup>2</sup> As per the previous two chapters, personal narratives reviewed in this chapter are presented in standard text formatting, and do not include graphic design elements that may have appeared in originals. Grammar and spelling in the narratives is as appeared in original online posts. Narratives are presented in phrases or units of talk. Pseudonyms are used throughout the chapter.

or lifeworld experiences, and by directly asserting their interpretations of these experiences in ways that resist, re-inform, and reinforce discourse about mental illness. In this chapter I examine three main themes about recovery that are evident in the personal narratives reviewed for this thesis, these include narratives wherein people aim to redefine recovery, narratives about personal recovery practices, and narratives about the importance of peers and a community of recovery.

### **Personal Narratives Redefining Recovery**

Foucault's (1965) assessment of language as the "first and last structure of madness" is certainly recognizable in personal narratives posted on websites that aim to support people experiencing mental illness. However, whereas Foucault's (1965) description is used in reference to broad socio-historic forces that shape discourse about mental illness, it is evident in the personal narratives examined here that people realize language impacts their experiences, and more pointedly they recognize they have influence by asserting personal appeals to change or redefine language and its' meaning. With my examination of narratives about recovery I notice in particular how people draw attention to their medical experiences as a starting point for redefining recovery. They describe what it's like being a patient and how the health system's approach to mental illness provides little support for alternative views of recovery; few indicated the health system provided positive and practical support for recovery as a life practice. With this as a starting point people position themselves as patients and draw on their experience to contrast and re-inform discourse about mental illness and recovery that has traditionally been about curing illness. In this section I examine narratives wherein people aim to redefine recovery in three ways 1) by describing their preferences for how recovery should be defined, 2) by

explaining what recovery means from a personal perspective, and 3) by describing the importance of hope as a meaningful part of new definitions of recovery.

#### *Narratives describing preferred language for recovery*

The narratives in this subsection demonstrate how people work to reconcile their experiences with discourse about mental illness that relies on psychiatric language. These narratives align closely with the narratives reviewed in Chapter 5 about diagnosis, and in Chapter 6 about the ways people are categorized in the health system by medical language. In this chapter narratives about recovery manage medicalization by providing a personal perspective that counters traditional medical language that has long defined recovery as a state in which a patient returns to full health and demonstrates an absence of disease, in other words they are cured. Collier (2010) points out there are now two ways that recovery can be defined including traditional “medical recovery” and its newer counterpart “life recovery”, which refers to “a process of change and personal growth” (p. 17). In the narratives examined here people story their experiences in terms of “life recovery” definitions and to do this they posit the need for new language to describe their experiences. People resist and re-inform discourse about mental illness by pointing out the challenges of traditional medical definitions of recovery, and by offering personal reflections on how they reconcile their experiences with medical language. The following narratives highlight the personal challenges that existing medical language constructs in discourse about mental illness and recovery and how people reconcile their experience with this discourse. The narratives indicate people prefer alternative ways to talk about and give meaning to their experiences and to do this they offer personalized interpretations of recovery in mental illness.



In the following narrative “Don” uses the phrase “I’m a person in recovery” to describe his experience, but he points out that he doesn’t “even like that expression” but uses it “because the alternative expressions are worse”. The phrase has gained popularity, and can be traced back to various 12-step recovery programs where people make an admission of an addiction or personal issue, and never consider themselves fully free of the problem, but rather view it as an ongoing process. It is not surprising “Don” does not like the phrase, given this background and it’s assumed or implied ideas such as blame, will-power, and lack-of-self control. “Don” explains there is a need to change language about recovery because it is “so alienating, and disempowering, and simple inaccurate (sic)”. He refers to a peer community as “we” to further explain how he and other people “struggle to ind new words for how we desecrivbe ourselves in oru lives (sic)”.

I'm a person in recovery. I don't even like that expression, but the alternative expressions are even worse.

the language we use these days is so alienating, and disempowering, and simple inaccurate, that we have to struggle to ind new words for how we desecrivbe ourselves in oru lives.

“Don’s” narrative resists discourse about mental illness in two ways. He resists discourse that is informed by medical conceptions of mental illness as something that cannot be cured when he uses the phrase “I’m a person in recovery”. The long-held belief that mental illness is incurable is now transforming in light of numerous developments in the mental health field and in relationships between consumer/survivors and health care professionals (Amering & Schmolke, 2009). The phrasing “in recovery” signals that recovery in mental illness is a personal and ongoing process, and this counters traditional medical discourse that suggests recovery means cure. Additionally however, “Don” resists discourse about mental illness that is shifting to this

new definition of recovery when he states “but the alternative expressions are even worse”. Further emphasizing this, and making a connection between experience and discourse, “Don” explains how he and others continue to search for new ways to describe and explain their experiences of recovery. My examination of this narrative brings to light how changes in discourse about recovery are still evolving, and more significantly for my thesis it shows personal narratives are a site where meanings of recovery are negotiated and where criticism and new conceptions arise that can shape and manage medicalization.

In their narratives people also used more personalized ways to connect their experience with discourse about mental illness and recovery. For instance in his narrative “Don” gives a memorable description of the way he manages the “psychiatric terms” that describe his experience as “obsessive compulsive disorder” (OCD). Initially he explains that he uses “psychiatric language as a sort of code or obscure way of making reference to things” and he describes medical discourse as “some kind of medieval map of consciousness”. “Don” personalizes his view of medical language by reflecting on the serious matter of “what it means to be a human being” and how psychiatric language is there “when we need a new map of what it means to be a human being”. Following this reflection, “Don” explains how he refers to his disorder as “Howard Hughes Syndrome”, thereby connecting his own experience to popular culture and giving it meaning that is intentionally outside of medical discourse. He gives a plausible reason for re-naming OCD after Howard Hughes and his reasoning is in line with medical approaches to nomenclature. He explains it is “a traditional medical practice -- to name the condition after the most famous person who suffered from that condition”. And not only does “Don” provide a reasonable explanation for his re-working of the OCD label, but he follows this by describing his personal affinity for the name, and draws meaning back to himself and others

by explaining “anyone with the least bit of recovery from the condition is better off than a billionaire who had no recovery during his who life”.

I'm going to use the psychaitric term of obsessive compulsive disorder to describe my conditon, because I like to use psychiatric language as a sort of code or obscure way of making references to things, like some kind of medieval map of consciuousenss -- when we need a new map of what it means to be a human being and the states of consciousness that human beings have.

The only thing that I've been able to accomplish is to re-name obsessive compulsive disorder "Howard Hughes Syndrome," which is a traditional medical practice -- to name the condition after the most famous person who suffered from that condition.

I like the expression "Howard Hughes Syndrome" because the implication is that anyone who has the least bit of recovery from that condition is better off than a billionaire who had no recovery during his whole life.

“Don’s” narrative includes some distinctly sophisticated discursive moves where discourse about mental illness and recovery is resisted, re-informed and reinforced. First, discourse is resisted when he gives a negative description of psychiatric language “as a sort of code or obscure way of making references to things”, and when he describes it as a “medieval map” and indicates it is constantly changing depending on the various “states of consciousness” psychiatry recognizes and defines. Next he re-informs discourse by asserting what to him is a more positive use of language and labelling, and brings in a reference to a famous person. The narrative reinforces discourse about psychiatric labels when “Don” explains that his approach to re-naming OCD complies with “traditional medical practice”. Granted this may also be viewed as an effort to gain credibility in support of the new psychiatric label. This narrative effectively associates and blends various meanings from across a range of discourses including, traditional medical approaches, mapping human consciousness, celebrity status in popular culture, and the value of

health versus fame and money. Simply by asserting his reflections on recovery experience “Don” creates an opportunity to negotiate and develop the way discourse about mental illness is understood, which further supports the idea in this thesis that personal narratives manage medicalization by narratively bridging meaning between experience and discourse about mental illness.

In the next narrative, “Ivan” not only connects his personal experience with discourse about stigma and language, but draws on his career experience as a journalist to describe how he “criticizes inappropriate reporting in the press and electronic media”. The point he makes is that there are opportunities to “counteract the stigmatization of people with mental health problems”. Without directly mentioning any instances of his own experience with mental illness “Ivan” still connects his experience to discourse about mental illness and recovery, but does so using his credentials as a journalist. The claims he makes about ways to “counteract” stigma rely on these credentials, but they become more personally meaningful when considering that “Ivan” is evidently no longer working in his career as a journalist likely due to his mental illness experiences. “Ivan” explains there is a need for “the creation of affirmative expressions in (language) for a person who is recovering from mental distress”. Like “Don”, “Ivan” uses phrasing that is in line with definitions of life recovery rather than medical recovery (as described above), but “Ivan’s” use of the terms “recovering from” followed by his recommendations suggests it is an active and positive way to position “mental distress” in public accounts that are aimed at reducing stigma.

I believe much can be done to counteract the stigmatization of people with mental health problems:

from the creation of affirmative expressions in (language) for a person who is recovering from mental distress, through the

presentation to the media of positive examples of people with these problems, to the raising of awareness about the consequences of stigmatization.

Having worked as a journalist for many years, I use my knowledge to criticize inappropriate reporting in the press and electronic media, for example, on suicide.

I send memos to both the editors initiating the stories and the journalists writing them, to inform them about the right approach.

In his narrative, “Ivan” connects his experience to discourse about mental illness and recovery when he draws on his career experiences and uses them to address stigma. The narrative demonstrates how personal narratives manage medicalization in a more direct way as people make active efforts to change how mental illness and recovery are understood in society. Personal narratives that describe preferences for changes in language about mental illness and recovery invoke discourse about a range of themes and topics including popular culture and career experiences. In these narratives people generally preface their recommendations for new language about mental illness by referencing their experience, but here they also include some reflection and interpretation of their experience as a way to change public perception.

#### *Narratives explaining personal definitions of recovery*

A notable contributor to the shifting definition of recovery as a life practice, rather than as an indication of cure and absence of disease, are the many and varied personal definitions that appear in personal narratives. Although much attention has been given to this new view of recovery only recently are there empirical studies of these new conceptions, additionally, as Rudnick (2012) points out “philosophical and related research on this matter is lagging far behind” (p. 3). In my examination of narratives it is evident the effort and opportunity to define a

personal vision of recovery creates meaning for people and I would argue it is in-and-of itself a meaningful practice of recovery. I base this idea on the fact that in the narratives I reviewed for this thesis people invariably mention their view of recovery in some way, even if only providing a single line of text about their experience.

The following brief excerpts offer an indication of the variety of personal definitions of recovery that circulate in the narratives people share about their experiences of mental illness. In the first narrative “Darla” defines recovery as something different from “psychiatric rehabilitation” which she sees as an “external structure” whereas recovery is “an internal process”.

I have come to think of psychiatric rehabilitation as providing an external structure, while recovery is the internal process.

Below “Chad” points out people talk about the ways “recovery exists, or can exist, within the context of illness”, which suggests the idea remains rooted in medicalized discourse, but he notes the current shift in thinking and discourse about recovery when he says “recovery doesn’t mean cure”. “Chad’s” narrative highlights the way this new definition of recovery requires people to take personal responsibility for recovery, and indicates shifts in medical discourse that no longer define recovery as simply the absence of disease. He describes how recovery now means “living with the illness, managing it and getting better within certain limitations”, with this line the meaning of recovery shifts back slightly to include the idea of medical recovery and a non-curable status in mental illness.

