

**Individual Meanings, Co-Constructing Narratives of Identity and Community in Journeys  
with Schizophrenia**

by

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### **Author's Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

## Abstract

Through my previous journey as a recreation therapist in the mental health field I enabled a dominant narrative that favoured outcomes, independence, and pathological identities. I also envisioned community to be the ideal setting for persons with schizophrenia. Upon reflection, the communities I worked in were *institutions without walls* (McKnight, 1995). In this narrative study, I used critical thought to shed light on understandings of identity and community for people who experience schizophrenia and explore how dominate narratives segregate people living in community. The purpose of this critical narrative study was to explore identity and community for three persons with a schizophrenia spectrum disorder. Guiding the purpose are three research questions: What dominant cultural narratives play out in participants' communities? How do those narratives constrain participants' identities and positions in community? How do persons take up or challenge these constructions in their own narrative of self? The narratives consisted of an audio-recorded conversation and continued through community walk-a-bouts with each participant. A personal reflexive journal guided me through the research process before, during, and after meeting my participants. The narratives told a different side to the experiences had with schizophrenia than previously held. The three narratives brought forth counternarratives to notions of power, control, and dependency. The narratives presented resilience against defective identities and stigma. The findings suggest a lack of accessible resources and communication that exist in "ideal communities." Further exploration of peer advocacy and participatory action research would be of benefit for future research.

## **Acknowledgements**

Thanks.

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## Chapter One: Introduction to the Narrative Study

*I was traveling on the city bus one February night from my home to the local mall here in [City B]. As people were getting on and off the bus at stops along the route I noticed what seemed like two health care service providers get on the bus, followed by a young gentleman who may have been a consumer of some mental health services. He was smiling and seemed like a friendly guy. He said hello to the two workers, clearly recognizing them from whatever agency they worked. He sat next to one of the ladies, who looked like she was in her fifties. She seemed uncomfortable with him sitting that close to her. In a friendly manner he asked her what part of town she lived, a perfectly appropriate question in that particular context. They were on a bus together, it was after work, the question didn't seem to have any harm behind it, and vague enough to keep some privacy. I observed her body language as he spoke to her, she seemed to have built up walls, some barriers to block him out. She said coldly "I don't discuss those things" which left the gentleman with a guilty look of shame on his face. It seemed like the coldness of her words chilled over his body, blowing the smile and friendly attitude too far away for him to hold on to. She made it seem like he asked an extremely personal question but in fact, in that situation he asked a perfectly appropriate question. "What a bitch", I thought to myself. But what would I have said? Would I give the same response she did? Four years ago I would have most likely given a similar response. At one of my past jobs as a recreation therapist we didn't even display out last name on our work badge when working on the mental health unit. Where does this narrative come from? How could she or I have answered that question differently? She was on the bus that went to her house; did she not think that he would take notice of where she got off the bus? She could have told him a neighbourhood or intersection or a bus stop. Or a landmark that gives no number or street name if she wanted to keep some privacy, but to say she doesn't discuss those things made the inequities in their power so evident since every personal detail about him is known by every staff and student who works with him. Where is his privacy? So when she got off the bus and he could see where she lived, she looked foolish, brash, and cold. She othered him in a way she can't take back, in the community no less!*

When I first started working as a recreation therapist in community mental health, I struggled with similar situations. My fears of being attacked or not knowing what crazy or bizarre behaviours to expect from people led me to make preconceived judgments about persons with a mental health disability. At first, I struggled to feel comfortable and safe when working with persons with schizophrenia; however, I neglected to consider their feelings and comfort. I became so wrapped up in my own fear that it hindered my ability to develop a caring and supportive relationship. The nature of the recreation therapy profession can create a more meaningful engagement and understanding of a person's identity as discussions around leisure

interests, likes, and dislikes attempt to explore the core of a person. As time passed, I became less fearful and started to really care for the people I worked with, just as I felt them caring for me. Indeed we created a relationship – a reciprocal authentic relationship, something that some recreation therapy professionals would advocate not to do for a naïve sense of protecting the client from getting hurt. I learned that forming a caring relationship was a risk to the person that was not ours (mental health service providers) to safeguard. When I started to let go of these relationship safeguards, it helped me become a better recreation therapist by supporting the persons I worked with and by building a trusting relationship. Saks (2007) discusses how when people who cared for her built those type of authentic, reciprocal relationships those people had the biggest impact on her wellbeing and quality of life. The way we do research can be looked at in a similar way. As Dupuis (1999) reflected on bringing her own doubts and questions of herself into the research, I hope to do the same. As she notes, “Yet my human self not only played a role in what I chose to study, it also played a role in which questions I would ask, how I would design the research, and how I interpreted my data” (Dupuis, 1999, p. 46). A reflective journal supported my reflexivity throughout the research process and helped to ensure I was present in all aspects of the study.

Danforth (1995) suggests a possibility for the un-learning of self-identified pathology that occurs through inclusive programming. This requires a critical approach. Using a Marxian understanding of class hierarchy, Danforth (1995) describes that critical theory as “engages the assumed, objectified realities of language, knowledge, work, and institutional processes in terms of the social relations of dominance and subjugation” (p. 139). Danforth (1995) used a critical theoretical approach for his study on “those considered emotionally disturbed” children. While I explored narratives of persons with schizophrenia, there was a similar power struggle as their



human rights have been withheld or suspended. In this narrative study, I used critical thought to shed light on understandings of identity and community for people who experience schizophrenia and how current dominant narratives segregate people living in community.

**The purpose of this critical narrative study was to explore identity and community for three persons with a schizophrenia spectrum disorder.** This narrative study focused on three persons with a schizophrenia spectrum disorder living in a community-based setting and involved in a recovery process with a mental health service provider. Three research questions guided this study:

1. What dominant cultural narratives play out in participants' communities?
2. How do those narratives constrain participants' identities and positions in community?
3. How do persons take up or challenge these constructions in their own narrative of self?

