

“You can tell when people like you. You can’t describe it but you know it”

An exploration of ‘care’ from the perspectives of
mental health clients and case managers:
Towards a transformative education

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Abstract

This qualitative study explores the construct of care from the perspective of people diagnosed with severe mental illness as well from the perspective of mental health case managers. The study explores what it is like for case managers to care about their clients, and what it is like for clients to feel cared about by their case managers. The design of the study builds on the ways in which care is conceptualized in the literature, notably care as a noun (care as a provision), care as an adjective (to describe a quality in a person or of a relationship) and care as a verb (to care about someone). Nineteen (n=19) persons diagnosed with mental illness were interviewed. Five (n=5) persons employed as mental health case managers were also interviewed. Interviews were transcribed and analyzed using Malterud's method of analysis called "Systematic Text Condensation" (STC, 2012). The present study is the first known to this author that uses STC for education research. It is also the first known study that uses STC to explore two perspectives on the same phenomenon.

One of the goals of the study is to consider the implications of the experience of care for a professional education that addresses the challenges faced by mental health case workers while at the same time considering the expressed needs of clients. Perspectives and stories about care provide insight into areas often neglected in case managers' education. The findings point to the importance of interrogating taken-for-granted assumptions about the nature of professional relationships. For clients, the experience of being cared for will, at times, require that workers "break the rules." The workers in the study struggle with these boundaries, as they attempt to maintain a certain level of distance while at the same time remain authentically connected to their clients. The findings call for a "transformative education," an education that encourages a form of self-reflection which addresses how

worker biases are often communicated to clients via subtle gestures, and hence potentially perpetuate the very stigma workers seek to avoid.

Résumé

Cette étude qualitative est une exploration de l'expérience de la sollicitude (care) du point-de-vue des personnes atteintes de maladie mentale grave et du point-de-vue des gestionnaires de cas en santé mentale. L'étude est fondée sur les trois conceptualisations de la sollicitude qu'on retrouve dans la littérature, notamment sollicitude comme un nom (soins en tant que disposition), comme un adjectif (pour décrire une qualité d'une personne ou d'une relation) et comme un verbe (se soucier de quelqu'un). Dix-neuf (n = 19) personnes diagnostiquées avec une maladie mentale ainsi que cinq (n = 5) personnes employées en tant que gestionnaires de cas en santé mentale ont été interviewées. Les entretiens ont été transcrits et analysés en utilisant la méthode de Malterud d'analyse appelé "Systematic Text Condensation" (STC, 2012). La présente étude est la première connue de l'auteure de cette thèse qui utilise STC pour une étude ancrée en éducation.

L'un des objectifs de l'étude est d'examiner les implications de l'expérience de la sollicitude pour une formation professionnelle qui répond aux défis auxquels sont confrontés les gestionnaires de cas en santé mentale tout en répondant aux besoins exprimés par des clients. Les perspectives des gestionnaires et des clients nous pointent dans des directions souvent négligées dans la formation professionnelle. Pour les clients, l'expérience d'être soignés avec sollicitude, parfois, exige que les gestionnaires «enfreignent les règles." De leur côté, les gestionnaires s'efforcent de naviguer un point de tension entre l'importance de maintenir un certain niveau de distance et en même temps rester liés de façon authentique à leurs clients. Les conclusions appellent à une «éducation transformatrice» qui encourage une réflexion sur sa pratique et qui permet aux gestionnaires d'interroger leurs préjugés, lesquels sont souvent communiqués aux clients par de gestes subtils, et qui, par le fait même, contribuent à perpétuer la stigmatisation des personnes souffrant d'une maladie mentale.

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recovery. Your stories are invaluable and your experiences will undoubtedly be instrumental in moving us towards a recovery model that incorporates humanness, kindness and love.

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CHAPTER 1: INTRODUCTION

1.1 Problem statement

Mental health service users have said that care is lacking in the mental health care that they receive (Davidson & Strauss, 1992; Anthony, 1993; Deegan, 1999). In fact, the mental health consumer movement, as a whole, is largely united by the shared experience of substandard mental health care. This study investigates 'care' as a general construct in the mental health context. How do clients perceive mental health care? How do mental health case managers perceive care?

1.2 Purpose of the study

The purpose of this study is to further investigate care in the mental health context. A crucial component of mental health case management is the ability of case managers to provide recovery-oriented care to the client. In Canada, this has been the focus of a great deal of research. Many efforts towards best practice and recovery-oriented policies have been made in Canada. Despite this, there have been expressions that care is lacking and that this is a cause for concern. Furthermore, mental health case managers have been identified as an at-risk group of professionals. In his text about mental health case management, Paul Brodwin writes,

“Two of the most oppressed groups in mental health are clients and their case managers...Basically they are the lowest paid, the lowest on the organizational hierarchy, and are the least credentialed, yet have the most cases and the most ambitious goals established for their work. They also have to complete the most paperwork, go to the same meetings as others, and are the most supervised members of the organization. They have the least control of their jobs and have the least influence over organizational or client matters.” (Rapp, 1998, 55)

The purpose of this study is to gain a more complete understanding of “care” in the context of mental health case management so that we may better understand why it is lacking and how to best support case managers in delivering recovery-oriented care.

There is an important educational dimension to this program of study. It is my contention that the ways of educating mental health practitioners must change. I began my study with the contention that these practitioners require a different kind of educational support. Mental health case managers’ and clients’ perspectives on care may help inform the development of this educational support.

1.3 Study objectives

This program of research is guided by three objectives:

- (i) Explore mental health case managers’ perceptions and experiences of care
- (ii) Explore mental health clients’ perceptions and experiences of care
- (iii) Deepen our understanding of ‘care’ from both perspectives and develop a preliminary framework to address care in mental health practitioners’ education.

I hope to gain a contextualized understanding of the construct of care. How might subjective accounts of care inform how care is addressed in practitioners' education? Are there nuances about care that are particularly pertinent to the case manager role that have not yet been addressed in education models?

1.4 Situating the researcher

This thesis is the product of my attempt to deconstruct the term Care as it is used in relation to mental health case management. I started my doctoral studies two years into my work as a case manager. It is through this experience that I started to read the consumer literature. I was especially concerned about the literature that addressed mental health practitioners' discrimination and absence of care towards their clients. The scholars Coni Kalinowski and Pat Risser asserted that clinicians are not immune from the pervasive effects of prejudice against people who have received psychiatric diagnoses (2000). In Otto Wahl's study in 1999, clients reported that professional caregivers treated them as less competent, discouraged them from setting high goals, mocked them and shamed them (1999). One woman diagnosed with Bipolar Disorder reported that her practitioner told her "people with your problem will have a very low level type of life" (1999, P. 473). Nearly a decade later, Schulze found similar results. In this study, Schulze found that one-quarter of all stigma experiences reported by consumers occurred in their interactions with mental healthcare professionals (2007).

As a practitioner myself, I was particularly troubled by these kinds of findings. To me this represents a kind of betrayal, where the people you count on for support actually perpetuate and contribute to the harm done by stigmatizing. At the time that I began reading the literature described above, I carried a caseload of 38 clients, each of whom was

diagnosed with one or more mental disorders. I spoke to these clients regularly, supported them in finding homes, jobs, emotional wellness, resources and medical treatment. I was a part of their everyday lives. The idea that I may be guilty of perpetuating such maltreatment towards my clients, even if this was unintentional, was a horrifying thought to me. These feelings of concern sent me on a five-year quest for clarity on this construct 'care' in mental health case management.

1.5 Overview of thesis chapters

The background chapter (Chapter 2), provides a brief review of care in the mental health context in Canada. In this chapter, I review how the construct of care has changed over time as perspectives on mental health and illness have changed. Psychoanalytical and biological dimensions of mental illness are examples of these differing perspectives that will be reviewed in this chapter.

Chapter 3 provides a review of the relevant literature on care as it relates to mental health practice. This review provides the conceptual framework for the study. The construct of care is teased apart into three main categories; caring *for*, where care is a provision; *being* caring, where care is an adjective that describes either a personality type or the quality of the helpful therapeutic relationship (that is, it is a caring one). And finally, this review also reveals a more recent conceptualization of care, which is more closely related to caring *about*. Not only are case managers expected to be caring people and provide care to a client, but there is also an emerging expectation that they must also care *about* their clients.

The methodological framework and precise study design are presented in Chapter 4. This study is an exploratory, qualitative study on the construct of care. In order to gain a more complete understanding of caring "about" as it is addressed in the literature, I sought the

experiences and perceptions of case managers as well as clients. This chapter reviews qualitative methods and justifies the use of qualitative methods for this study, as well as grounding this study in phenomenology. Chapter 4 will also review Systematic Text Condensation (STC) which is a unique approach to data analysis that focuses on capturing the essence of a person's experience and creating a narrative using the person's own words (Malterud, 2012)

Chapter 5 presents the results of this research. Fundamental to STC, interviewees' narratives were largely kept intact, and are presented in large chunks of text. The purpose of this format is to maintain the integrity of individual experiences in context as a story. These narratives are organized into general themes. Clients' stories, for example, touched on themes around explicit and subtle demonstrations of care and non-care by their case manager. Case managers' stories of care centered more on what care means to them in their professional practice as well as challenges they experience in providing care to their clients.

In Chapter 6 I discuss the educational implications of my interpretive understandings of the narratives as expressed by clients and case managers. I draw from 3 educational models that have particular relevance to the themes that emerged in this research: (1) Mezirow's Transformative Education theory, (2) Nel Noddings' Care Theory and (3) the narrative approach in education. These models are discussed in developing an educational framework to support mental health case managers.

1.6 A note on terminology

Throughout my study of mental health case management, there is overlap in terms of who is the official "case manager". The terms "practitioner", "professional" "clinician" or "worker" were used interchangeably with the designation "case manager". In addition, the

terms 'nurse', 'social worker' and 'counselor' present themselves throughout the literature because much of the mental health literature is grounded in these respective disciplines (nursing, social work and counseling/ psychotherapy). Despite the difference in terminology, this literature was still included in my review, considering that the role and responsibilities of these workers overlap. A 'case manager' is the professional who is primarily responsible for conducting needs assessments, developing individual plans, coordinating access to needed services, and monitoring mental state and social functioning. At times this person may be a nurse, a social worker or a counselor; in other situations, occupational therapists or psychiatrists assume the role of 'case manager'. There are several terms used in referring to the service recipient: client, patient, consumer and psychiatric survivor. I tried to use one consistent term (client) throughout this thesis. The term "consumer" may be off-putting to readers outside of the mental health field given the connotation this term has in marketing or consumer models. However, this term is commonly used in the mental health literature and carries with it a tone of empowerment and agency to the recipient of mental health services.

CHAPTER 2: BACKGROUND AND CONTEXT: A Review of the Literature

2.1 Changes in mental health care

The construct of care has changed over time. In the Canadian context the phenomenon of “care” is a recent theme in the literature on mental health and recovery. Most notably, the construct of care is a source of concern for consumers who refer primarily to the *lack* of care in mental health services (Crawford, Gilbert, Gilbert, Gale & Harvey, 2013).

Just as the construct of care has changed over time, perspectives on mental illness and treatment have changed considerably. Each perspective comes with a particular vision of what constitutes care. For example, in the first half of the 20th century, when Freudian, neo-Freudian and psychodynamic theories were prominent (Berkenkotter, 2009), theories assumed conflicts of childhood to be of critical importance in the development of “neurotic disorders” (p. 33). These theories suggested that neuroses in adulthood develop when the balance between the pressures of the drives and the defensive forces of the ego are upset (p.33). Care is provided through psychotherapeutic means in the form of various types of therapies and psychoanalysis.

Moving towards mid-century, focus shifts to biological explanations of mental illness. This focus places mental illness as an “inherited deficiency” (Thompson, 1994, p.989). In the middle of the 20st century, psychiatric research and clinical practice was becoming “medicalized” (Berkenkotter, 2009, p.130) focusing largely on biological and genetic reasons for mental illness. In its purest form, the biological orientation explains psychiatric problems to be “deviations from the norm of measurable biological variables” (Engel, 1977, p. 130). Psychopathology, according to this biomedical ideology, is the manifestation of “disordered

brain processes” (Cooper, 2013, p.60). Psychiatric illnesses were thought to be chemical imbalances in the brain chemistry. In this purist perspective, the experience of hearing voices, for example, which is a common symptom of “schizophrenia”, might be explained by physiological reasons related to activation in subcortical nuclei, limbic structures and paralimbic regions of the brain (Silbersweig et al, 1994). In this model, ‘care’ may be provided through psychopharmacology (psychiatric medications) by medical staff.

Psychiatric research and new medical breakthroughs produced new medications and meant shorter stays in hospitals. For example, Brodwin writes “[in 1954] the first phenothiazine drugs were introduced into American hospital use (Cooper, 2013, p. 30). These medications had the “dramatic effect of calming belligerent and loud patients and making it easier to discharge them without opposition from family members or neighbors” (Cooper, 2013, p. 30). With advancements in medications there was a general shift away from care in institutions and toward care in the community.

Historically, case management in Canada has its roots in de-institutionalization in the 1950’s and 60’s (Howgego et al, 2003). As psychiatric patients were reintegrated into the community from hospitals, they were assigned a case manager, usually a nurse, a social worker or a community counselor. The case manager’s role was to assess clients’ needs, link clients’ to services and monitor their service use and outcomes (Davidson et al, 2009, p.151). Case management was primarily a ‘brokering’ role; practitioners coordinated social benefits, (such as welfare, housing, employment) medical benefits, and recreational activities.

2.2 The consumer movement

The consumer movement prompted a major ideological shift in how mental health care is conceptualized. In many ways, the consumer movement is defined by its frustrations with

the mental health care system and is bound together by its prescriptions for change. The biological focus is criticized by patients who say it is reductionistic. They assert that a purely biological focus reduces a person to his or her disease. In a book called 'Beyond crazy: Journeys through mental illness' (2011), Nunes and Simmie compile a collection of personal stories written by people with experiences of mental illness. One such story comes from a woman named Colleen McDonagh. She speaks to the problem of reducing a person to an illness. She writes,

“Hell is not underground. It is here, on the sixteenth floor... electroconvulsive therapy and drugs like Haldol and Prozac are the chief residents, and everyone lives by their rules... each time I reach out for help, my soul is anaesthetized with drugs I cannot tolerate” (p. 192).

The mental health system treating patients as non-human is a theme repeated throughout memoirs like the one above.

Critics agree that mental health system and society at large has treated people with serious mental illness as less than human (Davidson & Stayner, 1997). Biological treatment neglects to consider other vital aspects to a person's humanity. In 2007, Farkas wrote: “patients appreciate when practitioners express interest in them as a person in roles other than “patient”... (they) may feel damaged by practitioners who refuse to connect in a more holistic way” (p. 7). Anonymous said in 1989 that “therapists need to understand that patients need the human touch or compassion just as much as they need the technical expertise of the profession” (p. 637). A seminal article in the 1990's by William Anthony explains that consumer recovery “involves the development of new meaning and purpose in one's life as

one grows beyond the catastrophic effects of mental illness” (1993, p. 527). Recovery has been defined as a multifaceted process that moves beyond biological factors.

2.3 Models and perspectives of mental health recovery

In 2010, Whitley and Drake proposed a five dimensional taxonomy of the key dimensions of recovery: clinical recovery (encompassing symptoms, medical care and psychotropic medications); functional recovery (encompassing employment, education and housing); existential recovery (encompassing religion and spirituality, agency and self-efficacy and personal empowerment); physical recovery (encompassing diet, exercise, smoking and substance use); and social recovery (encompassing family, friends, community and social activity). The individual client defines the relative significance of each dimension. Person-centered care, therefore, must address and integrate aspects to a person’s life depending on the value attached to this aspect. (2010). Case managers do more than merely broker between their clients’ services. Rather, recovery-oriented care involves inquiry into a client’s “hopes, dreams, interests, talents, and skills and, perhaps most important, asking “How can I help?” (Davidson et al., 2009, p. 155). In other words, recovery may involve “medication, education, peer support, psychotherapy or alternative methods of healing and self-help” (2009, p. 49). This conceptualization of mental illness and treatment is in line with the “vulnerability-stress model” or the “diathesis-stress model” of mental illness which combine pre-dispositional vulnerabilities (such as biology or genetics) with life factors and stressors (such as cultural influences, the experience of trauma or abuse) in understanding mental illness and perspectives on treatment (Pihl & Nantel-Vivier, 2005).

As the meaning of mental illness shifts, conceptualization of “care” in case management changes as well. It is integrative and has evolved into a complex role involving

more than coordinating and expediting care to a role that includes more therapeutic functions. Frank and Davidson (2014) quote Amy Johnson, an exceptionally talented and bright woman who has been living with mental illness for decades. Johnson says “they [clinicians] must be super compassionate, trying to imagine all the time what it must be like for me, and, willing to sit down with me and give me lots of their time, as we struggle to understand each other” (2014). This kind of care is also emphasized in a meta-analysis conducted by Ziguras, Geoffrey and Stuart who found that most studies on case managers emphasized the importance for the case manager to establish a therapeutic relationship and providing ongoing care rather than acting merely as an administrative service broker (2000).

Models of care have been suggested in the literature. One such model proposes that case managers assume a “coaching” role (Oades, Crowe & Nguyen, 2009), specifying that a case manager act as a “guide on the side rather than a sage on the stage” (Dr. Marilyn Herie, personal communication, August 2015). Lee’s model of case management (2013) explains that the role of the mental health case manager must adapt according to various phases of a person’s recovery (High Risk Phase, Acute Phase, Stabilization Phase and Stability Phase). In the High Risk Phase, the role of the case manager is to provide supportive counseling, stress management, social skills and improving self-esteem. In the Acute Phase, the role is to provide supportive counseling, coordinate services, mediate disputes, and to provide psycho-education to clients and/or significant others. In the Stabilization Phase, the case manager’s responsibilities include re-integration, addressing co-morbidity, handling grief and loss, providing psycho-education, goal setting, and crisis management. In the Stability Phase, case managers engage in relapse prevention, healthy lifestyle support, crisis management and stress management.

Case management, according to this description is flexible, integrative and adaptive to the stages of recovery. Further responsibilities of the case manager are highlighted in

Davidson and colleagues text (2008). They write that the case manager might be called upon to help one client “find furniture for a new apartment, offer testimony before the legislature, purchase a dress for Sunday services or take a bus to visit an elderly parent” (2008, p.38).

In response to the changing needs of mental health service users and providers, in May 2012, the Mental Health Commission of Canada, released a mental health “strategy” for Canada. This strategy, presented in a 156-page document called “Changing Directions, Changing Lives” focuses on “recovery” as the central aim of mental health reform across Canada (2012). Although Canadian policy supports a recovery orientation, and recommended models of best practice are abundant in the mental health discourse, consumers’ shared narratives reveal a general deficit in care. These narratives illuminate a different kind of care that clients need from their practitioners.

This deficit in care has been the subject of research in Norway. Karlsson, Borg, Revheim and Jonassen, for example, reported that “... service users’ narratives about their experiences with mental health professionals reflect issues of not feeling respected, not being listened to, professionals talking over one’s head and not valuing person-centered approaches” (2013, p. 2). This feedback is shared in Jane Lowry’s account of one particular hospitalization she endured due to a postpartum psychosis following the birth of her second child in Canada. Her account is shared in the aforementioned text written by Nunes and Simmie (2002). She writes, “my five month old baby wasn’t allowed to stay with me...the insensitive nurse...said the baby was old enough to stop breast feeding anyway...” (p.92) This nurse did not consider her wish and right to breastfeed her infant. Kalinowski and Risser write that “negative stereotypes and assumptions are often interwoven with clinical practice, language, procedure and even the physical environment” (2000, p. 32).

Such experiences of discrimination harm recovery. Clayton writes: “it felt deflating to face such a blank wall, and eventually I realized that he (psychiatrist) was not interested in me

as a person. To him, I was just a diagnosis of borderline personality disorder, a set of behaviors” (2013, p. 624). In another text, Unzicker writes about his experience with his psychiatrist. He writes that “all hope has been sucked out of him by a system populated by mental health workers who are so demoralized, dehumanized and stuck on whatever the new hot model is...they’ve forgotten they’re dealing with individuals, not labels” (1989, p. 76). Anonymous wrote in 1989: “some (practitioners) were quite formal and distant, I felt like a “patient” not a person”.

Professor Elyn Saks alludes to this sort of care in her memoir “The Center Cannot Hold.” It is her account of living with schizophrenia. She writes about one of her psychiatrists:

“there was something a bit different about this conversation and, indeed, about the doctor himself- he seemed more alert than I was used to, and genuinely interested in hearing everything that was on my mind. I had a palpable sense of actually being *heard*, but not judged. And so, instead of keeping my darkest thoughts to myself...I told Dr. Storr everything... his eyes didn’t widen in surprise or horror; he didn’t tsk-tsk, he didn’t shake his head in dismay. He simply leaned forward, kept eye contact with me, and listened intently, without flinching, to every word...”

The psychiatrist gave her the feeling that she was heard and had “somehow *seen* me as well” (2007, p. 86).

Some of the feedback from consumers is not as explicit as Professor Saks’ above. Judi Chamberlain coined the term *mentalism* to describe covert discrimination against people who have received psychiatric treatment (Kalinowski & Risser, 2000). Examples of mentalism include referring to clients as “crazy” or “nuts”, judging clients to be “high” or “low” functioning, or treating clients like second class-citizens. Mentalism is deep rooted in our society.

Scholars have indicated that clinicians are not immune from the widespread effects of prejudice against people who have received psychiatric diagnoses (Kalinowski & Risser, 2000; Henderson & Thornicroft, 2009). Sue Goodwin explains a more subtle experience of discrimination when she writes “I saw a psychiatrist once a week who put me on an antidepressant...but he didn’t talk to me...” (Nunes and Simmie, p.104)

CHAPTER 3: Literature Review

HOW IS CARE IS CONCEPTUALIZED IN THE LITERATURE?

This chapter presents my conceptual or theoretical framework for the study. According to Maxwell (2013), a conceptual framework represents “the system of concepts, assumptions, expectations, beliefs and theories” that supports research. As such, it is a basic component of research design. The conceptual framework is the “idea context” for the study (p. 39). This framework is critical because it helps to define goals, raise questions, and select methods. It is different from a general review of the literature in that it does not aim to “cover the field,” but rather it aims to focus “on studies and research that are particularly relevant” to the study (p. 40). The idea context provides a way of thinking about the design and the research findings.

It is important to emphasize, however, that a conceptual framework is “a tentative theory of the phenomenon” under investigation (p. 39). It should not foreclose the possibility of developing new theories, or the possibility of drawing from ideas not originally identified in the conceptual framework. This danger of foreclosure is why Paechter (2003) is ambivalent about establishing a theoretical foundation for a study. As a theorist herself, she emphasizes the value of grounding educational research in theory. She emphasizes, however, that theory building does not end with the conceptual framework. “It is possible,” she notes, “to build theory directly from empirical findings” (p. 111).

In this chapter I examine the mental health related literature that addresses care, either implicitly or explicitly, in order to obtain a general sense of how the construct is understood in the field. This review of the care literature provides a conceptual framework for my research study. It will help me define study goals, develop specific questions and select the methods I will use. As I read, the broad questions I keep in mind are: How does this text talk about

care? What assumptions, expectations and beliefs are inherent to this text? How might this literature inform the way care is addressed in education? By identifying and comparing the different perspectives on care I provide a conceptual map of the idea of care.

3.1 Overview of the chapter

Concerns have been raised about lack of care in modern mental health practice. But what exactly is 'care'? In the literature 'care' is utilized to convey various factors in an array of contexts. In one way, care is a noun referring to the service that is provided by one person (practitioner) to another (client). 'He provides care to the client' means the practitioner provides a therapy service to the client. The construct of care reflects the particular intervention that the practitioner employs, be it psycho-education, assertive community treatment programs or developing ones multicultural competence. These forms of care are called evidence-based because they have been empirically studied and quantifiable in mental health research. Evidence-based practice is the gold standard. When care is said to be lacking, it calls to question the quality of these provisions or services.

Care in mental health literature also reflects an adjective. In this context, care is used to describe a core quality of the relationship between the practitioner and the client ("The therapeutic relationship is a caring one"), or to describe the quality of the person who is providing the service ("she is a caring person"). When care is said to be lacking in mental health care, it calls to question the quality of the therapeutic relationship or the quality in the individual practitioner.

More recently, a particular faction within the recovery movement has alluded to the construct of care as a verb ("he cares *about* his client"). When care is said to be lacking, it calls to the forefront a client's perspective that the practitioner does not care *about* him or her.

This type of caring may transcend traditional professional boundaries in mental health care which indicates that these professional boundaries have to be reexamined.