Another thing patients will tell you is that recovery exists, or can exist, within the context of illness. In other words, recovery doesn't mean cure. It means living with the illness, managing it and getting better within certain limitations.

Along a different track but with similar underlying meaning, “Tanya” connects her ideas about recovery to having a “chance to better yourself”. Her definition aligns with narratives about work place and the value of being productive. She explains in “there is no failure in recovery” only opportunities to “work toward wellness” and to “do whatever you want in life, including finding work that really gives your life meaning”. This brief narrative makes meaningful connections to discourse about mental illness by framing recovery according to value of being productive in society and being true to self, as “Tanya” describes it, “you are the one who is in charge of your dreams”. However, this positions people as agents responsible for the course and development of their recovery.

There is no failure in recovery; there’s only a chance to better yourself.

Working toward wellness can be anything you want it to be; you are the one who is in charge of your dreams.

You can do whatever you want in life, including finding work that really gives your life meaning.

The idea of being productive and working to toward recovery appears in many narratives, including “Darla’s” below, wherein she explains recovery as a process of discovering personal strength shows she is “capable of making changes toward more satisfaction and success in my life”. She adds this has “greatly improved” her “quality” of life, but points out in the second line that she also has recognition of her “limitations” which is what gives her greater “belief in my own unique possibilities”. “Darla” personalizes the narrative and offers a new version of the “person in recovery” narrative (reviewed in the previous subsection), when she states “I am not a finished product”, thereby connecting her experience to discourse about mental illness and recovery as a process.

Through recovery I have found myself capable of making changes toward more satisfaction and success in my life. The quality of my life has greatly improved.

I still have my limitations—I am not a finished product. And from an acceptance of my limitations has come a belief in my own unique possibilities. I have the power to move toward wholeness.

The idea is again evident in “Chad’s” narrative where he emphasizes the idea of recovery as an active process that takes him from being a “passive recipient of a pill” to the “author of my recovery”. “Chad’s” narrative includes analogy, description of his credentials as “writer, father and husband”, and a reference to popular culture to make a meaningful connection between his experience and discourse about mental illness and recovery. He describes his “own process” of recovery as a “journey” with a “self-directed path” where he takes himself from being “a patient” to finding ways to “use my obsessive ways adaptively” like a detective in a television show.

That's what I found in my own process. That my journey was a self-directed path, one in which I saw myself as the author of my recovery rather than as a passive recipient of a pill, made all the difference.

Ultimately I no longer saw myself as a patient but as a writer, father and husband.

Ultimately I found ways to use my obsessive ways adaptively. A little like Monk, the television detective who uses his OCD to solve crimes, I re-purposed or redefined my illness to write and research with extra drive.

Like the other narratives reviewed above, “Chad’s” narrative defines recovery as a positive and active process that is successful because of personal reflection and personal efforts.

For “Darla” recovery is “deeply personal” and she too takes up the current definition of recovery as something that “is not a return to a former level of functioning”. “Darla” supports her points by describing how she has “heard many people—professional and survivors alike—say that mental illness is not curable” and she acknowledges people cannot “return to our



“premorbid” selves”. From this point “Darla” explains “recovery is deeply personal” and a “unique process of changing one’s attitudes, values, self-concept, and goals”. She explains it involves actively finding “ways to live” in the present not the past, despite the impact of “major happenings”. Using a temporal frame, “Darla” is able to connect her experience to discourse about mental illness and recovery by indicating recovery is something to move toward, and like her counterparts in the narratives reviewed above she includes a point about acceptance of limitations.

Recovery is not a return to a former level of functioning. I have heard so many people—professionals and survivors alike—say that mental illness is not curable.

I agree that we can never go back to our “premorbid” selves. The experience of the disability, and the stigma attached to it, changes us forever.

Instead, recovery is a deeply personal and unique process of changing one’s attitudes, values, self-concept, and goals. It is finding ways to live a hopeful, satisfying, active, and contributing life.

Everyone is changed by major happenings in their lives. We cannot return to the past.

Recovery involves the development of a new meaning and purpose in one’s life. It is looking realistically at both the limitations and the possibilities. It is much more than mere symptom relief.

What becomes increasingly apparent about these personally based definitions of recovery is the way they include both reference to people taking responsibility for their own actions, and they also include points about peoples’ need to accept limitations in order to practice recovery. Certainly, on the surface these narratives suggest a positive direction for people, and come across with common sense regarding acceptance of personal limitations. Additionally, when viewed as agency or emancipation from medicalization these narratives show people taking back control of

their experiences. However, when considered as part of broader discourse about mental illness, the meaning these narratives convey suggests little has changed with regard to how people are implicated in the design of their mental illness and responsible for its management. This stands in contrast to the medical model that suggests mental illness is a biologically based, disease or disorder of the brain that cannot be controlled except by medical means, such as medication. I see this contradiction in meaning as one reason the practice of narrative bridging involves resistance, re-informing, and reinforcing discourse about mental illness that is predominantly medical, because people must negotiate meanings that move them between personal experience and system discourse. With this in mind, personal narratives about recovery can be seen to contribute new views that shape medicalization and shift its direction, however, at the same time the risk that personal definitions become part of medical discourse ensures that medicalization continues to expand.

#### *Narratives describing the importance of hope in recovery*

A significant number of personal narratives include some reference to the importance of hope, faith and spirituality, which adds a dimension of lifeworld experience to discourse about mental illness and recovery. Although concepts like “hope” are challenging to measure empirically, efforts are being made to understand the relationship between mental illness, recovery and hope. For instance Copic, Deane, Crowe, and Oades (2011) used a variety of psychological measurement scales to measure peoples’ level of hope over a six-month period. The research indicates the level of hope people express increases over time and is related to their “stage” in the recovery process but not in a “parallel” or “linear fashion” (p. 61). According to Copic et al. (2011) people who are in later stages of recovery demonstrate greater hope than

people initially diagnosed. What studies like this do not do is develop a conception of the links between personal experience and discourse about recovery, which I see as significant for understanding how people manage the medicalization of their experiences. My examination of the narratives in this subsection indicates as people reflect upon their experiences of recovery they resist and re-inform medical discourse about recovery, but medicalization is extended because people orient to and situate their experience in medical contexts.

The next three narratives show that by orienting to medical experiences to explain hope and recovery, people establish a connection between their experiences and discourse that is grounded in medical meanings. In the first of the three narratives “Owen” explains that he thinks people who have been patients have “more hope” when it comes to recovery than the “mental health industry”. He explains how the aim of therapy is merely to bring people to a state where they are “once again able to conform to the society which cast him/her out” and he uses this assessment to support his claim that the health system’s “highest hope for the “cured” mental patient” is lacking because it does not encompass a more meaningful view of hope.

In a sense, I think we have more hope for the recovery of “mental patients” than the mental health industry does.

Mainstream therapy’s highest hope for the “cured” mental patient is that he or she is once again able to conform to the society which cast him/her out.

We believe that (ex)mental patients are a group of people who have the creativity and dynamism necessary to change that society.

“Owen” begins his narrative by explaining what he thinks about the health system’s approach to hope and recovery and he uses the word “I” which indicates this is his personal view as an “(ex)patient”, following this he describes how the health system’s view of hope is limited. The first two lines of the narrative position him in a medical framework as a patient, but the third line

of the narrative shifts attention to his position as an “(ex)mental patient” giving him credibility for his claims about hope and recovery on two fronts—as a patient and as an ex-patient.

In the next narrative “Julie”, like “Owen”, begins with a personal statement that gives her view of recovery, which she then follows with a critique of the health system that resists ideas that the health system supports a hopeful view of recovery for people with mental illness. She follows with examples of how the health system is not helpful and draws on experience to reflect on how being a patient means being “constantly indoctrinated with the message, explicit or implicit, that we are defective human beings and shouldn’t aim to high”. “Julie” explains when people have “diagnostic labels” they face contradictory circumstances where any efforts to be hopeful are considered part of their mental illness. She explains how terms such as “grandiosity” and “lack of insight” are reminders to “us that our dreams and hopes are seen as barriers to recovery instead of one of its vital components”.

One of the elements that makes recovery possible is the regaining of one's belief in oneself.

Patients are constantly indoctrinated with the message, explicit or implicit, that we are defective human beings who shouldn't aim too high.

In fact, there are diagnostic labels, including "grandiosity" and "lack of insight," to remind us that our dreams and hopes are often seen as barriers to recovery instead of one its vital components.

With personal reflections based upon her experience as a patient “Julie” reinforces discourse about mental illness as a medical condition to recover from, but she also resists this discourse by bringing attention to the ways medical meanings reduce hope of recovery.

In her narrative about being a “mental patient” “Shelley” orients us to medical meanings of recovery, but makes an immediate connection to shift attention to her new state as a

“responsible” and “whole person”. Unlike the two previous narratives, “Shelley” includes points about her experience of recovery outside of medical contexts when she describes her weight loss and “healthy new relationships”. Even so after these positive points she returns to medical context and lists why she is “glad at recent exposure of psychiatry (sic)” explaining how there is better awareness of the “absurdity, the labeling, making person think there is no hope, no future, no meaning (sic)”. “Shelley” points out how psychiatry relies on medication and offers no other alternatives, and she emphasizes labels brand people “for life”.

For too long I believed I was the “mental patient”. I am responsible for my own happiness, contentment and success as a whole person.

I slowly was able to start healthy new relationships and lost all of the 100 pounds.

I am glad at recent exposure of psychiatry-it’s absurdity, the labeling, making person think there is no hope, no future, no meaning. That taking mind-altering drugs is all there is. Offering no other choices. We shouldn’t be branded for life.

Hope should never be taken away.

In her narrative “Shelley” orients us to her position as a patient and draws on this experience to explain how the health system reduces hope of recovery via psychiatric “labeling” and “mind-altering drugs”, this reinforce ideas about recovery as a medically defined state. But by layering in personal experiences the narrative shifts focus and provides an explanation that supports a lifeworld view of recovery that includes “hope” and stresses that “hope must never be taken away”.

Bringing the idea of recovery and hope onto an existential plane are personal narratives that include references to personally informed concepts such as faith and spirituality. “Shannon” gives a description of her state of mind when she found faith, which led to her experience of hope and recovery. Her narrative indicates the levels of confusion and inner turmoil she felt and

how she struggled to make a connection to something that would draw her to recovery. “Shannon” describes how she “puzzled together in her muddled mind that faith was the beginning of hope” and she locates hope in something “bigger than myself”. Her description of the “fog” that isolated her and made her feel alone creates imagery that speaks to the way hope is connected to intangible as well as tangible meanings. In this case “Shannon” connects hope to faith and to her efforts to quell loneliness and the experience of being “alone in this nightmare”.

I puzzled together in my muddled mind that faith was the beginning of hope; believing in something bigger than myself. I grasped onto that and in this fog I understood that while I was physically alone I might not feel so alone if I could find faith in that thing that was bigger than me, faith that I was no longer alone in this nightmare.

And with that – with finding faith in that thing that was bigger than me – I believed that I was no longer alone and I found the hope to continue and...I could finally trust and believe that no matter the price I had to pay that I would make it.