Narrative holds open space for people to story their own lives and in doing so, to make meaning and construct identity. Danforth (1995) advocates narrative inquiry for people who have been marginalized as this methodology is not limited to the pathological conditions by which they have been labeled. Each person will be known as the *narrator* of his or her story and will be referred to as such for the remainder of this thesis. Since there are different ways of experiencing schizophrenia and significant differences in supports and resources available to each person, this narrative research explored how persons with schizophrenia know identity and community among the multiple and dominant narratives constructed in society. In the following sections, I draw on the literature to consider some of the usual narratives that shape the lives of persons

with schizophrenia. Lenses from critical theory (and one from postmodern thought) are used to illuminate these narratives.

## **Identity Narratives of Pathology and Defect**

Narratives of identity that shape the lives of persons who experience schizophrenia have been explored in journeys with schizophrenia. In the literature, five main narratives about identity emerge from the presence of the medical model and shape how we think about and speak about persons with schizophrenia. These narratives frame non-medical problems as medical conditions that require medical rather than social solutions (Devine & Sylvester, 2005; Gadacz, 2003).

### **Identity as pathology**

In dominant narratives framed within the medical model, people are defined by their symptomology and pathology. According to the Government of Canada's (2006) *Human Face of Mental Health and Mental Illness* report, schizophrenia is defined as a serious brain disease with common symptoms such as mixed-up thoughts, delusions, hallucinations, lack of motivation, lack of insight, and social withdrawal. The American Psychological Association ([APA], 2013) defines schizophrenia similar to the Canadian report however excludes "mixed-up thoughts" and includes more categorical symptoms including grossly disorganized or abnormal motor behaviour (including catatonia). A diagnosis of schizophrenia is made when a person exhibits one of these symptoms for an approximate time period of six months (APA, 2013). Assessing for common symptoms of schizophrenia involves using a number of different measures (Abnormal Involuntary Movement Scale, Brief Psychiatric Rating Scale, Positive and Negative Syndrome Scale, and Scale for the Assessment of Negative Symptoms to name a few) implemented by the attending psychiatrist, psychologist, or general practitioner (APA, 2013).

A person displaying one or more of five domains within the schizophrenia spectrum for at least six months will receive a diagnosis of schizophrenia (APA, 2013). The five domains include: (1) delusions including persecutory, referential, somatic, religious, and grandiose fixed beliefs not easily changed when presented with conflicting evidence; (2) hallucinations or “perception-like experiences that occur without an external stimulus” (APA, 2013, p. 87); (3) disorganized thinking including speech, switching from one topic to another, answering to questions in an unrelated way, or can be completely incoherent; (4) grossly disorganized behavior that is unpredictable, from childlike “silliness” to agitation (APA, 2013); and (5) negative symptoms such as diminished emotional expression including “reductions in the expression of emotions in the face, eye contact, intonation of speech (prosody), movements of the hand, head, and face that normally give an emotional emphasis to speech” (APA, 2013, p. 88), and avolition or a lack of engagement or motivation in purposeful activities that are self-directed.

Further refined in the dominant narrative is the identification of who is included in the diagnosis of “abnormal” and who is not. In the *Human Face of Mental Health and Mental Illness*, the prevalence of schizophrenia is generally accepted as 1% of the general population, and men and women are affected equally, although the onset of the disorder is earlier in men than women (Government of Canada, 2006). Some estimates are anywhere between 0.2% and 2% of the population; however, this differs according to the instruments used to measure the disorder (Government of Canada, 2006)<sup>1</sup>.

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<sup>1</sup> The reason the Canadian Government can only estimate the prevalence of people with schizophrenia is because “the survey team did not reach those individuals with schizophrenia who were homeless, in hospital or in supervised residential settings” (Government of Canada, 2006, p. 75).

## **The defective identity**

The American Psychological Association (2013) presents characteristics of schizophrenia such as grossly disorganized or catatonic behaviour, affective flattening, social/occupational dysfunction (interpersonal relations, self-care, etc.), and disorganized speech that could impact a person's ability to be included in a society that does not provide supports. Within the schizophrenia spectrum, a diagnosis of schizotypal personality disorder is characterized by reduced capacity for close relationships and cognitive or perceptual distortions. This is reminiscent of Peter's (2000) work on the construction of a *defective identity*. A defective identity is portrayed in case files depicting deficiency in many different areas; the person is identified as incompetent, unable to learn, or having behavioural problems. Peter (2000) claims this limits the support of that person by having this defective identity categorized by the health care system, and then re-enforced through society. The defective identity is created in the health care system and then transitioned into the community and society at large as being the person's social identity. This notion of the defective identity is advanced in narratives that further problematize the person. Some persons with schizophrenia were also labeled "too difficult" for community placement (Sealy & Whitehead, 2004) suggesting the behaviours and overall functioning of those persons could not be supported by their communities.

The defective identity then needs *improving* for the person to be able to be placed in a community. Aubin, Stip, Gélinas, Rainville, and Chapparo (2009) explored how negative symptoms of schizophrenia affect community functioning. Similar to other studies negative symptoms were associated with lower overall community functioning of persons with schizophrenia (Insel, 2010). Effective medications have been linked to decreases in negative symptoms of schizophrenia (Aubin et al., 2009). In this narrative of the defective identity,

medications seem to be the answer to effective treatment as they improve the person for ideal community functioning.

I am reminded of a vignette of my experience working on a community treatment team specifically dealing with persons labeled as difficult. A nurse on the team, who had been working in the mental health system for over 20 years, was having a particularly troubling time making the transition from in-patient care to out-patient or community care. “I wish there was a manual of how to deal with this stuff, it’s a lot different from the inpatient work,” she said to me. “I want a script of what to answer to questions Johnny (pseudonym) asks me,” she continued. “They don’t seem to need anything from me, all I seem to do is hand out meds,” she concluded. However she was unable to see the complexities of recovery in the community and upheld the defective identity of the persons in her caseload even though no symptoms were present at that time.

### **Connecting identity and greater health risk and dependency**

Once the identity has been secured, there are further implications as the narrative continues. Schizophrenia is described as placing a person at further risk. This narrative is often constructed in statistics. For example, schizophrenia places a person at risk of hospitalization. It is one of the leading reasons for hospitalization out of all mental health disabilities, with 19.9% accounted for in general hospitals and 30.9% in psychiatric hospitals (Government of Canada, 2006).