Care, in these three senses will be presented in more detail in the following review. A major challenge of such a review, for comparative purposes, is that the boundaries of care are not clearly defined. At times, care as a noun, adjective or verb converge or overlap rendering the construct elusive and hard to place. Nevertheless, by focusing on the general scope of each piece of literature, these three sections emerged. Although these constructs of care are interrelated, I will consider them one at a time and present the relevant literature with each. By immersing myself in the literature on care and teasing it apart according to the way its conveyed in the mental health literature, caring *about* emerged as a construct of interest in its own right, distinct from the other forms of care.

3.1.1 Care as a noun

This section reviews the literature that addresses care as a noun. In the most basic sense, mental health “care” is the system that is in place to support someone as they go through recovery. Care may be a deliverable service or an intervention that is provided by the professional to the client. At times, the literature will refer to a clients’ *care plan*, which might be individual therapy, medication support, community involvement or employment (Weed, 2004). When it is said that care is lacking, as was described above, it calls into question the quality of these care services and provisions, which may be inadequate and oppressive. Many efforts have been made to improve the quality of mental health care services including research and practical developments in evidence-based research (Drake, Merrens & Lynde, 2005), and development of multicultural counseling competencies (Sue & Sue, 2003). This will be presented in the following section.

3.1.1.1 Evidence-based research

One way in which the mental health community has responded to the feedback that care is lacking has been to focus efforts on developing and expanding ‘evidence-based’ (EBPs) or ‘evidence-informed’ mental health research. EBPs are well-defined clinical interventions that can be replicated and have demonstrated effectiveness across a wide variety of settings (Drake & Goldman, 2001; Koehn & Lehman, 2008). This is “an approach to classifying health care outcome research according to the quality and quantity of empirical evidence supporting a particular intervention” (Anthony, Rogers & Farkas, 2003, p.103). Premised on the belief that mental health care should be guided by research, evidence-based practice involves teaching students the values and skills they will need to “identify, critically appraise, and apply practice-relevant scientific evidence over the course of their professional careers” (Howard, McMillen & Pollio, 2003, p. 241).

Research efforts have been made to increase the accessibility and usability of EBP’s to practitioners in their everyday practice. Workshops and continuing education programs exist and have as their aim to help mental health professionals integrate the research into their practices (Geddes, Reynolds, Streiner & Szatmari, 1997). For example, the first evidence based journal ‘Evidence Based Mental Health’ (EBMH) was published in 1998 with the aim to provide mental health clinicians with the best information with “value added” abstracts. These abstracts describe practical *how-to* messages for practitioners. As an example, the research studies presented in the EBMH journal follow an easy to read format. Subject headings include: *What is already known on this topic? Methods of the study and what does this paper add? What is next in research? Do these results change our practices and why?* The research and the way in which this research is presented are accessible and useful to clinicians. Straus and colleagues write about the value of evidence based practices

that are taught to medical students: “direct clinical application of EBM and tactics to practice ... teach EBM in real-time” (2005)

The goal of EBP's is to integrate (a) clinical expertise/expert opinion, (b) external scientific evidence, and (c) client/patient/caregiver perspectives in order to provide the highest quality mental health services. These services should reflect the interests, values, needs and choices of the individuals served (Sackett, Rosenberg, Gray, Haynes & Richardson, 1996) Despite the findings indicating that EBP's may be slow to uptake (Lyons, Brown, Tseng, Casey & McDonald, 2011), it is still agreed that evidence-based research is a leading framework with which to orient mental health care.

3.1.1.1.1 Psycho-education

Psycho-education is an example of an evidence-based service provided by practitioners. Psycho-education often happens in a group setting and may involve specific interventions like problem solving sessions (Dowrick, 2000), coping strategies (Honey, Bennett & Morgan, 2003), or affect management groups (Coon, Thompson, Steffen, Sorocco & Gallagher-Thompson, 2003). Lukens and McFarlane note that psycho-education is effective because it “integrates and synergizes” both psychotherapeutic and educational interventions (2003). Psycho-education involves educating the client about the issue at hand, usually in a group setting, rather than simply treating the issue at hand. Psycho-education has been associated with positive client outcomes. In their study on binge eating disorder, Petersen, Mitchell, Engbloom, Nugent, Mussell and Miller (2003) found that psycho-education groups were associated with reduced bingeing behaviours by women diagnosed with the disorder. Miklowitz, George, Richards, Simoneau and Suddath (2003) found that psycho-education groups for people with bipolar disorder and their families was associated with fewer

relapses, reduced symptoms and better medication compliance. In a similar study, Rea and colleagues (2003) confirmed these results. Psycho-education is an example of 'care' as a noun. This program is appreciated because it is quantifiable and produces measurable results.

3.1.1.1.2 Assertive community treatment (ACT)

Assertive community treatment is another example of an evidence-based practice. ACT is a "client-centered, recovery-oriented *service* designed specifically for people aged 18 to 65 with serious mental illness" (http://toronto.cmha.ca/programs_services/assertive-community-treatment-act-teams/#.V0xSfEu9Uds Retrieved January, 20, 2016). ACT has evolved as mental health care has advanced and improved. Initially ACT possessed a clinician driven approach. It was adapted, however, to a patient driven approach as people with mental health troubles re-gained authority over their lives and their mental health care (Stein and Test, 1980). ACT now includes an emphasis on community outreach, smaller caseloads, and team rather than individual case management (Ziguras & Stuart, 2000). Greene, Kondrat, Lee, Clement, Siebert, Mentzer & Pinnell write that ACT "articulates an in-vivo approach to services provision, 24 hours a day, 7 days a week" (2006, p. 342). ACT involves interaction with clients on a day-to-day basis (Cooper, 2012). Today it helps people with social, economic, housing and mental health related issues. Programs of ACT have also been adapted to include programs for reducing homelessness (Salyers and Tsemberis, 2007).

Case management is a service that is provided as part of the ACT practice. In 2000, Ziguras, Geoffrey & Stuart conducted a meta-analysis of the effectiveness of mental health case management over 20 years (1980-1998). Their study revealed that clients who received

case management services experienced positive outcomes greater than those who did not receive it. The clients who received case management services experienced greater improvement in symptoms, fewer days spent in the hospital, more contacts and less dropout with both mental health and other services, greater improvements in level of social functioning, greater client and family satisfaction with care, less family burden of care, and lower total cost of care (p. 1410-1412). In their study, Borg and Kristiansen assert that case managers were effective in facilitating recovery by conveying hope, sharing power and decision making responsibilities with clients as well as being open to alternative treatments (2004).

In the literature on evidence-based practices such as psycho-education, assertive community treatment, and case management, 'care' is looked at as a provision of a service. In the following section, I review multicultural counseling competencies care is used as a noun in referring to improving the quality of care by improving multicultural competencies.

3.1.1.1.3 Multicultural Counselling / Counselling for Diversity

There has been a general shift towards counselling services that better reflect the diversity in Canada. Palmer, for example, argues that counseling and psychotherapy should be like "a mosaic reflecting the unique cultural, linguistic and contextual realities of Canada" (Martin, Turcotte, Matte & Shepard, 2013, p.46). This shift was first seen in 1971 when the multicultural policy in Canada was developed (laws-lois.justice.gc.ca). The Canadian Counselling and Psychotherapy Association, for example, reflect the changing nature of counselling. The official statement of the association asserts that components such as "cognitive, affective, expressive, somatic, spiritual, developmental, behavioral, learning, and systemic principles" should be incorporated into culturally sensitive counseling services

(<http://www.ccpa-accp.ca/profession/> Retrieved November 2015). In this context, there is greater acceptance of indigenous healing practices and a general movement towards making counseling approaches more accessible and culturally aligned with diverse group across Canada (McCabe, 2007).

Despite these optimistic developments in developing culturally competent counselors, it is estimated that 11 million adults (about 5% of the population) experienced mental illness serious enough to interfere with major life activities. Only 60.2% of these individuals received treatment (Kuehn 2009). Theories about why people do not seek help include fear of stigma by the professional (Wahl, 1999), fear of judgment and hopelessness (Link & Phelan, 2001; Schulze, 2007). Sue and Sue write that, “counseling and psychotherapy are rooted in and reflect the dominant values of the larger society. As a result, forms of treatment may represent cultural oppression and may reflect primarily a Eurocentric worldview that may damage and do great harm to culturally diverse clients” (2003, p. XV). Although carrying a diagnosis of a mental illness may not qualify as a cultural group per se, certainly people who have mental illness are considered divergent from the larger, “normal” society. They experience stigma, prejudice, discrimination and oppression just as other marginalized cultural groups do.

Developing culturally competent counsellors has been a priority in the research and in the classroom. Sue and Sue established a guideline outlining the criteria for multicultural competence (2003). These criteria emphasize three main competencies: awareness, skills and knowledge. Awareness refers to the practitioner’s awareness of his or her own assumptions, values and biases that if unnoticed may (likely) interfere with their ability to work in a culturally sensitive and respectful way with diverse clients. The knowledge dimension refers to counsellors’ requirement to understand the worldviews of culturally diverse clients. The skill competency refers to developing appropriate intervention strategies and techniques.

These competencies refer to care as though it were *something* that can be learned and mastered in educational settings and later applied when working with clients in real practice. Care in the form of multi-cultural competence may be deconstructed into individual competencies.

3.1.1.2 Care as a noun; the downside

Looking at care exclusively as a provision is reductionistic and presents important challenges. Tronto warns that thinking about care as a commodity risks slipping into the thinking that care is scarce and that it must be monitored (2010). When care is regarded in this way a practitioner has to decide who gets the care, and who gets “cut” (p.164). This has been referred to as the “zero-sum” model of healthcare (Tronto, 2010). Another challenge with care as a noun is the risk of overemphasizing skills and techniques in mental health care, suggesting that active listening, for example, is mostly about technique. It does not consider care as a way of being in relationship. This risks rendering the care as feeling inauthentic to the person receiving it. Looking at care strictly as a provision strips the humanity from the therapeutic dynamic and is likely connected to consumers’ experiences of lack of care in mental health.

3.1.2 Care as an adjective: Care as a personal quality or a quality of a relationship

Care as a noun is only part of the picture. In the literature care is not merely about *what* the practitioner does, but also *who* the practitioner is. In the next section, I present literature that addresses care as an adjective. Care is described as a critical quality of either the therapeutic relationship itself, or an important character trait of the mental health

practitioner. To say that care is lacking calls into question both the quality of the relationship and the practitioner's personal caring characteristics. The literature explores the therapeutic relationship as a critical component of care.

3.1.2.1 Care as a critical component of the therapeutic relationship

There is a considerable body of research that highlights the importance of the helping relationship in facilitating patient change and therapeutic outcomes (Solomon, Draine & Delaney, 1995; Borg & Kristiansen, 2004; Rogers 1957; Strong, 1968; Bordin, 1979). The therapeutic relationship is also called the “working alliance”, “therapeutic bond”, or “therapeutic alliance”. The therapeutic relationship is vital to the effectiveness of therapy treatment (Horvath, 2001; Flückiger, Del Re, Wampold, Symonds & Horvath, 2012; Martin, Garske & Davis, 2000). Better patient outcomes are associated with positive therapeutic relationships with providers (Howgego, Yellowlees, Meldrum, 2003). This is conveyed by client narratives. As Anthony writes, “recovery literature is full of narratives, voices, experiences of service users and scholars who articulate the importance of professional and other relationships to the recovery process” (Anthony et al, 2003, p. 108).

Norcross and Wampold argue that the therapy relationship makes “substantial and consistent contributions to psychotherapy outcome” regardless of which specific type of treatment was provided (2011). Said another way, two practitioners who have similar training and similar skills may achieve different results with their clients. The therapeutic relationship between the client and the practitioner is the active ingredient. The relationship is the mechanism of change (Norcross & Wampold, 2011).

This notion is reflected in what is known as the ‘Dodo bird conjecture’, which is a term referring to the scenario when different treatments that intended to be therapeutic are

compared and the difference between treatments is zero (Rosensweig, 1936; Luborsky 1995; Norcross & Wampold 2011). The treatment approach that was used was not as important as the quality of the relationship between service provider and receiver. This is reflected in Lester Tritter and Sorohan's study of mental health patients' views on their general health care (2005). Patients expressed preference in consulting their own general practitioner who "listened and was willing to learn" over being referred to a different practitioner *even if* that practitioner had specific mental health expertise (2005, p1122). That patients preferred to work with a known practitioner over an unknown expert speaks to the importance of the actual relationship.

Accounts of client's recovery processes have brought attention to the central role and power of human relationships (Borg & Kristiansen, 2003). In their meta-analysis of the effectiveness of case managers, Ziguras, Geoffrey and Stuart found that the majority of case managers were the most effective when they established a therapeutic relationship with the client, rather than merely acting as an administrative service broker (2000). Clients value and appreciate the relationship itself. In their study, Piat, Sabetti and Bloom found that clients expressed satisfaction at being able to communicate their concerns about medication, for example, to providers, and from having their views taken into account (2010). Clients underlined the importance of a strong therapeutic relationship in their recovery. Strong therapeutic relationships were associated with greater medication adherence on the part of the client (Piat, Sabetti & Bloom, 2009, p. 483). They report that a caring therapeutic relationship provides the context in which clients determine the personal meanings of medication, and decide on medication use (2009).

Some research efforts have attempted to identify what exactly it is about the relationship that is so important. Here the literature points to the interactive nature of the relationship and how it helps clients learn about themselves. Essentially, this research

suggests that through relationships that people get to know themselves. Kondrat and Teater write, that “although there is a degree of consistence to the self, the self develops through interactions with others” (2012, p. 273). Anthony’s adds that “recovery is a deeply human experience, facilitated by the deeply human responses of others...” (1993, p.18). In another article about the therapeutic alliance, Howgego and colleagues points out that the relationship is not in and of itself represented as an intervention, “rather it is a vehicle within which therapeutic gain may be facilitated” (2003, p. 172). Essentially, it is through relationship and interaction with others that a person gets to know him or herself.

A theory of the self called *the looking glass self* (Cooley, 1902) states that the therapeutic relationship is important to someone who is in mental health recovery because through the reactions with others, people develop a sense of themselves. The looking glass self consists of three steps (a) the person considers how he or she looks to the other (b) this leads to the person considering how the other evaluates him or her and (c) the person develops some feeling, either positive or negative, about this judgment. Through interactions in the therapeutic relationship “service users interpret what the professional’s words and actions are telling them about what it means to be living with severe mental illness”, which in turn has an impact on the consumer’s conception of self. The relationship therefore serves as a platform for where this exchange can occur and therefore represents a critical aspect of recovery.

Common factors such as empathy and warmth in the therapeutic relationship have been shown to correlate more highly with client outcome than any particular treatment plan (Lambert & Barley 2001). The importance of the therapeutic relationship lies in the connection between worker and client. Schneider notes that this element of “humanism” is the curative component of therapy. Schneider, Pierson and Bugental write that “... in all psychotherapies there is a real relationship between the therapist and the client... this bond is unique - the

therapist is expected to remain in this relationship, empathic and caring, despite what the client divulges” (2014, p. 446). For these authors it is “the real relationship, which brings to the client belongingness, (that) is in and of itself therapeutic - human connections are essential to well-being” (2014, p. 446).

In trying to identify what it is about the therapeutic relationship that is so important, Adnoy and colleagues quote Stern who refers to “inter-subjective contact” (2014). Essentially, inter-subjective contact is the shared experience of two people; i.e. *I know that you know that I know, or I feel that you feel that I feel*” (2014). The inter-subjective contact is a shared mental terrain in a moment of time (Adnoy, Arman, Davidson, Sundfor, Karlsson, 2014). Conversely, the *lack* of inter-subjective sharing may lead to an experience of rejection and alienation from others. The person may experience the sense that others are not concerned about him or her. The scholars write that “caring is based on recognition; it is an acknowledgement of the fundamental likeness we share as human beings” (2014).

Charles Taylor’s work on the Politics of Recognition (1997) supports and elaborates on this idea. He proposes the link between recognition and one’s identity. He writes, “... our identity is partly shaped by recognition or its absence, often by the *mis*recognition of others, and so a person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them a confining or demeaning or contemptible picture of themselves. Nonrecognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being” (p. 27). In this book Taylor focuses specifically on multiculturalism, however, the message rings true and powerful when considering this notion as it relates to mental health recovery.

Davidson and Johnson refer to a similar construct in their article about the “little things” that make a big difference in someone’s recovery; “These little things such as saying ‘excuse me’ when you reach over someone to reach for a piece of paper, like saying ‘God bless you’

when someone sneezes, things like asking if you'd like some water when you get up to get some for yourself. Its basic, and it may seem trivial to you, but to people like me its water to a dying parched husk of a person" (2012, p. 78). Johnson notes that "interactions like the(se) have more positive impact on the consumer than any elaborate treatment plan ever could" (2014).

These seemingly ordinary experiences serve as building blocks in the recovery process. Rich data like Johnson's account of the "little things" that help her build towards a recovered self serves to inform the literature on what makes the relationship so helpful. Adnoy and colleagues write that "in every new encounter the response from others (including professionals) carries with it the potential to either promote or threaten the person's dignity (2014). The relationship, thus, opens up or limits opportunities to be included and feel valued. Researchers have suggested that there is a social aspect to a healing therapeutic relationship: "It is through social interactions that we rebuild a sense of ourselves as social agents, and it is only to the degree that these interactions are positive or successful that we come to see ourselves as effective social agents" (Davidson, et al., 2009, p. 2).

There is a body of literature suggesting that the relationship itself is important because it is through this relationship that a person feels that their humanity is validated. A person is a person because he or she is one of the people in this relationship. Wampold (2012) asserts that humanism, in itself, is a common factor in psychotherapy. He bases this assertion on Baumeister's (2005) research that indicates that attached individuals are more mentally and physically fit than unattached individuals. He writes that feelings of belongingness and connectedness are essential for survival. Johnson writes about her experience with illness and recovery:

“You want to know why I’m still alive? It’s because of you...I work hard but I need somebody to love me... for a person who has been crushed by vaginal rape and anal rape, a person crushed at the hands of mental health professionals, a person who was crushed by racism, to have an outside person assure me that I am human, that I am always human, it whispers to me when no one is here, it hugs me when life comes along and kicks me in the ass.” (Davidson and Johnson, 2014, p.79)

Quality interactions are far from banal: “how other people react to and interact with a person with schizophrenia can either further exacerbate the illness or provide a foundation for the person’s efforts to rebuild a self and a life” (Johnson, p. 4). The compassionate clinician reflects to the client that he or she is somebody worthy of compassion (Kondrat and Teater, 2012). When we listen deeply, we affirm the value of the other. Why would we listen if the person did not matter? I know I have value when the other recognizes me as worthy of being listened to. In his book *The Lost Art of Listening*, Nichols speaks to this point: “... a sympathetic ear is such a powerful force in human relationship... the failure to be heard is so painful... it is especially hurtful not to be listened to in those relationships you count on for understanding” (1995, p. 1).

Spandler and Stickley comment “a key element of compassion is the recognition that it operates in and through social relationships” (2011, p. 558). Similarly, the *lack* of experienced compassion felt in the relationship can be damaging. Farkas notes: “patients appreciate when practitioners express interest in them as a person in roles other than *patient*... (and) may feel damaged by practitioners who refuse to connect in a more holistic way” (2007, p. 7).

Some of the literature suggests that clinicians need to be self-reflective. Cooley’s concept of the looking glass self, for example, reminds practitioners to be aware of the

reflective nature of human interaction. The “reflective appraisal process helps consumers move toward mental health recovery when practitioners mirror the possibility of recovery” (Kondrat and Teater, 2012, p. 271). Practitioners are taught to draw from a broad bank of skills and therapeutic approaches and to utilize skills like self-awareness.

One of the defining competencies of psychotherapy practice, commonly referred to as *safe and effective use of self*, refers to the therapist’s learned capacity to understand his or her own subjective context and patterns of interaction as they inform his or her participation in the therapeutic relationship with the client (www.crpo.ca). It also speaks to the therapist’s self-reflective use of his or her personality, insights, perceptions, and judgments in order to enhance interactions with clients in the therapeutic process.

3.1.2.2 Care and the *personhood* of the practitioner

This section reviews the literature that focuses on the practitioners themselves, rather than the therapeutic relationship per se. Here the focus is on who the practitioner is rather than what they do. Farkas writes: “recovery research ... has ... broadened the kinds of questions we study... [and has] made explicit questions pertaining to the character of the practitioner himself...” (2007, p.69). The Canadian Association of Social Workers states in their standards of practice and ethics that “registered social workers are caring professionals...” (<http://www.casw-acts.ca/en/51-standards-practice-and-ethics>). Helpers are also presumed to be skilled at forming relationships (Davidson & Chan, 2014). Johnson, a psychiatric survivor, writes of her practitioners: “they must be super compassionate, trying to imagine all the time what it must be like for me, and, willing to sit down with me and give me lots of their time, as we struggle to understand each other” (Frank & Davidson, 2014, p. 32).

There is an assumption and an expectation in her comment that helping professionals are generally caring people.

“Therapist effects” are factors related to the therapist that account for the differences in therapy outcome (Wampold, Mondin, Moody & Stich, 1997). In 1991 Crits-Christoph and colleagues compared therapist effects in a meta-analysis of 15 psychotherapy outcome studies (Crits-Cristoph, Baranackie, Kurcias, 1991). Their review confirmed therapist effects on psychotherapy and in particular found that therapists who used treatment manuals and had more experience had effects on the success of therapy. Another meta-analysis of therapist effects in 2012 by Fluckiger and colleagues, found that therapist contribution to the therapeutic relationship is important for improved patient outcomes and is in fact more important than the patients contribution. In 2010 Whitley, Kostick and Bush explored competencies in individual placement and support counsellors and found that practitioners believed qualities such as initiative, outreach, persistence, hardiness, empathy, passion, team orientation and level of professionalism were all important competencies. This is an important finding considering the 30 years of psychotherapy research that has consistently found that therapeutic relationship is a critical aspect of and predictor of successful treatment (Horvath & Bedi, 2002; Horvath, Del Re, Flückiger, & Symonds, 2011; Horvath & Symonds, 1991; Martin, Garske, & Davis, 2000).

Chinman and colleagues conducted a study that speaks to the notion of therapist effects. They investigated whether therapists’ personal experience with support groups played a role in their referring clients to support groups (2002). The researchers found that being a rehabilitation worker and possessing more advanced training, greater numbers of years in their setting and discipline, and personal experience with psychiatric disorders or mutual support were associated with more favorable attitudes and behaviors toward mutual support.

These findings support that the therapists' personal experience indeed has a direct impact on practice.

Tattan and Tarrier found that mental health staff attitudes and behaviours had an effect on clinical outcomes of patients (2000). They looked at practitioners' levels of expressed emotion (EE) as it related to patient outcome in therapy. Staff that possessed high levels of expressed emotion were critical of socially embarrassing behaviour, disruptive behaviour and negative symptoms. They found prompting patients frustrating and they tended to overlook the patients' viewpoint. It is no surprise that this group was associated with negative therapy outcome as compared to the low EE group who were calmer, more accepting, warmer and more positive about some aspects of the patient.

Farkas refers to the connection between therapist traits and client outcomes when she writes that "professionals who lack hope themselves cannot promote recovery orientation" (2007, p. 72). The personality of the practitioner can have both positive and negative effects. Clayton's writes about one psychiatrist she saw, "he seemed to be just going through the motions. It felt deflating to face such a blank wall, and eventually I realized that he was not interested in me as a person...to him I was just a diagnosis..." (2013, p. 624). The effect of her therapist being a "blank wall" affected her negatively. Parker Palmer makes a related comment about teaching; "teaching emerges from one's inwardness, for better or worse...as I teach, I project the condition of my soul onto my students, my subject, and our way of being together" (2007, p. 2).

The preceding section reviewed *care* as an adjective to describe either the importance of the therapeutic relationship or to describe the nature of the individual practitioner. Throughout this literature, the terms *care* and *compassion* are at times used interchangeably. Despite the plethora of articles that address the importance of the therapeutic relationship in client recovery, as well as the therapist effects on consumers' quality of treatment, little is

known about how exactly to develop such a positive therapeutic relationship. This question may be addressed in the following section which reviews care as a verb.

3.1.3 Care as a verb: Caring *about* our clients

The tone of care is different within one body of the recovery literature. This group of literature sees care as a verb, as in, the practitioner not only cares *for* her client, but cares *about* her client. When it is said that care is lacking in this sense, essentially it implies that clients do not feel that their practitioners care *about* them. This subtle distinction, though seemingly small, is in fact significant. In mental health practice, when a clinician cares *about* his client it tends to signal alarm. The practitioner may be cautioned against blurring the professional boundary and might be advised to resolve personal issues that may be clouding his professional judgment. The practitioner may also be cautioned to avoid “countertransference” which is an emotional reaction to the client. Caring *about* one’s client might imply that the professional is experiencing countertransference and through the therapeutic relationship is inadvertently – and unprofessionally - sorting through personal unresolved issues.