I find this narrative interesting as an example of how hope is connected to faith but also for the way “Shannon” composes her account using repetition to emphasize the value of faith by describing how “faith in that thing that was bigger than me” led to her to “believe that I was no longer alone” and this then led to her ability to “finally trust and believe” that she “would make it”. As far as providing tangible or substantive details about her experience this narrative has none, nevertheless “Shannon” successfully reflects upon and conveys her experience of hope and recovery.

The narratives in this subsection indicate people make connections between their experience and discourse about mental illness and recovery that suggest hope comes from the support of others, and without that people are vulnerable to risks of self-harm in order to reduce feelings of despair. “Corrie” describes people who have someone to support them as “fortunate”.

She explains support comes from knowing there is “one person does not retreat in the face of a mind in chaos”, but she explains this is difficult “when delusions and hallucinations implicate their loved ones in sinister conspiracies”. “Corrie’s” narrative, written in third person, is significant for the way it highlights both the need for hope and the realities that can prevent a person from accepting help and experiencing hope and recovery.

If they are fortunate, there will be at least one person who doesn't give up, one person who does not retreat in the face of a mind in chaos.

But trusting that person is another matter. When delusions and hallucinations implicate their loved ones in sinister conspiracies, they feel alone in the most fundamental of ways.

It's understandable that many people give up hope and make decisions based on the need to ease the pain of the moment.

“Corrie’s” narrative brings a sense of reality to the idea of recovery because it is a reminder that at anytime the lived realities of mental illness can bring about a crisis or episode that prevents people from experiencing hope and practicing recovery.

“Gracie” connects her experience to discourse about recovery and hope by describing that she “learnt that there are two things that heal mental distress; love and work, or meaningful activity”. She further personalizes her definition of recovery by including “two more things; time and hope”. In this narrative “Gracie” does not mention recovery in any medical sense and as such she shifts attention away from medical contexts and redefines it relationally. “Gracie” does not position herself as a patient instead she stories her account from her point-of-view as a daughter who has to rely on her mother during a “breakdown”. As a way to reflect on her own experience, “Gracie” considers her mother’s perspective and explains how her mother “suggested Time, and patience” are the things that helped her maintain hope and remain

committed to “Gracie’s” recovery. To emphasize the value and importance of having someone remain hopeful during her episode “Gracie” describes how “there were months when I made no progress whatsoever” and she explains how this kept her “stuck on a ferris wheel of regret and self-recrimination”. “Gracie” then personalizes her recovery experience further by reflecting on what “it must have felt like” for her mother to watch as “Gracie” changed “over the course of my breakdown and subsequent depression”.

I have learnt that there are two things that heal mental distress; love and work, or meaningful activity. I would like to add two more things; time and hope.

My mother suggested Time, and patience, as she watched me gradually change over the course of my breakdown and subsequent depression, and, of course, it must have felt like forever for her. There were months when I made no progress whatsoever and was stuck on a ferris wheel of regret and self-recrimination.

Although the narrative does not directly address the idea of hope in recovery, the narrative work “Gracie” does to story her experiences in terms of her relationships with her mother indicate that hope is a requisite part of recovery for them both. Narratives describing the importance of hope in recovery are comprised of personal reflections and include references to contexts outside of medical ones, and in this way people connect their experience to discourse about recovery and mental illness.

#### *Section Summary: Narratives redefining recovery*

In narratives aimed at redefining recovery it is difficult to move away from traditional medical views of recovery that view it as a return to so called normal functioning, even though traditional perspectives are changing. The narratives in this section indicate people draw on their experiences of what it’s like being a patient and in doing so create a contrasting view of recovery



that is personalized rather than medicalized. The narratives also include peoples' experiences in relationships and how these relationships contribute to personal recovery. The narratives describe how the language of medical discourse is limiting and does not offer many options for new views of recovery, although in theory this is now changing with the addition of personal narratives (as indicated in Chapter 2). From these storied accounts it is evident people are aware of the power of medical language to influence their experiences of recovery, but they also recognize opportunities to make recovery personal. People accomplish this by layering their accounts to include both a medical version of recovery and personal ones and as a result the idea of recovery is now characterized as an experience that is fluid and that is most effectively practiced when people reflect on and interpret what works for them.

### **Personal Narratives about Recovery Practices**

Personal narratives about the various recovery practices people use to manage their experiences are good examples of how and why recovery is personal. The narratives in this section resist and re-inform discourse about mental illness that negates the use or value of nonmedical alternatives, although increasingly even medical approaches are including recommendations for improving health with complementary, alternative, and common sense life choices. In the narratives that follow in this section people describe how acceptance of their situations and experiences helps to inspire their recovery as a form of independence, they explain how being aware of various personal triggers helps them to manage and mitigate the onset and development of personal crises or episodes of distress, and they list and describe a myriad of alternatives that work for them as they manage their recovery. What is notable about these narratives is that when people describe and explain the things they do the tone of the narratives is

positive but not directive. I notice when describing alternatives people present their experiences as examples of what helped them and do not directly make recommendations about what is best. The idea that recovery is personal is evident in these narratives because people describe everyday contexts, activities and situations with little use of medical language or contexts, and in this way they re-inform discourse about recovery from a lifeworld perspective. The narratives indicate people bridge meaning with their narratives by reflecting on their experience and contributing ideas about alternatives to discourse about recovery. This section is comprised of three subsections in which I examine and describe narratives about acceptance, awareness, and the alternatives people use to make recovery less medical and more personal.

#### *Narratives describing the importance of acceptance and choice*

According to Mizock, Russinova, and Millner (2014) although there are studies about social acceptance and stigma, and studies about peoples' acceptance of specific psychiatric labels, "there is a general lack of research on the acceptance of mental illness" by people who experience it (p. 97). This indicates there is an opportunity to further explore how acceptance plays into the ways people manage mental illness generally, and how acceptance influences recovery more specifically. My examination of narratives about recovery suggests that acceptance is an essential dimension of personal recovery. As the narratives in this subsection indicate, when people reflect on their experience of mental illness and recovery they invariably include some reference to a moment when they realized they had a choice, or describe how acceptance helped them discover things that worked for them.

In her narrative, "Reena" conveys a feeling of excitement and confidence as she explains how she realized "all of a sudden, my recovery was totally up to me". In the narrative "Reena"

initially presents herself in connection with medical contexts in which she is the recipient of medical care, and in which she sees herself and her recovery as dependent upon medical care. However, she adapts this discourse to fit her newly discovered sense of personal recovery after explaining, “no longer could I blame doctors, therapists, or medications not working for my not getting better”. With this line “Reena” shifts attention to what she did to learn about her “illnesses” and take charge of her recovery, and she explains how she “spent a ton of time browsing the web” and “in essence, took control” of her life. Reflecting on this experience “Reena” offers an interpretation of what acceptance means when she says she “became my own treatment provider”. This phrase both resists and reinforces discourse about mental illness as a medical and a personal phenomenon because in effect it shows “Reena” transferring responsibility for her care from the medical community to herself.

All of the sudden, my recovery was totally up to me.

No longer could I blame doctors, therapists, or medications not working for my not getting better. Suddenly, I had no choice but to take responsibility for myself.

I spent a ton of time browsing the web to learn as much about my illnesses as I could. It was then that, in essence, I took control of my life and became my own treatment provider.

No longer was it okay to just understand what would help me. It was time to implement it.

“Reena’s” description of how she came to accept and act on her own behalf to manage her recovery retains a bit of the medical perspective as she references her experiences as “illnesses” and takes on the role of being her own “treatment provider”. But this context provides a framework for “Reena” as she positions herself as someone who has accepted her experiences and made a choice to move away from the health system because it is not helping her. She explains she “had no choice but to take responsibility for myself” and the use of medical

language to describe her actions lends credibility to her choices, as does her effort to “learn as much about my illnesses as I could”. With this narrative “Reena” reflects on her acceptance of her “illnesses” and of the medical system’s inability to treat or manage them, and in doing so she shifts responsibility for recovery to herself.

In the following narrative “Lara”, like “Reena”, describes how “suddenly, for the first time in my life, it occurred to me that I had a choice”. In reflecting on this moment “Lara” notes that with choice comes the ability to accept her situation and decide she “was no longer going to consume what they were offering” and she recalls “in that moment, my entire life changed”. “Lara” gives a critical description of her experience with the health system that supports her choice and decision to accept her situation and move away from the medical system, she explains the system “had long ago killed my spirit and numbed my mind with drugs and psychobabble”. From this point “Lara” uses a familiar analogy to describe how she “stepped onto a new path—a path uncertain but filled with possibility” and with this description she begins to story her experience as part of an adventure and exploration for new opportunities.

Suddenly, for the first time in my life, it occurred to me that I had a choice—at that point in time I could decide that I was no longer going to consume what they were offering. In that moment, my entire life changed.

With my rejection of the system that had long killed my spirit and numbed my mind with drugs and psychobabble, I stepped on to a new path—a path uncertain but filled with possibility.

It was a long, hard, lonely road decolonizing my mind. Every time I had an extreme emotion or heard a voice that scared me, I thought that maybe I was wrong and they were right and that I needed to go back to their system.

In “Lara’s” narrative “choice” aligns with decisions to act independently of the health system, and it is apparent that this involves acceptance of the limits of the system, as well as acceptance

of the unknowns of self-reliance. “Lara’s narrative suggests that “rejecting the system” means accepting possibilities that distressing episodes of “extreme emotion” and hearing voices will continue.

The next two narratives are examples of two different ways people manage the medicalization of their experiences, that is, one narrative is about accepting medical intervention to practice recovery and the other is about accepting and managing the unique experiences of mental illness and rejecting medical approaches. In the first narrative “Kelly” describes having accepted the need for medications as a stabilizing factor, which helps her to manage her experiences and to “move on with my life”. The narrative explains her recovery as a result of acceptance of “an atypical antipsychotic” suggesting “Kelly” understands her experience to be unique and her need for medications in her recovery becomes acceptable.

My recovery didn't begin until I was stabilized on an atypical antipsychotic, clozapine, along with antidepressants.

Once stable and free from any positive and negative symptoms of schizophrenia, I was developing enough insight to move on with my life.

In the second narrative “Lara” indicates her acceptance of hearing voices as a defining point in her practice of recovery. She explains, “I could survive extreme emotions, I could work with the voices”. In this narrative “Lara” shifts attention from acceptance of medical intervention as a help for her recovery, explaining how “without psychiatric intervention, I could emerge out of emotional distress relatively quickly”.

But slowly, I discovered that I could survive extreme emotions, I could work with voices.

Amazingly, I noticed that without psychiatric intervention, I could emerge out of emotional distress relatively quickly. Every time I had this experience, it fortified my identity as a sensitive human

being on a very human path. Messy perhaps, but far more beautiful than the sanitized, manicured path psychiatry would have had me tread.

In her narrative “Lara” reflects on her experience and adds a personal reflection when she explains how her ability to independently manage “emotional distress” improved her confidence and “fortified my identity as a sensitive human being on a very human path”. With this comment “Lara” presents herself as someone back in the mainstream and no longer isolated because of her experiences of mental illness. Her comments suggest that her acceptance of hearing voices, and its resultant complexity, are what make her experience unique and give greater meaning, and are “far more beautiful than the sanitized, manicured path psychiatry would have me tread”.