Schizophrenia is also described as placing individuals at greater health risk. The Government of Canada (2006) notes that in the early phases of onset, schizophrenia could lead to disruptions in sleep, inability to relax and concentrate on school or work. The chapter found that

approximately 80% of persons with schizophrenia abuses substances during their life. The dominant narrative also outlines the social health of persons with schizophrenia. An alarming statistic from the Government of Canada's (2006) report found that 60%-70% of persons with schizophrenia are unmarried, have limited social networks or supports. The Government of Canada (2006) then states these limited social networks leads to ongoing social problems and as a result we see an over-represented number of persons with schizophrenia in prison or homeless, and 10% of persons with schizophrenia will commit suicide. As this dominant narrative goes, poor social health is related to poor recovery, suicidal ideation, and violence.

The Government of Canada (2006) report also indicates health risk for family members of people with schizophrenia. The report notes that the primary caregivers of persons with schizophrenia are family members to whom the majority of financial, social, and physical (to name a few) responsibilities fall (Government of Canada, 2006).

The culmination and continuation of this dependency narrative is connected to call for deinstitutionalization to a community setting and its critiques which shed light on the reliance of persons with schizophrenia on the health care system, family members, and forced into poverty and congregated housing. This narrative also gives ways to narratives linked to advocacy for persons with schizophrenia which call for improvements in housing conditions, education availability, and other structural interventions to enhance the person's quality of life, sense of satisfaction, and well-being (Packer, Husted, Cohen, & Tomlinson, 1997).

### **Identity of the defective consumer**

The narrative of the defective consumer is brought about through ideas such as *mental health literacy* and *social cognition*; that is the defective consumer is the one who lacks the

literacy to read the landscape of community services and the social cognition to read and engage with people. Research suggests that improving the knowledge persons with schizophrenia have about existing treatment options could improve their help-seeking abilities (Marcus & Westra, 2012). This has been termed *mental health literacy* and is defined as the ability to understand the disability well enough to make treatment decisions (Kurtz, Rose, & Wexler, 2011; Marcus & Westra, 2012). Few studies have explored the mental health literacy, especially in Canada (Marcus and Westra, 2012). The notion of *mental health literacy* described by Marcus and Westra (2012) suggests youth, in particular, are not seeking proper mental health care due to poor understanding of mental illness and how to access supports. The idea that persons with schizophrenia lack knowledge and education about their disability leads to services devoted to informing those persons the limits they have been assigned.

In contrast to the idea of mental health literacy, Pijnenborg et al. (2009), *social cognition* was the best predictor in community functioning compared to general cognition or negative symptoms. Pijnenborg et al. (2009) conceptualized social cognition based on Brothers (1990) definition as “mental operations underlying social interactions, which include the human ability and capacity to perceive the intentions and dispositions of others” (p. 239-240). This idea of social cognition would imply that the defective consumer is one who is unable to perceive the intentions and dispositions of others.

### **Constructing personal and social identities in communicative practice: A different way forward**

As Hutchison & McGill (1992) describe, “Segregation and congregation lead to further stigmatization and ostracizing of the person by accentuating differences” (p. 19). In many mental health disabilities, a concern with acceptance of the diagnosis by the person is a difficult issue,

especially as it leads to stigma (Roe & Davidson, 2005). Farone (2006) indicates the core issue of community integration for persons with a mental health disability is for an achievement of a sense of self, free from symptoms or labels that are restricting and constraining. Similarly Lysaker et al. (2007) study of persons with a schizophrenia spectrum disorder to have better social functioning if they rejected stigma associated with the disorder and if they accepted their illness. Rejecting the stigma and accepting the illness was moderated in the study by higher hope and self-esteem and better adaptation to the illness of the participants led to improved social functioning in the community. But how?

Foucault (1997) states “our science enables us to call your madness a disease, and consequently we doctors are qualified to intervene and diagnose a madness in you that prevents you from being a patient like others: so you will be a mental patient” (p. 49). A power dynamic takes place between doctor and patient in every hospital, clinic, and ward; however, does it occur in the community? How does this power dynamic contribute to the person’s narrative in terms of identity formation?

What Danforth (1995) has observed by using narrative inquiry are rich texts of life experiences drawn from the margins of society, a space beyond the logic, a truly alternative perspective for a deeper understanding. Similarly, in Schneider’s (2003) research, focuses not on *what* identities were created through the narrative process, but rather on *how* people constructed identity in certain social interactions; how schizophrenia “is used as a resource for constructing identity” (p. 190). Schneider’s work is an important standpoint in my viewing the importance of identity construction; however this study will look at both aspects of identity – both *what* and *how* as both are used for critical thought. Schneider (2003) regarded the self as fragmented, as a product of active construction from moment to moment through social interactions. The self is in



always a state of change, losing any sense of one static identity but rather a free-flowing formation that adapts to the social environment the person is found in. Identity then according to Schneider (2003) is to be understood:

Not as a fixed characteristic of individuals, something we simply are or have, but rather as something actively constructed and reconstructed in communicative practice. We assemble and negotiate identity in the course of social interactions as we take up or resist the larger cultural discourses within which our lives are embedded, and our identity negotiations in turn reinforce or reshape those larger cultural discourses (p. 186).

Narratives of identity may focus on negotiations and resistance to placement in and practices of power related to categories. Identity is then explored from a relative and contextual categorical view, the category one seeks to put self in, and the category imposed upon them by society (Schneider, 2003). Bagatell (2007) discussed two possible forms of identity: *personal identity* and *social identity*. The categories are then subject to negotiations and maintenance similar to identities because of the way they are used in social interactions (Schneider, 2003).