The notion of caring *about* invokes discussions that pertain to professional boundaries because caring *about* implicates a greater emotional involvement than providing care *to* a client (such as an intervention or a program as described in section 3.1.1, which described care as a noun). Case managers face many challenges and uncertainties in the course of their daily clinical activities that challenge the existing guidelines of care (2009). As the recovery movement gains power and speed, the role of the practitioner changes too, instigating a change to the therapeutic relationship and therefore a change to boundaries that frame this relationship (Davidson, 2009). Suppose, for example, a client asks a practitioner to

help her choose furniture for her new apartment. Is it considered professional for the worker to assist the client in this task? Or does it blur the line between 'professional' and 'friend'? What if the client does not have other friends to go with her? What if the furniture store is only open on the weekend necessitating a meeting outside of "work hours"? What if furniture shopping takes more than the standard one hour session time limit?

In regards to the changing demands on practitioners, Slade and Hayword comment about case management: "goals are user-defined and therefore ... sometimes ethically challenging for staff to work with. Case management is not an exact science and when practitioners find themselves in the muddy zones of practice that challenge professional boundaries, they must be able to detect, understand and respond effectively and ethically to their clients" (2007, p. 81). Each new situation can present a range of ambiguous and complex boundary dilemmas that challenge the workers emotional investment (Davidson, 2009). Curtis and Hodge (1993) have suggested that practitioners who do *not* face such issues in their daily work are probably not doing their jobs (Davidson, 2009, p. 194).

Although it is accepted that practitioners will have a certain level emotional investment in their clients' well-being, the literature suggests that the quality and quantity of this emotional investment is vague. This is reflected in Balint's following comment about medicine; "the most frequently used drug in general practice is the doctor. Yet, no pharmacology of this important drug exists. There is no guidance as to the dosage to which the doctor should prescribe himself..." (Malterud & Hollnagel, 2005, p. 351).

In 1989, an anonymous mental health service user wrote of the ambiguous role of the mental health practitioner in his or her treatment. Anonymous notes that doctors act as therapists, mentors, friends and allies as well as a person's link to society (1989). In their study of persons experiencing psychosis, Tidefors and Olin found that clients needed practitioners to act as parental figures "by providing care, safety, and help in dealing with the

outside world” (2011, p.1). To bend the traditional role of the therapist as described in the examples above implicates that the practitioner cares *about* the client. One would not break the rules, go out of their way or help a client in their personal time or care for clients as though they were their own children if they did not care about them in ways that transcended the traditional therapeutic boundary.

Marit Borg and Kristjana Kristiansen asked mental health clients in Norway about helpful relationships with their mental health workers (2004). Their findings reinforce the idea that the practitioner’s roles in recovery varies and may include behaviors that “may be seen as on the edge of what is typically considered as “professional conduct” (p. 499). In fact, practitioners who went out of their way, on their own time, or who “broke the rules” were experienced as being particularly helpful (p. 499). One client reported: “What’s good about them is the fact that they don’t just want to talk about problems, but ordinary stuff too...They kid around with me...so we talk normally...” (p.497). The benefits of “breaking the rules” can be found in mental health recovery literature. For example, lending a client some money to help him get through the weekend, going church dress shopping with a client, or accepting a gift from a client may be significant gestures to establish trust in the relationship (Borg & Kristiansen, p. 499). In some cultures, the act of refusing a gift would be highly offensive, hurtful and potentially destructive to the development of a trusting relationship between two people. A gift has important cultural value. Moreover, to accept a gift says something about the reciprocity of the relationship. It recognizes the act of generosity (Godbout, Caillé & Winkler, 1998).

In her memoir of her experience in a psychiatric hospital, Clayton writes about one particular nurse who would sit with her in her doorway to play chess during movie time because “I was sick of watching Happy Gilmore for the twenty fifth time” (2013, p. 625). What is considered helpful may break the traditional rules of the therapeutic relationship. Closeness

and familiarity between practitioners and clients as described here is frowned upon in psychotherapy literature, research and training.

Buidling on this idea, Karlsson, Borg, Revheim and Jonassen conducted an interesting study in 2013 in which the study challenged traditional boundaries between client and practitioner. This study brought professionals and patients together to take part in a study course. They were then asked to explore subjective experiences of attending this study course together (2013). In this setup the traditional boundaries of the therapeutic relationship are challenged by positioning the clients and practitioners non-hierarchically. The authors write: “awareness of power issues in treatment is essential and there is a need to change traditional authoritarian attitudes among mental health professionals” (p. 3). The experience of doing this course together was expressed by participants to be very positive and possessed great potential for “strengthening both the therapeutic relationship and collaborative partnerships between patients and therapists” (p. 10).

From the program of recovery and community health at Yale University, Larry Davidson, a professor, and Amy Johnson, a psychiatric survivor, have coauthored several articles that are particularly relevant to the topic of caring *about*. Johnson writes: “to have schizophrenia is not to be loved. I feel you love me, Larry...to you, I am always a human being worthy of love and inclusion and support” (Davidson & Johnson, 2014, p. 2). To speak of mental health practice as a “labor of love” is reflected throughout several of their texts (2011, 2012). Davidson suggests that “therapeutic work with persons with the most severe psychotic disorders requires and engaged, compassionate, and deeply respectful stance to their nascent personhood; a stance that we have taken the risk to describe as one of “love” (2011, p. 6). It is their contention that “recovery oriented practice...requires a rethinking of the traditional therapeutic stance of abstinence in favor of a more engaged and compassionate stance which falls under the broad rubric of ‘love’ ... recognizing personhood in another is

considered a fundamentally *loving* act” (Davidson, 2011, p.106). In a personal communication with Professor Davidson, he noted that he felt comfortable taking the position that mental health practice is a “labour of love” only once he became tenured. This is very revealing of the way in which the mental health field views this type of care.

In 1989, Unzicker wrote about his recovery in an article called “On my own, a personal journey through madness and re-emergence.” He wrote of his practitioner: “I expected and wanted a kindly and loving person who would be concerned with my needs, wishes and fantasies” (1989, p.72). Anonymous, also in 1989, distinguishes between care as a provision and care as a verb. “Therapists need to understand that patients need the human touch or compassion just as much as they need the technical expertise of the profession” (1989). Adnoy and Davidson add that “being open about who you are is possible when the other person has your best interest at heart because he or she really cares about you (2014, p.111).

This plea to go beyond technical expertise is highlighted Moller’s study on the experience of dying in hospitals. Moller writes: “The emotional neutrality and objective-technical emphasis of the medical caretakers facilitate the isolation of emotional and social needs of dying patients...one of the major consequences of the technological management of the process of dying is to remand and banish the human meanings of the dying to the private, isolated milieu of patients and their loved ones” (2000, p. 2-3). Although Moller’s note is not specifically in reference to mental health care per se, it reinforces the idea presented in this chapter that technical expertise is not sufficient when health care involves the serious illness of vulnerable persons.

3.1.3.1 How much care is *too much* care?

Some literature sees care as something that workers perceive they have to manage or limit. Crawford found that “time pressures, care processes and organizational tensions ... compromise best practice and point to the emergence of a production line mentality” (2013, p. 719). This is reflected in the following comments from practitioners: ‘You mean I not only have to care for and treat people, but now I have to do recovery too?’ or ‘Sure we’ll be happy to do recovery, just give us the money it will take to start a (new) recovery program’” (Davidson, O’Connell, Tondora, Styron and Kangas 2006, p. 642). The responsibility to manage how much one cares about clients represents quite a challenge for some practitioners. Here care is seen as impersonal as the practitioner seeks to maintain a professional distance. Practitioners may also keep professional distance through language. Crawford and colleagues found that practitioners’ language indicated a “depletion” of compassionate mentalities (2006, p. 721). Managing care, here, carries a tone similar to the way one manages money. This tone reflects the idea that care is a commodity.

In a seminal article written in 1977, the psychiatrist Thomas Main wrote about the “plight of the therapist” and the effort needed during and after treatment sessions to “extricate oneself from alien mad feelings, confusions, despairs, rages, guilts...” (p. 460). Although Main’s language is not politically correct by today’s standards, his underlying message articulates an ongoing concern about the purpose of professional distance and boundaries. These boundaries are not only intended to protect the client’s from potential harm. The aim is to protect the practitioner as well from becoming consumed or overinvolved in a client’s care.

Professional boundaries are the limits established by representative bodies that guide professional behavior. The Canadian Psychological Association, for example, states very clearly in the practice guide that a practitioner must maintain professional boundaries. In fact,

it states that violation of professional boundaries represents one of the most frequent complaints of professional misconduct. Professional boundaries serve two purposes: (1) to protect the client from abuse of power, oppression, sexual abuse, being burdened by the worker and (2) to protect the practitioner by providing limits and guidelines to the practitioners. These boundaries set expectations about the job responsibilities and serve to make it acceptable that practitioners maintain some emotional distance. There's an implicit assumption inherent in these boundaries that emotion compromises judgment.

Professionals' experiences with professional boundaries represent a subject of interest in some of the literature. Larue and her colleagues' study of psychiatric nurses, for example, found that nurses were particularly afraid of abusing their power (2010). Nehls asked case managers about their experience working with people diagnosed with borderline personality disorder and found that workers felt an "ongoing need to monitor the boundaries of the relationship" (2010, p. 15). Nehls' study also reflected the practitioners' "fear of being soaked up" (2010, p. 15). One worker explained that she felt she needed to "dispel the illusion of friendship" (2000, p.15).

3.2 Summary of the Chapter

In this chapter I reviewed the mental health literature that addresses care in professional practice. The perspectives on care generally fall into three main categories (1) care as a noun, (2) care as an adjective, and (3) care as a verb. By teasing apart the construct "care" in this way, the third category, care as a verb emerged as a construct of interest in its own right. It appears that *care* as a verb poses a challenge to traditional professional boundaries, yet it is precisely this type of care that mental health clients have deemed important.

I have created a table below that summarizes the key concepts, assumptions, beliefs and expectations of care as they are presented in this chapter. In looking at this table, it becomes evident that a key area for future development, and the justification for this study, lies in the expectation that practitioners possess the ability to navigate the boundary between 'breaking the rules' and "professionalism".

3.2.1 Figure 1: Concept Map

| | Concept | Beliefs | Expectations/Assumptions |
|--|---|---|---|
| <p>Care as a noun</p> <p>“The practitioner provides care <i>to</i> the client”</p> | <p>Care is a provision or a service</p> <p>Care is delivered through techniques or therapeutic skills</p> <p>Examples: evidence-based-practices like assertive community treatment programs, multicultural counselling competency</p> | <p>Delivering these skills and techniques will result in client wellness & recovery</p> | <p>Case manager learns these skills and develops these competencies in education and training.</p> |
| <p>Care as an adjective</p> <p>“The helping relationship is a caring one”</p> <p>“The practitioner is a caring person”</p> | <p>Care is a necessary quality of the helping relationship</p> <p>Associated with personal qualities like warmth, empathy, genuineness, kindness, compassion</p> | <p>The helping relationship and helping professional should be unconditionally caring, warm & supportive</p> <p>Caring relationship and a caring professional will result in client wellness & recovery</p> | <p>Case manager possesses caring qualities</p> <p>Case manager knows how to cultivate caring relationship</p> |
| <p>Care as a verb</p> <p>“The practitioner cares <i>about</i> his client”</p> | <p>Caring <i>about</i> someone involves an emotional investment on the part of the carer</p> <p>Clients have reported that they appreciate when their case manager goes “above and beyond” the regular call of duty</p> | <p>A case manager who “breaks the rules” makes clients feel that he or she is someone worth breaking the rules for.</p> <p>This makes person feel cared about, which results in clients wellness and recovery</p> | <p>The case manager possesses the ability & skill to properly navigate the boundary between ‘breaking the rules’ & upholding them</p> |

CHAPTER 4: Methodological Framework

4.1 Chapter overview

This section will provide an overview of the methodology grounding the program of research for the thesis. The research is qualitative in nature. It draws primarily from phenomenology. The chapter also discusses the concept of triangulation as an attempt to obtain multiple perspectives on the phenomenon in question. Obtaining numerous perspectives provides a more complete understanding of the phenomenon in question. It also provides the opportunity to listen to the voices of a group of people who have traditionally been disempowered in the mental health discourse. As Bogdan and Biklen (1998) argue, giving voice is empowering to a group of people who have otherwise been silenced. I then provide several examples of other studies in the mental health domain as well as the education domain that draw on multiple perspectives and place value on voice. The methods employed throughout this study are then described in detail.

4.2 Methodology: Qualitative research and phenomenology

Qualitative research is understood in this thesis as a method of inquiry employed to gain a better understanding of a phenomenon, an experience, or a process from the perspective of the subject. Central to good qualitative research is whether the research participants' subjective meanings, actions and social contexts, as understood by them, are illuminated. Sarah Peters says of mental health research, "...qualitative methods, which are...

multifactorial in their etiology and their consequences... are better suited to the task of identifying subtleties of perception that can provide new insight into the nuances of illness” (2010, p. 35). The open-ended and loosely structured interviews invite the description of subjective experiences.

The qualitative research of this study is anchored theoretically in phenomenology. Phenomenology does not seek to determine the events that took place, but rather how participants experienced these events. The purpose of phenomenological research is to generate rather than test theory. Phenomenology asks: What are the meaning, structure, and essence of the lived experience of this phenomenon for this person or group? (Patton, 2002, p. 104). Bryman writes that “any attempt to understand social reality must be grounded in people’s experience of that social reality” (Cahill, 1996, p. 791). For Giorgi, the aim of the researcher is to describe the phenomenon as accurately as possible (1985). Edmund Husserl wrote in the early 1900’s that “...knowledge can be ascertained from how things appear to us in experience, given that our only access to objects, and to the world at large, is through experience itself. Restricting our attention therefore to the realm of experience, we develop our science based on what can be learned about the structures and components of experience itself” (Davidson, 2003, p. 4).

Davidson suggests that a phenomenological approach to analyzing the experiences of participants provides a theoretical foundation that is grounded in meaning as opposed to causality (Davidson, 2003). The focus of inquiry is not merely on *what* happened (e.g., “she cared about me, and I recovered”), but also on *how* what happened is understood (e.g., she cared about me, and it made me feel loved, which helped in my recovery”).

The study sought to illicit stories about the experience of caring. I asked case managers about times when they cared about a client. I asked clients about times when they felt their case manager cared about them. I wanted to know what it was like to care about a

client from the perspective of the subject who is posing a gesture of care. Were there facilitators or hindrances related to that care? What is it like for clients to feel cared about by their practitioner? What is its relative importance in a client's recovery?

Butler-Kisber (2010) contends that voice is valued in qualitative research. Voice can be defined as the right to make oneself heard, to have ones' perspectives and experiences made clear to others, and to be permitted to cooperate in the process of representing oneself (Ashby, 2011). Giving voice to the participants in this research study was particularly important because mental health clients as well as their case managers represent groups of people who have traditionally been silenced in predominantly quantitatively-oriented research. In quantitative research, some scholars argue that the presence of voice is absent because the measurement of operationalized constructs is more highly valued and seen as more likely to uncover universal laws and truths (Goles & Hirschheim, 2000). The subjective perspectives of clients and case managers presented in this study provide personal and situational accounts in context representing an invaluable perspective on the phenomenon in question.

A phenomenological approach rejects the objectivist epistemology of positivistic approaches which claim that knowledge exists in itself independent of the knowing subject. As Johnson (1993) writes, an objectivist theory of knowledge assumes it is possible to achieve an absolute or pure form of knowing. To promote a "humanly realistic" sense of objectivity, and to focus on the subject while avoiding subjectivism, requires an inquiry characterized by openness, critical self-reflection, dialogue and "trans-perspectivity." "Human objectivity is what characterizes a reflective process by means of which we are able to take up multiple perspectives as a way of both criticizing and transforming our views and those of others" (p. 241).

Triangulation allows the researcher to pursue this more realistically human sense of objectivity. It is a term used to describe the act of using multiple methods or perspectives to measure a single construct (Shih, 1997, p.632). In this research study, obtaining the perceptions of both clients and practitioners offered a triangulated approach to understanding the phenomenon in question. Triangulation, in this way, can “capture a more complete, holistic and contextual portrayal of the unit under study (Jick, 1979, p.138). Jick (1979), Fielding & Fielding (1986), and Murphy (1989) have linked the term triangulation to the goal of completeness. They suggest that staff and clients perspectives add valuable pieces to the puzzle (Shih p. 633).

4.3 Obtaining multiple perspectives in mental health research

The value of multiple perspectives has been addressed in the counseling related research. The “Rashomon” phenomenon, by Mintz, Auerbach, Luborsky & Johnson in 1973, refers to three distinct and equally valuable viewpoints on therapy: that of the client, the therapist, and a detached observer. The researchers suggest that all three perspectives must be included in order to gain an adequate picture of the therapeutic process.

Obtaining perspectives of both clients and practitioners has provided insights into discrepancies between professional and patient expectations. For example, Lester and Tritter’s study explored the experiences of providing and receiving care from the perspectives of physicians and patients with serious mental illness. When asked if they would rather consult a practitioner with an expertise in mental health, patients opted for their own physician whom they had a “continuous doctor-patient relationship” with and a “positive attitude and willingness to learn” (2005, p. 1123). Patient perspectives contrasted with practitioners’ presumption that the patient would have preferred to be referred to the expert. The

physicians' comments also suggested their perceived incompetence to deal with mental health issues, a stark contrast to client perceptions. Obtaining patient and doctor perspectives helped to highlight this important discrepancy. This finding may also suggest that we need to re-conceptualize how 'expertise' is defined across academic and training programs.

Llewelyn writes that obtaining the perspectives of the therapist as well as the client may "give an indication of the 'ingredients' which are likely to be most therapeutic" (1988, p. 223). Obtaining two perspectives can also illuminate differences in how clients and practitioners conceptualize such ingredients. For example, in her examination of patients' and therapists' views on the therapeutic alliance, Bachelor found discrepancies and differences in perceptions (2013). Therapists attached greater importance to the client "contributing to the therapeutic endeavor than clients did" (p. 128). The author suggests that this may be a reflection of how clinicians are trained. Her study also found that clients and therapists differed in how they conceptualized the therapeutic bond. Clients valued consideration, liking, empathy, and trust whereas therapists valued "commitment and confidence in the provision of help to their clients" as a critical component to the therapeutic bond (2013, p.128).

Pekarik and Finney-Owen (1987), and later Hunsley and colleagues (1999) found that therapists underestimated the role of dissatisfaction with therapy and the therapist himself in clients' decisions to end treatment. Hunsley and colleagues sought the perspectives of both clients and practitioners. Whereas patients reported that they stopped seeking therapy due to "dissatisfaction with therapy and/or the therapist", this was rarely reported by therapists as a reason for termination (1999, p. 381).

4.4 Obtaining multiple perspectives in education research

Obtaining two perspectives in education research has also been used widely and is especially fruitful. Getting teachers and students' perspectives provides a more complete understanding of a phenomenon in question. Obtaining multiple perspectives also allows teachers to adapt teaching styles according to students' described needs. Ternel, for example, interviewed students and teachers and found a significant "mismatch" between student learning styles and teachers' teaching methods (2000). Brinkworth and colleagues found a similar mismatch in university professor and students. For example, students experienced teacher feedback as an important source of support and comfort, contrasted with teachers' self-reported practice of providing feedback (2009). Students also placed more importance on teacher availability than did the teachers. Obtaining multiple perspectives on the issue illuminated the possibility that this discrepancy in teachers and students expectations was related to school retention rates and informed a recommendation plan to develop a program designed to facilitate the transitional period between high school and university (2009).

In another study in 2005, Konings, Brand-Gruwel & Merrienboer used the Combination of Perspectives model (COOP) to compare and contrast perspectives of educational designers, teachers and students in creating "powerful learning environments". They note that the goal of the COOP model is to make "any possible discrepancy between the participants visible and, eventually, to promote fine-tuning between them" (2005, p. 657).

Obtaining dual perspectives on the construct of care is valuable for two main reasons. The first is that, simply put, we can assess whether the therapist is providing the kind of service that the client needs. Second, there is still little known about the construct of caring *about*. Phenomenological design is appropriate when the researcher's goal is to explore a

phenomenon about which little has been written, and obtaining two perspectives will provide even richer data in this area. There is an added value in getting clients perspectives. Norcross and Wampold write, “the clients observational perspective on the therapy relationship best predicts outcome rather than the therapists observational perspective, while valuable, does not predict outcome as well” (2011, p. 101).

4.5 Methods: steps and procedures

4.5.1 Interview guide development

In this section I describe the precise steps and procedures I followed in the research. My first step was to consult with Larry Davidson, professor and the director of the program for recovery and community health (PRCH) at Yale University in New Haven, Connecticut to create interview questions. Davidson is a bold and influential scholar in the area of mental health recovery and phenomenology in mental health. Most importantly for this study in particular, Davidson is a believer that caring *about* is a critical aspect of proper mental health care. The year prior to this meeting, I had completed a four-month research practicum at PRCH under Davidson’s supervision and he became a mentor to me throughout this project.

After establishing that my goal was to elicit and capture descriptions of care, Davidson and I role-played, asking each other different questions and ultimately settling on the ones that elicited the richest information during pilot interviews. These questions are open-ended so that I could capture the participants’ point of view without imposing my own predetermined categories (Patton, 2002, p. 21). Unlike quantitative research, which is “succinct, parsimonious and easily aggregated for analysis” (Patton, 2002, p. 20), qualitative findings are richer, more detailed and variable in content; analysis and making meaning of this data can be a challenge.

4.5.2 Obtaining ethical approval

Before starting the research, all academic and ethical approvals from Research Ethics Board at McGill University were obtained (appendix A.1). An information sheet and consent form (appendix A.2 and A.3) was provided to all participants at the time of the study outlining the general theme of the study, protection of confidentiality, and the right to withdraw all information provided at interviews within a designated period of time post interview. The participant was also provided with \$10 as reimbursement for their time. Each interview was audio-recorded on a password-protected i-pad. The commitment to confidentiality was upheld to the strictest degree. An important part of my ethics proposal was to be allowed to have three research assistants who would help me in the analysis phase of this study.

4.5.3 Sampling

Sampling in qualitative research is purposive, deliberately recruiting individuals with the requisite characteristics, and homogeneous, allowing for an in-depth understanding of the group under study (Whitley, 2011). I recruited people from Agence Ometz, a Jewish social services organization in Montreal, Quebec. As I had previously worked as a case manager in the mental health division of the agency, I had access to the population I was hoping to study. Unlike public sector organizations such as le centre de santé et de service sociaux (CSSS) or the hospital networks where case managers may have as many as 100 clients, this organization is privately funded and case managers have smaller caseloads of approximately 35 clients per case manager. Interestingly, “compassion” is specified as a core competency in the organization’s professional mandate. Ometz is a progressive organization that is always

striving to improve their services. This is further reflected in the organization's agreement to allow me to do this research with their full support.

4.5.3.1 Recruitment

Participants were recruited via advertisement (appendix A.4) in the organizations' monthly newsletter. Client participants were invited to send me an e-mail or to call me. In some cases, the clients' respective case manager contacted me and relayed the message that a client had received the advertisement in the mail and had wanted me to contact them, which I did. I also gave case managers extra copies of the advertisements to keep on their desks for clients to take.

The process of recruiting case managers was smooth as I had pre-established relationships with each one of the five whom I interviewed from having worked at this organization myself two years prior. When I left the organization to pursue my studies on a full time basis, my coworkers (and future study participants) had conveyed interest and enthusiasm in my research and were eager to participate. There are benefits to being considered an "insider," as noted in Goodwin's, Pope, Mort & Smith's (2003). As an insider the researcher has an understanding of the environment, the expectations and realities of the work. This facilitates communication and creates the sense that both researcher and participants are engaged in a shared exploration of the terrain of case management. In my first interview I noticed that one disadvantage to being an insider was my tendency to say, "I know what you mean" as the person was describing an experience. This was precisely what Patton warned about when cautioning about the researcher imposing his or her own predetermined categories into an interview (2003, p. 21). I had to consciously force myself to

be curious about the participants' experiences rather than presuming that I understood the experiences.

4.5.3.2 Case manager interviews and interview guide

In total, I interviewed five case managers (n=5). These case managers had academic backgrounds in either Special Care Counselling (Diploma) or Social Work (Masters Degree) and sought professional development opportunities regularly (seminars or conferences on mental health related topics). They are all full-time employees and had a minimum of 10 years of experience in the helping profession. I asked case managers to complete a short socio-demographic form, which can be found in the appendix of his thesis. Interviews took place in the case manager's office at the organization. These interviews lasted approximately 60 minutes. Interviews were semi-structured and open-ended, allowing for me to flow with the conversation and follow the participants' direction. I also asked case managers for some background information, such as how many years they had been working at the agency, and what kinds of education and training they had completed (appendix A.5).