The narratives of “Kelly” and “Lara” show the variation in what it means to accept mental illness and by acceptance what it means to manage recovery, in both cases, as in the others in this subsection acceptance inspires a sense independence that is storied as a critical factor in recovery.

#### *Narratives explaining the importance of watching for personal triggers*

The narratives in this subsection are about the ways people self-monitor or watch for signs that they are at risk of experiencing problems or an episode of mental distress. People explain that being aware of early warning signs and watching for triggers are paramount to managing their well being and maintaining personal recovery. These personal reflections are increasingly being integrated into discourse about recovery and mental illness, however, research on mental illness and self-monitoring has mainly focused on having people keep track of their physical health in response to medical interventions (such as medication use); additionally research has been done in the area of chronic illness for severe physical health issues such as

heart disease and diabetes (McKeown & Colman, 2006). Finnell and Ditz (2007) suggest in addition to monitoring physical health in mental illness, people should keep track of their personal “health habits” as this will add to professional knowledge about the influence of self-care practices on mental illness. However, as the narratives below suggest watching for personal triggers is a personal effort and although various ideas seem generalizable and useful for medical approaches, the narratives indicate it is the personal expression and application of these ideas that makes them work for people.

In “Liam’s” case he describes watching for “early warning signs” and using “wellness tools” that include maintaining physical health. His points about spirituality are unique to the experience of mental illness, particularly where he reflects on spirituality as a way to understand his experience of hearing voices and puts value on “exploring their meaning”. “Liam” describes an instance where he “heard a loud voice telling me to do yoga or I would die” and he interprets this “frightening” experience in a positive way suggesting it was “like the voice of an angry parent or guardian looking out for me”.

I also watch for early warning signs of problems, and have wellness tools to support myself, such as regular exercise and paying close attention to my sleep patterns.

I also began to consider the spiritual aspects of what I was going through, listening to the voices I heard and exploring their meaning.

At one point back in San Francisco, for example, I heard a loud voice telling me I had to do yoga or I would die. It was frightening, but I realized it was like the voice of an angry parent or guardian looking out for me. So that voice is why I began to practice yoga.

“Liam’s” efforts of self-monitoring are easily understood because he provides an everyday example of how he manages his experiences. The narrative does not include any references to

medical contexts and simply indicates that recovery in mental illness is a personal experience that involves self-reflection and applying personal interpretations. “Liam” makes meaningful connections between his experience and discourse about mental illness by interpreting his experience in everyday ways and this re-informs medical views of recovery.

In the next narrative, “Tina” lists the “signs” she watches for and explains how her family helps her “to quietly monitor my moods”. As she reflects on her experiences “Tina” does not include references to medical contexts and uses everyday language to explain her “life has been a challenge for all four” family members. She describes the various ways she manages her “moods” and recognizes the difficulties she and her family experience. “Tina” draws on contexts of family and close relationships to make connections between her experience and discourse about mental illness, but in her description she uses words such as “moods” and “behaviour” avoiding medical language and thereby giving her experience personal meaning that can be easily accepted and understood outside of medical contexts. The narrative re-informs the ways mental illness can be talked about and given meaning, and it suggests managing recovery is more personal than medical.

Signs I watch for: rapid speech, lack of sleep, too many appointments in my day-timer, irritability for extended periods of time, and overly extroverted behavior for starters.

I write poetry, garden, sew, and work part time currently.

With (children) and a husband who has stood by me even though it has been very difficult, I am very fortunate. We continue to quietly monitor my moods and maintain our love for each other although my life has been a challenge for all four of us.

In the following narrative “Wynona” explains that being aware of what “triggers” her “psychotic experiences” has helped her to see them as “less threatening”. Her use of the word



“psychotic” connects to medical discourse and suggests her experiences are something that requires medical intervention, however she explains how she has “learned to describe them and thereby make them less threatening”. This suggests that self-monitoring and self-reflection are valid and important ways people make sense of their experience, in other words, re-phrasing and giving personal meaning to what are typically defined as experiences of serious mental illness makes recovery, as an ongoing practice, a possibility.

Today, my psychotic experiences are no longer a mystery to me. I know what triggers them and what makes my memories turn into uncontrollable flashbacks and incomprehensible hallucinations. I have learned to describe them and thereby make them less threatening.

For me, it has been effective to discover the association between psychosis and life history. It diminishes my self-mistrust, because it makes my psychotic experiences understandable.

“Wynona” mentions a connection between her experience of “psychosis and life history” explaining that making this “association” has helped her to reduce “self-mistrust, because it makes her “experiences understandable”. To be sure, the word “psychosis” understood in medical terms has many implications and carries negative connotations particularly with regard to recovery and peoples’ abilities to self-monitor. However, “Wynona’s” interpretation of her experience resists these negative ideas and re-informs medical meanings by contributing personal meanings. My examination of the narratives in this subsection aims to show that when people explain the ways they monitor and manage recovery and describe the ways they give meaning to their experiences they shift attention away from medically defined conceptions of mental illness. The narratives indicate when people actively attend to what triggers their experiences, and when they reflect on and redefine their experiences from a personal or lifeworld perspective the traditional meanings of recovery are managed and re-informed.

### *Narratives describing personal alternatives that help with recovery*

In my review of the narratives posted online it quickly became apparent that in the majority of narratives people include some personal description of the alternatives they use to manage their experiences and practice recovery. The narratives read like testimonials rather than as directives for what others should do. In the narratives people present descriptions and lists of what works for them and explain how they have changed habits or relied on themselves to find and use personal alternatives to help with recovery. Due to the great number of narratives about alternatives and the similarity between them I limited the number of examples in this subsection to three; one narrative demonstrates the ways people list alternatives and reflect on these as a way to manage recovery, the second narrative provides an example of narratives wherein people compare what life was like before they made more positive choices to manage recovery, and I include the third narrative as an example of how people describe themselves as being responsible for success in recovery because of changes they made that would mitigate the effects of self-harm. Overall narratives describing personal alternatives that help with recovery reinforce discourse that suggests people need to be active in efforts at self-care, but each narrative also re-informs discourse by providing unique interpretations of self-care activities and why they work. My examination of these narratives aims to show why recovery is personal, particularly where people make choices and reflect on alternatives that work for them.

The narrative below is just one example of a narrative where someone lists the details of self-care alternatives. The narrative was chosen because it includes many of the things people list when they describe alternatives. “Milly” describes doing exercise, yoga, and breathing techniques, abstaining from alcohol and other drugs, trying various complementary and

alternative therapies, relying on friends, family and pets for comfort and support, doing everyday hobbies, reading self-help literature, connecting with people online, eating healthy, allowing feelings to flow, journaling, and praying. The length and tone of “Milly’s” narrative make it an intriguing example because it does not include much context or make direct connections to medical experiences. If considered to be just a list of alternatives the narrative has limited meaning on a personal level. It is simply a list of what “Milly” did.

What helped me recover? I have no idea if any of the things worked that I implemented but I will list what I did.

I exercised throughout the taper (I ran 3 marathons), I practiced yoga and deep breathing exercises, I quit alcohol and all supplements, I tried EMDR and EFT. I forced myself to call my friends and be social even though I could not really connect with any of them. I read every self help book I could get my hands on. I did jigsaw puzzles as I could not concentrate on reading or following the plot of anything I would read. I spent days on the forum just reading and crying. I tried to keep my diet organic and healthy. I journaled my feelings daily. I practiced yoga and deep breathing. I prayed. I snuggled with my cats and cried.

I truly believe that time is the greatest healer.

But the list is composed between two lines, which provide some sense of context and connects the alternatives to personal experience. With the first line “Milly” takes the view that she has “no idea if any of the things worked that I implemented” and after listing everything she states “I believe that time is the greatest healer”, a point which both supports the efforts to try alternatives and also negates any sense that there are any so called magic bullets or secret recipes for success. In its simplicity the narrative lists alternatives, but a possible underlying meaning, might suggest that managing recovery from mental illness (as well as the medical experiences it involves) is about positive life choices and making efforts to explore and adapt these choices over time to find what works best for each individual. Narratives where people list the alternatives they try re-

inform discourse about mental illness by offering ideas about possibilities and options for recovery that connect to everyday contexts and needs.

The second narrative in this subsection is an example of narratives wherein people not only list the things they do to manage recovery, but they also describe what their life was like before they made lifestyle changes. “Laurel” gives two brief descriptions of her experience, and effectively sets them in a way that shows contrast between her past experience and her present experience. In the first part of the narrative she describes life as a patient in hospital and she lists the everyday things she did, describing how she “played Truth or Dare in empty hospital rooms”, “made fun of psychiatric nurses”, “bummed cigarettes from people who thought they were Jesus”. After listing these examples she describes things she did that she believes caused people concern including “drawing scary pictures that everybody was afraid of and thought I was nuts because of”. Then “Laurel’s” narrative shifts as she includes the line: “the turning point for me was that I went on and did normal things” she then lists these “normal” things, which include “eating clean food and getting reasonable exercise”; also in this part of the narrative “Laurel” describes the things she avoids such as “coffee”, artificial sweetener, and “cigarettes”. “Laurel” gives meaning to these lists when she connects her experience to that of another activist (“John”) indicating she is part of a larger community of peers that support alternative choices as a way to manage recovery.

Like, Hmm... I played Truth or Dare in empty hospital rooms, I made fun of psychiatric nurses, I bummed cigarettes from people that thought they were Jesus. I skate boarded and listened to death metal and I drew scary pictures that everybody was afraid of and thought I was nuts because of.

The turning point for me was that I went on and did normal things.

And like (“John”) said, eating clean food and getting reasonable

exercise and taking better care of myself physically has made a really huge difference. Not using things like caffeine and (ABC artificial sweetener). I used to drink like pots of coffee and smoke like a pack of cigarettes a day and use tons of (ABC artificial sweetener). Just getting off of those three things alone in the last 5 years I am a lot more level-headed.

In the narrative “Laurel” sets up comparisons between life in hospital and life after hospital, doing “normal things” as opposed to things people thought she was “nuts because of”, and she details these comparisons with her references to smoking, drinking coffee and using artificial sweetener. Of interest here is that each of these things are common activities of a major portion of society who we can assume are not or have not experienced being in hospital for mental illness, but the examples are significant for “Laurel” as she explains them as excess, perhaps indicating this is not a “normal thing”. All of these points are made to show that this narrative connects “Laurel’s” personal experience to discourse and contexts in ways that create meaning around the idea of choosing alternatives as a way to manage and practice recovery.

The next narrative is an example of how people resourcefully develop personal alternatives that help them to manage their recovery. In this narrative “Reena” describes how she manages her experiences by recognizing triggers and warning signs, and by developing alternatives that provide effective relief from her distress but cause minimal harm. For example, she explains “instead of cutting or burning myself, I would hold a piece of ice in my hand until it melted” she adds that she is unsure why this worked nevertheless “it served the same purpose and left no scars”. “Reena” also describes managing her schedule to mitigate the onset of “racing thoughts” at particular times and in certain circumstances, forcing herself to socialize with co-workers and “say hi to strangers when I encountered them” and using self-help materials as a way to manage feelings.

Since most of my difficulties, especially racing thoughts and suicidal feelings, occurred after midnight, I made sure that I was in bed by 11:30.

Instead of cutting or burning myself, I would hold a piece of ice in my hand until it melted. I'm not sure why, but it served the same purpose and left no scars.