Identity is shaped by the practices and structures that exert power to shape our lives. One of the most significant Canadian reports on mental health came out on May 9<sup>th</sup>, 2006 from the Standing Senate Committee on Social Affairs, Science and Technology. The report was called *Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada*. This report included dozens of personal stories that shed light onto the current issues and problems persons face in society. Included in the multiple voices was the following story of James on his frustration with the system and of how he constructs his identity:

In short, I gave up all hope in life. I no longer have any hope or expectation that I will recover, nor do I feel that the government will ever provide me with any kind of meaningful treatment to help me overcome this illness. I live in a single room, alone, where I live out my days. The only reason I haven't killed myself is to spare my parents the pain it would cause. I have never turned down a treatment, not even experimental drugs which I have tested on a couple occasions. However, without an advocate or a willing psychiatrist, I'm in no condition to face the continual rejection by specialists who hear my story and feel they can't help me. So by giving up all hope I never find myself forced deeper into depression by a rejection and the quashing of hope. (The Standing Senate Committee on Social Affairs, Science and Technology, 2006, pp. 3-4).

Bagatell (2007) proposes a question when discussing identity and the power of discourse to a person, which is of greater importance, personal identity or social identity? Bagatell (2007) shares a story of a young man named Ben with autism who is struggling to *fit in* and belong to a community, group, and friendship circle. What Bagatell discovers is that Ben's *personal identity* changes as he is introduced to different perspectives and ways in which the label of autism can unfold. For Ben that meant going to a conference run by the Autistic Adults Coming Together (AACT) and hearing the different voices of people who experience Autism. AACT was founded by people with Autism who felt a need for a community (Bagatell, 2007). The social adaptations that Bagatell believes are important for the identity to change are missing in this study. Ben was "discovering how to orchestrate these voices and, in the process, author himself" (Bagatell, 2007, p. 423), regardless of the social world around him. To change the social perspective for Ben and others with a disability requires new thought and approaches on the process of accepting persons with disabilities into communities across Canada.

Ben changed his personal identity by learning and embracing the wide scope and fluidity of such label, however did his social identity change? Schneider (2003) discussed ways in which a person diagnosed with schizophrenia may object to the identity imposed on them by either disputing membership in that category, or they can dispute the meanings and boundaries of the category. In Schneider's analysis of narratives of schizophrenia identity, the author saw how persons felt the need to distance themselves or disassociate themselves altogether from the negative meanings of the category of schizophrenia and how much effort they apply to do so on a regular basis.

In an alternative narrative, identity is understood as fluid and multiplicitous and therefore the categories needed to problematize schizophrenia are challenged. Delanty (2003) states that self-identity is a major theme in postmodernist thought. Similar to Estroff (1989), Delanty (2003) states that within every self is another self, a multiplicity of selves. Estroff (1989) states that "schizophrenia is more than an illness that one has; it is something a person is or may become" (p. 189). Estroff (1989) defines the self as "a fluid process, the pace and rhythm of which varies over time and by context or audience" (p. 190). Multiplicity of self is acknowledged by Estroff (1989); however the author distinguishes between two selves; private and public. The author furthers the distinguishing as inner and outer, secret and shared, individual and social, and subjective and objective. By using narrative inquiry, the narrators will be given an opportunity to shed light on their unique story, a firm sense of self, and hopefully a feeling of positive difference (Fullagar & Owler, 1998). The stories allow us to reflect on what the narrators like and do not like, allow them to reminisce of the ability to overcome personal struggles and fears, and learn new things. However, one of the most significant developments in the past few decades in the social sciences is the insight that society is made and imagined, that it is a product of

human beings rather than the expression or reflection of some underlying natural order (Touraine, 1981; Unger, 1987, as cited in Gadacz, 2003).

### **Shifting Narratives of Community**

Inherent in identity narratives described in the previous section is an underlying narrative emphasizing a goal of independence, and the shortcoming of the individual who is not able to achieve independent functioning in community. This growing emphasis on individualism and independence in community recreation and leisure field is noted within Western society, at the expense of an emphasis on relationships and the collective (Arai and Pedlar, 2003; Chan, Ungvari, Shek, & Leung, 2003). This emphasis on individualism views independence in community-based placement as the end goal of treatment. This lies in contrast to other models such as the social model or a traditional Chinese socio-cultural tradition of meeting the needs of others. A similar critique was raised for therapeutic recreation by Dieser, Magnuson, and Scholl (2005) who suggest existing programming emphasizes Euro-North American individualism and focuses on individual outcomes. Providing a cross-cultural critique they note that Euro-North American individualism makes assumptions about human development and excludes certain people with other views such as Asian American awareness of mutual interdependence.

These challenges to individualism led many authors to explore the person-in-community and how we create spaces in which relationships form the basis of community living. Modern narratives of community include: deinstitutionalization and the “ideal” of community, and narratives about safety and belonging or relational narratives about findings one’s place in community. A third understanding of community, a postmodern concept of community as fluid and boundary-free, provides a counter-narrative that can shed light on other narratives once they

have been heard. These shifting and often contested community narratives are explored in the following sections.

### **Deinstitutionalization: Being *in the ideal of community***

The narrative of deinstitutionalization may have the largest impact on the lives of persons with schizophrenia. Deinstitutionalization primarily began in the late 1960s and 1970s. The movement in Canada was away from large psychiatric hospitals dislocated from community to smaller organizations of support in community. This led to people being forced to leave the confines of the hospital or facility (from what some considered being home) into a community (Sealy & Whitehead, 2004). As persons with a mental disability were being moved into community as a result of deinstitutionalization, the hope was that community-based health services were to increase and expand to address the needs of people now living in the community (Hutchison & Potschaske, 1998). A 40-year empirical analysis by Sealy and Whitehead (2004) of Canada's psychiatric services reveals three hoped for outcomes of deinstitutionalization. The first outcome was to be a shift from *dependence* on mental health hospitals/institutes. This dependence still exists and was transferred to outpatient teams, or family members. The second outcome was to be an increase of mental health beds in general hospitals. This however, continued a narrative of dependence of the health care institutions. The final outcome was to be an increase in per capita spending on community-based psychiatric services. These outcomes suggest persons with a mental health disability need to be integrated into mainstream health care and not segregated into isolated facilities and services.