The question guideline for the case manager interviews was:

- Have you ever had a client who you've cared about?
- What was that experience like?
- Do you think the client could tell that you cared?
- Has there ever been a time when you cared less about a client?

- What was that experience like?
- Do you think the client could tell that you cared less?

4.5.3.3 Client interviews and interview guide

In total, 19 clients were interviewed (n=19). I conducted 17 of these interviews, and two interviews were conducted by a research assistant. The interviews were held at various locations of the participants' choosing: participant's home, local coffee shops, parks, or in several cases in the lobby of the community organization itself. These interviews lasted anywhere from 10 minutes to 90 minutes. Some interviews were particularly rich and for those interviews I took the liberty to stay longer and delve deeper into participants' experience. Interviews were semi-structured, and open-ended, permitting me to follow the participants' direction.

The question guideline for the client interviews was:

- Have you ever felt that your case manager cared about you?
- How could you tell?
- What was that like?
- Have you ever had a case manager who you felt didn't care?
- How could you tell?
- What was that like?

Taking an iterative approach to data collection allowed me to supplement my interview question guide with an additional question: "If you had the opportunity to teach case managers, what would you want them to know?" Interviews yield direct quotations from

people about their experiences opinions, feelings, and knowledge (Patton, 2002, p. 4). They focus on experiences with the phenomenon in question, whether they acknowledged it, how they discussed it and the relative importance they attached to it.

I transcribed the interviews verbatim. All identifying information was omitted from these texts. It is important to emphasize that interviewing people who are currently seeing case managers, and who are experiencing the phenomenon being studied, provides a unique opportunity for greater insight into the phenomenon. As Davidson (2003) writes, it “affords us an opportunity to incorporate a degree of rigor often recommended, but rarely pursued, in psychological research” (p. 30). Moreover, interviewing people who are currently experiencing the phenomenon in question provides validity to the results. As Whitley writes: “Given that such a model and theory is grounded in the experience of “experts” (study participants) rather than theoretical musings, emergent models are considered to have strong face and internal validity” (2010, p. 517).

4.5.4 Systematic Text Condensation

Systematic Text Condensation (STC) is a method of analysis in qualitative research that was developed by Giorgi’s psychological phenomenological analysis (1985) and then later modified by Kristi Malterud in 2012. STC helps make meaning from large amounts of data (such as the hundreds of pages of transcripts of the interviews) by offering a strategy to condense text by grouping related themes into a “narrative” written entirely in the participants words, that can be more easily and quickly reviewed, while maintaining the integrity and main message of the person’s shared experience. Analyzing the interview data through STC enabled me to take advantage of its strength to retain the meaning of participants’ responses rather reporting my interpretation of them.

STC offers the novice researcher “a process of inter-subjectivity, reflexivity, and feasibility, while maintaining a responsible level of methodological rigor” (Malterud, 2012, p. 804). STC is frequently used in health care research (2012) to synthesize lengthy material. As medical care moves toward more person-centered care, STC has been used more frequently to synthesize patient perspectives to inform medical research and education. In Bjorkman & Malterud’s study, for example, narratives that were collected and analyzed using STC revealed the necessary interconnectedness of the practitioners’ awareness, attitude and knowledge, a nuance that STC could reveal (2009).

4.5.4.1 Steps of STC

(1) Gain a holistic understanding of the text. The transcripts were first examined as a whole in order to obtain an overall understanding and a general sense of the complete statement.

(2) Identify meaning units. I looked for preliminary themes and marked these themes in the margins of the transcripts. Examples of such themes that came up with clients are “case manager as a friend” and “case manager goes out of her way”. Examples of themes that came up in case manager interviews are “what does professional mean?” and “perspectives on boundaries”. Because I transcribed the interviews, I had the opportunity to become immersed in the data and generate emergent preliminary insights associated with each participant’s experiences related to care. Moustakas described the use of the researcher’s self as an experiencing interpreter” (1994, p. 85) which is relevant in the context of this study. Because I conducted the interviews myself, the analysis began as soon as I began the very first interview.

(3) Consider abstract insights that are contained in meaning units. For example, in the case of the theme “case manager goes out of her way”, the meaning attached to this action was that of appreciation. Going out of her way conveyed to the client that the case manager cared about her. In the case of the case manager theme, the meaning attached to the theme “perspectives on boundaries” in some cases was that these boundaries hindered or facilitated how the case manager cared about the client.

(4) Use the meaning units as a guide and make a statement or a “narrative”. This narrative is a one to one-and-a-half page story, entirely in the participant’s words, which captured the essence of the person’s shared experience. This narrative is organized according to the meaning units and codes.

4.5.4.2 Respondent validation

In this study, I obtained participant feedback by revisiting each study participant and asking them to read the one-page “narrative” in order to ensure that the condensed document accurately reflected their story and experience. Participant feedback enhances the credibility of qualitative research by offering another check on researcher biases. It also allows the participant to be a collaborator in the research process. A second return visit allowed for follow up questions, reflections and in some cases clarifications to what the participant meant by a certain comment in the document. Penrod and Hupcey suggest that the number of sample “units” provides a clearer idea of what was involved in the data collection than does the number of participants (2005). For example, one person (sample size of one) may be interviewed three times and observed twice, giving a sample unit of five. For my research I

had one interview, a follow-up interview (feedback check) and at times several telephone conversations in between either scheduling a time to meet or answering other questions people had about the research. Each sample unit was considered to be a rich source of data. Participant feedback was integrated into the final version of the document that was examined by the analysis team.

Sandelowski's uses the following principle for determining sample size: "An adequate sample size... is one that permits - by virtue of not being too large - the deep, case-oriented analysis that is a hallmark of all qualitative inquiry, and that results in - by virtue of not being too small - a new and richly textured understanding of experience (Sandelowski, 1995, p. 183). Sandelowski argues that numbers have a place in ensuring that a sample is fully adequate to support particular qualitative enterprises but that determining an adequate sample size is ultimately a matter of judgment and experience (1995). Scholars have proposed various sample sizes for qualitative work. For example, Kuzel suggests five to eight sampling units will generally suffice for a rich understanding of a well-defined subject area (1999). Morse has recommended that phenomenology-directed research should include about six participants (1991). I reached theoretical saturation with both groups of participants: case managers and clients.

4.5.4.3 Analysis

The analysis of the narratives was partly conducted by a research group and partly by me. Hycner cautions that 'analysis' has dangerous connotations for phenomenology because the term "usually means a 'breaking into parts' and therefore often means a loss of the whole phenomenon..." (Lester, 1999, p. 161). Therefore, I referred to the group as a discussion group whose purpose was to examine, rather than interpret or add a value judgment, to

clients experiences. Data was substantial and required that the group meet on two different occasions. The principal investigator began this discussion with the question, what is this person's story about?" This group did two main things: identified common meanings and possible themes that emerged and referred to select text to support the themes. Emergent themes in the narratives were discussed among individual coders and discussed in relation and comparison to other themes raised in the narratives. I recorded discussed themes and comments in a notepad throughout the discussion and also audio-recorded these discussions so that I could return to this discussion when writing the Results chapter.

Diversity within the group was a deliberate methodological decision. All students came from various disciplinarian backgrounds (education, business, and human resources) as well as cultural backgrounds (Iranian-Canadian, Korean-Canadian and European-Canadian). Interestingly, all research team members had been touched by mental illness either through personal experience or the experience of a family member or friend. Given how close I was to the research and the organization from where I recruited participants, I wanted "outsiders" to help question and challenge my assumptions. Consistent with the constructivist lens of multiple perspectives and multiple social realities, it was neither the intention nor the expectation that multiple researchers from five varied disciplinary perspectives would arrive at a "true meaning" for the data set. Rather, the idea was that various perspectives would foster dialog, to lead to the development of complementary as well as divergent understandings of "care" and to provide a context in which the principal researchers' (me) often hidden beliefs, values, perspectives, and assumptions could be revealed and contested (qualres.org).

4.6 Limitations

Qualitative methods have been criticized for being subjective, anecdotal, and highly prone to investigator bias (Whitley and Crawford, 2005). Here, bias is particularly problematic for the way it can distort findings (Patton, 2002). Critics argue that researchers in non-hypothesis driven research may be tempted to selectively interpret data to fit into conscious or unconscious preconceptions (Whitley & Crawford, 2005). These criticisms and concerns are particularly relevant for research conducted in a qualitative paradigm. As discussed above, qualitative research rejects the assumption that researchers know “the truth” in itself, independent from the subjectivity of the knower (researcher). In his seminal and highly influential work “Truth and Method,” Gadamer (1976) observes that we enter the world already pre-interpreted in language, and that the place outside of language does not exist. The challenge here, as Zullo and Whitehead argue, “is not cool objectivity, but a clarity and honesty about where we begin” (cited in Morris, 1994, p. 28). As Malterud puts it, “preconceptions” become biases when “the researcher fails to mention them” (2001, p.484).

In an attempt to become more aware of how my preconceptions were affecting the study I began journaling as soon as I started this research. I also met regularly with colleagues, supervisors, and academic mentors from various departments, continually seeking fresh perspectives and contests to my thought processes and interpretations. On several occasions, I would ask my family members for their opinions on a particular participant narrative or comment. I kept in mind Bentz and Shapiro’s ‘lifeworld’, which explains that “research is always carried out by an individual with a life and a lifeworld, a personality, a social context and various personal and practical challenges and conflicts” (2008, pg. 4).

Another potential limitation to this research program is the relatively low number of participants (“n”) interviewed. The 5 case managers (n=5) and 19 clients (n=19) interviewed at the Jewish community center represent a homogeneous sample that is not necessarily representative of the general population of mental health clients and case workers. However, although these participants’ shared experiences may not be generalizable to the greater community of clients and case managers, they still shed valuable light on the construct in question. In talking to these participants, I got to know them on a deeper level and am therefore able to write about the complexity and nuances of their experiences with ‘care’.

4.7 Reflexivity

Reflexivity refers to the “ability to engage critically in understanding the contribution the researcher’s experiences and circumstances have had in shaping a given study (and its findings)” (Thompson & Harper, 2011, p.6). Reflexivity is an attitude of attending systematically to the context of knowledge construction, and especially to its effect on the researcher, at every step of the research process. There are two strands of reflexivity: one is personal reflexivity, which is concerned with the researchers own history. The other is epistemological reflexivity which is concerned with exploring how the assumptions of the approach taken shaped the study (2011, p.6)

The reflexive process was vital to the integrity of this research program, as the project was largely based on my personal experience working as a case manager. In addition, reflection is important when working with subjective reports. Bentz and Shapiro assert that research inquiry develops from a researcher’s ‘lifeworld’; explaining that “research is always carried out by an individual with a life and a lifeworld, a personality, a social context and various personal and practical challenges and conflicts” (2008, p. 4). Malterud writes that a

researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions...the perspective or position of the researcher shapes all research- quantitative, qualitative, even laboratory science" (2001, p. 483).

I tried to revisit my initial motivation for wanting to conduct this study, and I reflected on if and how these motivations changed throughout the duration of the project. For example, whereas my initial intention was to deepen understandings of care, my intentions were modified and in time it became a priority for me to also provide space in my project for participants' voices to be heard. This process reminded me to distinguish between what I was hoping to learn about care and what the data in front of me actually conveyed. This was a reminder to allow participants' stories to speak to me, rather than impose my own ideas onto the research. Through reflection with mentors, I realized that I was eager to find something – *anything*- meaningful that I could give back to the mental health community. The participants' stories were certainly anecdotal, however as the intention of this research was to explore a construct rather than generalize a construct, this was acceptable.

Another possible source of bias was my four years of experience as a case manager in a mental health department. I had struggled with certain parts of my job, and I had to be aware of whether I was looking for reassurance that I was not alone in experiencing this kind of tension. I also wanted to find out how fix the problem, a desire which I later recognized was grounded in my initial positivist thinking. Here I assumed that there exists a single truth, and that my job was to "fix" the so-called problem of subjectivity by removing all biases. I tried to adopt Miller and Crabtree's "bracketing" which means that I tried to "bracket" my preconceptions and enter the world and perspective of the research participant. I considered

myself an experiencing interpreter in order to be open to the participant's experiences (Miller and Crabtree, 1992, p. 24)

The data was amenable to systematic text condensation. It was important to me that I captured the participants' stories. I wanted to keep them in context. The systematic text condensation approach made this possible. As one of my most valued mentors, John Strauss, pointed out, experiences are shared through language, "and you know the thing about language, it's always a little inadequate" (John Strauss, personal communication, August 2013). One can never fully describe an experience as it is experienced. Language is secondary; it is experience that is the center. Participants' experiences are subjective, and I hoped to capture stories to keep the details in context. I sought the collaboration of a multidisciplinary analysis team. The use of multiple analysts in triangulation helps to create richer interpretations of the stories. In triangulating analysts, two or more people independently analyze the same qualitative data and then compare their findings. This also provides a safeguard against omissions or errors. In the present study, the analysis team was composed of four individuals, adding additional perspective to the triangulation process.

This section on reflexivity is one way in which I hope to show transparency with respect to my position as a researcher. My interest in this project grew out of my experience as a case manager. While practicing, I noticed in team meetings and informal conversation that my colleagues and I each possessed unique ways that we "cared" about our clients. Some practitioners seemed to "out of their way" more often, believing whole heartedly that going above and beyond was essential to good case management. Other colleagues insisted on upholding strict boundaries in their relationships with clients. I also noticed a tension between the notion of "caring" for clients and practitioners' notions of "professional boundaries". I set out to better understand the meaning of "care." Upon reflection, I can now recognize that at that time my thinking process was in line with a positivist paradigm. I wondered what the

single true meaning of care was, and how I could best provide it. I fantasized about providing a “how-to” guide for case managers on how to best care about their clients. My position as a researcher forced me to challenge this search for a single truth, and to look more holistically and critically at the data before me. I had to become more comfortable with indeterminate variables that did not adhere to positivist paradigms. I revisit this experience of reflexivity in the conclusion to the thesis.

Another discovery I had was the realization that having worked as a case manager myself, I held an “insider status”. As noted above, being an insider provides a more contextual understanding of the participants’ work environment. Goodwin observes that interviewed nurses as an anesthetic nurse broke down certain barriers and hence facilitated communication. Having an insider status, however, also had the potential to invite perspectives that are consistent with the status quo (Bishop, 2005). This was one of the reasons why I wanted the ‘analysis’ team to come from various backgrounds and disciplines.

The benefits of being an insider far outweighed the disadvantages. I believe that my proximity to the case managers and my understanding of the work involved in case management allowed for rich discussions and reflections with case manager participants that might not have been possible for a non-case manager. This was a notable advantage. I also had to be careful when having conversations in the familiar ‘case management language’ not to assume that I understood what case managers were describing. As was noted above, I had to be particularly discerning because such language emerged ever so subtly, from practitioners (“oh, you know how it is”), or from me (“I know what you mean”).

My insider status also had an effect with clients. During one interview early in the data collection phase a client stopped himself midsentence in describing troubles he had experienced with his case managers. He said “Oh, no offense, I bet you were not like that...” His comment made me reflect upon how my past experience and position as a case manager

interacted with my current role as a researcher. Would my status limit the ease with which client participants confided in me? Another client participant started a story by saying “please don’t tell my case manager but...” After this experience, I stressed very carefully at the onset of each interviewing that everything shared would be kept strictly confidential.

A breakthrough moment came when I was able to understand that I had a particular perspective on “care” and that it was only one perspective. Care is not necessarily something someone *does*, it may be a way someone *is*. Care may be interactive, it may be a process, it may not be easily put into language, and it may not be measurable in the way that I know how to measure. Developing an appreciation and understanding of how perspective influences the whole research process, from inception of question to analysis and writing results, has not only sparked a curiosity for how others view issues related to care in mental health, but has also reinforced my alignment with the shift away from the bio-medical approaches to illness and “treatment.”

CHAPTER 5: Presentation of Findings

5.1 Overview of the chapter

This study aims to better understand clients' and case managers' experiences with care. The findings are presented in this chapter. Both the workers and client participants were asked to talk about the experience of care, times when they felt cared about and times when they felt less cared about.

The clients' stories reflect experiences of 'care' and 'non-care'. Practitioners showed clients that they cared about them in both explicit and subtle ways. Similarly, 'non-care' was demonstrated to clients by practitioners in both explicit and subtle ways. As my intention was to maintain the integrity of the participants' stories, I kept them intact and in context. Large chunks of respondents' words are presented in this chapter. By leaving this text intact, I provide readers with the opportunities to make their own meaning of these stories. I also provide commentary between excerpts. Presenting the participants' shared narratives in this way also acts as a way to limit my bias on the data. The text is rich and nuanced, and certainly open to many perspectives. I organized the texts into categorized themes that emerged through discussions among the multidisciplinary research team.

The question guideline for the client interviews was:

- Have you ever felt that your case manager cared about you?
- How could you tell?
- What was that like?
- Have you ever had a case manager who you felt didn't care about you?
- How could you tell?
- What was that like?
- Supplemental question: If you had the chance to teach case managers, what would you want to teach them?

5.2 Clients stories about care

Stories about care fall into two main categories: explicit and subtle demonstrations of care. Explicit demonstrations of care are more easily identifiable. They may be tangible or observable behaviors or actions that a practitioner does. Subtle demonstrations of care are more implicit; for example, an unspoken understanding between two people, or a subtle facial expression. In an attempt to honour research participants' voice, I drew on their words as often as possible when labeling each theme. Themes are presented in order of importance. For example, that clients considered case workers more as friends than professionals was a predominant theme in the interviews therefore the theme "friendship" is presented first.

5.2.1 Themes of explicit demonstrations of care

Theme *Friendship*

These excerpts reflect clients' perspectives that the therapeutic relationship they have with their practitioners more closely resembled a friendship rather than a traditional practitioner-client relationship. Each excerpt comes from a different client. In these excerpts, clients described actions displayed by their practitioners such as accompanying the client to a doctor's appointment, talking about shared interests and hobbies and going out of ones way to visit the client. In several excerpts, clients explicitly referred to their practitioner as a "friend". This theme is noteworthy because of the stark contrast between what clients value and what practitioners are taught in training. I recall having numerous discussions in my own academic training as a counselor not to confuse my role as a counselor with the role of a friend. A supervisor once told me "be friendly, but not friends." The fact that clients considered – and valued - their case managers' friendship is significant. In section 5.4, the reader will note that case managers mentioned explicitly that they felt they had to manage the boundary between professional and friend.

One woman in her 40's who had been diagnosed with schizophrenia said:

"... One time, I had to [get a medical procedure]. She came to the appointment with me. She was even going to come into the room where they were going to operate on me. That's how much she caredFeels good. Feels like someone cares about you. And that you're not alone in this world and that there's people who care. Because when you're at rock bottom deep in drugs and you can't get out... there's people who care. Because there's people who will give up on you ... that's how I see it...."

The notion of going out of one's way is also reflected in the following excerpt. This client, a 30 year old woman said:

“... He used to come to me, ... he'd be taking the bus...it's the middle of winter ... at the end of his workday... this was his time... he'd bring ... movies ... he'd bring me snacks... he knew I didn't have anyone in my life at that point because everyone was tough love ... he could sense how lonely I was ... how sick I was, and I didn't even realize till I was healthy ... wow, he... really cares. ... he's one of the people in my life ... that has really been proud to see the way I've changed and treats me now like a person and even an equal as opposed to “client” ... he'll call me ... two times a week... Just to check up with me ... how have you been doing? Have you been sleeping? ... and when I told him I was gonna get a job he really encouraged me ... when you're trying to come back to yourself, or your new self ... it's nice to know that you have that kind of support no matter what. He's ... thoughtful... there [was] an event going on ... he said ‘I think you could really use a night out’ ... And it was such a good night...”

When the practitioner expressed interest in the client's experience, it was greatly appreciated by the client and interpreted as a gesture of thoughtfulness on the part of the worker. Another client said:

“...[Another doctor] went private after he retired from the hospital and ... he saw me for free... he said ‘I'll just see you as a friend’ ... it was nice of him to take me...”

(60 year-old woman.)

Clients spoke of their workers being their friend. One man in his 50's said about his case manager:

"I saw her at the museum on Wednesday... and you know, we're friends ... there's something extra ... she's friendly... It's better than just being ... professional, kind of thing ... and ... keeping distance ... It just felt closer ... it [feels] good ... It makes it more than just talking about illness or something all the time ..."

The idea of friendship is presented in the following excerpts as well. One male in his 60's said:

"... I'm not just a name and a number. It's almost like a friendship. It's like a friend... and... they just [check in]... they want to make sure everything's ok ... in an emergency they always say 'call me'..."

Another client remarked:

"... also when I went on welfare ... we go to the welfare office ... And then ... once or twice ... we had bit of lunch, and we had a lot of papers to ... fill out. ... on my birthday I think we went out for a ... coffee ... it was nice ... he actually came ... to [my neighborhood] ..." (man in his 60's)

The following excerpt was shared by a woman in her 30's. She describes in detail why it is important for her to stay in touch with her case manager. Her comments touch on professional boundaries and friendship.

“... I was upset when the time came and she had to go ... the thing is, even if they cared about me I find that after their stage was over I didn't really keep in contact with them. Do you know what I mean? ... except one, I have their phone number. I sneaked it off the internet... I wish I could still keep in contact with previous [workers] ... I don't like it when relationships end because I like to stay in touch with people ... I have friends from school years ago they've all moved on and we don't keep in touch anymore ... I don't like change ... It's good to keep in touch with people ... it makes me feel like part of the community and people...”

One man in his 50's expressed how important his case worker was in his recovery:

“... the way we used to talk together. The relationship was very good...I liked her very much. I still miss her... wish I could get her back (it felt) good. Excellent (to be cared about by her)...it was good for my pride. My ego. For my integrity. I had three life or death surgeries ... and... she called me in the hospital several times ... I was so afraid. I didn't know what happened to me ...Several times she called me...she lifted my heart ... Like close like a relative. She saved my life...”

One woman in her 40's said about her case worker:

“... when I'm with [workers who care], they treat me like we're friends ... we have many ... things in common... recently, I said ... 'I really want to go out dancing... Is that appropriate for us to do?' ... She's like 'probably [not] ...in the way [the organization] would see it'... I can understand how it would put her in a funny position. But just the

way we can interact with each other when we're together it doesn't feel ... strictly professional. I can ask anything about your personal life, I can be concerned about you ... it's ... not to the point where ... if at 3 o'clock in the morning I was having a bad time, I wouldn't interrupt their private time to talk to them about it ..."

The issue of professional boundaries is salient throughout these texts. In some professional contexts these boundaries are obvious and the transgressions are easily identifiable. A sexual relationship between a client and a professional, for example, is unquestioningly inappropriate (according to medical ethics). These excerpts suggest, however, that a friendship between a client and a case manager may be appropriate and even necessary. Although some feel mental health clients represent a vulnerable population and practitioners must remain mindful of that vulnerability so as to avoid taking advantage of the person, it is important to note that client narratives suggest that clients desperately need to be in contact with people who care, and care is something that friends do. It is important to note here that there is a growing body of empowerment literature that pushes back on labeling people diagnosed with mental illness "vulnerable".

Theme *Going out of your way* or '*compassion*'

The following excerpts reflect that clients appreciated when their practitioners went out of their way for them. Going out of their way means that practitioners did things that went above and beyond the expected call of duty. For example, one client talks about a time when his worker visited him at a rehabilitation clinic that was hours away. Another client shares a time when his case manager was going to attend a musical gig he had one evening (after

work hours). Again, these actions of going above and beyond the traditional professional role were considered favorably by the clients. The gestures were appreciated greatly.

One 40 year-old woman remarked;

“... they might put their hand on your shoulder... [one case manager] hugs, he shakes my hand... kind of feels that he's connecting with you on a different level... [another case worker] ... came in today when I was in a different program ... to ... answer ... questions I had asked ... She could have sent me an email... that's really the compassion I'm talking about...”

One client describes a time when her case manager visited her in a rehabilitation clinic that was several hours away.

“... I was in rehab, and I felt alone in rehab and she came up and she got lost and everything, but she still came. She found a way to get there. And I felt so good that day. Because [the rehab manager] came and was like “your worker is coming, she's coming. She just got lost” and I felt good that day. I felt like, the worker didn't give up on me. She still came. She found a way to get there. That's the first thing that comes to my mind... I realized [it] before with her because she was just so nice to me always. But that day I truly felt...I was alright...”

This 30 year-old client talked about a time when her doctor personally walked her over to the emergency room. Here, the gesture of accompaniment was received with gratitude and interpreted as a gesture of going out of his way:

“...I went to see him when I was in the emergency and he personally walked with me to the emergency department and admitted me there. And I felt cared for then. Because he didn't send me [by] myself. He walked with me...”