I forced myself to eat lunch with co-workers, to participate in work-related social events and to accept invitations to various events/activities in the community.

While it was extremely uncomfortable, I began looking at people when they talked to me and said hi to strangers when I encountered them.

I actually read the "(ABC self-help book)" that I'd been given during partial hospitalization years earlier and started using the practice exercises. I had a blank copy of a mood log on my computer at home and at work and used it when I sensed that things were a bit out of control.

"Reena's" narrative suggests that finding and using alternatives may mean managing and easing the severity of mental illness experiences by rather than eliminating them, and this speaks as an example of how recovery from a personal perspective is about ongoing practices, rather than sure-fire cures. Moreover, the narrative emphasizes that people draw on a broad range of alternatives and are resourceful at finding which ones work for them—making the experience of recovery all the more personal. In the three narratives examined in this subsection the idea of alternatives is expressed as something people do that contrasts with previous experiences, such as take better care of physical health, or use support resources to manage recovery. The narratives also indicate as far as alternatives are concerned, people do not try to assert or overlay their ideas on others, they resist and avoid giving directions, and instead they suggest "what worked for me" and provide examples for others so they too can discover personal alternatives.

*Section Summary: Narratives about personal recovery practices*

Narratives about personal recovery practices are notably the most direct and individually storied way people manage medicalization as they resist, re-inform, and reinforce particular ways that recovery is given meaning in discourse. The narratives in this section reflect and contribute to changes in how recovery about mental illness is understood in society, and as each subsection highlights the various reasons why recovery is personal. In the first instance, people include descriptions of the ways they come to accept their situation and explain how this acceptance leads to choice, which enables them to make decisions about how to manage to their particular circumstances of mental illness, either by accepting the need for medical support or by rejecting medical support to adopt new recovery practices. The narratives examined in the second subsection show people place great importance on recognizing personal cues or triggers that signal they are at risk of experiencing an episode of mental distress. This is significant because recognizing potential onset of mental illness experiences is not something that happens in medical contexts, rather the precursors to mental illness likely are part of a person's lifeworld experience. Therefore as people take responsibility for noticing what brings about a crisis or episode they can work to reduce the possibility that they will need to seek medical intervention. Out watching for signs resists and re-informs discourse about mental illness and recovery by emphasizing that recovery requires personal vigilance and support in everyday contexts, rather than just medical intervention following or during crises. The third set of narratives demonstrates people know and understand the importance of using everyday approaches to manage their mental health. People include lists of the things they do to maintain and improve their recovery including but not limited to taking better care of physical and emotional health by engaging in exercise, social activities, improving diet, and reducing smoking and use of recreational drugs. In

some cases people describe how they have resourcefully adapted bad habits into less harmful habits that still can provide some relief for their anxiety and distress. Although people describe similar recovery practices the way they connect these practices to their personal experience in various circumstances, and how they adapt them to fit their needs highlights why (and how) recovery is a personal experience.

### **Personal Narratives about Peer Support and a Community of Recovery**

So far throughout this chapter I have examined a wide range of personal narratives that describe peoples' experiences of recovery in order to show why recovery is personal. In this final section I turn my attention to narratives about recovery and peer support. The idea of peer support is formally credited to psychologist Harry Stack Sullivan who, in the 1920s, included past patients as assistants in the hospital where he worked (Davidson et al., 1999). Today the existence of formal and informal support groups and activist communities is the topic of numerous studies and yet according to Coatsworth-Puspoky, Forchuk, and Ward-Griffin (2006) the ways peer relationships "develop or deteriorate or what factors influence these relationships" has received little attention. In my examination of personal narratives about peer support it is apparent as people resist, re-inform and reinforce discourse about mental illness and recovery they are advancing and shaping peer relationships in ways that manage medicalization.

As indicated by the personal narratives reviewed for this thesis people place great value on having peers and a community of support, and take an active interest supporting others. In these narratives there are clear efforts to resist discourse about mental illness as something that should be managed medically and by the health system. The narratives show people actively re-inform discourse about mental illness and recovery by providing advice to others, by describing



why they participate in peer support communities as advocates and activists, and by explaining the personal value peers bring to their experiences. The narratives examined in this section manage medicalization by promoting and supporting alternative approaches to recovery and recovery practices, and by building a community of recovery that arises out of resistance to traditional medical approaches to mental illness and recovery.

### *Narratives giving advice*

Generally speaking, given the opportunity people are eager to share advice about a variety of issues and topics, and as the narratives in this section indicate this holds true for peers in mental illness support communities. The narratives reviewed here include advice about the usual practices of self-care and are similar in content to those described in the last section on recovery practices. They offer practical advice on specific topics and make recommendations for how the health system and peer community can work to provide better social support. Additionally, in personal narratives people express advice and support as calls to action or as demands for improved treatment. On a broader scale when people offer advice in personal narratives they publicly contribute to discourse about recovery as an ongoing practice.

In the first narrative “Jack” explains “stable employment is a very important aspect of daily life” and he adds this is true for a “mental health consumer or a non-consumer” but “may be much more important to consumers” as it helps to support “self-validation”. Given as advice this narrative connects personal experiences of recovery to discourse about mental illness and work and how people benefit from having the opportunity to be contributing members in their community.

Stable employment is a very important aspect of daily life, whether you're a mental health consumer or a non-consumer.

However, employment status may be much more important to consumers, because they often have a greater need for self-validation.

Stable employment can give the consumer a sense that life is not so dreadful after all. It can provide much-needed encouragement.

It can also keep him or her mentally occupied in a positive way, add a sense of accomplishment and, yes, validate the consumer's self-worth.

“Jack” makes the point that work gives people a sense that “life is not so dreadful after all” which he explains provides “consumers” with “much-needed encouragement”. “Jack” adds that employment supports personal recovery because it is a way to keep people “mentally occupied in a positive way, add a sense of accomplishment, and, yes, validate the consumer's self worth”. Unlike narratives about alternatives this narrative offers direct advice, but it is written in third person and it includes no personal details about “Jack's” personal experience, which makes it a formal appeal about the value of work for recovery.

In “Chara's” narrative she takes a direct stand by asking and then answering the question, “what else do we need?” Her response includes a familiar list of alternatives and she stresses these are “the things we talk about all the time that we know are healing”. In addition to listing the physical and spiritual supports desired for recovery, “Chara” points out how “relationships with one another are the cornerstone to all of this” and she highlights that being “healthier” individuals contributes to better relationships between peers. After describing the so-called usual things people need for recovery she directly addresses consumer/survivors telling them “you cannot afford to withhold your brilliance from the world”. The narrative initially draws on a variety of contexts pointing out the importance of healthy life style choices and how positive

relationships matter for recovery. Then with “Chara’s” call to action she draws on her experience to offer personal reflections about what people can do to enhance their recovery. She connects this with shared experiences of psychiatric labelling pointing out “whatever society calls it” people can view their experience of mental illness as “a gift and the world needs it”.

What else do we need?

The things we talk about all the time that we know are healing-all of the arts, exercise, meditation and prayer, access to alternative medicine like acupuncture, herbs, bodywork and excellent nutrition.

Our relationships with one another are a cornerstone to all of this and they grow stronger and healthier when we take good care of our souls, bodies and inner creative artists.

You cannot afford to withhold your brilliance from the world, even if it is labeled madness.

Whatever society calls it, and people will find all different names and explanations, it is your gift and the world needs it.

In her narrative “Chara” begins by asking “what else do we need?” and after this she lists the general things that are needed to help people with recovery and “healing”. The narrative moves through three levels that coincide with Fairclough’s (1992) dimensions of discourse as described in Chapter 3, that is, “Chara” begins with individual needs, then describes relational needs, and then broadens her discussion to include ideological needs. The narrative makes connections to a variety of contexts and works to re-inform and reinforce discourse about life recovery rather than medical recovery.

The two previous narratives gave advice using lengthy narratives and more detailed connections to discourse, however, many personal narratives reviewed for this thesis included a few lines about what would help to improve social care and support of people in their recovery

practices. For example, “Angie” suggests connecting people who have just left hospital with a community guide who can help them adjust to living on their own.

Another idea is that a person leaving the hospital be put in contact with an experienced user on the outside, who can help and guide the “newcomer“ in his or her first steps through the mental health system on the outside.

And “Liam” brings attention to the ways others should respond to help people in recovery. He advises people to “listen without judgement or preconception to people diagnosed with mental illness”, and asks people to essentially imagine how they would like to be treated.

Experiences that get called mental illness are shrouded in fear and misunderstanding. Take the time to listen without judgment or preconception to people diagnosed with mental illness and have the courage to speak up if you've ever had a brush with madness yourself.

These narratives show at a certain point in their experience of mental illness and stage of recovery, people express their desire to offer advice and support others in their so-called journey of recovery. The narratives above indicate people connect to a variety of contexts to make their narratives meaningful to themselves and others and to develop relationships with peers and build a peer community that includes and offers many points of guidance to its members.

#### *Narratives describing advocacy and activism*

Personal narratives on the topics of advocacy and activism are among the most prevalent on the websites reviewed for this thesis. I was particularly intrigued by the ways people found confidence to assert their views after being relegated to a marginalized and stigmatized role. People explain their intentions to share personal accounts with others as a way to help others, but they are quick to point out that the opportunity to share their stories also has a significant impact

on their healing and recovery practices. “Jerry” is clear in his description of why he tells his story, “not for the high five or a kudos (sic)” and “not to get an “atta-boy” or a pat on the back (sic)”. His story is told to offer a “glimmer of hope” and for his “own well-being”, as “Jerry” explains “it is my last step to fully embrace it”, it being mental illness and the process of recovery.

I want to tell my story, but not for a high five or a kudos. It is not to get an “atta-boy” or a pat on the back.

I want to tell it because it is time to look at the view atop the mountain that I have been climbing for over ten years.

I want to tell it because I hope that maybe someone is looking for a glimmer of hope no matter what DIS-ease your body is telling you.

My story is meant to be told for my own well-being and it is my last step to fully embrace it.

In his narrative “Jerry” draws on his experience and makes a meaningful connection to discourse about the value of helping others. The discourse he invokes emerges from lifeworld experiences and is most significantly a communicative act in the Habermasian sense because it explains his experience not in view of discourse about mental illness that is connected to medical or social issues, but rather it makes claims aimed at enhancing shared understanding about mental illness as a lived experience in need of better understanding.

“Raj’s” narrative echoes the message “Jerry” wishes to convey. As he describes having had “difficult times like many of you” he connects to discourse about peer support in recovery, but he goes on to explain the actions he is going to take to “fulfill my dream of helping others with severe mental illness”. He situates his credibility for making claims and helping other in his personal experiences and explains how he will draw upon his “story” to write about what he experienced and the “lessons I have learned and my future directions”. “Raj’s” narrative is a

straightforward example of how many people expressed their desire to advocate for others, and narratives such as these indicate people build their peer community based upon shared experiences and the desire to act as guides for others, until such time as the relationship changes because people move on and “overcome their difficulties and live full lives”.

I have gone through difficult times like many of you. In my story, I am going to write about my past, my illness, the lessons I have learned and my future directions. By sharing openly with you, I hope to fulfill my dream of helping others with severe mental illness overcome their difficulties and live full lives.