The narrative outcomes is a focus on shifting dependence from formalized institutions to community-based services, and communities as the ideal living space for persons with a mental health disability. The narrative of being placed *in* community is related to the quality of life of

the persons after discharge. Prince and Gerber (2005) found that simply having physical presence in the community is associated with greater overall life-satisfaction. Gerber, Coleman, Johnson, and Lafave (1994) found that when a person was placed in community, their living standards and social skills improved which meant a drop in hospital re-admissions and overall length of stay in hospitals. People were less likely to need the same support they were receiving in hospital now that they were in the community. What Gerber et al.'s (1994) study lacked is why and how these changes occurred and what support was given in the community to have this recovery effect. Being *in* community is not necessarily a panacea. In some cases, communities were not able to accommodate increasing needs of persons now living in the local neighbourhoods and cities (Warner, 2004). Community becomes less able to support and nurture persons. Does this make community the ideal place or experience for persons with schizophrenia? In rare cases, persons who experience a psychotic relapse were treated briefly in hospitals and discharged to no fixed address according to Warner (2004). Cycles developed due to inadequate community living arrangements and persons were then labeled as *revolving-door patients*.

### **Safety and belonging: Critical relational narratives about being *of* community**

Shortly after initiation of the deinstitutionalization movement, a counter-narrative arose. Many outcomes that were the promise of deinstitutionalization (decrease of dependence being one of them) were not achieved, and other issues were exposed. The community living movement began to raise concerns about the quality of life of the people involved in the shift (Pedlar, 1990). For persons making the transition from hospital to a community, an opportunity to develop meaningful relationships with others was deemed as being as important as the previous emphasis on “bricks and mortar” and hospital beds. McKnight (1995) discussed the difference between being *in* community (spatially) and being part *of* a community and belonging

to a community (relationally). A person does not simply belong to a community by placing a person into these communities that are “institutions without walls” (McKnight, 1995, p. xii).

Farone (2006) emphasized community as a *space* of security. Studies of community integration reveal rather narrow participation *in* community. The participatory mapping study by Townley et al. (2009) found most participants stated home was where they spent the most time in and experienced a sense of belonging. Within the proximal ‘zone’ persons would choose their home to partake in leisure more often than other facilities. This may mean a feeling of security or ‘safe havens’ in which people feel more supported by their neighbours and community members. Within an activity location such as a person’s home, Fullagar and Owler (1998) explore how activities of leisure provide a chance for person’s with a disability to create a positive narrative by changing their relation to themselves. How can the sense of belonging be expanded from the individual’s home to other spaces? Narratives of being part *of* one’s community (sometimes known as psychological integration or sense of community) are connected to greater overall life satisfaction (Prince & Gerber, 2005; Hutchison & Potschaske, 1998). Nelson, Lord, and Ochocka (2001) found that as persons with a mental health disability were more involved in the community, the more skills and resources they acquired, and the better they felt about themselves.

Bringing the possibility of a less intrusive environment that breaks down some barriers to participation and integrating in which a person can be a part *of* a community. Inherent in this narrative is an emphasis on expanding networks of relationships in which the person participated in a meaningful way. This approach attempts to counter dominant narratives of stigma in the community (Lysaker, Roe, & Yanos, 2007; Hutchison and Potschaske, 1998). Critical perspectives explored the *relationships of power* that surround a person with a physical or mental

impairment. As McKnight (1995) describes “our institutions are too powerful, authoritative, and strong. Our problem is weak communities, made ever more impotent by our strong service systems” (p. iv). For Gadacz (2003), “[t]his power relationship is manifested by the able-bodied with respect to imposed definitions, control of the environment, and in the determination of the types of treatment, services, amenities and programs deemed appropriate to the needs of disabled people” (p. 5). McKnight (1995) suggests citizens need to take the *power* back and states, “[i]t is only in community that we can find care” (p. 172). “Community is what takes place through others and for others”, writes Nancy (1991, p. 15). Hutchison & McGill (1992) highlighted that for some making this transition to community, support is needed due to limited relationships with family and the hardship of making and maintaining friendships in the community. This is heightened by experiences of poverty. Common among persons with a mental disability are the state of the social welfare system, supportive housing, and access to medication to name a few (Arai and Burke, 2010; Centre for Addiction and Mental Health, 2013). Noting that persons with disabilities have a higher chance to live below the poverty level compared to all Canadians, Arai and Burke (2010) define poverty as a social and relational issue, not an individual trait or deficiency; it influences how we relate and how we understand our interrelatedness. Similarly, Gadacz (2003) claims the focus of care should not be on the impairment that a person or a group encounters, but the social environment (building of meaningful relationships). When we change the social environment, we will successfully demedicalize and deconstruct the label of disability. In narratives of being a part of one’s community there is an important shift from the individual to community as the site for intervention. By expanding a community’s awareness and understanding of barriers persons with schizophrenia encounter Gadacz (2003) asserts that



community centres, self-help groups, and independent living centres will change the narrative by focusing on reducing ignorance, isolation, and dependency of the persons involved.

### **Fluid and boundary-free: Choice and emotion in narratives of postmodern community**

Narratives that seem to not be in or of a community and not of relationships or spaces directly show the limitations of modernist thinking. These narratives move away from the emphasis on cohesion, belonging, and sameness found in modernist notions of community. Fullagar and Owler (1998) claim that “when recreation is provided solely within a group context there is a discourse of sameness produced which works to conceal the diversity and difference that exists between people who have a disability” (p. 444). The authors continue, “The story of sameness in the provision of leisure services perpetuates a sense of exclusion for the individual within the community, which often manifests as a negative attitude towards oneself” (p. 444). As we explore leisure services and recreation groups as a metaphor for the prior narratives of community and identity, there is an exposure to the limits and possible damaging consequence of what these narratives have on the lives of persons with schizophrenia.