In the following excerpt, the 50 year-old client describes a time when his case manager was going to help him remodel his apartment “on his own time”. The act of doing something in the workers “own time” was greatly appreciated.

“... He said he was gonna come over and help me remodel ... Like on his own [time] ... at the end of the day or whatever ... [he] is always good at getting me knowledge ... like there were clothes to be given away ... and he told me about it ... I haven't ever had any problems getting in touch with [him] ... He's usually pretty prompt for whatever I ask of him. He's been pretty good...”

Another client spoke of a time when his worker “went above and beyond the average worker”:

“... I'm a singer ... and ... he was gonna come to my show. So he obviously has a lot more care than you know, just the average Joe. ... he seems to take care... makes me feel that way ... he sort of goes above and beyond the average worker ... outside the traditional 9 to 5... he's a very good advocate for me and he fights for me... it's great, because you know, when I moved out, I had nobody really ... I'm on my own ... to be on my own was awful and to actually have somebody who was there made a lot of difference ...”

The following excerpts describe scenarios when case managers were emotionally invested in clients.

“... It’s a nice feeling to know people are worried about you ...she showed up at my apartment one day and I was high as a kite and she came in, and I remember she called my doctor ... and she put me in the car and brought me to the hospital. She wasn’t happy ... it was tough love...” (40 year-old woman)

Another client describes what it feels like to be worried about:

“... I was in trouble once, and I needed to find a place, and I needed some money and she ... expedited it ... that’s like one indication that she really wanted to help me. And was worried about me. You know, kind of like a mother is to a kid... it’s [a] more comfortable feeling” (50 year-old man)

This client describes a worker who expressed wishing she could do more for the client. This made the client feel that the worker cared about him:

“... she helped to get me vouchers... and she was even saying “I wish I could have gotten you more” ... she’s always trying to be helpful in a successful proactive way...” Cause there's no tension there. Cause if someone doesn't like you then you ... have a tendency to react badly... “ (45 year-old man)

Theme *Recognition of individualism*

Clients appreciated when their practitioners conveyed recognition that they were unique. The following section includes excerpts of clients who had workers that encouraged clients to pursue their dreams, encouraged personal goals, recognized unique talents. These gestures had the effect of instilling hope in clients. One 60-year old woman described one worker:

“... I talked to her about ... my writing ... and how I'm not crazy about my job ... I don't know if I want to go on with my job, and she was like “keep the job! It's practical! And that way you can just write” ... I thought that was good advice ... I'm part schizophrenic patient is trying to keep her place clean and do all the practical things, you know? And can you be a writer if you're schizophrenic? ... she encouraged me to enter [a writing competition] ...I read her my stuff ... she really supported me ...”

One 40 year-old male remarked that his case worker did not put pressure on him, which was greatly appreciated.

“... And she's nice too ... I never felt like she was disappointed in my progress or that I had to prove anything to her... I never felt that kind of pressure from her ... “

A 60-year old male client remarked that his worker was

“...more understanding, more warm... said, ‘you be the best you can be’... Positive things. ... it felt good ... one time she brought me in and we talked about stuff and she

says 'you know, maybe you'll get a car one day, you'll get another job, you can get yourself a small car. How do you feel about not having a car? How's it going?'..."

This client talks about the age of the worker. She describes that with age comes experience that younger case managers lack. This life experience was valued. What is also significant here is the expectation that the worker will share this experience with the client, again raising the issues of professional boundaries. Professionals are not "supposed" to share personal experiences with their clients.

"... I'll be quite honest with you. Sometimes I wish case managers ...were kind of older. Like in their 50's or 60's ... I remember when things were horrible for me with my [child], I was losing [child] and I had a social worker ... she was ... this wise older lady ... and boy was she good for me ... I remember she kept on saying "your [child] is so special..." ... it just felt good ... it was so soothing and comforting. And you have the feeling that you're not completely lost ... they've really gone through life ... and they know a thing or two..."

Theme *"Took the time to listen to me"*

These stories reflect client's experiences of feeling respected by their practitioner. This was conveyed through the case manager explicitly paying attention to the client and valuing his or her experience. Several clients mentioned an appreciation for being listened to intently. Two clients mentioned feeling disrespected when the case manager answered a phone call during a meeting.

“... Before ... going to see [case manager] I ... mentally prepare a few things that are important that I want to share ... whether it was a bad experience ...or... something that bothers me ... or whatever it is I can go and ... get it off my chest. And not feel pressured to stop if the phone rings... sometimes [case manager] will not even answer the phone, she'll say, 'keep going'... And that is a way that she shows me that I matter ... Whenever there's a bazaar or something, she will ... tell me about it ... she'll look at my finances and [ask] 'how about you tell me how everything is going? Do you need a little extra money? Do you feel like what you're getting is fair? Do you think we can go over what your spending is?' And then we do ...” (30 year-old woman)

One 50 year-old man spoke about the link between listening and care.

“... They took time to listen to me and to hear...and understand... what I had to say and not just decide on their own what was the best for me because that was their job...And...not just what was good for them, that they wrote it down on paper and it looked good on paper. But they actually thought about what I had to say and what should be done for me and not just what they wanted to do for me... I didn't feel just like a number in an assembly line ...like we'll do this and we'll do that, and who cares what you think...”

Being listened to was a notable theme throughout these interviews.

“... She was very cooperative and I could work with her and she was lenient with me... Like she would listen to me...when I would ask her for something, she would... think about it, and she would go about it and hopefully do it...” (60 year-old man)

The following client goes into more detail about what being “listened to” actually means:

“... They want to see what I’m capable of. They don’t just want to put me in a shelf ... stamp a label on me ... They want to hear what I have to say ... and ask me my opinion ... not just lectur[e] me ... that opens up doors. That means I can trust this person [her] attitude was ‘You have a brain in your head and you should use it’... and one of the things she said to me was ‘you need to be heard’. So, I started writing poetry, to try and practice expressing myself more fluently and more clearly rather than just saying facts ... “ (60 year-old man)

Another client referred to the importance of respect.

“... they talk to you ... they give you advice.... Stuff like that ... they sent over Passover baskets, and Rosh Hashanah baskets.... They put my name on the list... it feels like they respect you. That they really want to help you. It feels good...”

Theme *Advice and concrete tools*

The following accounts describe workers that provided clients with advice and concrete tools to help with their recovery. In these particular texts , clients describe feeling cared for when their case manager execute tasks in a prompt and expert manner.

“... a competent worker... [is] very good at resolving issues ... right away... someone you can rely on. Someone who is going to be working for you ... when you have faith in the person, belief in their abilities ... [with one of my best workers] ... There was no...

emotional connection. There didn't have to be ... because for every issue... It was done in a very quick ...manner ... there was no hesitation ... I presented it, there was no problem with him comprehending it ... ok here's the issue, boom. And they do it ..."

(40 year-old man)

The following excerpt was shared by a 45 year-old male client who describes a similar experience to the one above. He values task-oriented meetings:

"... I thought of her as a therapist ... because we had sessions ... like if there were five things to discuss we'd go one by one. ... getting over the problems that I had ... And then her time with me ended ... and now if I go back I have to go to the intake..... start over again..."

The following 35 year-old woman reiterates the value of being task-oriented

"... [my case manager] is amazing...very nice... clearly tells me what we ... need to do. Everything is very organized... I leave the office feeling happy... [case manager] gives me a list... never tells me what to do with the money I get every week. I get to do what I want with it.... She listens from A-Z and then she will give you her opinion. And if I stray from the conversation she will bring me back to the original question ..."

The following client took the time to describe in great detail how a case manager conveys true listening. Here listening is an act of empathy.

“... if the patient is describing something he or she went through, the case manager must put themselves in the patients shoes ... every patient has a frightening ... and shocking... story to tell. That’s why they’re in front of a case manager... when a patient is talking, your mouth is shut ... it is the most sincere sign that you’re listening ... giving ... full attention ... respond to the patient as if the patient is there and you have a relationship with the patient. ...as if you ... have a stake in helping the patient...” (60 year-old male)

The following client also underscored the importance of empathy...”to put yourself into other people’s shoes.”

“... She was nice but not for people with mental illness. She didn’t know anything about it. She said so herself ... And not just to know things, and read up on it but you have to actually feel for the people. Because it’s really an illness like any other... Life isn’t easy when you have a mental illness. You should try to understand what it’s like, what we go through. To put yourself into other people’s shoes. That’s important ... you have to know when the [client] is having hard times and not. Not just in the surroundings but on the inside. Like [one worker], she was trying to help me get into school ... after I didn’t get in... she called me ... and it made me feel better...” (30 year-old female)

In the preceding narrative, the client described the importance of practitioners to be emotionally attuned to their clients. She describes an emotional intelligence required to be a good worker (“you have to know when the [client] is having hard times and not. Not just in the surroundings but on the inside”). In the following text, the client described a similar emotional

intelligence required on the part of the worker. The worker needs to understand that the client may not always be operating from his or her optimum capacity due to illness.

“...It’s very difficult for someone who has ... recently been in hospital. At least for me, it really changes the way you’re able to communicate about a situation ... you’re more defensive than you would be normally. It’s harder to articulate... memory can be temporarily impaired ... and [workers need] to know that [the patients] probably have a limited capacity to... represent themselves, how they feel. Their ideas might be a little clouded ... the medication... you might not be dealing with the person’s typical personality and memory... it might ... require a little more patience and compassion ... it’s like a weak point in their life... a person’s humanity... takes a back seat for a while ...” (40 year-old male)

This client articulated a similar emotional intelligence required by the practitioner. He explains that workers need to listen with a “soft ear”.

“... She was very adamant right away. She said “no”... She goes all the way with the rules. She won’t bend, nothing...she has a hard ear. [The first worker] had a soft ear... when you ask for something and the way they respond immediately, they say ‘no’... it’s so cold. You get offended. You get hurt. You feel bad. You feel neglected...” (60 year-old male)

Another client added that listening is about openness.

“... Seeing the good in people is exactly what people should do. Everybody...
*ouverture d’esprit. An open spirit...il y a partout des opinions différentes. Ca laisse la
porte ouverte pour nouvelle, pour aider les gens. Pas juste rentrer dans un moule et
rentrer comme ca...*” (60 year-old female)

The following client added that listening involves more than providing Band-Aid solutions to complex problems.

“...[Case manager] should say to me, ‘you know, I’ve got this form, do you want to fill it out or would you like me to do that? What would be better for you?’ ... my illness ... can be debilitating. So the first thing you want is ... to feel that you can do stuff and you’re going somewhere and you’re able. To make myself better I should be making appointments for myself. ... that [is] part of the process of getting better is taking care of yourself and starting to make decisions ... I need help, I need hook-ups ... but I need my independence at the same time ... And if you take that away from me, you’re not helping ... it’s a little bit crappy in that respect ... I feel that I’m taken care of, and they’re concerned, but the solution to my problem is not being met ... I’d rather not be helped actually in a way... cause it’s teasing me. It’s helping me to a point and then its leaving me ... And then I’m left fighting ... we’re looking at Band-Aid fixing things but the main problem is not being addressed ...” (55 year-old male)

The preceding section highlighted selected excerpts from various client narratives that centered on general themes: friendship, going out of your way, recognition of individualism,

listening, respect, advice giving and concrete tools. These themes were easily identifiable and explicit. In the following section, I present excerpts from narratives that speak to subtler demonstrations of care. These themes reflect more intangible expressions of care.

5.2.2 Subtle demonstrations of care

Theme “*You can just tell*”

In the following section I present excerpts that reflect something that the analysis team struggled to categorize because we could not easily grasp the narrative’s theme. These stories reflected *something* that was slightly obscure. This *something* was well captured in one respondents’ expression, ‘you *just* know’ when someone cares about you or not. There is not anything concrete per se, rather, these statements reflected a feeling or a hunch. One 50 year-old man remarked:

“... You can’t teach this. This is the real person coming through. You can’t teach someone to be open-minded or not to be arrogant. These are people... with good intentions but they have a way of diminishing you. You can’t really teach that in a profession...the case worker that I really liked, the thing about her was that she didn’t seem to know much at all about psychology...But it didn’t really matter because she was great. I loved going there and she always put a smile on my face and she just gave me a boost...”

Another client reiterated that care is communicated through ones personality. Care is not something that can be concretely or overtly taught; rather, you simply are a caring person or not.

“... When the person being cared for sees that they’re cared for, it improves their morale and their self-esteem and that kind of thing ... I think you have to be a caring person to begin with. And if you aren’t then you’re probably in the wrong job...”
(35 year-old man)

The following texts reflect clients’ experiences with professionalism, what is and is not helpful, and the subtle clues when you can “just” tell that someone cares about you. Descriptions of empathy, connection and humanness are mentioned. Many of the stories overlap, and it was a challenge to categorize them into one topic. For example,

“... You could tell by the manner they talk to you. The way they look at you... the facial expression sometimes would tell more than any words could actually speak... They show you that you matter. They don’t brush you off, ‘hey, we only have 10 minutes, I have a next appointment, let’s be quick...’ ... I don’t like to feel rushed...”
(45 year-old female)

Another 50 year-old male client remarked:

“... I did feel cared for many times [by a worker]... it’s a feeling I get... that they care. I feel like it’s not just their job...”

The following excerpt touches on this notion of intangibility. The client could not describe exactly what happened except that she experienced some sort of connection.

“... [one psychiatrist] ... I remember him ... this guy was older... we just hit it off...it felt wonderful...” (60 year-old female)

In the following remark, the client refers to the sense “something” happened. This “something” was good.

“... sometimes just the way the person is ... There was a ... nurse ... I remember after she spoke to me ... I felt something in my heart... I don’t know what it was ... Like some sort of jolt or something... in a good way... “ (60 year-old male)

Another client referred to the warmth of the worker.

“... [one student]... her personality was very warm. She has this beautiful laugh. She likes humour and all that...” (35 year-old female)

Another referred to *something* that was not quite right.

“... I sometimes get the feeling that she wasn’t quite comfortable with me either ... I ... didn’t feel that she was particularly concerned...” (55 year-old female)

In the following excerpt the client describes how she felt good meeting with her worker yet suspects that her positive demeanor was more of a professional role than a genuine expression of care. This excerpt highlights how there are different levels and perceptions of care.

“...I always liked meeting with her ... She had that air of professional compassionate ... calmness to her and she’s very professional and nice and balanced and... it was nice to see her. It felt good. Some kind of stability there ... I didn’t necessarily feel ... that she cared about me ... she would be that way with all her patients ... it had nothing to do with me or how I acted. So I thought it was ... less personal, but more ‘professional compassion’ ... that’s part of [being] a good social worker...”

5.3 Clients’ stories about non-care

The following section lays out clients’ stories about non-care. Similar to the preceding section, this section is categorized in two broad themes: explicit demonstrations of non-care and subtle demonstrations of non-care.

5.3.1 Themes of explicit demonstrations of non-care

In the following section I present excerpts from client’s stories that demonstrate non-care or barriers to the client feeling cared about. Some of these excerpts note that issues exist not in the individual worker him or herself, but rather in the mental health system itself. Body language, pessimism and gestures that communicated disinterest were perceived by clients to be barriers to connection and care.

Theme *Barriers to care*

One 50 year-old man noted:

“... One thing I don’t like is if someone screws up ... I get screwed but nothing happens to them. No consequences. ... I once had a worker who was habitually late. He should have been fired ... or get reprimanded and forced to change. I had no respect for that worker...None of the baby talk. These are not infants. These are not feeble minded seniors ...”

This client continues:

“... When you have four workers in two years ... That was an issue ... it was insane ... How can you ask for people to give a commitment when the second the worker gets a better offer somewhere else they’re gone? And they’ll get a pat on the shoulder. There’s no consequence to them taking off ... the ones who are the worst are the recent graduates ... I had three ... all left for ... maternity leave ... So, why would someone want someone who is ... young, a woman, who is guaranteed to leave? ...”

Another client remarked how frustrating it is to have someone just go through the motions.

“... She came... she’s being paid to listen to me... she has a salary just because she is listening to me. I’d prefer not to have someone... it’s hard. It’s not fun at all. And me, I’m getting old, I’m not young, and I felt there was a big...*un écart de génération. Lui, il est trop jeune, moi je suis vielle, on se...* he could be my son...I can not [talk about personal things] ...that’s why I stopped seeing [him]...” (60 year-old woman)

The following excerpts describe actions by case managers that conveyed disinterest to the client.

“... a case manager who takes calls [during appointments] ... And then might have a long conversation on the phone, to take up your appointment ... It speaks volumes ... I figure ok they're not interested. ... I'm not putting any of my effort into this ...”

(45 year-old male)

The following was shared by a 45 year-old woman who was particularly sensitive to her case managers tone of voice:

“...she was basically ... spitting out the information in a way that you knew she had to get off the phone quickly ... I ... took it personal ... [I felt] like [I was] last on the list...am I bothering them by talking to them again?...”

The following excerpt reflects a pessimistic attitude on the part of the worker that had deleterious effects on the therapeutic relationship:

“... I found her rough and her mannerisms ... to be too tough and harsh... cold.... ... ‘you’re not doing this, or this, or this... ‘It should be this, this, this..’ ... Like nit picking. ... everyone’s got good and bad in life... what about my good points? ... It’s like the glass is ... half empty... that’s the reason why I left ... I couldn’t take any more...”

(55 year-old man)

5.3.2 Themes of subtle demonstrations of non-care

The following themes reflect subtler demonstrations of non-care. These themes, similar to the subtle demonstrations of care in section 5.2.2, presented a challenge when categorizing them because the problematic behavior on the part of the worker is not always explicit.

Theme *Denying personhood*

“... [Another doctor is] extremely cold ... he barely looks at you because he’s either looking at his notes or looking at his computer. So he’s not engaging you... I interpret that as being a little bit difficult ...” (45 year-old female)

The following comment was shared by a 50 year-old male. He touches on important topics that relate to the notion of denying one’s personhood, dangers of paternalism, and to the literature around microaggressions. He expresses:

“... One time a psychologist ...started talking to me in a bar ... I knew exactly who she was...She didn’t know who I was ...and then she saw me ...in the lobby [of the hospital] and she just kinda ... put her head down and she kept [walking]... [she didn’t want to] get involved with someone who has a big psycho history...

...A lot of times these workers or psychologists... give me a bad feeling... they don’t mean to, it just comes through ... makes me feel like some kind of monster, some kind of freak... It’s a subtle thing. I can tell you some examples... of being insulted... I’m a fairly funny person. I tend to make a lot of jokes... one of my workers said to me “you

people kill me” ...the “you people” ... means ...‘ ... all you...crazy people’ ... I don’t really ... put myself in the same category ...I’m...very atypical... highly functional ... I had a lot of friends...nobody would really think that I had been through what I had been through... So I kind of grew up with this... duality where I’ve been through this terrible stuff...But then I... come off as a regular person and so it’s very important for me and my clarity... to reconcile that duality and when a worker ... tell[s] me I’m just a textbook ... I find that it’s inaccurate and... insulting and it’s negating all the complexity and the problems of my condition... [another worker]... used to say “I think you’re a nice Jewish boy” ... I ... thought that was a stupid thing to say... I never like to be ... stereotyped...there was a lot of presumption there... I ... thought it was very unprofessional, disrespectful ... small-minded... it’s just making me small...that’s part of the nightmare...You shouldn’t be diminishing someone or referring to them like a cute cliché ...

He continues:

“You know, I prefer...if someone is cold... than if they’re subtly diminishing or disrespectful, I don’t really care...I don’t expect you to care about me. It’s a bit much to expect a stranger or a professional to care about you... I just expect not to feel worse about myself. I expect not to get insulted or patronized. So, its more a question of respect than actually caring... I mean, you can’t force someone to care...”

Along the same lines, another client said:

“ ... sometimes I feel as though there's not enough being done because I'm a little bit of a special case... I'm unique... [my case manager will] say 'I'll call this person' ... and I'll say 'It's OK, I'll do it'... it's very nice... but in a way sometimes it's a bit of an insult because he should know beforehand that ... I'm capable. It makes me a bit fed up with him...” (50-year old male)

Another client focused on the importance of trust.

“... [another case manager's] ... attitude was ... was 'Look, you're just another person here, you're not special... and I'll discipline you like I'll discipline anyone else here'... I couldn't trust [her].... And I didn't open up to her very much...” (60-year old male)

And another refers to listening and trust.

“... most of them ... I've felt cared. Maybe one didn't care that much...she was very like, by the book, kind of.... she asked me questions that she had to ask me... that's it. I didn't feel like she was listening to me... she was trying to get me in and out... to check me off the list ... I wouldn't feel comfortable trusting her. I wouldn't call her in an emergency...” (40-year-old woman)

The following excerpts reflect challenges and barriers to connection as experienced by clients. This 60 year-old female client speaks about the vulnerability she feels given her status as “client”:

“... I’m not comfortable with a social worker... Because I feel open without my permission, I open my heart, I open my soul to her... but I regret it a lot ...I will give you an example. At forward house I had this worker, he used to come give a *rendez -vous*, I feel very bad with him. Because, you know, I feel naked sometimes... And it was not very...it was not helping me at all. I feel stupid, you know?...”

Another client commented on the consequences of making assumptions about the client.

“... I'm sharing so much of my life, my personal everything, you know, some subjects sometimes are a bit touchy, and I don't necessarily want to talk about certain things. So being at ease with the case worker is, you know, crucial to me because if I'm not at ease, I can't really open up. And be honest ... [I had another worker] ... And I talked to her about ... hanging around with [certain] people... And I really didn't appreciate the questions...you know, some things were super ... personal and overboard, and ... she made assumptions ...” (35 year-old female)

5.4 Case managers stories about care

In the following section, I present excerpts from the case manager narratives. My goal was to gather stories about caring and non-caring from these workers. These excerpts fall

into two main categories: What does caring mean to case managers? What are the challenges to care for case managers?

The question guideline for the case manager interviews was:

- Have you ever had a client who you've cared about?
- What was that experience like?
- Do you think the client could tell that you cared?
- Has there ever been a time when you cared less about a client?
- What was that experience like?
- Do you think the client could tell that you cared less?

5.4.1 What does caring mean?

The following section sheds light on case managers' perspectives on care. Caring about clients was described in three general contexts, which I have labeled empowerment, person-centeredness and whole-heartedness.

Theme Empowerment

At some point during every interview I conducted with case managers, practitioners expressed the desire to “empower” clients and explained that this was a critical aspect of their role. Empowerment is in line with recovery-oriented care. One case manager said:

“... But my approach has always been ... Allow the people to take over as much control as they can...”

Another case manager explained why empowering clients is so important:

“... You’re... there to repair what has been done to them ... You’re trying to heal ... it’s kind of a... privileged position ... One thing they value above all is being treated like an equal ... “

The following also focuses on the importance of autonomy and empowerment.

“... We can talk a little bit about some simple stuff but really I’m here to do my job...To set goals and like that ... My style... is very much where I want to empower the client to achieve their goals as much as they can with my support ... where can I give them the tools or advocate for them ... to move them forward ... But I also want them to do it on their own...”

Similarly, another case manager commented that:

“... I’m not going to be doing them any favours by coddling and handling them moving forward ...”

The following case manager noted that not only was it her job to empower her clients, but that an important aspect to her job was also to be a role model to her clients:

“... You gotta look for resources ... You gotta network ... It’s like another skill base you ... need... in addition to working one-on-one with a client ... I think it’s also teaching the client ... I’m not here 24/7. If you’re feeling crappy at 3 o’clock in the morning, who are you gonna ... talk to? ... Or if I see things that clients can take advantage of ... Little things... for them ... it ends up meaning more ... but for me it means nothing ... for instance, I bought ... two agendas ... what ... am I gonna do with the extra one? ... it was ... a way to get this client more organized ... I said ‘you know what? ... Here’s an agenda ... we’ll get you organized’... that’s one of the things she wanted to work on. So I used that and it was also ... a little gift ... she ... bought her own for this year. So it was also role modeling...”

Another case manager made a similar comment:

“... now this kind of brings up the whole issue of ... sharing ... sometimes your clients will know that you’re going through periods that are difficult ... when they see that you’re able to ... come back ... and you’re strong again ... I’ve always seen myself as a teacher, I guess in a way...”

Theme *Person-centeredness*

Person-centered models of care is a relatively new concept in the medical discourse that stands in contrast to the disease-centered model of care. Whereas a disease based approach to health care views individuals as ‘cases’, a person-centered approach to health care views humanistic and sociocultural aspects as critical to a person’s care. A patient is not a “schizophrenic” but rather a person first and foremost, who also carries a diagnosis of

schizophrenia. Similarly, we do not call a patient with cancer “a cancer”; but rather a person who has cancer. A predominant theme among case managers narratives was to look at their clients as people first, and not just as patients.