Despite the value placed on advocacy and activism in this next narrative “Lara” gave a detailed account of how language is a challenge when people talk about their experiences in terms of their relationships with the c/s/x movement. Her narrative indicates there is a struggle in meaning about mental illness that plays out not only in medical discourse but also in the discourse used in advocacy and activism. Her narrative describes the complexity of activism as it relates to language use and this parallels the challenges raised about medical language. In this narrative “Lara” explains her initial experiences with the “mad movement” and how she discovered a “whole slew of other labels”. She has a critical one as she lists the various consumer/survivor labels and uses sarcasm when she describes the “oh-so-compelling acronym “c/s/x” (consumer/survivor/ex-patient)”. Her critique of movement language is pointed and accurate when she explains how activist labels arise from a medicalized frame of reference and a position of resistance to medicalization, and as such they “still define us primarily in relation to an oppressive system”. She notes that people like herself who have been “deeply wounded by those labels, are especially sensitive to the ways in which language can limit us and liberate us”. Her comments regarding the “consumer flag” are insightful as they indicate how such a term merely shift attention to a new subjectivity as a consumer, which as she notes, “implies that I am

not an entirely active agent in my own destiny”, she adds “they are selling, and I am buying”. “Lara” also addresses the way the terms “patient” and “survivor” readily describe her experience and are “an important part of my history”, and she uses this as a starting point for describing her dedication to “fighting for the rights and dignity of others who suffer psychiatric abuse”. As the narrative continues “Lara” describes the “need to go beyond even these labels” in order to fulfill her personal mission of helping others. She explains this involves people telling their stories and “using our collective stories of oppression and liberation” to “create a world that is safe to go crazy in”.

In my mid-twenties I discovered the mad movement, and with it a whole slew of other labels: ex-patient, psychiatric survivor, consumer, user, consumer/survivor, and the oh-so-compelling acronym “c/s/x” (consumer/survivor/ex-patient). These terms, while all partially accurate, still define us primarily in relation to an oppressive system.

Perhaps those of us who have been labeled, and deeply wounded by those labels, are especially sensitive to the ways in which language can limit us and liberate us.

The “consumer” flag perhaps troubles me the most. It is the passivity implicit in the term that disturbs me. Yes I can be an “educated consumer,” an “informed consumer,” but in the end, “consumer” implies that I am not an entirely active agent in my own destiny. They are selling, and I am buying.

It’s also true that I was once a “patient,” and I am a “survivor of psychiatric abuse.” That is an important part of my history, and as a result, I have dedicated my life to fighting for the rights and dignity of others who suffer psychiatric abuse. But I need to go beyond even these labels.

I don’t know if I want to define myself as the survivor of bad things that happened to me.

I want to use my story, and our collective stories of oppression and liberation, to fight the soul-killing institutions and human rights violations that persist in the name of “treatment,” but at the same time I believe that we can dedicate an equal amount of energy to

envisioning and creating a world that is safe to go crazy in, or better yet, a world that does not drive people to madness.

Perhaps this would be labeled as “grandiose” (haha!) but I personally embrace the term “mad visionary.”

In the last line of the narrative “Lara” takes a metaphoric step back from her passionate and well-considered narrative, she shifts attention from the external assessment of the c/s/x movement and language, and addresses these challenges by connecting more directly to her own experience and her personal efforts to come up with a new label for herself. She proposes a new name that is representative of her big ideas and passions to help others, and it also alludes to her experiences as a patient. She explains “perhaps this would be labeled as “grandiose” (haha!) but I personally embrace the term “mad visionary.” “Lara’s” narrative connects her experience with discourse about the consumer/survivor movement and alludes to ideas about how labels, and those who have the power to give them meaning, also influence the direction of discourse about mental illness and recovery. The narrative is indicative of a struggle for meaning in discourse between the medical system, and “industry”, and the c/s/x movement while also providing an example of how the meaning of all this discourse is negotiated in personal narratives, and how medicalization come to be shaped and directed in everyday narratives.

### *Narratives describing peers as a “bridge”*

At the outset of my thesis I suggested people bridge meaning between their experience and discourse about mental illness, and throughout my examination of literature and my analysis of the narratives collected from support websites it is apparent people create this bridge as they resist, re-inform, and reinforce discourse. I posit this constitutes an ongoing negotiation in discourse, which manages medicalization. In this final section of my analysis I examine three



narratives that support these ideas, and the first uses the analogy of a bridge to convey how he feels about recovery and his relationships with his peers. “Travis” uses the idea of a bridge to connect his past psychiatric experiences with his present experiences with peers in a supportive community. He explains he does “not know how I would cope without them” adding, “they are a bridge that unites my past experience in psychiatry with my present life”. The narrative extends the analogy as “Travis” describes the strength of the bond he has with his peers as it “cements the fracture separating my period of forced hospitalization from my present freedom”. With regard to recovery and the support of a peer community “Travis” states these relationships make “my wounds heal”.

When I am with my peers in the self-help group, I feel I can breathe. I do not know how I would cope with life without them.

They are the bridge that unites my past experience in psychiatry with my present life.

Their loving company cements the fracture separating my period of forced hospitalization from my present freedom. It makes my wounds heal.

Throughout the chapter my examination of the narratives has emphasized how narratives show that recovery is a personal and ongoing practice, and with this section and narratives like “Travis’s”, it is clear that although it is personal, it also involves and requires support from others who have personal insight into the experience of mental illness on all of its various dimensions.

In the next narrative “Lara” describes how the companionship and shared understanding of a peer community provides unique support. She explains that having “friends in and out of the “mad movement” provides “great validation of my experiences” particularly when she is able to share her experiences of “extreme states”; for instance when her “friends say, “Oh, you heard

voices too? You thought you were the Messiah?” Moreover for “Lara” knowing someone else has “been through that too” is made more tangible when others share “some of the things that have been helpful” to their recovery. “Lara” mentions individual things she does to practice recovery such as “educating myself on alternatives” and “healing my body and spirit”, but she credits her ability to “stay afloat in a sea of toxic culture” to “being part of a community of people who struggle” as she does to maintain personal recovery in everyday contexts, not medical ones.

I have found great validation of my experiences, not from any psychiatric label but from friends in and out of the “mad movement.” They have shown me that I’m not alone.

I’ve talked about my extreme states and have had friends say, “Oh, you heard voices? You thought you were the Messiah? I’ve been through that too, and here are some of the things that have been helpful to me.”

Through skill-shares and educating myself on alternatives to corporate psychiatric schemes, I’ve discovered many non-pharmaceutical, non-invasive ways of healing my body and spirit.

I feel part of a community of people who struggle to stay afloat in a sea of toxic culture.

The peer community and sense of support that “Lara’s” narrative describes mediates her experiences of mental illness and recovery. That is, it shows that being part of a support community and having the ability to contextualize her experiences with her peers, “Lara” has a way to connect her experience to discourse about mental illness and is able to resist, re-inform, and reinforce various meanings in discourse as she manages her recovery.

The final narrative I examine for my thesis shows the practice of recovery involves the deliberate and ongoing process of discovering support comes from within and from a community of peers. “Giada’s” narrative reminds us “some people are so skeptical about (sic) real and

complete recoveries”, and we might think this is because there are many people we hear about and read about that continue to have severe challenges with mental illness and recovery. But “Giada” takes a different tack. She explains it “is because a lot of people who achieve it move on” and “they don’t hang around the mental health blogosphere” or “go on working in mental health”. “Giada’s” phrasing and choice of words create an image of someone progressing positively into the future both technologically and personally. “Giada” connects her personal experience to discourse about recovery by describing and re-informing what can be considered stereotypical discourse about mental illness and recovery. She further explains that people “go off and live ordinary lives” noting that this is “as it should be” because “they are out there and they are thriving”. She draws attention back to her personal experience and her choice to remain part of the community of peers seeking recovery when she explains her “career has always been in mental health and so it will continue to be when I’ve recovered”.

Part of the reason some people are so skeptical about real and complete recoveries is because a lot of people who achieve it move on.

They don’t hang around the mental health blogosphere and most of them don’t go into working in mental health like I probably will.

Most of them go off and live their ordinary lives—as it should be—I wish I could move on but I seem to be a survivor with a mission!!

But they are out there and they are thriving.

My career has always been in mental health and so it will continue to be when I’ve recovered,

but for most people life simply continues in whatever realms of interest they have.

“Giada” explains she remains committed to supporting others by staying focused on the system to help manage and influence its course saying, “I wish I could move on but I seem to be a

survivor with a mission!!” whereas “for most people life simply continues in whatever realms of interest they have”. The final line of “Giada’s” narrative—where she says “whatever realms of interest they have” —confirms the idea that recovery is a personal and ongoing experience. As with so many other narratives examined for this thesis, “Giada” connects personal experience with discourse about mental illness and in doing so resists, re-informs, and reinforces discourse in ways that manage medicalization of madness by bringing attention to everyday contexts and lifeworld experiences.

*Section Summary: Narratives about peer support and a community of recovery*

The narratives in this section highlight the importance and value of peers and community support for recovery. My examination of the narratives shows people make connection between experience and discourse when they offer advice, and when they describe and explain reasons for advocacy and activism, and when they reflect on their experiences with peers. Narratives offering advice include new ideas and options for recovery practices, and improvements for social care. People draw on personal experience and make suggests that reinforce ideas about the kinds of things that are helpful to people in recovery, such as employment. These narratives also reiterate many of the “usual things” that people need to manage recovery, such as healthy living practices and strong social support. Where social support is concerned people offer narratives about that explain why they participate in advocacy and activist efforts, such as wanting to give back to the community, and finding that advocacy is a beneficial practice for personal recovery. The narratives also include concerns and critiques of activism, for example, pointing out the implications and negative connotations of consumer/survivor labels and social movement language. Finally, in narratives about peer support people describe the way they benefit from

being part of a community of people who share similar experiences and who have faced similar challenges. In these narratives people connect experience with discourse that reinforces general ideas about the value of community support, and emphasize how peers are a vital part of personal recovery.

### **Chapter 7 Summary Discussion**

While the personal narratives examined in this chapter all relate to recovery in various ways, they also reference or connect to other contexts and circumstances that are discussed in the previous two analysis chapters. Many narratives in this chapter could have been placed among the examples about what it is like being a patient (chapter 5), and used as examples of how relationships matter outside of medical contexts (chapter 6). They are specifically included in this chapter because they emphasize or make direct reference to issues and topics of recovery, and to do so they include and draw together a variety of discourses about mental illness.

What I find interesting is how this supports the idea I posit throughout the thesis, that is, personal narratives manage medicalization as people make meaningful connections between their experience and discourse about mental illness. I see this happening in three ways when it comes to narratives about personal recovery: 1) people directly call into question medical perspectives and approaches thereby resisting and re-informing discourse about mental illness, and 2) people offer advice and ideas to others thereby encouraging the development of a community of peers, and 3) people include personal reflections and interpretations of their experience and their views on recovery. In the first instance the narratives have a directive tone regarding the way discourse and perspectives on recovery should be approached. In the second instance the tone is moderate, and there is a distinct sense that even as people give advice and make suggestions for recovery

practices etc., they are keenly aware that recovery is a personal endeavour that cannot be prescribed, either by medicine or by peers who share similar experiences of mental illness. And in the third instance, the tone is conciliatory and the narratives offer a glimpse into the ways people give meaning to their experiences and the ways they make recovery personal.