Moving away from ideas of community as a place, a space, a proximal boundary or the people you engage in/with, Gulcur, Tsemberis, Stefancic, & Greenwood (2007) explore community as a boundary-free concept. This perspective looks at community as being not physically or spatially defined as a house or a zone or a neighbourhood and may present itself in some of the narratives as emotions, experiences, or communications shared. As Delanty (2003) states, in postmodern society group memberships are more fluid than in modern society, with multiple belongings of members, similar to the multiple selves discussed in identity formation. “Postmodern communities- are nomadic, highly mobile, emotional and communicative. They are

a “fractured community” that emerges along with the creation of non-foundational, heterogeneous societies” (Delanty, 2003, p.130). An example of this expression of community in the observation of death might be the worldwide mourning that followed the death of Princess Diana in 1997. “A community of mourning emerged around a cultural icon which had a purely imaginary dimension, as opposed to a normative one” (Delanty, 2003, p. 136). Delanty (2003) views community as an experience one has, that has no connection to a spatial structure from which modern day societies claim it to be (i.e., gated communities). In viewing community as is, Delanty (2003) proposes that community cannot be instrumentalized or institutionalized – it is *inoperative*. This statement counters the narrative of dependence in the community, where community is an institution without walls.

In viewing current concepts of community, Lash (1994, 2002) states community is more likely to be chosen rather than ‘assigned’ and is therefore more reflexive. A reflexive community according to Lash (2002) continues to suggest members are not born into communities as they once were and also that communities are stretched over ‘abstract’ spaces as the example of Princess Diana. However with the narrative of deinstitutionalization creating a story of forced emergence into forced communities, will the narrators be given a choice or opportunity for a reflexive community?

An exclusion from community narrative could also have some implications of postmodern thinking around community experiences. According to Delanty (2003), community is only experienced as an absence, which can be desired by individuals but never fulfilled. “Community is the experience of a loss but not a loss of something that was once possessed” (Delanty, 2003, p. 136).

Delanty (2003) suggests postmodern communities are beyond unity and identity – a group of its own. Within this new narrative of community, three ideas of embodiment occur; everyday life, friendship, and new age travelers. Everyday life is seen as the many smaller groups’ people take part in in these ‘in-transit’ sites such as airport lounges, coffee shops, and commuting buses or trains (Delanty, 2003). These temporary everyday groups were once seen as non-social places where communality would not exist, however as seen in extreme cases such as the terror attacks on September 11<sup>th</sup> 2001, a liminal community can be constructed out of shared experiences (Delanty, 2003). The next concept of a postmodern community is the idea that friendships have been known to be the foundations of a community, replacing traditional communities based on family and kin relations. Delanty (2003) ascribed this change to the likelihood that people are moving further away from family members and must create self-sustaining supports that take form of friendships. The new age traveler’s concept is the movement that pushes back against the modern community in search for an alternative in which freedom is the dominant aspect of life (Delanty, 2003).

For Delanty (2003) “postmodern community is neither traditional nor modern; it is sustained by its own reflexivity, creativity and awareness of its limits. Postmodern conceptions of community stress the fluidity of relations between self and other, leading to a view of community as open rather than closed” (p. 141).

By building and shaping communities in a different way when we move forward from this study, we as researchers and members of the community need to do so without relying on past ways of dominance or segregation. Expanding our inclusive community should focus on inclusion pathways, what is needed for all members to thrive, to participate, to live. Focusing on

exclusive criteria will only bring back old dependencies of which persons with disabilities are subjected to such as stigma, domination, discrimination, segregation, and congregation.

## **Narratives of Health and Healing**

As we have explored identity and community already, we now begin to look at the recovery of persons with schizophrenia when under the health and healing lens. We begin with a discussion of narratives of the cure for schizophrenia and narratives about what determines health for people with schizophrenia. In this section the recovery paradigm will also be explored as a “new” story of recovery. Closely related to the recovery paradigm is the narrative of faith, hope and empowerment.

### **Narratives of “the cure”**

As part of the narrative of the medical model, there is also a narrative focused on “the cure” for schizophrenia. The Schizophrenia Society of Ontario (2013) states in their vision statement that schizophrenia must be recognized as a serious brain disease and a cure must be found. All statements listed on the Schizophrenia Society of Ontario (2013) website tend to encompass a view framed within the medical model. Finding a cure, as the Schizophrenia Society of Ontario states, is different from the dominant research focus of managing symptoms (Warner, 2004) and providing support systems (Hutchison & McGill, 1992). Claiming a cure impacts person’s currently experiencing schizophrenia. Similar to the defective identity narrative discussed previously, the cure narrative has real implications for those persons experiencing schizophrenia living in the community. The narrative of a cure suggests people experiencing schizophrenia can at one point be *fixed* or *devoid* of schizophrenia and any symptom or effect it has on a person. Coupled with the narrative of the defective identity, the narrative of the cure

now implicates the individual and us in our collective failure to find a cure for this disability. Is this what we wish to portray for persons experiencing schizophrenia and their families?

The cure narrative also has implications for how we think about community resources and services. With the onset of schizophrenia being youth aged 18-24 years (Marcus and Westra, 2012), there is the possibility that a mindset toward prevention begins to accompany this narrative of the cure and when coupled with the idea of mental health literacy there arises an emphasis on personal responsibility.

### **A basket of community supports: Narratives about what determines health**

The Canadian Mental Health Association-Grand River Branch ([CMHA-GRB], 2011) annual report provided a comprehensive set of recommendations based on the Ministry's Advisory Group. The recommendations were to "highlight a full range of prevention, community support and integrated delivery of health services bringing together primary care, addictions and mental health with other human and justice services" (p. 4). As part of CMHA-GRB's (2011) Strategic Plan 2008-2012, the first goal is to "demonstrate the recovery philosophy through continuous improvement in the quality of services offered across a continuum from prevention to intensive support" (p. 6). To achieve this goal, CMHA-GRB states that training and education about the recovery philosophy will be emphasized throughout the organization. Other ways of obtaining this goal is to maintain and develop partnerships with community services. CMHA-GRB (2011) claim that community is the answer. In keeping with this shift to community, texts on service provision, community planning, and research emphasize the *determinants of health*. This view notes that structural conditions income and social status, social support networks, physical environments, employment, education, culture, and health services determine health of the individual. This was seen as advancement beyond earlier definitions that defined health in

terms of the absence of disease, emphasizing the medical model and the treatment of disease (World Health Organization, 2013).