“... Initially ... I want to find out ... what their interests are. I don’t ... go into the illness part ... I ...want to get to know them as a person ... I’m not a psychiatrist, I’m not a medical professional so ... I ... go with where they’re at. I’m very unassuming ...unstructured ...”

Another case manager asserted:

“... so for me its meeting the person where they’re at, no judgment, no expectation, no ... agenda...”

One case manager shared:

“... they are people and that’s how we want to see them first ... in case management we ... meet with people in our offices. ...Frankly I prefer the other model ... the real work is done in the community, in coffee shops or in going places... in their homes ... in group settings. ... people are multifaceted so I like to see the whole person ...”

One practitioner reiterated this idea of focusing on the “human”:

“...You want them to be safe. You go that little extra mile for them. It’s like you care for them... little parts of my personality come in and parts of their personality might come

out ... it makes you a little more human to them so they feel a little more comfortable...”

Theme *Whole-heartedness*

A theme emerged among case managers which indicated that at times the case manager would put their whole heart into their work. I have labeled this theme “whole-heartedness”. In this context, one worker noted:

“... There are some people that you like more than others ... that you ... like spending more time with than others ... Absolutely. We’re humans ... I think it just comes out naturally ...”

Another worker emoted:

“... We have a ... burning desire... a passion to help ... It’s something I like to call the psychological salary ... knowing that you’re one of the good people in their lives...”

The following worker talks about the important personal connection she has with her work:

“... [in the hospital]... everybody [has] became a discharge planner ... I can’t work like that. ... I’m a person who’s based on relationship ... that’s where I feel I accelerate ... [that’s] what’s important to me... as a person... as a human being... That’s why I went into social work...”

5.4.2 Challenges to care

Case managers also expressed challenges they face while caring about their clients. These challenges were, at times, described in relation to the development or hindrance of the therapeutic relationship. I assigned labels to these themes by drawing on the words of participants. These themes are: Managing boundaries, testing behaviours and taking it personally. I have presented these themes in order of importance.

Theme *Managing boundaries*

A predominant theme that arose in the case manager interviews was the idea that case managers felt they needed to uphold certain professional boundaries for their client's benefit. The following case manager describes aspects to this boundary, and expresses that managing this boundary is precisely what the client "needs" in order to recover.

"... I try not to make it show ... it's better to be ... neutral with all your clients ... you gotta keep your judgment to yourself. Not supposed to show all those things. At least I don't think you should ... I think you can tell them when you've been disappointed in them ... if you've been working on a plan and they haven't followed through ... you can say ... 'if I'm gonna help you then you gotta try to help yourself a little bit' ... as a case manager in mental health, you're the person who kind of pieces together the person's life. ... so you're dealing with welfare ... housing ... You're managing their life almost ... you ... have to be really genuine ... if you can do that little extra then you do it ... Because that's what they need..."

The following case manager acknowledges that there is a professional boundary to uphold, and that preventing this boundary from becoming “blurred” is a major responsibility of the case manager. There is a certain amount of care that is appropriate and a certain amount of care that is “too much”.

“... You do tend to start to care more for some clients ... I think it’s important to acknowledge that ... that’s happening because ... if you deny ... your boundaries can become quite blurred. Some clients have expressed ... ‘we’re like friends!’ And then I say, ‘Well, no, we’re not. We might act friendly with each other and we’ve gotten to know each other very well and it’s very natural that this feeling is there but we have to always remember that this is a client relationship. Which is different than a friendship’. So clients sometimes have to be reminded of that ... I mean, you’re not going to go out with them and have a beer, right? I still need to maintain that professional boundary... If I wasn’t in this position as a case manager ... I’d go shopping with them all the time! ... because you know that’s what they need!...”

The following case manager cautions against becoming “friends” as this blurs the boundary.

“... You gotta be careful that they don’t start to see you as a friend ... you need to remember that you are in a helping role ... you are there as a support but also as a guide...”

This case manager reiterates this caution against becoming friends.

“... Sometimes though...I find... I have to be like OK, I can't do that, or that is too much.... I'm not your buddy... I have a professional role... [A client] wanted to go shopping with me but...it has to be for specific things... I'm not gonna go hang out [at] Dollarama just for fun... [Another client] was like, “do you want to come for a wine and cheese?” I was like ‘noooo’... I just find it really tricky. [When another client] was hospitalized.... she has no one to take care of her cats. I went to feed her cats...it'd be really good if... other people [could] feed her cats but right now there's nobody else ... I can't let her cats die. They're her reason for living... I remember my manager] said ‘well, you just have to set your boundaries... set limits with [the client]’. But I'm like, she's in the hospital... set boundaries how? What do you mean? I don't understand. We'll do more... we'll go out of the way and do extra... Which, is not necessarily a good thing... I think it just blurs things...”

The following case manager challenges traditional professional boundaries. She expresses that at times she relies on her “gut” rather than the “traditional teaching methods in university”.

“... I think boundaries have to be an individual thing. ... trust my gut ... you're not going to give a hug to somebody who you think might be romantically involved with you ... You're going to ... let them know that the boundaries are very ...strong. But someone whose mother just died ... of course... you might give them a hug ... I tend to give more hugs than most people do ... we value too much ... verbal communication. ... I ... have ... a prejudice against ... the traditional teaching methods in university. Where they teach people to have strict boundaries... to be able to disengage ... I have clients

... if they decide they want to call me at some point and ... have a coffee in the city, I'll never say no. I would say no if my gut told me that that person was not healthy... “

In the proceeding statement, the case manager talks about managing her self while managing the boundary with her client. Managing her self is perceived as an important method of self-defense.

“... I think it just comes out naturally... Maybe some of them don't like me! ... it's not one sided ... If you like that person and they're enjoyable ... and they're pleasant ... They're coming in, and their personality ... how they want to try to work at things ... How they look at things ... I don't make it a point to tell them “I love meeting with you” ... I don't go to that extent ... I think they just pick it up on their own ... they're smart. They know ... As opposed to someone who's ... totally negative all the time ... it's draining ... a lot of the times ... it's not just personality... it's part of their illness ... it's what they're living on a day-to-day basis...”

The notion of defending the self against burnout was repeated in the following interview as well:

“... I have 34 on my case load ... there [are] some weeks [when] 34's too much. But then you prioritize... that's when you set your limits ... you have to look inside of yourself ... you can't do it all. You can't be everything for every person ...”

This case manager talks about managing her self as well for the benefit of the client.

“... But I’m not going to be doing them any favours by coddling and handling them moving forward ... I have to be aware... Am I doing too much for this client because it’s making me feel better, because I’m helping this client? Am I really doing this client a favor by doing all these things for them? ... It’s also when you’ve been working so hard with a client in achieving something and then it all falls apart because a client didn’t follow through and then you’re all upset. But it’s not about you, right?...It’s very hard ... When you have a client who might be a little bit needier ... or, you have more contact ... and you ... take the case management approach and ... get involved ... you become invested, you know? ...you get this empathy, this sympathy for these clients that you may not have for others that you may not see as often. ... I have some clients that I’ve been working with for seven years... that have been on my caseload from the beginning. So it’s like ... a seven-year relationship. It’s longer than some friendships. It’s longer than some romantic relationships. It’s longer than some marriages.... And then you have the clients that fall in between. You know they aren’t super needy [but] they’re not where they don’t want outreach at all. And its hard to get a handle on those ones, exactly what they want out of this relationship, from the agency, from you ...”

Theme “*Testing*” behaviours

Case managers talked about certain behaviours that clients exhibited that created an additional challenge to their job. In the mental health field, these behaviors are commonly referred to as “testing behaviours.” Such behaviours are exhibited by people who may act in challenging ways to test the commitment level of people in his or her life.

“... there’s no question it has its share of stressors ... its hard to put limits ... and ... give ... tough love. Sometimes we need to let people fall, if ... we’re kind of breaking our heads trying to prevent the sabotage ... sometimes we need to let it fall apart ...”

Another case manager commented that:

“... just knowing that they are suffering is a personal issue for us... At least those of us who really belong in this field... Advocating verbally for clients, that’s where I still need improvement ... not becoming flustered and ... holding back the frustration... it’s a very on-your-feet kind of skill... not becoming too emotionally driven... you get the doctor on the phone and ... you’re lucky ... if he gives you two minutes ... I don’t want it to become counterproductive ... Even though I’m nowhere near a psychiatrist ... I know the clients better ... you almost have valuable knowledge that the medical system can benefit from ... and that should count for more than it does...”

One case manager shares uncertainty about what is “OK” and “not OK”:

“... there are some who don’t want to work on anything concrete... they just need to hear that friendly supportive voice ... I’m still not sure I understand what makes the difference between what’s OK ... and when it’s not OK...”

The following case manager’s use of the word “tolerate” speaks to the personal challenge that may exist in a relationship with a person who is under mental distress:

“... we'll tolerate a lot more than the average person will in a relationship ...”

This case manager expresses the difficulty she experiences in enduring clients' “testing behaviours”:

“... It's a lot of testing behaviours that go on. Especially with people ... who have been emotionally injured. ... They want to see that ... you're not going to drop them ... you're going to be there for the long term ... But ... frankly there can be quite abusive behaviours. Especially during the testing phases ... swearing... sometimes people get really angry at you and tell you that you are the source of their problems. And you need to have a very strong personality of your own to be able to see that it ... is their problem that they are bouncing off of you ... It's the recovery from the trauma ...”

This case manager describes the challenge with dealing with certain clients:

“... There's one guy, when he calls ... I think it's his energy, his personality ... I can feel my heart like, oh dear. OK... I have to kind of brace myself ... 'cause he's ... really aggressive and it's hard...”

Theme *Taking it personally*

These excerpts demonstrate a need that case managers have to protect the self from getting too involved in their clients' struggles.

“... separating yourself from that is not as easy when you're tired ... needing a vacation and when you start to take things more personally ... it's an indication that you have to

take a step back and take care of yourself ... you can only take so much of that ...
allow... yourself to recover ... we need a lot of support ...”

Efforts to not take client challenges personally were reflected throughout the narratives. Case managers described that it could be difficult to leave professional problems at the office when they went home at the end of their day.

“... Some of them might never realize and stay bitter and they'll never deal with that worker again... I try to not take anything personally and not take it as a reflection on how strong you are as a person ... I'd be lying if I said that I never take it home with me...it's not healthy of course ... but it's so complicated ... we're so inextricably intertwined with our clients lives ... we can't ... just turn it off like a switch once we're out of the office ...”

CHAPTER 6: Interpretation of findings & Educational Implications

6.1 Chapter overview

Part I of this chapter will address my interpretations of the results presented in chapter 5. How do case managers and clients experience the sense of caring? What can we learn from these experiences? Having two perspectives on care provides a fuller picture of the construct. It allows for a more dynamic understanding of the experience, recognizing care to be relational and a process. The table from chapter 3 is presented again below as a point of reference for the interpretation of the findings.

Figure 1: Concept Map

| | Concept | Beliefs | Expectations/Assumptions |
|--|---|---|---|
| <p>Care as a noun</p> <p>“The practitioner provides care <i>to</i> the client”</p> | <p>Care is a provision or a service</p> <p>Care is delivered through techniques or therapeutic skills</p> <p>Examples: evidence-based-practices like assertive community treatment programs, multicultural counselling competency</p> | <p>Delivering these skills and techniques will result in client wellness & recovery</p> | <p>Case manager learns these skills and develops these competencies in education and training.</p> |
| <p>Care as an adjective</p> <p>“The helping relationship is a caring one”</p> <p>“The practitioner is a caring person”</p> | <p>Care is a necessary quality of the helping relationship</p> <p>Associated with personal qualities like warmth, empathy, genuineness, kindness, compassion</p> | <p>The helping relationship and helping professional should be unconditionally caring, warm & supportive</p> <p>Caring relationship and a caring professional will result in client wellness & recovery</p> | <p>Case manager possesses caring qualities</p> <p>Case manager knows how to cultivate caring relationship</p> |
| <p>Care as a verb</p> <p>“The practitioner cares <i>about</i> his client”</p> | <p>Caring <i>about</i> someone involves an emotional investment on the part of the carer</p> <p>Clients have reported that they appreciate when their case manager goes “above and beyond” the regular call of duty</p> | <p>A case manager who “breaks the rules” makes clients feel that he or she is someone worth breaking the rules for.</p> <p>This makes person feel cared about, which results in clients wellness and recovery</p> | <p>The case manager possesses the ability & skill to properly navigate the boundary between ‘breaking the rules’ & upholding them</p> |

Part II focuses on the educational implications of these experiences for case managers' education. Based on themes that emerged in the interviews, for example, that care cannot be "faked," I draw from 3 educational models that have particular relevance to the themes that emerged in this research: (1) Mezirow's Transformative Education theory, (2) Nel Noddings' Care Theory and (3) the narrative approach in education. These models are discussed in developing an educational framework to support mental health case managers.

6.2 Part I: Interpretations

In this chapter, I include several additional excerpts from the participant narratives. Although it is not standard to include interview excerpts in the discussion chapter of a doctoral thesis, I do so in this thesis because the excerpts selected reflect salient issues and help guide this discussion. In addition, as is the case in many qualitative research programs, the presentation of findings section tends to overlap with the discussion section. At times, these sections are presented simultaneously.

Theme You can just tell

When asked about how they could tell their worker cared about them, clients' shared that they could just tell.

"... their eyes sort of sparkle when they see you even if you're having a really rough day. It's almost like they see something in you that you probably know deep down in yourself but you're just not able to manifest ... right now ... it gives me that hope, that I can actually get this back..."

Another client commented:

But they cared about me ... we got along pretty well...I could just tell ... that she liked me... my character ... the way they look at you... you can see it in their eyes ... the way they talk to you, tone of voice, what they say ... the way she smiled at me ... body language ...their aura... it's all of that ... **you can tell when people like you... You can't describe it, but you know it** ... so I always felt that she liked me...

Even though these cues were subtle (“I could just tell” or “their eyes sort of sparkle”) they were significant in communicating to the client that the worker cared about him or her. These responses suggest that the experience of care may not necessarily be something that can be taught to students (can you teach someone to “sparkle” their eyes?) The clients’ responses focused not necessarily on *what* the practitioner did to make the client feel cared about, but rather on *who* the practitioner was. This finding is in contrast with the literature that was presented in chapter 3 that describes the importance of teaching “caring behaviours” such as non-judgmental listening, use of humour, mirroring, which can be “mastered” over time.

One client commented on the subtle “realness” of his doctor:

“... [Once] there was a change in his expression ... his eyes were a little bit watery ... you ... can almost see that he's kind of remembering something that was painful for him, and then ... he'll eventually say, ‘...you're not crazy to believe ... [that] this is terrible’ ... like... understanding that I'm not just ... hysterical... It's reassuring... He's real....”

There is some indescribable quality that people experience when they feel truly cared about by another. One aspect of this quality is associated with clients feeling that their worker was authentic and emotionally invested in them. One client remarked about her practitioner, “I see her sometimes and ... her ‘*hi, how are you?*’ is just fake”. The scholar Marianne Farkas speaks to this element of authenticity. She writes “professionals who lack hope themselves cannot promote recovery orientation” (2007). Her contention is that in order for professionals to instill hope in a client, they have to truly feel hopeful about the client’s future. This sense of hope cannot be faked; rather it must be genuine. Professionals should not fake is because it is ineffective. Clients can distinguish between authenticity and inauthenticity in their worker “... If I had one lesson... be professional, and if you don’t like the job don’t do it because you’re not gonna be as good at it. Do it cause you want to do it, not only for the money...[or] because you ... don’t know what else to do in life...”

This subtlety is reflected as well in the following statement made by a 35 year old male.

“...I don’t think he liked me... His body language and his smirk... He had a smirk...”

Theme Micro-gestures: Microaggressions: barriers of care

A theme that stood out throughout the interviews with clients was reminiscent of the literature on racial micro-aggressions as described by Sue and colleagues (2007).

Racial microaggressions are “brief and commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial slights and insults toward people of color” (p. 271). The critical factor to consider about microaggressions is that even though these gestures are subtle (“micro”), and seemingly “innocuous and insignificant” (p. 279), they are not. The power of

racial microaggressions lies in their “invisibility to the perpetrator and, oftentimes, the recipient” (p. 279). The cumulative effects of microaggressions may result in “diminished mortality, augmented morbidity and flattened confidence” (Pierce, 1995, p. 281). Nadal and his colleagues describe the harm sexual orientation microaggressions can have on LGBT youth. They call this article “Death by a Thousand Cuts” (2011).

In this research program, clients described subtle gestures by their workers that communicated discrimination, or non-care. One client I interviewed said the following about the practitioners he had worked with over the years:

“...when someone says something like, “you both”... to me and someone else who has different symptoms... that’s categorizing us both in the same box even though we’re not the same...to someone like me, that would [hurt]...or to be given a stenciled response ... the same words they say to everybody who they put in that category...that’s the kind of thing I don’t like ...”

This comment speaks to a similar racial microaggression termed “color blindness” as defined by Sue and colleagues (2007). The scholars explain that when “... a client of color stresses the importance of racial experiences only to have the therapist reply, ‘We are all human beings or the same under the skin’... these colorblind statements, which were intended to be supportive ... may leave the client feeling misunderstood, negated, invalidated, and unimportant” (2007, p. 281). That this client’s case manager compared him to another client by saying “you both” was invalidating to his unique experience as a person.

These microaggressions are reminiscent of what Judi Chamberlain termed *mentalism*. Mentalism is a term used to describe covert discrimination against people who have received

psychiatric treatment (Kalinowski & Risser, 2000). Examples of such covert gestures include referring to clients as “crazy” or “nuts,” judging consumers to be “high” or “low” functioning, or treating clients like second class-citizens. A common example of this would be a case manager encouraging a client to take an apartment that he or she would never live in herself. These gestures, no matter how insignificant they may seem, carry infinite weight in a person’s sense of wellness and recovery.

Theme Micro-gestures; Micro-affirmations: facilitators of care

Clients also spoke to subtle gestures by case managers that affirmed their humanity (“micro-affirmation”). These micro-gestures are connected to the clients’ experiences of care.

Can you teach someone to care about another? That clients are in tune with such subtleties in the practitioner suggests that practitioners need to be highly self-aware. Compassion focused therapy, as described in chapter 3 is an example of one such approach that addresses practitioners’ self-awareness. The approach speaks to subtle gestures exhibited by a practitioner such as their tone of voice or body language that may advertently or inadvertently send messages to a client. The experiences of clients interviewed in this study confirmed a salient notion of compassion-focused therapy which is that clients are highly attuned to their case managers’ gestures, no matter their subtlety. As was expressed by one client,

“... I had such a great case manager before... there was an immediate connection that I hadn’t had with anyone ... That is not something that’s ever happened before... It was so obvious that we both recognized it ... [when] there's a connection ... my message

will get through ... You understand each other ... what made this so special was it was on both sides. Which is something that is very rare ... it was surprising. Startling ... And even if they screw up... which she did ... you are willing to forgive them ... because you really know the person is trying ... I had faith....”

Borg and Kristianssen write, “professionals have typically offered little hope to persons with severe mental illness diagnoses, instead conceptualizing these experiences as chronic conditions with limited prospects for recovery” (2004, p. 493). In this study, giving hope was mentioned by one case manager

“... we need to constantly be giving them hope ... blowing on the embers ... we have to ... convince them, you do deserve to have a better life... you do deserve our help ... whenever it was conveyed to a client that I was worried about them, like I had trouble sleeping one night because I was worried ... they seemed pretty ... flattered ... touched... like they are important... they count ...”

The case manager’s comment above about “blowing on the embers” provokes an interesting question in relation to Borg and Kristianssen’s assertion that professionals offer little hope to their clients. Is the hope that practitioners believe they “give” to their clients interpreted by clients as hopeful? It also elicits questions that pertain to the practitioners’ authenticity in giving hope. In order for the practitioner to “convince” the client that he or she deserves to have a better life, as the case manager asserts above, the practitioner must first truly believe that the client deserves this life. The clients’ attention to their practitioner’s subtle cues, such as the “sparkle” in one doctor’s eye as described by a client, or a practitioner’s tone of voice as described by another client, suggests that clients can detect whether or not their

practitioners are genuine. This idea speaks directly to the authenticity that is required on the part of the case manager in order to convey care. This relates to a comment that was made in the previous chapter when one client, when asked how he could tell if his worker cared about him responded “I can just tell”.

Theme Tensions around professionalism

Breaking the rules & friendship

Clients and case managers spoke to the idea of professionalism. Clients’ experienced that their case managers cared when he or she “broke the rules”. Case managers’ narratives speak to tensions felt in managing these rules of professionalism.

Clients talked a great deal about friendship. Repeatedly they talked about their case manager acting in ways that surpassed the traditional, expected case manager role. For example, informants shared that their workers were their friends, bent the traditional rules of professionalism or went out of their way. One respondent remarked, “... he will do things outside of what’s necessary that has to be done ... I’m a singer ... and ... he was gonna come to my show. So he obviously has a lot more care than you know, just the average Joe ...” This client distinguishes between a case manager who cares for him versus one who cares about him. A case manager who cares *about* him goes above and beyond the traditional role of the case manager, for example, this worker who was going to attend his performance outside of work hours. One interesting point is that although clients did not expect to become friends with their case manager, if and when they did feel that connection it was a wonderful bonus.

“... He's become like a friend...not my worker. When I'm no longer a client ... [we] would like to be friends. [he] opened up to me... which gave me so much ... more respect ... you know, even ... community workers ... have lives and problems too ... it doesn't make [them] weak ... I think his big fear is ... that I'll [threaten him] ... he's done so much for me as a person I want to be able to be there for him ... so, there is a very fine line...

...[another] social worker ... became one of my closest friends, and when I went to the organization ... I spent an hour in her office and then when we went down for the meeting had to pretend [that] I haven't seen her in a year ... “you know what, you're a cool person, I want you in my life... but I can't tell anyone... because I could lose my job” ... I totally respect ... that it needs to stay professional so I can't say anything, but these are services that I used as a very sick person... and I'm not there anymore, so it makes me feel good to know that people see that I'm a different person and that I'm educated ... I'm responsible, I'm accountable, I'm dependable. I'm not who I was...”

The idea that the traditional professional rules may require updating is reflected in the above comment. The relationship this woman has with her practitioner that she later felt obliged to hide forces a re-examination of our traditional stance on what constitutes professionalism. Moreover, it forces us to think critically about how current systems shape these rules of professionalism. Who made these rules? Under what context were they created? Have clients' needs changed? Have workers' needs changed?

Borg and Kristiansen's study described good helpers as ones who “broke the rules” (2004, p. 499). Breaking the rules is described as going above and beyond the traditional case managers' duty. The term refers to behavior that may be seen as on the edge of what is

typically considered professional conduct. My findings support their study. Consistently, clients' stories about care acknowledged workers as friends or *more* than a typical case manager.

Reciprocity

About reciprocal relationships, Larry Davidson writes that although, "traditional client-clinician therapeutic boundaries and roles forbid such a two way street, such a reciprocal relationship may be a critical component to recovery" (2009, p. 163). He continues "many persons with psychiatric disabilities ... may ... be accustomed to having their offers of reciprocity, such as a birthday gift, rejected because the traditional client-practitioner therapeutic boundaries and roles forbid such a two-way street." (p. 163). Anthony writes, "Recovery is a deeply human experience, facilitated by the deeply human responses of others..." (1993, p.18). In Borg and Kristiansen's study of client perspectives on their recovery, informants highlighted the importance of '*being seen*' within their helping relationships (2004, p. 496). Clients in this study noted being seen as a person rather than a patient important. At times, they felt that having a friendship with the case manager was one way in which they were seen as individuals. One client said,

"[case managers] have to be a humanist ... try to find the humanity in yourself and in the other person ... Cause it's hard for us to be treated like cases... it's really hard. Especially when you're isolated, and, you don't have that many friends because you're ill. And you're struggling with a difficult situation already. Don't talk down ... Remember that the people that you're dealing with are patients ... they're ill and ... not at their hundred percent capacity ... don't constantly put them in the position where they feel

that they have to be proactive ... I'm telling you, I can't do it. It's not a lack of motivation, it's not a lack of willpower, I just cannot do it. I tried ... Check-up, re-check ... don't put me in a position that I feel like ... I'm walking outta here again ... on my own. [we've] been let down so many times by the system ... [case managers should] put themselves in the place of the actual patient ... having that perspective ... rather than ... this is ... not really a person, it's just a chore. ...Cause you're not really seeing the human side of it..."

When describing this relationship, clients placed value on this relationship being bi-directional, such as appreciating when the practitioner self-disclosed. One client remarked, "...we can connect, we both have anxiety ... She talked to me about it....Another student, we connected over [our favourite game]..." This comment is noteworthy because traditionally self-disclosure on the part of the therapist challenges the codes of professionalism.