Additionally, in these narratives it is evident that people are increasingly taking up an active rather than a passive role in redefining and managing their experiences of recovery in mental illness. The literature on mental illness and recovery practices suggests this is due in part to a new market-oriented approach to health care, which positions people as active participants rather than passive recipients of the health system. When I consider how narrative bridging happens in these narratives my initial inclination is to suggest changes in definitions of recovery for mental illness are due to demands made by patients taking an active stand as consumers/survivors of the health system. However, in my review of narratives about recovery I find few narratives containing direct references to consumer discourse; except in the case where people speak about their experiences with a consumer/survivor activist or advocacy group. Although consumer/survivor discourse encourages and inspires peoples' demands or calls for change in the health system, in actuality people story their experiences as personal reflections on recovery.

My review of narratives about recovery indicates people make connections between their experience and discourse by offering personal reflections and interpretations of recovery. I refer to this as an *expression of lifeworld* because these narratives bring attention to peoples' everyday perspectives of recovery as they draw on existing meaning to produce new meaning. And although I see this happening in the narratives about what it is like being a patient, and in narratives about how relationships matter, I think it is most evident in narratives about why

recovery is personal because in these narratives it is easiest to see people reflecting on their experiences. For this idea I draw on Habermas (1987) to explain how lifeworld is both maintained and changed.

This stock of knowledge supplies members with unproblematic, common, background convictions that are assumed to be guaranteed; it is from these that contexts for processes of reaching understanding get shaped, processes in which those involved use tried and true situation definitions or negotiate new ones. (Habermas, 1987, p. 125)

Narratives about recovery include various connections to medical contexts and relationships (similar to narratives discussed in Chapters 5 and 6), however making these connections meaningful are the ways people reflect upon, interpret and explain their experience of recovery. My analysis suggests personal narratives about recovery manage medicalization by negotiating new meanings for recovery based upon personal—lifeworld—experience that resists, re-informs, reinforces, and therefore shapes, medical meanings. And yet, because many of the personal reflections are storied as opposition to medical meanings, medicalization remains central as a point for creating contrast and contestation. Still, personal narratives about recovery are not constructed anew outside of a medical arena but work to resist medicalization because they remain situated within it, suggesting perhaps that personal stories succeed in managing medicalization by co-opting medicalized discourse from within and emphasizing experiential meaning.

### **Summary Review of Analysis Chapters 5, 6, and 7**

The analysis chapters examined three thematic areas that appeared most prevalently in the personal stories including stories about medical experiences, relationships, and recovery.

Specifically, Chapter 5 examined personal stories about *what it's like being a patient* with a focus on narratives about psychiatric diagnoses, medications, and hospital treatments. These narratives indicate how invoking patient status and using medical language to resist medical practices both helps and hinders efforts to manage medicalization of madness experiences. The analysis in Chapter 6 focused on narratives people tell about *how relationships matter*, and discussed personal narratives about relationships with family, relationships in the workplace, and the relationships people have with the health system. Analysis of these narratives demonstrates people resist and re-inform medicalization by discussing madness experiences outside of medical contexts, however this highlights a need for social care and support that at this time is based upon medical responses to mental illness. In the final analysis Chapter 7 examined narratives that describe *why recovery is personal*, and in these descriptions people make claims about the challenges of medical language, helpful personal care practices, and the value of peer community, and to do so they directly and indirectly draw on and respond to medicalized conceptions that are prevalent in discourse about mental illness.



## CHAPTER 8 CONCLUSION

### Introduction

This thesis demonstrates people respond to discourse about mental illness by invoking medical meanings and by asserting personal meanings and interpretations of their experiences in discourse. In the preceding analysis chapters, I described and explained how people story their personal experiences in ways that make meaningful connections between lifeworld experience and discourse about mental illness. My analysis shows how people narratively bridge meaning between their experience and discourse about mental illness by using narrative strategies of resisting, re-informing and reinforcing these discourses. As people story what has happened to them, they use these strategies to respond to dominant discourse about mental illness, and in doing so, take up and re-work medicalized conceptions of madness that underlie these discourses in ways that support their claims. The consequences of this are an expansion of medicalization as personal meanings are taken up and integrated into prevalent medicalized discourses about mental illness, a point which is well-discussed in literature about medicalization, and in literature about personal narratives and madness (Costa et al., 2012; Speed, 2006).

With my analysis I contend that personal narratives, in responding to discourse about mental illness, are a reciprocal force that influences medicalization. I frame and support this claim with social science literature and with the theoretical and methodological concepts discussed throughout this thesis. With my conception of *narrative bridging* I build on and operationalize the metaphor in literature that describes narratives as a bridge. I have explored this as a communicative connection where meaning is assumed to travel in both directions, and by asking how personal narratives manage medicalization I have emphasized the everyday lifeworld perspective hoping to have complemented literature that takes a top-down perspective of system

influences of medicalization on everyday discourse. Overall, my thesis describes personal narratives as a discursive practice involved in bridging and negotiating meaning between experience and discourse about mental illness. I conclude that the practice of narrative bridging indicates there is a struggle for meaning about madness taking place in discourse and narratives are an essential participant in this struggle, and it is through this struggle medicalization is managed and influenced by personal narratives.

### **Contributions and Implications**

In the remainder of the chapter I discuss contributions and implications my thesis makes regarding the study of personal narratives and medicalization of madness, with respect to how personal narratives may be recognized in social change, and with consideration to theoretical and methodological perspectives on the relationship between lifeworld and system. This is followed by a description of the limitations of the research, and some ideas regarding areas for future inquiry into the study of medicalization, madness and narrative.

#### *Studying Personal Narratives and Medicalization of Madness (why it matters)*

Less than five years ago health organizations and media worldwide declared that one in five people experiences mental illness in their lifetime, today the message has been refined claiming “1 in 4 people will experience some kind of mental health problem in the course of a year” (Mental Health Foundation UK, 2014; Johns Hopkins Medicine, 2014). The World Health Organization (WHO) (2010) has prioritized mental illness in order to address what it calls a global crisis in mental health. Five of the top ten “leading causes of disability and premature mortality” are attributed to “mental and behavioural disorders” (Saraceno, 2001). There is

concern about the ability to adequately provide services for an aging population facing uncertain mental acuity in old age (key issues include depression, dementia, and Alzheimer's disease; see Pederson, 2010; Kleinman, 2009). According to the Canadian Mental Health Association (2014) current statistics indicate "20% of Canadians will personally experience a mental illness in their lifetime." In Canada, mental illness is the "fastest growing category of disability" costing an estimated 33 billion dollars per year (Acharya & Yew, 2009). Additionally, the increasing identification of disorders in the ever-expanding DSM make understanding the rise and development of mental illness in discourse of significant importance (Erickson, 2008; Scull, 2010). Statistics such as these speak to the urgency of addressing the challenges and issues of mental illness and headline the intense focus and changeable nature of broad discourse about mental illness. The dominance of medical meanings seems relatively unshaken, spurred on by advances in medical technology and bio-chemical understandings of the brain. The pervasive scientific and societal preoccupation with madness as mental illness indicates that its meaning and discourse about it continue to be securely bound to (and emerge from) medicalized constructions.

However, while proponents of medical and psychiatric approaches focus on clinical and psycho-pharmaceutical treatments for mental illness, advocates and activists comprising the c/s/x movement work to oppose medical approaches suggesting mental illness and its increased prevalence are due to over medicalization of life (Rapley et al., 2011). Discourse is focused on issues and concepts whose meaning is still being negotiated, such as recovery, stigma, and service-user involvement in research. The inclusion and appreciation of consumer/survivor perspectives in medical discourse is a catalyst for renewed interest in meanings about mental illness. These discussions provide comprehensive accountings of the ways perspectives and

meanings about madness have come to be intimately tied to medicalized discourse and raises points about the negative effects of medicalization.

Whether either the medical or the consumer/survivor view is correct continues to be up for debate, and that is not the focus here. In the work of Conrad (2007), a preeminent scholar in the area of medicalization, I find a fitting articulation of the perspective taken in this thesis.

According to Conrad (2007)

I am not interested in adjudicating whether any particular problem is *really* a medical problem. That is far beyond the scope of my expertise and the boundaries of this book. I am interested in the social underpinnings of the expansion of medical jurisdiction and the implications of this development. We can examine the medicalization of human problems and bracket the question of whether they are “real” medical problems. What constitutes a real medical problem may be largely in the eyes of the beholder or in the realm of those who have the authority to define a problem as medical. In this sense it is the visibility of the designation rather than the validity of the diagnosis that is grist for the sociological mill. (Conrad, 2007, p. 4)

Like Conrad (2007) my interest is not in determining whether an issue or problem is medical. My attention is focused on how medicalization is managed and develops in everyday discursive practice, and this involves looking to narratives to see how people define experiences as medical or not, and analyzing how this fits into discourse about mental illness. My thesis makes visible the many and varied ways discourse about mental illness is resisted, re-informed, and reinforced in personal narratives across a number of contexts. It indicates personal narratives are involved in a negotiation of meaning as people make meaningful connections to bridge their experiences with discourse. The implications of this suggest continued focus on discourse about mental illness will benefit from the inclusion of various assessments of language and meaning from both medical and consumer/survivor perspectives, and how they are related. This matters because

focusing on either the medical or the personal perspective does not show *how* meaning is negotiated in discourse nor what influences discourse to develop in particular ways, therefore it is key to look at how various stakeholders in discourse make claims and connections to dominant ideas about mental illness. As Sakalys (2000) points out the study of narratives encourages dialogue where “the desired outcome of the dialogue is not reversal of dominance” (p. 1473) but rather greater recognition and understanding of how perspectives in narratives contribute to existing discourse.

### *Personal Narratives and Social Change*

By asking how narratives about mental illness in society work to manage medicalization and convey and participate in meaning-making the thesis has implications for the ways everyday discourse may be valued as a contributor to social change. Instead of a singular focus on what is said in stories or what structure stories have, the questions become about how and why people tell the stories they do, in the ways they do, and what this accomplishes for them and in society. Over these many pages I have examined personal narratives for the ways they actively work to strategically address discourse about mental illness and following from this how narratives are recognizable as significant contributors to social change. Although I did not examine specific outcomes of particular narratives on discourse about mental illness my analysis and the existing literature on social implications of narratives provide support for my assertion. This analysis of narratives has implications for the ways they can be seen to contribute to and influence social change with respect to three points, narratives are examined as practices in discourse that accomplish things for people, narratives are not privileged above other forms of discourse as more truthful but are viewed as contributors and participants in discourse, and the development

of narrative themes in the analysis chapters suggests people are confident their stories make a difference.

The analysis of narratives in this thesis highlights a struggle for meaning in discourse as people assert meaning based upon personal experience. If this were to mark the conclusion of the analysis an important point would be missed, that is, that narratives are analyzed for how they participate in discourse they do not stand above it as a privileged form of discourse. As Atkinson and Delamont (2006) remind us examining narratives out of context and as if they hold some innate power to carry truth, limits what can be learned from them as situated discursive practices among many other forms of discursive practice. Viewed in this way, personal narratives are not set apart or above other discourse as more or less relevant, but they can be examined for how they work with and engage in the development of discourse. It follows then that looking at how narratives work, we become attuned to what it is they are accomplishing and what influence this has not only in discourse but also on social practices (Gubrium and Holstein, 2009). Fairclough (1992) points out examining changes in discourse on societal and individual levels “can make a significant contribution to current debates on social change” (p. 99). According to Fairclough (1992) changes in society come about with the inclusion and spread of everyday discourse as a participant in reworking discourse by creating new discursive combinations and challenging existing hegemonic discourse.