Adequate income has the ability to meet the basic needs of persons with schizophrenia which includes safe housing, healthy living conditions such as sufficient good food and recreation options, access to medications, transportation, and clothing (Government of Canada, 2006). The issue of income seems to play a large part in the perceived mental health of a person living in Canada. The Centre of Addiction and Mental Health ([CAMH], 2013) report that some of their clients do not receive adequate income. CAMH (2013) share a narrative of a client of theirs that is ‘supported’ by Ontario Disability Support Program (ODSP). The client was receiving \$650 per month and lives in a Metro Housing apartment in the Greater Toronto Area. She has her rent subsidized however runs out of money before the end of the month and resorts to prostitution in which she is charged and put in jail. Being in jail her psychiatric symptoms are exacerbated, however she continues to resort to prostitution. She was also banned and even sued by a local grocery store for stealing food to eat due to her running out of money every month. This narrative highlights those who do not receive adequate income and the secondary issues related to living in poverty in Canada; however, the relationship between income and mental health is a complicated and complex process that needs more critical thinking and exploration. The Government of Canada (2006) makes it clear that simply increasing the amount of money to acquire material goods does not necessarily mean greater life satisfaction or lead to psychological health, however as we heard in the story presented by CAMH, basic needs of safe housing and food were not always being met each month.

Similarly to income, social support (or lack of) has a profound impact on mental health (Government of Canada, 2006; Hutchison & McGill, 1992). Social connections (especially the

family) have been seen to influence mental health and detour from isolation and loneliness (Government of Canada, 2006). “High levels of social engagement create social conditions that support the development of trust between people, a deeper sense of meaning in life, and an enhanced sense of coherence, control and positive self-regard” (Government of Canada, 2006, pp. 12). Belonging to a supportive community can create high levels of social engagement; however the report of the Government of Canada (2006) found that sense of belonging to a community for people under 45 years of age is not as strong as those over 45 years of age. The report indicates there may be a change of sense of belonging to people’s community during the second half of the 20<sup>th</sup> century (Government of Canada, 2006).

### **Beyond symptom relief: A “new” story of recovery**

Following the exploration of narratives of identity and community, we now move into narrating the complexity around the idea of recovery for persons with schizophrenia. Peebles et al. (2007) chronicled some of the concerns regarding quality of life for persons with a mental health disability living in the community after deinstitutionalization and identified symptom relief models of care (medical/disease models, psychosocial rehabilitation, and the bio-psychosocial perspective) as creating a major barrier for persons to achieve optimal health and quality of life. Peebles et al. (2007) identify the symptom relief models have a hierarchical dynamic that “place clients or patients in a one-down relationship with practitioners” (pp. 570). In contrast, the recovery model places emphasis on client empowerment and allows for a narrative to present a collaborative, non-hierarchical approach. Recovery according to the definition provided above is summarized as living a life beyond illness. Ryan et al. (2012) states three different ways for persons to be a part of the recovery process:

1. Hope – sustaining motivation and supporting expectations of an individually fulfilled life.
2. Agency – recovering a sense of personal control and a level of understanding of what has happened to them.
3. Opportunity – using circumstances to gain favourable ends. Social inclusion or participation in a wider society and/or community.

The identity of the patient or client also shifts in the recovery model. Peebles et al. (2007) found that in a recovery model, persons with a mental health disability become integral members of the treatment team for other individuals becoming a peer specialist. Similar to the Alcoholics Anonymous framework, a person is linked to another “survivor” or “consumer” in supporting recovery and sharing testimonials/narratives (Peebles et al., 2007; Yalom & Leszcz, 2005). The recovery narrative highlighted four key elements for using recovery in a pragmatic way by health care providers:

1. Person orientation (or, view of clients from a holistic perspective and with a full awareness of their strengths and weaknesses)
2. Person involvement (or, intimate consumer involvement in treatment planning and program development)
3. Self-determination/choice (or, emphasis on a partnership among consumers and those who provide interventions)
4. Growth potential (or, commitment to fostering hope and removing barriers to progress)

(cited in Peebles et al., 2007, p. 572)



Lester & Gask (2006) ask, “Are we intending to deliver (mostly if not entirely) medical care for a chronic condition, or promoting collaborative models of care to improve recovery?” (p. 402). Lester and Gask (2006) use language of *deliver* (medical) and *promoting* (recovery) to highlight to us the difference in understandings between the two models. When it comes to mental health services, the recovery process of care has started to challenge the narrative of the medical model; however there are places in which the medical model remains firmly entrenched (Glover, 2012, in Ryan, Ramon, & Greacen 2012). Ryan et al. (2012) claim the recovery paradigm is still in the infancy stage in many parts of the world and the more dominant medical narrative still exists and is adapted. The medical model has roots buried deep in the health care systems for century’s, which are somewhat reluctant to be uprooted. The narrative of the “new” recovery came from the realization that not all mental health disabilities were chronic conditions, and that recovery, be it little or full, can exist (Ryan et al., 2012). As Warner (2010) describes, “[recovery] refers to the subjective experience of optimism about outcome from psychosis, to a belief in the value of the empowerment of people with mental illness, and to focus on services in which decisions about treatment are taken collaboratively with the user and which aim to find productive roles for people with mental illness” (p. 3). The recovery narrative allows more positive stories or persons with schizophrenia to be shared and related to in a community – a role modeling of viewing life.

Roe and Davidson (2005) suggest “the emerging “recovery” paradigm in community mental health opens an exciting new window onto the rich but relatively unexplored terrain of self and life reconstruction that occurs throughout the recovery process” (p. 89). Despite the growing body of knowledge and support from researchers and consumers of the recovery

paradigm, the model has yet to make a significant presence in mental health practice (Lester & Gask, 2006).

According to Warner (2010) “Collaborative models, like the psychosocial clubhouse and educational programmes that involve both professionals and clients as teachers, are seen as important elements of recovery-oriented services” (p. 3). Lester and Gask (2006) also discussed the need for collaborative approach to care to improve recovery. Lester and Gask (2006) propose employing people who have used the mental health care system and have lived experience, and peer run organizations, will be a desirable asset within the mental health structure. By implementing these proposed items, the power to create and frame the narrative flows from health care providers to persons in the recovery process.