Some clients reported that they worried about their practitioner as they would a close friend or family member. One client shared, "... We reached a good relationship, rapport. Communicating wise...just by being polite myself ... understanding her wants and needs ..." Another client said, "... I try to help [the practitioner] as much as possible ... getting the papers in ... there's red tape they have to go through... they don't want it either ... I know it's a hard job and they don't get paid ... all that much ... and also people tell them all sorts of stories ... it can be painful work too, you know?"

These statements reflect a sense that perceiving the practitioner as a friend was not only a good thing, but also a beneficial component to connection and recovery. The stories collected from clients suggest that seeing the worker as a human being was just as important

as the worker seeing the client as a human being. At times this was expressed through descriptions of an *absence* of humanity.

According to Karlsson and colleagues, “the idea of neutrality and the distance of the therapist have been confronted by the recovery movement” (2013, p. 9). Some critical characteristics of a recovery-oriented relationship are described as highly collaborative and equal. Peer support is based on the very premise that shared experience may be a critical component to recovery. These theories are in stark contrast to the traditional distanced and unbiased therapist. The image of Freud’s “opaque” therapist comes to mind here. This therapist remains unseen to the patient both literally (the patient lay on a sofa looking up at the ceiling rather than at the therapist), and metaphorically (the therapist would keep all personal judgments and biases to himself). In essence, it does not matter who the therapist is. Personal qualities and characteristics are unimportant. What matters is that the therapist is opaque or *unseen*.

There is a related discourse surrounding the role of the teacher in Quebec’s Ethics and Religious Culture Program. In this program teachers are expected to remain professional by adopting a posture of neutrality and impartiality. Teachers are told not reveal where they stand on critical issues so that students learn to think for themselves (Morris, 2011). This expected professional posture of teachers is seen as a way of avoiding indoctrination and proselytizing. Interesting, this is one of the most discussed and contested aspects of the program in the scholarly literature (Bouchard, Haeck, Plante, Venditti, 2016). Although there is a consensus that teachers should never impose their perspectives and values, several scholars wonder if a posture of neutrality gives discussions an inauthentic gamy quality. Critics ask if neutrality is possible or even desirable. To what end? What do the students prefer? Could a greater engagement with the ideas and the students bring more substance to the learning experience? Does the norm of impartiality necessary imply a posture of

neutrality? The same questions hold true in mental health practitioner: Should the practitioner remain neutral? To what end? What do clients prefer? Does of posture of neutrality contribute to a form of “hollowing” of the worker-client relationship? Does the action of “breaking the rules” necessarily comprise the practitioner’s professional responsibilities? What is lost? What is gained? These important questions about professionalism emerged from my data. As I noted in the literature review chapter of this thesis, Paechter (2003) writes that theory may be built directly from empirical findings.

The findings of my study point to importance of interrogating taken-for-granted assumptions about the nature of professional relationships. These rhetorical questions presented above represent fruitful directions for future research in this area. Another potential avenue of future research could be exploring mental health professionals’ and trainees’ comfortability in the area of self-disclosure and relaxing of “professional” boundaries.

Whole-heartedness and Burnout

One especially fruitful theme is related to challenges practitioners experience in managing boundaries within the professional relationship. In their study of recovery, Borg and Kristiansen, found that clients appreciated practitioners who were “ready to share the good and the bad experiences of a fellow human being’s totality, both the times of suffering as well as the hopeful opportunities” (2004, p. 496). What is noteworthy here is that although this message of instilling hope was echoed among clients in this study, the case managers spoke directly to avoiding this type of involvement with clients. As one practitioner commented:

“... they’re gonna have their ups and downs ... we can’t allow ourselves to go on a roller coaster with them ... we don’t want to have the empathy burnout ... “

This notion, that there is such a thing as caring “too much,” is reflected in other practitioners’ narratives as well. One practitioner, for example, said:

“... I know that I am a pretty good candidate [for burnout], like I’ve always... sort of gone overboard with work...and I think a lot of it is just seeing people suffering is just not right ... I know that that’s just part of social work ... I’m still struggling with that ...”

Another practitioner said:

There are times when ... I cared more ... than they do... I felt like I was investing my heart and soul, investing so much energy to the ends of the earth... they were just quicker to give up...

It is possible that practitioners associate caring “too much” with emotional burnout, and that maintaining a distance is professionally appropriate and healthy for both the practitioner himself as well as the client. The importance of professional boundaries in psychotherapy and other related professional faculties such as nursing and social work have long histories. Professional boundaries are intended to protect both the practitioner and the client. In his seminal article, Thomas Main (1977) argues that a certain “distancing” of psychotherapists is a necessary technique to defend the self from “from alien mad feelings, confusions, despairs, rages, guilts, and so on . . . we cannot blame therapists for seeking ways to alleviate these strains of the close encounter, by distancing themselves from patients in various ways... and by adopting various mental defences against their own capacities to feel deeply about overwhelming distresses in another...” (1977, p. 460)

One case manager commented:

“... I do know that I have to figure out how to be more detached and not take it home... being open hearted is great and I think it’s a great thing in life... But ... Less heart, more detachment... I don’t know exactly how to do that yet ... I often feel like ... I take too much on ... it’s hard to not be overinvested... I feel that I get overwhelmed ... I feel like maybe I need to care less... “

In her study of case managers of people diagnosed with Borderline Personality Disorder, Nehls found that case managers deliberately created a certain distance from clients to protect the self from being “soaked up” (2000). Case managers in her study consistently “monitored themselves” in terms of expressing concern and setting boundaries with clients. They monitored not only what they did, but also what they disclosed (2000, p.15). This finding poses a challenge to some of my findings that clients appreciate when case managers reveal their true selves, for it is precisely this that makes the case manager not an “artificial person.” I will discuss Frank’s notion of the artificial person below.

Case managers took the responsibility of managing the professional boundary. The College of Registered Psychiatric Nurses of Manitoba, as an example, delineates “every act or behavior of the Registered Psychiatric Nurse must benefit the client (CRPNM, 1999). This standard holds true in social work: “It is the responsibility of social workers to establish the tenor of their professional relationship ... and to maintain professional boundaries... that serve the needs of clients (code, 2005, page 7). Case managers felt it was their role to manage the connection in this relationship. This was for the clients benefit.

A mentor, John Strauss once asked me, 'if a client doesn't get better, whose fault is that?' One of the practitioners I interviewed spoke directly to this question:

"... there were clients who ... maybe some personality clash or countertransference issues ... and ultimately I had to give them up... I just wasn't effective ... couldn't convey enough caring ... it just wasn't there ... it was enormously frustrating. It was hard not to berate myself over it ... because I just wasn't able to develop the skills on my own to ... figure them out ... anything we did together ... was ... going in circles and almost causing a mutual neuroses ..."

This comment suggests that the worker assumed much responsibility not merely for the connection with the client, but also for the recovery of the client. This comment begs the question, how much care is enough? How much care is too much?

Related to genuineness, another notable theme that emerged in the case manager interviews was their desire to be wholehearted in their work. One practitioner shared:

"... For me, if I'm going to be working, I have to be enjoying my work and really doing it full on and I need to be me in it. [for example] I had two extra tickets for the... exhibit at the botanical gardens... So I asked (a client) and ...so she went and she called back and she said '...I think this is the first time in ten years when I felt like a woman. I felt like a regular citizen of the city going to an event' ... and it got me thinking holy crap, this is fucking recovery. This is what it is ... and it made me feel so good...that's the kind of thing I want to do....it calms me.... it makes me feel like I would be living my values... it feels expansive and exciting and real. And it feels right. It's those little things that make my job worthwhile..."

Another practitioner stated:

... you come in because you're passionate about people.... you think you can make a difference ... sometimes you do and sometimes you don't and sometimes you don't know if you do ... you have to accept that ... I do it for my own health as well ... I think that's another way that I've build trust with people ... by saying we're two human beings here. I have something that I can help you with and I'm going to learn a lot from you ... So I guess that's what keeps me in.

The desire to be wholehearted and compassionate in ones work did not necessarily mean that practitioners felt at liberty to actually be wholehearted and compassionate. In fact, many practitioners spoke of challenges related to practicing in a wholehearted way.

Another client's remark acknowledges the humanity of the practitioner as a justification for the practitioner's shortcomings. This client said,

"...And the other thing that I've come to understand too is that case workers aren't forever... they go, they come... I have a friend, he is almost 80 and he's my case worker ... He's a wise old man and... he knows me... for nearly 20 years. ...he's my big support ... he offers so much wisdom... I think younger girls, they're concerned with husbands and children, and friends, and their careers ..."

Technocratic thinking

Arthur Frank's memoir about his experiences with health care staff challenge current conceptions of professionalism (2002). The memoir speaks to a tension in our conceptions of professionalism. Frank writes of an interaction he had with his oncology doctor; "what was wrong with that conversation, for me as an ill person, was precisely what made my physician's performance so professional. To be professional is to be cool and management oriented" (2002, p.10). Could there be a third position here on the issue of professional boundaries? Is it possible to navigate through a posture that erects professional boundaries while at the same time avoiding a posture that is cold and detached?

In another text that he published several years later, Frank describes the risk that medical practitioners who are bound by inflexible professional boundaries become the "artificial person" (Frank, 2004, p. 131). The artificial person assumes "responsibility for the rules and regulations but not for the effects of those rules on persons. The artificial person offloads responsibility. Here the moral agent disappears and becomes without flesh, invisible. According to Frank, the justification for the artificial person is "organizational efficiency" (p.129). Frank is not against organizational efficiency. He is concerned, however, that a slide toward a form of artificial personhood seriously undermines the generosity necessary for building relationships.

The way in which case managers perceive that they have to manage the professional boundary is reminiscent of technocratic or instrumental thinking. Technocratic thinking, according to Morris (2003), emphasizes systems or practices that value maximum efficiency as a measure of success. A technocrat is essentially an artificial person who upholds the rules and regulations, but not the effects of those rules on the person. Morris asserts that technocratic thinking is fundamentally incompatible with ethics. "Whereas ethical reasoning

attempts to contextualize nuance, examine from multiple perspectives, wrestle with paradox and ambiguity, and perform imaginative empathic projections, technocratic thinking seeks uniformity and standardization” (2003, p. 3). Although his insights on this incompatibility focus on an educational context, they may be relevant to the mental health realm as well. The relationship between a worker and a client, like the relationship between teacher and student, is profoundly ethical in nature.

The clients’ stories described in this research (in addition to the thousands of consumer writings) suggest that technocratic systems, for example those that seek standardization and value efficiency (re: caseloads running upwards of 100 clients) run the risk of making clients feel rushed, unimportant and inhuman. One client commented:

“... try to do your best to help the people ... take [the client’s] perspective ... try to understand their life ... there’s somebody living there ...[don’t] treat [them] as a number... you have to give your time, you can’t just look at the clock ... and hope to get out. The ones that weren’t caring ... they don’t give you time ... [One worker]... answered a phone call when I was there yesterday, I didn’t mind ... but... I mean, I prefer not...”

This client’s comment speaks directly to the idea that case managers who act as technocrats are unhelpful and arguably damaging to a clients’ recovery process. Treating another person as a number is not conducive to the development of a trusting bond between two people. It is incompatible with the personal journey of recovery. Brene Brown writes that trust is a “slow-building, layered process that happens over time” (2012, p. 47).

Mental health workers run the risk of becoming technocrats or artificial persons if they are not mindful, or given opportunities to be mindful, of how systems can affect their

relationships with clients. Tronto points out that a vital component to care is “something extra” on the part of the practitioners (2010, p. 160). She remarks, “if caring is the ‘extra’, then how can we ever discuss it in institutional terms? It would seem that for institutions to provide ‘extra’ is already to move it from the status of ‘extra’ to ‘routine’? (p.160). That mental health case managers are doing “extra” suggests that it may be timely to re-examine what has been “routine”. This re-examination is necessary, argues De Gaulejac, if we are to avoid a “managerial ideology,” that is, a workplace culture where all actions, policies, and relationships are determined by the imperative to manage efficiency. Ironically, writes De Gaulejac, it is the managerial ideology of institutions, including health care, which makes us sick by undermining that which is necessary to human flourishing.

The term “consumer” may be off-putting to readers outside of the mental health field given the connotation this term has in marketing or consumer models. However, this term is commonly used in the mental health literature and carries with it a tone of empowerment and agency to the recipient of mental health services. One question to consider is whether this language has implications for or reflects in some way the relationship between the practitioner and the client. In education the increasing usage of the term client reflects how the market model of education is taking hold. Does the language we use on a daily basis empower case workers and clients or does it reflect the encroachment of the market model and the managerial ideology in health care practice?

6.3 Part II: Educational Implications

What can we learn from these experiences? In part I, I reviewed some salient interpretations of clients' and case managers' experiences surrounding the construct of care. Clients spoke of something subtle to the experience of being cared about ("you can just tell when someone cares about you"). This subtlety points to a need for educational models to address this subtlety, that is hard to define, but perhaps is something intrinsic to people. This brings to light a very important question; can you teach someone to care? Another interpretation I made was that clients could tell that their worker cared about them or not through micro-gestures. These are subtle gestures, oftentimes beyond the workers awareness, that signal to the recipient that he or she is cared about. That clients perceived such subtle gestures suggests a need for educational models to address student's biases, values and preconceived notions on mental illness because these are coming through to clients via subtle gestures. A final salient interpretation comes from the perspectives of clients and case workers. This theme is that clients appreciate when workers "break the rules." This was spoken about, for example, in clients talking about developing friendships with workers. To this topic, workers struggled in managing this boundary between friend and professional. Educational support needs to address the management of this boundary.

Can care be taught?

Compassion-Focused Therapy

In this body of literature, 'care' is often linked to 'compassion'. In fact, the question of whether compassion can be taught is the subject of numerous articles in the realm of health care education (Pence, 1983; Brown, 2011; McLean, 2011). One therapeutic orientation

called “compassion focused therapy” focuses on the healing properties of compassion (Gilbert, 2005). Compassion-focused therapy is an integrated and multimodal approach that draws from evolutionary, social, developmental and Buddhist psychology, and neuroscience (Gilbert, 2009). Essentially, trainees are taught how to be compassionate. The therapeutic approach is interactive, and is rooted in the premise that compassion is experienced first by the practitioner and is then reflected onto the client. This exchange places great importance on the practitioner. Gilbert writes: “one can only speculate on the effects of an insecure therapist who signals alarm, threat or disgust, or one who tries to be a ‘blank screen’ to a patients inner experiences” (p. 42).

Compassion focused therapy can be taught. A compassion-focused therapist undergoes intensive training and skill development. For example, facial expressions, voice tone and mirroring are some of the skills utilized by practitioners to convey safety, caring or alarm to clients. Gilbert writes that “compassion can be thought of as a skill that one can train in, with increasing evidence that focusing on and practicing compassion can influence neurophysiological and immune systems” (2009, p. 199).

McLean agrees that care and compassion can be taught. He presents a vision of nursing preparation which, in his view, should focus on the development of critical and analytical “skills” in trainees “which they will require to deliver care in the future” (2012, p. 162). Brown writes about teaching nurse trainees to be compassionate, “if caring is indeed the essence of nursing, then it becomes our responsibility to make affective behaviors that demonstrate caring equally visible as the cognitive and psychomotor components of nursing education” (2011, p. 360). She argues that nursing education needs to include “teaching caring behaviors” (2011, p. 360). Other skills to convey care that mental health practitioners are taught include non-judgmental listening, (Slade, 2009, p.16) and use of humour (Borg & Kristiansen, 2004). Tidefors and Olin found that the “mirroring” technique defined by good

listening, understanding and looking for the clients' viewpoint strengthened the clients' sense of self. Caring, in this sense, may be "mastered" over time (2011, p. 360).

Other scholars believe that compassion cannot be taught. This faction contends that compassion is a universal human virtue that cannot be taught, rather, it should be cultivated. Pence contends that compassion naturally occurs when humans are around suffering (1983). Bray and colleagues assert that "compassion is more than being kind, but is an emotional connection that involves seeing the person in the patient" (2013, p. 1). According to McLean, "educators cannot endow students with these [compassionate] qualities, but have the role in nurturing and inspiring students on their own personal journey" (2011, p. 159). Care is not merely something that practitioners *learn* or *do*, but instead care is something you *have* or you *are*. Henry Emmons speaks to this quality; "if you have seen the heart of the healer, you know how strong the pull is to somehow take all of one's individual gifts and attributes and make of oneself an instrument of service in a world of suffering..." (Intrator, 2005, p. 31). The implication is that people who choose to go into the helping profession uniquely possess compassion that is to be cherished, cultivated and supported through education.

In 1983, Pence suggested that in order for medical students to be compassionate, teachers needed to systematically accept that compassion was a practice worth encouraging (1983). Students would learn compassion through osmosis and role modeling. Teachers should embody compassion thereby teaching students how to be compassionate. Kraus and Stein's study in 2013 reinforces this connection. They found that practitioners who worked with recovery-oriented, compassionate agencies experienced more work satisfaction and less burnout than practitioners who worked in agencies where they were not supported. What this suggests is that compassion may be cultivated through the environment. Organizational cultures that value and promote compassion cultivate compassionate workers.

Care Theory

Nel Noddings, an educational philosopher and psychologist, developed a theory about care in education (2013). Care theory, simply proposes that teachers can teach students to be caring individuals by caring about them. Caring, in this way is learned by modeling but also through the experience of being in a caring relationship. There is an essential interactive component to the connection between the teacher and the student - the 'carer' and the 'cared for' (2013). She asserts that care is necessarily relational and that each party has a role that requires the other. The carer (the teacher), for example, has a required role in this caring relationship to listen and attend to the students' expressed needs as well as respond to those needs. The person who is cared for (the student) has a responsibility to respond to this caring. Noddings notes that the students' response does not necessarily have to be in gratitude *per se*. Rather, any acknowledgment of the teachers' care may look like staying awake in class or even laughing at a teachers joke. This acknowledgment is sufficient in order for the teacher to feel positive about his or her work and continue teaching. In this way, both the student and teacher contribute to and are required for the caring relationship to exist.

Noddings' theory understands caring as a relational process rather than an individualistic trait or characteristic. Although Noddings suggests that this theory of care is rooted in the attachment theory which states that human beings are by nature designed to care for others and feel cared for by others, (2013), this is an assumption not necessarily shared by others. Adnoy, Arman, Davidson, Sundfor and Karlsson, for example, point out that care theory makes an assumption that people *wish* to connect with others (2014).

Transformative Learning

In addressing micro-aggressions and micro-affirmations, I believe that Mezirow's model of transformative learning is particularly relevant for case managers education.

Transformative learning occurs when student's inherent biases, values and assumptions are transformed when they are brought to their awareness and are challenged. Mezirow writes that learning "transforms a person's frame of reference... to make it more inclusive, discriminating, open, reflective, and emotionally able to change" (2003, p. 58).

According to Mezirow, a person's frame of reference is made up of two components: "habits of mind" and "point of view". Habits of mind can be thought of as a person's habitual ways of thinking and feeling. Habits are made stronger and more durable over time and may be reinforced by cultural, educational, economic, psychological codes. In the context of mental health practice, one such habit of mind is the common belief that people with mental illness require help and that the mental health practitioner is best equipped to provide this help. Educational models reinforce this habit of mind by offering programs in the 'helping' professions and teaching trainees to be "helpers". Treating illness may be one of the most respected occupations in our society confirming this habit of mind.

The other component of one's frame of reference is the point of view. The point of view is less durable than a habit of mind. It is subject to change and modification as a person reflects on their assumptions and biases. Persons may modify their point of view as they gain experience navigating problems and receiving feedback from others. When life experiences do not make sense because old ways of thinking and meaning making do not apply, they are defined as "disorienting dilemmas" (Mezirow, 1991).

The theory of transformative learning provides a language in which to talk about case managers' experiences related to caring about their clients. When a case manager's practices

go above and beyond the call of duty, when they break the rules, a consequence may be an internal struggle between the desire to break these rules and the pressures to uphold them. Transformative theory might consider this struggle a "disorienting dilemma". The experience of caring *about* challenges the workers' preconceived conception of what professional care looks like - for example as reinforced through educational models- and what caring *about* actually feels like in real practice. Transformative learning theory suggests that students need a supportive space where they can sift through their evolving habits of mind and frames of reference. This can be a challenging process. Discussions around mental illness go hand in hand with conversations about oppression, discrimination and power. These topics oftentimes also bring up feelings of shame and guilt which need to be managed in a supportive setting.

Caring about clients requires the acknowledgment that this experience is and should be transformative. Clients expressed the view that they can "just tell" when a worker does or does not care about them. The cues are subtle suggesting that case managers need to be exceptionally self-aware of their habits of mind and points of view. In their discussion of developing counselor cultural competence, Sue and colleagues write that education and training must "promote inquiry among trainees and challenge trainees to experience discomfort and vulnerability" (2007, p. 283). I suggest that Transformative education models may be well suited for this process to occur. Transformative learning happens both in clinicians' training (for example in formal academic institutions) placing part of the onus on educators to facilitate this process. Transformative learning also happens in-vivo; that is, in everyday practice with clients. When working with humans, every situation encountered is unique and requires an individualized process of decision-making. This indicates a need for ongoing support for workers in navigating the real-life demands of their jobs.

The importance of narrative in education has been addressed by many scholars. Rita Charon, for example, asserts that effective practice of medicine necessitates narrative competence, that is, “the ability to acknowledge, absorb, interpret, and act on the stories and plights of others” (2001, p. 1897). Charon proposes that physicians develop narrative competence, called *narrative medicine*, in order to practice with an effective and humane perspective. She contends that when a physician possesses narrative competence, they “can reach and join their patients in illness, recognize their own personal journeys through medicine, acknowledge kinship with and duties toward other health care professionals, and inaugurate consequential discourse with the public about health care” (2001, p. 1897). In a basic example, a physician and a patient meet and a conversation ensues, “...A story—a state of affairs or a set of events—is recounted by the patient in his or her acts of narrating, resulting in a complicated narrative of illness told in words, gestures, physical findings, and silences and burdened not only with the objective information about the illness but also with the fears, hopes, and implications associated with it” (p. 1899). At this point the physician who possesses narrative competence will be able to make meaning of the patient’s experience and attend to the varying needs as expressed-overtly or covertly- by the patient and having a more accurate diagnostic work-up of this patient. Narrative competence means that the practitioner listens carefully, critically and openly.

Morris speaks to the importance of narrative in moral education. He asserts that students “need opportunities to author their own moral stories in dialogue with others” (2002, p. 212). In this context, the narrative competence falls on the students who are encouraged “to think through the moral questions and conflicts of their own lives” (p. 212). In the previous section I suggested that transformative learning could be a valuable model on which to build

an educational framework for mental health case managers. Transformative learning posits that students learn as their preconceived notions, values and assumptions- frames of mind- become known and challenged. For example, students' preconceived notions of what the life of someone with psychosis looks like might be challenged when meeting someone who does not meet this preconceived belief.

Trainees' use of narrative, in this context, would be invaluable. As Morris argues, students need opportunities to author their own moral stories in dialogue with others. There are numerous important questions that need to be addressed in creating these moral stories. Some important questions students need to ask themselves are: what was it like to meet someone with psychosis who is also (as an example) successful? What assumptions did the student make that are being challenged? What factors reinforced these assumptions? What implications do these assumptions have on the student's professional development? As an example, if a student went into the mental health field because they assumed they would be working with patients who were at a "low" level of functioning, what is it like for this student to learn that his or her client is extremely intelligent, educated and successful?

Morris (2011) asserts that students need opportunities to think *with* other voices in order to think about their own stories. Stories from the wider culture, for example novels, biographies or movies are important for students' development of moral agency. In this way, this research is unique and offers such a perspective. In *The Renewal of Generosity*, Frank writes: "A physician once asked me if I had ever expressed "unqualified gratitude" to the doctors who treated me when I had cancer. I hadn't. The other side of the question is how often I felt I was being cared for with unqualified generosity. Not often enough. I regret that, for all of us" (p. 2). The concern expressed here is not situated in mental health practice. However, it does, speak directly to this study. This research has implications for narrative

research. My findings suggest that we need to question the education frameworks in which mental health trainees are taught.

Conclusion

In this conclusion I review the original objectives of this research program. I also reflect on my growth as researcher, and outline my findings in the context of study's three objectives. In the introductory chapter of this thesis, I noted that mental health service users have expressed that care is lacking in the mental health care that they receive. I proposed that I would investigate 'care' as a general construct in the mental health context. I wanted to know how clients perceived the mental health care they received. Did they feel that their case managers cared about them? How so? A crucial component of mental health case management is the ability of case managers to provide recovery-oriented care to the client. Therefore, I sought out the perspectives of case managers as well in order to get a more complete understanding of "care". The purpose of this study was to gain a more complete understanding of "care" in the context of mental health case management so that we may better understand why it is lacking and how we can best support case managers in providing it to clients.