As this study shows people describe their experiences in ways that relate to dominant discourses, and as such the stories work as a sign and a catalyst for social action by highlighting when and where possibilities for change may begin. Throughout this thesis I have aimed to show how people do not just describe instances of their experiences without intent. In their stories people actively draw on other discourses and contexts to give meaning to their stories, meaning

that others can relate to and that will be accepted. I suggest by accomplishing a level of validity for the claims in their stories, people shift attention to issues that warrant change in society. Drawing attention to these topics and connecting them with other discourse creates new meaning or challenges existing meaning and provides reasoning for advancing social change.

With regard to medicalization this action is realized as people both invoke and give new meaning to medical discourse. Unable to completely separate from the dominant hegemonic discourse people “always remain somewhat complicit and work with components and parts of the existent frame ‘from within’ “ (Bamberg, 2004, p. 363), while presupposing their ability to resist, re-inform and reinforce the discourse with their stories. Framing experiences medically gives people an opportunity to challenge or reinforce medical meanings, selectively resisting and re-informing meaning, which will “feed back into that expert discourse, influencing and shaping it” (Schneider, 2007, p. 137). My analysis shows people shift attention away from medicalized conceptions of mental illness drawing on other discourses, contexts and circumstances they have experienced and in doing so they add to and shape medicalized conceptions of mental illness, by interweaving interpretations and meanings that come from their personal experiences.

However, this also indicates people remain under a medical gaze because even resisting medical discourse reasserts its presence and influence as dominant discourse, and as such the struggle for meaning continues. The implications here are twofold: first, if narratives influence medicalization care could be taken to understand just how and to what degree personal stories might be able to hone in on ways to consciously adjust discourse (and this too has implications). Secondly, with regard to demedicalizing madness, there would need to be concerted effort to develop language that in no way resembles or is connected to medical discourse—something that seems unlikely given the advanced development of medicalization over other areas of lifeworld

besides mental illness. Therefore, this thesis argues for a reconsideration of the ways medicalization of madness is addressed, by directing attention to how discourse that is predominantly informed by medical conceptions of madness is resisted, re-informed and yet reinforced in personal narratives told by people with first-hand experiences of madness and medicalization. One avenue to explore more deeply on this point is the way personal narratives and system discourses relate.

### *Relating Lifeworld and System*

My analysis of the narratives for this thesis indicates there is a struggle for meaning in discourse about mental illness where personal narratives provide communicative connections between personal experience and system discourse. In this section I briefly consider the ways this study might contribute to thinking theoretically about the relationship between everyday lifeworld discourse and dominant system discourse. Having framed the thesis on Habermas's (1987) distinction between lifeworld and system I suggest this study has implications for understanding the relationship between lifeworld and system in terms of how colonization—in this case characterized as medicalization—works. As discussed in Chapter 3, lifeworld is the taken-for-granted background of life that informs shared social meanings and where communicative actions involve efforts to establish consensus and shared truths. System is comprised of the structures of society, including language, which aim to strengthen social order and shared norms that develop as a result of lifeworld demands for greater rationalization in the face of lifeworld issues and challenges. Habermas (19987) describes the relationships between them in scope and detail beyond my abilities and aims here, but proposing my thinking on this demonstrates some manner of contribution and implications of the study.



With the idea of colonization Habermas (1987) explains change in society suggesting that the ongoing growth of systems to claim jurisdiction over lifeworld issues and experiences (as seen in the development of medical approaches to explain social issues). He explains over time the expansion of system leads to an uncoupling of system and lifeworld resulting in a crisis of legitimation. In this crisis system no longer holds the requisite value preferred by lifeworld—that is, issues in society become so systematized that they are no longer driven by values of lifeworld, but by the instrumental and strategic demands of system (i.e. money, law, commodification, medicalization). Therefore system looks to lifeworld to replenish those values. Following from this I suggest that colonization of lifeworld is not a sustained encroachment of system over lifeworld but rather a back and forth struggle in discourse constituting and contributing to negotiations of meaning. The analogy of a pendulum serves to illustrate this relationship.

As lifeworld and system each aim to retain, redefine and privilege their accounts of meaning, and promote the requisite communicative actions and goals, a struggle and negotiation of meaning ensues. Employing a liberal adaptation of Anthony Giddens's (1984) concept of the "double hermeneutic" (Loyal, 2003) I suggest that with each swing of the pendulum, lifeworld and system alternately reinform and resist one another. In the first swing, lifeworld provides the initial impetus for rationalization, but does so in terms of moral and consensual demands that aim to remain true to basic communicative actions and validity claims (truth, sincerity, and rightness). System strategically takes up these demands and offers alternatives that are reframed as instrumental and strategic actions based on system imperatives (power or money). Lifeworld resists when the system responses fail to meet the demands of lifeworld and/or to provide adequate meaning. Unsatisfied with system responses agents in lifeworld then attempt to

reestablish the underlying morals and order that constitute lifeworld, but do so by reasserting demands in terms of the alternatives presented by system. In this thesis the struggle for meaning in discourse about madness may be explained by this relationship as there is the negotiation between lifeworld and system is represented in discourse by personal narratives and medicalized discourse, respectively.

Thinking about these ideas in terms of narratives and dominant discourse suggests that narratives have an essential role in negotiating meaning and social change via resisting, re-informing and reinforcing discourse about mental illness. For instance, through a back and forth negotiation of meaning, discourse about mental illness is informed by personal narratives. Medical discourse adapts to resistance and calls for improved approaches made in personal narratives by integrating and co-opting meanings from the narratives and interpreting them medically. In this negotiation, people are encouraged to continue responding and resisting, and to call for approaches based upon values of human rights and citizenship, which aim to satisfy lifeworld values. On the surface it appears as though lifeworld is gaining meaning and support from an informed and sympathetic system, but in actuality lifeworld increasingly becomes rationalized under the influence of system. Increasingly, social and individual meanings become defined in terms of instrumental and strategic actions—as seen with the shift from a doctor-patient relations in medicine to consumer/survivor subjectivity in health today. The interdependent nature of the relationship between lifeworld and system sketched here suggests narratives participate and are involved in negotiations of meaning in discourse about mental illness, and therefore following the negotiation is one way to explore what narratives accomplish with regard to social change.

## **Limitations of the Study and Considerations for Future Research**

In its attempts to be both broad and inclusive the thesis runs aground in a few areas thus opening up considerations for future research. In this section I discuss the limitations and the opportunities that arise from them, suggesting the study had both limiting and productive results for considering how personal narratives manage medicalization.

First, by identifying and characterizing three broad thematic areas in the narratives the analysis was limited in its ability to take an in-depth look at the variety of experiences people wrote about in their stories. Rather than look at one specific area to see how people managed medicalization of experiences, say in the workplace, the intent of the thesis was to explore a full and comprehensive collection of narratives to identify and characterize how personal narratives engage with and in discourse about mental illness. That being the case, the thesis highlights opportunities to examine particular topics and the influence personal narratives have in contributing to changing discourse in these areas. And with regard to extending an analysis of the ways personal narratives manage medicalization, it would be of interest to identify and characterize topic specific instances of narrative bridging and the narrative strategies people use to manage medicalization. On this point it would also be interesting to examine other areas where personal narratives are considered to have some social influence to see if and how narrative bridging and narratives strategies work on other substantive topics.

A second limitation of the study is in regards to the method and the sourcing of narratives as collected from the internet. Given the close focus on the workings of the narratives and the ways medicalization is managed there was much less focus on the implications and contributions the study makes with regard to the study of personal narratives posted online. My interest in analyzing the internet as a site where personal narratives become public was set aside in this

study. That said, opportunities now remain for examination of the significance of personal narratives posted online as an influence in discourse, as well as opportunities to focus on specific websites (medical, individual, community support, activist) and look at how narratives are presented and what they accomplish as part of online discourse about specific topics in mental illness.

Reviewing over 400 narratives for this study there were decisions made about how to code and thematize them into a manageable number for discussion in the analyses. As a result I could not include many poignant and interesting narratives in which people managed the medicalization of their experiences. It would be of interest to examine narratives from a specific website to follow how medicalization is managed in view of varying perspectives on medical approaches. And although deciding to follow prevalent themes in narratives from across all the websites helped to demonstrate medicalization is managed on various topics and contexts, opportunities remain to study fewer narratives in greater detail to lend further support to the idea that narratives manage medicalization. The thesis highlights an opportunity to study changes in narratives over time to see how they compare and how discourse and approaches to mental illness in society have shifted to include language and meaning first conveyed in personal narratives.

In this thesis I have aimed to show how medicalization is managed in personal narratives as people connect experience with discourse in ways that manage hegemonic discourse and keep personal meaning relevant as people explain circumstances based on personal experience and interpretations. To do so people describe what it is like being a patient and directly address issues with diagnosis, medications and hospital treatments based upon their experience and drawing on medical discourse. They draw attention away from medical discourse by discussing contexts

outside of medical ones and explain how their relationships in other areas of life were influenced by, and influenced their experiences of mental illness; areas such as relationships with family and friends, in the workplace, and with regard to the health system. In their stories people also manage discourse about mental illness by directly addressing medical language and its effects as well as by describing personal recovery practices and emphasizing the importance of peers and community support. My analysis of personal narratives demonstrates people connect experience with discourse about mental illness and challenge medicalization of madness by making active claims in their stories.

This thesis shows how people manage medicalization in their personal narratives as they connect their experience to socially prevalent discourses about mental illness. I suggest personal narratives are discursive practices whereby people resist, re-inform and reinforce medicalized conceptions of madness, and that in doing so narratives influence medicalization.

### **A few reflections**

It is my belief that personal stories make a difference in the world. My interest in this topic is inspired when I look at the countless scores of books, articles and online texts that present, describe, emphasize, allude to, include, and even analyze personal narratives about mental illness, making me wonder why personal stories are invariably included in broad discourse about mental illness. From my initial readings of the narratives on the websites I was interested when I noticed how the stories were generally similar in narrative content and narrative structure no matter the mission or vision of the person or organization posting the stories. I was inspired by the ways people connected their stories to other discourses and events, and the things that people said about what concerned them, influenced them, and encouraged them to share their stories

publicly on the internet. Most of all I was keen to explore how personal narratives work to be such a compelling and prevalent part of societal discourse about mental illness.

People are generous with their stories and taking a close look at stories gives a glimpse into the ways they manage the meaning of their experiences, how they connect and convey that meaning to others, and to what degree personal meanings about life experiences are unravelled and re-woven into the proverbial social fabric. In this thesis I have been honoured with the opportunity to study personal narratives that were generously shared and publicly posted on the internet. Reviewing and analyzing the stories has proven to be as rewarding as I initially expected, and more humbling than I imagined. Medicalized or not, madness explained in a personal story tells us a lot, and perhaps the true meaning of these experiences can be found in the ways we help each other understand life's struggles as we share our stories. Mq.

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