This program of research was guided by three objectives:

- (i) Explore mental health case managers' perceptions and experiences of care
- (ii) Explore mental health clients' perceptions and experiences of care
- (iii) Deepen our understanding of 'care' from both perspectives and develop a preliminary framework to address care in mental health practitioners' education.

The process of conducting of the study contributed a great deal to my own growth as researcher. My reflection on this growth and the insights gained constitutes part of the study's

contribution to knowledge. Reflexivity has two purposes: 1) to help the researcher become more aware of his/her biases; 2) to gain greater insight into the subject of the research. Being reflexive contributes to my own my narrative competence, transformative learning and experience with care.

Moreover, reflexivity is one way in which I hope to show transparency with respect to my position as a researcher. My interest in this project grew out of my experience as a case manager. While practicing, I noticed in team meetings and informal conversation that my colleagues and I each possessed unique ways that we “cared” about our clients. Some practitioners seemed to go “out of their way” more often, believing whole-heartedly that going above and beyond the call of duty was essential to good case management. These practitioners seemed to be more emotionally invested in their clients. They would spend hours with clients even if it meant these hours exceeded the allotted hour-long appointment time. Sometimes these hours fell outside of work hours. Other colleagues insisted on upholding strict boundaries in their relationships with clients. These case managers were more observant of the scheduled hour-long appointment slots, did not go above and beyond the regular call of duty and shared that upholding these rules were “for the clients benefit”. Which case manager’s “care” was better? Which case managers practice was more recovery-oriented? I also noticed a tension between the notion of “caring” for clients and practitioners’ notions of “professional boundaries”. I set out to better understand the meaning of “care

Upon reflection, I can now recognize that at that time my thinking process was in line with a positivist paradigm. I wondered what the single true meaning of care was, and how I could best provide it. I fantasized about providing a “how-to” guide for case managers on how to best care about their clients. My position as a researcher forced me to challenge this search for a single truth, and to look more holistically and critically at the data before me. I had to become more comfortable with indeterminate variables that did not adhere to positivist

paradigms. For example, when I asked clients how they could tell that their worker cared about them, the response “I can just tell” was - at first- disheartening. This response was not going to fit in to my how-to guidebook very well. I pressed on, “but *how* could you just tell?” The responses to this question were just as vague. Clients reported that it was a look in their worker’s eye or the tone of the worker’s voice. Sometimes it was just a feeling that communicated to the client that their worker cared. Looking at the data in front of me with a more critical eye, I realized that perhaps the construct of care could not be molded to fit neatly into a how-to guide. Is there a part of care that is in fact indescribable? That care may be communicated between human beings through subtle and intangible cues is one finding of this research. The question of how to address such subtleties in education is an important question to consider in conceptualizing educational support for mental health case managers. Conducting this research program again in the future utilizing participant observation as a methodology could also add to this question of care in mental health work.

My overall objective was to supplement the current discourse on care with new voices and perspectives by the people who were directly involved in this care. I wanted to explore their narratives. What could we learn from these narratives? I wanted to give voice to people who had received mental health services: a group of people who have been consistently marginalized and oppressed in this society. Did they feel their workers cared about them? How could they tell? What was the relative importance of this care?

I also wanted to give voice to their case managers; another important group of people who have also been said to be at risk. As was mentioned in the introductory chapter of this thesis, Paul Brodwin quotes Rapp in his book about mental health case managers:

“Two of the most oppressed groups in mental health are clients and their case managers... Basically they are the lowest paid, the lowest on the

organizational hierarchy, and are the least credentialed, yet have the most cases and the most ambitious goals established for their work. They also have to complete the most paperwork, go to the same meetings as others, and are the most supervised members of the organization. They have the least control of their jobs and have the least influence over organizational or client matters.”
(Rapp, 1998, 55)

Palmer talks about teachers as the culture heroes of our time

(<https://www.youtube.com/watch?v=iO8pg7Bi4QQ> accessed August 1, 2016). A key finding of this research program parallels Palmers contention and suggests that mental health workers, too, represent a group of champions whose dedication and commitment to their clients may be considered heroic.

The third objective of this study was to deepen our understanding of ‘care’ from both perspectives and develop a preliminary framework to address care in mental health practitioners’ education. In addressing this objective, I drew from three educational models that spoke directly to the participants’ stories. These models speak to the questions: can care be taught? If so, how?

The question ‘can care be taught?’ was discussed first. Given that clients experienced that their worker cared about them through subtle cues, the question of how to address such subtleties in education is an important one. How do you teach someone to care about others? I reviewed compassion-focused therapy; a therapeutic orientation that proposes that care can be communicated through the act of compassion on the part of the practitioner. Compassion-focused therapy asserts that when the practitioner acts with compassion, the client will feel cared about. I also reviewed Nel Noddings’ Care Theory in education. Noddings contends that students learn to care when they feel cared about. Care, in this context, is relational and

reciprocal. The teacher cares about the student and requires that this care be acknowledged by the student in order for the care to be continued. Care Theory would suggest that teaching case management trainees to care about their clients would first start in the classroom. In this classroom the trainees themselves would experience a caring relationship with their teacher, and then through this relationship learn to care about others – such as future clients. This theory touches on notions of modeling; indeed, you teach someone to care about others by modeling for them what this care looks and feels like.

I also reviewed transformative learning in this discussion of how to teach care. Transformative learning is particularly relevant in light of the finding that care is communicated to clients through micro-gestures. It is possible that case managers send messages of care and non-care through subtle cues that are beyond their awareness. Mezirow asserts that when faced with “disorienting dilemmas” which are novel situations that challenge current modes of thinking, transformation occurs. Illness narratives, those are perspectives and stories of patients, add tremendous value to mental health pedagogy. Education must allow room for transformation to happen in trainees. Education must include a space for students to explore their points of view and disorienting dilemmas.

As a brief illustrative example, a case manager might hold the belief that people with psychosis cannot keep a job. When this case manager meets a person with psychosis who has a job, the result is a “disorienting dilemma”. Previous beliefs about psychosis and employment are challenged and this disorientation might surface as a facial expression by the case manager. This “look” then becomes a message of care or non-care; hope or skepticism, encouragement or doubt. The “look” becomes open to interpretation by the client. Although it is impossible to control every look on one's face or how others might interpret this look, this research does suggest that clients may be particularly attuned to such subtleties as a look on one's face. Case managers, therefore, need to be keenly aware of their personal beliefs,

values, assumptions and judgments as these might manifest subtly through a facial expression. The use of narrative in education is relevant here. Case managers need to be prepared to dialogue about their beliefs and assumptions about mental illness.

What struck me the most in pondering the data elicited was the general discordance in how clients and case managers experienced care. When asked about care, clients' talked about connection. They felt this connection in both subtle and overt ways. They spoke of friendship and love and trust. Case managers' stories, on the other hand, were essentially stories about boundaries. When I asked case managers about care, there was a high level of importance attached to maintaining these boundaries. Managing the professional boundary and not caring "too much" were points of discussion.

One of the original contributions of this study is the way it speaks to the dialogue between case manager and client voices and the element of reciprocity, rather than merely presenting two perspectives as if they are independent of each other. This dialogue between the voices has great pedagogical value. This thesis calls for an education that helps workers become more aware of the challenges and tensions around the experience of care. Both narrative and transformative education have a great deal of potential here. As we move towards a recovery-orientation in mental health practice, case managers are encouraged to be person-centered. We are reminded to look at a person beyond his or her illness. There has been a faulty assumption that case managers possess the ability to manage this boundary between person-centeredness and professionalism.

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A.1 McGill University Research Ethics Board II

Certificate of Ethical Acceptability of Research Involving Humans



Research Ethics Board Office
James Administration Bldg.
845 Sherbrooke Street West, Rm 429
Montreal, QC H3A 0G4

Tel: (514) 398-6831
Fax: (514) 398-4644
Website: www.mcgill.ca/research/researchers/compliance/human/

Research Ethics Board II Certificate of Ethical Acceptability of Research Involving Humans

REB File #: 256-1113

Project Title: EXPLORING CONSUMERS AND CASE MANAGERS PERSPECTIVES ON COMPASSION: A CASE STUDY; A STEP TOWARD MENTAL HEALTHCARE AND EDUCATION THAT MEETS THE REAL NEEDS OF REAL PEOPLE

Principal Investigator: Helen Costin

Department: Integrated Studies in Education

Status: Ph.D. Student

Supervisor: Prof. R. Morris

Co-Investigators/Other Researchers: Lily Han, Dara Gallinger, Gillian Pesner

Approval Period: Dec. 18, 2013 to Dec. 17, 2014

The REB-II reviewed and approved this project by delegated review in accordance with the requirements of the McGill University Policy on the Ethical Conduct of Research Involving Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.

Deanna Collin
Research Ethics Administrator

-
- * All research involving human participants requires review on an annual basis. A Request for Renewal form should be submitted 2-3 weeks before the above expiry date.
 - * When a project has been completed or terminated a Study Closure form must be submitted.
 - * Should any modification or other unanticipated development occur before the next required review, the REB must be informed and any modification can't be initiated until approval is received.

A.2 Consent form for clients



**CONSENT FORM (A) FOR PARTICIPATION IN A RESEARCH PROJECT
McGILL UNIVERSITY
DEPARTMENT OF INTEGRATED STUDIES IN EDUCATION**

TITLE: Exploring consumers' and case managers' perspectives on compassion in recovery; a step toward mental healthcare and education that meets the *real* needs of *real* people

PRINCIPAL INVESTIGATOR: Helen Costin, Ph.D Candidate at McGill University
NAME OF ORGANIZATION: Agence Ometz, Montreal

This informed consent form is for mental health consumers at Agence Ometz who are invited to participate in this research project.

This informed consent form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

I am Helen Costin, a Ph.D. student at McGill University in the Department of Integrated Studies in Education. I am doing research on the relative role of “compassion” in mental health services. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

Purpose of the research

Compassion on the part of the mental health provider has been said to be significant in a person's recovery from mental illness. As mental health services strive to become better, we want to explore “compassion” so that we have a better understanding of what it is, what compassionate practice looks like and how we can improve mental health services. We believe that you can help us by telling us what you know about compassion and how you have experienced compassion in the services you have received. We want to learn what compassionate practice means to you and how we can have more of it in mental healthcare.

Type of Research Intervention

This research will involve your participation in an interview that will take about one hour.

Participant Selection

You are being invited to take part in this research because we feel that your experience can contribute much to our understanding and knowledge of mental health services.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate all the services you receive at Agence Ometz will continue and nothing will change.

Procedures

A. We are asking you to help us learn more about the mental health services you have received. We are inviting you to take part in this research project. If you accept, you will be asked to meet with a researcher or myself for approximately one hour to answer a few questions about your experience receiving mental health services.

B. During the interview, I, or the other interviewer will sit down with you in a comfortable place at Agence Ometz. If it is better for you, the interview can take place in your home or a friend's home. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else will have access to the information documented during your interview. The entire interview will be tape-recorded, but no one will be identified by name on the tape. The tape will be kept locked up in a private office. The information recorded is confidential, and no one else except Helen Costin will have access to the tapes. The tapes will be destroyed after 6 months.

- I give permission to be audio-recorded _____
Signature / Date

Risks

We are asking you to share with us some personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

Benefits

There will be no direct benefit to you, but your participation is likely to help us find out more about how to improve mental health case management services.

Reimbursements

You will not be provided any incentive to take part in the research. However, we will give you \$10.00 for your time, and travel expense.

Confidentiality

The research being done in the community may draw attention and if you participate you may be asked questions by other people in the community. We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key. It will not be shared with or given to anyone.

Sharing the Results

The information gathered from this interview will be used for academic purposes only, and will remain completely anonymous. Your identity will not be linked to this data. The knowledge that we get from this research will be shared with you and your community before it is made widely available to the public. Each participant will receive a summary of the results. Following this, we will publish the results so that other interested people may learn from the research.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect the services you receive from Agence Ometz. You may stop participating in the interview or the research study at any time that you wish. I will give you an opportunity at the end of the interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

My academic standing will not be affected by your decision to withdraw from this research.

Who to Contact

If you have any questions or concerns regarding your rights or welfare as a participant in this research study, please contact the McGill Ethics Manager at 514-398-6831 or lynda.mcneil@mcgill.ca

You may also contact Ronald Morris who is supervising this research; Ronald.Morris@mcgill.ca

This research has been reviewed by the Research Ethics Board at McGill University and meets required ethical guidelines. The Research Ethics Board (REB) Office, a unit within the Office of

the Vice-Principal promotes the highest ethical standards of research involving humans with the primary goal of protecting the rights and welfare of the individuals who are participants in research. If you wish to find out more about the IRB, please visit <https://www.mcgill.ca/research/about>

All academic approvals have also been obtained.

Part II: Certificate of Consent

I have been invited to participate in research about improving mental health care. I have read the information provided in this document, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print Name of Participant _____

Signature of Participant _____

Date _____
Day/month/year

If Illiterate:

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____

Signature of witness _____

Date _____
Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands this research, its purpose, goals and implications.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent_____

Signature of Researcher /person taking the consent_____

Date _____
Day/month/year

A.3 Consent form for case managers



**CONSENT FORM (B) FOR PARTICIPATION IN A RESEARCH PROJECT
McGILL UNIVERSITY
DEPARTMENT OF INTEGRATED STUDIES IN EDUCATION**

TITLE: Exploring consumers' and case managers' perspectives on compassion in recovery; a step toward mental healthcare and education that meets the *real* needs of *real* people

PRINCIPAL INVESTIGATOR: Helen Costin, Ph.D Candidate at McGill University
NAME OF ORGANIZATION: Agence Ometz, Montreal

This informed consent form is for mental health case managers at Agence Ometz who are invited to participate in this research project.

This informed consent form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

I am Helen Costin, a Ph.D. student at McGill University in the Department of Integrated Studies in Education. I am doing research on the relative role of “compassion” in mental health services. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

Purpose of the research

Compassion on the part of the mental health provider has been said to be significant in a person's recovery from mental illness. As mental health services strive to become better, we want to explore “compassion” so that we have a better understanding of what it is, what compassionate practice looks like and how we can improve mental health services. We believe that you can help us by telling us what you know about compassion and how you have experienced compassion in the services you have provided. We want to learn what compassionate practice means to you and how we can have more of it in mental healthcare.

Type of Research Intervention

This research will involve your participation in an interview that will take about one hour.

Participant Selection

You are being invited to take part in this research because we feel that your experience can contribute much to our understanding and knowledge of mental health services.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate your employment at Agence Ometz will continue and nothing will change.

Procedures

A. We are asking you to help us learn more about the mental health services you have provided. We are inviting you to take part in this research project. If you accept, you will be asked to meet with a researcher or myself for approximately one hour to answer a few questions about your experience providing mental health services.

B. During the interview, I, or the other interviewer will sit down with you in a comfortable place at Agence Ometz. If it is better for you, the interview can take place in your home or a friend's home. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else will have access to the information documented during your interview. The entire interview will be tape-recorded, but no one will be identified by name on the tape. The tape will be kept locked up in a private office. The information recorded is confidential, and no one else except Helen Costin will have access to the tapes. The tapes will be destroyed after 6 months.

- ☐ I give permission to be audio-recorded _____
Signature / Date

Risks

We are asking you to share with us some personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

Benefits

There will be no direct benefit to you, but your participation is likely to help us find out more about how to improve mental health case management services.

Reimbursements

You will not be provided any incentive to take part in the research. However, we will give you \$10.00 for your time, and travel expense.

Confidentiality

The research being done in the community may draw attention and if you participate you may be asked questions by other people in the community. We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key. It will not be shared with or given to anyone.

Sharing the Results

The information gathered from this interview will be used for academic purposes only, and will remain completely anonymous. Your identity will not be linked to this data. The knowledge that we get from this research will be shared with you and your community before it is made widely available to the public. Each participant will receive a summary of the results. Following this, we will publish the results so that other interested people may learn from the research.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect the services you receive from Agence Ometz. You may stop participating in the interview or the research study at any time that you wish. I will give you an opportunity at the end of the interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

My academic standing will not be affected by your decision to withdraw from this research.

Who to Contact

If you have any questions or concerns regarding your rights or welfare as a participant in this research study, please contact the McGill Ethics Manager at 514-398-6831 or lynda.mcneil@mcgill.ca

You may also contact Ronald Morris who is supervising this research; Ronald.Morris@mcgill.ca

This research has been reviewed by the Research Ethics Board at McGill University and meets required ethical guidelines. The Research Ethics Board (REB) Office, a unit within the Office of the Vice-Principal promotes the highest ethical standards of research involving humans with the primary goal of protecting the rights and welfare of the individuals who are participants in

research. If you wish to find out more about the IRB, please visit <https://www.mcgill.ca/research/about>

All academic approvals have also been obtained.

Part II: Certificate of Consent

I have been invited to participate in research about improving mental health care. I have read the information provided in this document, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print Name of Participant _____

Signature of Participant _____

Date _____
Day/month/year

If Illiterate:

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____

Signature of witness _____

Date _____
Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands this research, its purpose, goals and implications.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____
Day/month/year

A.4 Research advertisement in community center monthly newsletter

PARTICIPATE IN INTERESTING AND VALUABLE RESEARCH!

WHAT? A researcher at McGill University is seeking people to participate in a study designed to improve mental health services. This exciting and important research project is directed by Helen Costin, Ph.D Candidate in the Department of Integrated Studies in Education at McGill University.

You are eligible if you are:

...an adult and you have been diagnosed with a mental illness (current or past)

or

... a mental health case manager

All participants will receive \$10 cash at the time of the interview as compensation for your travel and time. Participation includes a 60-minute interview about what good service looks like. All personal information is **strictly confidential** and will not be shared with third parties.

WHEN? At your convenience! Morning, afternoon or evening

WHERE? At any location that is convenient for you. Perhaps in the comfort of your own home or at a quiet coffee shop nearby

HOW? Please contact HELEN COSTIN directly at (514) 833-0008 or send an e-mail to Helen.Costin@mail.mcgill.ca

Please feel free to call or email with any questions you may have.

Looking forward to hearing from you!



McGill

Ronald.Morris@mcgill.ca

Project supervisor: Ron Morris:

A.5 Case manager demographic form

SOCIO-DEMOGRAPHIC FORM FOR CASE MANAGERS

1. What is your academic background? (example; Social Work, Psychology, Science...)

2. What kind of preparation / training in case management have you had? (example, CEGEP diploma, Bachelor's degree, Graduate degree, additional professional development...)

3. Are you a full time or part time worker?

4. What is your nationality?

5. What is your cultural/ religious/ spiritual background?

6. How many years have you worked in the helping profession?

7. How many months/years have you worked at Agence Ometz as a case manager in the mental health department?

A.6 Case manager demographics

1. What is your academic background? (example; Social Work, Psychology, Science...)

- 2 Social Work
- 3 Diplome d'Etude Professionnelles (DEP) in Special Care Counselling

2. What kind of preparation / training in case management have you had? (example, CEGEP diploma, Bachelor's degree, Graduate degree, additional professional development...)

- Bachelor of Social Work
- Seminars: DBT for clients with Borderline Personality Disorders, suicide ideation, anxiety disorders, depression, substance use and addiction, schizophrenia, mental health recovery and housing
- DEC in Social Counselling, Bachelor of social work, graduate certificate in grief counselling
- 2 Special Care Counselling and professional experience

3. Are you a full time or part time worker?

- 5 Full time

4. What is your nationality?

- 3 Canadian
- Italian
- Jewish Canadian

5. What is your cultural/ religious/ spiritual background?

- Agnostic Buddhist
- Roman Catholic
- Catholic
- Catholic (not observant)
- Jewish

6. How many years have you worked in the helping profession?

- 17 years
- 10 years
- 22 years
- 28 years
- 10 years

7. How many months/years have you worked at Agence Ometz as a case manager in the mental health department?

- 1 year
- 10 years
- 2 years
- 18 years
- 8 years

A.7 Sample Narrative:

Client narrative:

Well I had one case worker ... I felt like I had a good rapport with her... I got the idea that she enjoyed talking to me... it was very off the cuff, very relaxed. After she stopped working there... she went out of her way to call me ... It's almost like saying I'm not just a completely indifferent case worker...on some level, we were friends ... she wished me luck with whatever projects I had going on... that stigma wasn't there ...we are basically on the same level... making jokes and stuff like that... there's no pretense as in doctor-patient or...normal person/sick person...she wasn't judgmental...she had a really good attitude... that is how I evaluate a case worker... my current one is pretty good at pressing buttons...making you talk, and then you generally feel better...you get something off your chest ...especially for...a half hour...I have felt relief on a number of occasions...There are also ... practical things you go there for... like your taxes and so on...I have learned how to organize my life better ...they tend to be militantly organized...knowing who to call...I like that. It helps me...manage things.

...A lot of times these workers or psychologists... give me a bad feeling... they don't mean to, it just comes through. It just kinda makes me feel like some kind of monster, some kind of freak... It's a subtle thing. I can tell you some examples... of being insulted... I'm a fairly funny person. I tend to make a lot of jokes... one of my workers said to me "you people kill me" ...the "you people" thing means ...'you guys, all you...crazy people' ... I don't really ... put myself in the same category ...I'm...very atypical... highly functional ... I had a lot of friends...nobody would really think that I had been through what I had been through... So I kind of grew up with this... duality where I've been through this terrible stuff...But then I... come off as a regular person and so it's very important for me and my clarity... to reconcile that duality and when a worker ... tell[s] me I'm just a textbook... I find that it's inaccurate and... insulting and it's negating all the complexity and the problems of my condition... [another worker]... used to say "I think you're a nice Jewish boy" ... I ... thought that was a stupid thing to say... I never like to be ... stereotyped...there was a lot of presumption there... I ... thought it was very unprofessional, disrespectful ... small-minded... it's just making me small...that's part of the nightmare...You shouldn't be diminishing someone or referring to them like a cute cliché ... I remember ... studying "One Flew Over The cuckoo's nest" ...in high school ... English class and I just remember thinking what's wrong with these people? I'm not really comfortable around mentally ill people. ...Like if you look at me I'm not...I don't really exude a lot of that stuff. Like I'm not screaming and I'm not fidgety...

One time a psychologist ...started talking to me in a bar. And I knew exactly who she was...She didn't know who I was...and then she saw me ...in the lobby [of the hospital] and she just kinda ... put her head down and she kept [walking]... [she didn't want to] get involved with someone who has a big psycho history. The doctors and the case workers... They have a lot of self esteem issues and they have to really separate themselves...[they think] no way am I gonna be on the same level as someone like that...one worker ... I had known her for a very long time...I asked her once if she could ... check out... [some of my music] up on this site...She wanted no part of it... It's a matter of just a couple of minutes on your own time...I found that kind of offensive. You know the problem with her is she's so bloody pedantic... I really felt like a number... like I was just someone to put in a slot...regardless of what my ... experience was... it didn't matter if I needed attention or not... it was a lack of respect.

...But one time...I needed a couple of pills before I renewed my prescription. And so [another doctor] came up to me and he had this little bottle with like 2 pills in it... I can give him credit for that...

because he didn't have to... and he said these pills have been sitting in a drawer for a while... So he said the worst case scenario is they wouldn't be as effective as they would if they were recently issued. So I said ok thanks very much. And ... as I walked away I heard him say to the nurse 'we pulled that one from the cyanide drawer' ...he was joking...he was kind of ... arrogant ... So I turned around and ... he was just kinda ... stunned and then the nurse said to him 'go apologize'. So he said I'm sorry about that remark...I was so out of it, I did not care. I was just trying to survive... he could have spat on me. I didn't care. I was just trying to get through this horrible thing. I didn't care about being respected or disrespected...you're gonna put up with all sorts of things that you normally would not put up with. It's just a circumstantial thing.

You know, I prefer...if someone is cold... then if they're subtly diminishing or disrespectful, I don't really care...I don't expect you to care about me. It's a bit much to expect a stranger or a professional to care about you... I just expect not to feel worse about myself. I expect not to get insulted or patronized. So, its more a question of respect than actually caring... I mean, you can't force someone to care. What are you going to do, make all these people study Buddhism and open their hearts? Or take yoga? I don't know...I just expect not to be dissed. I get dissed worse [by professionals] than by strangers because they don't know there's anything up with me...I get dissed worse by these workers just because they know this about me.

You can't teach this. This is the real person coming through. You can't teach someone to be open-minded or not to be arrogant. These are people... with good intentions but they have a way of diminishing you. You can't really teach that in a profession...the case worker that I really liked, the thing about her was that she didn't seem to know much at all about psychology...But it didn't really matter because she was great. I loved going there and she always put a smile on my face and she just gave me a boost. I think she really did relate to me as an equal.

*Note: I would like to add a sample case manager narrative but I worry that because there were only 5 case managers in total, their anonymity will be compromised.