### **Beyond stigma: Narratives of hope, faith, and empowerment**

With the arrival of positive psychology and the recovery process came a movement away from medical management of the illness or impairment toward concepts of happiness, personal strength, personality traits, fulfillment, and personal quality of life (Peebles et al., 2007). Peebles et al. (2007) describe that at its current stage of development; the Recovery Model of service delivery is more a philosophical guide for providing treatment than an evidence-based model. This philosophical guide is linked to common factors of psychotherapy such as a collaborative relationship with the person seeking care, fostering empowerment and self-efficacy, and fostering and promoting hope (Peebles et al., 2007). Yalom and Leszcz (2005) state that hope or faith in a treatment model of care can in itself be beneficial. The author’s continues to state that group therapy allows for persons involved in treatment to feel a sense of hope as it allows that person to hear narratives of people in differing positions in the recovery continuum. Yalom and

Leszcz (2005) state that hope is flexible; it molds to the person in need and can redefine itself within immediate parameters of a situation.

The main element of this “new” recovery narrative is empowerment. Empowerment does not only take effect at an individual level, it has the potential to shape the structures of society as well (Arai, 1995; Richardson, 1990). Therefore empowerment can be used to change and construct personal identity and social identity of a person and a community. Arai (1997) states “empowerment begins with the individual’s self-defined needs and aspirations and then looks at the capacity development, resources and supports that are required to achieve those goals” (p. 4). Empowerment processes involve an embodied awareness of and a desire to change (e.g., anger, frustration). Not all desires of change will be verbalized by the person that has the awareness. The connecting and learning stage expands on the awareness of opportunities and choices and also involves developing support relationships with individuals and groups (Arai, 1997). In mobilization, the engagement of new activities allows for self-expression and may provide individuals to feel competence in these new social groups and activities. Making decisions, planning social events, or using skills then makes possible contribution, when there is a shift in understanding of self and having a sense of being accepted and belonging as an active member of the community. Similarly, Gadacz (2003) states that based on a medicalized narrative, empowerment is understood as “learning general action skills that are useful in playing a more conscious and assertive role in the ongoing social construction of one’s social and political environment, that is, structures” (p. 15). With an empowerment focus in mind, Gadacz (2003) and Lester and Gask (2006) state that active and informed persons who utilize the mental health care system are of highest importance when developing recovery-based services. Hutchison and McGill (1992) state “people who have been devalued say that they have been encouraged to be

part of the process of empowerment by knowing that someone else believes in them and shares with them a vision of change and personal growth” (p. 34).

## **Chapter Summary**

Chapter one explored the narratives of identity, community, and health and healing that exist in past and current society and literature. Narratives of identity have looked at the person as defective, a person defined based on the pathology and symptoms that are associated with schizophrenia. The narratives continue to tell us that schizophrenia has a “cure” that will fix their chosen identities. Other researchers counter this cure narrative by placing value on the individual differences as an important part *being of* community (Hutchison & McGill, 1992; McKnight, 1995; and Pedlar, 1990). A shift of focus onto the community being the ideal place for persons with schizophrenia to live is presented as a safe space that persons belong to. With an additional lens taking a postmodern approach, community is challenged as being a static concept that has boundaries by viewing community as fluid, similar to identity. Chapter one also challenged the narratives of health and healing in the recovery of schizophrenia by exploring stigma, empowerment, and what determines health. Throughout the chapter there were multiple stories of real person’s experiences with schizophrenia, community, and the identity of having a mental health disability.

It matters what stories people tell about themselves and about each other, so therefore I present the positive stories while acknowledging the hardships and struggles that have landed them to the place where they are now. We need to revise the discourse on mental health, specifically schizophrenia if we are to call our communities inclusive, integrated, and welcoming. The significance of using narrative structure is as Richardson (1990) contends that

the person who shares their story will feel empowered and that there will be a contribution (hopefully) to “liberating civic discourses” (p. 130).

In chapter two I discuss in depth the narrative methodology that this research is focused on. Included in this chapter are sections that address the narrators for this study, data collection (conversations, walk-a-bouts, and personal reflective journal), data analysis, my self-reflexivity, and finally assessing the quality of narrative studies to provide implications of this research project.

## **Chapter Two: Narrative Methodology and Recovery**

How we conduct research is as important as the questions we ask. There have been studies in which quality of life of persons with a mental health disability (schizophrenia in particular) have been quantified (Packer et al., 1997) and even ways in which the awareness and coherent nature of an person's narrative has been attempted to be quantitatively measured (Lysaker, Clements, Plascak-Hallberg, Knipscheer, & Wright, 2002). Roe and Davidson (2005) described the historical significance placed on standardized measures and operational criteria that then limited the range of important, rich data found through other methodologies such as narrative. Roe and Davidson (2005) suggest a more fluid approach to gathering information that engages persons with schizophrenia in conversation about how and what experiences impact their lives. The switch to a more fluid approach can be an emotional event and can happen at different times for different researchers. For Dupuis (1999) the switch "was not until I went out to conduct my own research that I became very away of the emotional aspects of what we do as qualitative researchers" (p. 50). Consequently, this study explored three person's narratives of identity and community about their experiences of living with schizophrenia in community.

Polkinghorne's (1988) approach to narrative borrows from multiple disciplines and may be used to expand the exploration of life experiences of persons with schizophrenia. Each discipline helps provide insight into the different complexities and vastness of experiences with schizophrenia. "One's personal story or personal identity is a recollected self in which the more complete the story is formed, the more integrated the self will be" (Polkinghorne, 1988, p. 106). Modern connotations of self are seen through the words of Polkinghorne but perhaps this paper need not take the extreme opposite view as eliminating identity and self. Holstein and Gubrium (2000) attest to those who have a viewpoint of late modern, wherein the self is complex,

frenzied, and diverse – it is very much present and “the fundamental reality of experience is not put into doubt” (p.57). As Polkinghorne describes there also needs to be a story about the future for identity formation to occur in a self-narrative process. “If a person fails to project a hopeful story about the future, he or she undergoes... unhappiness, a life without hope” (Polkinghorne, 1988, p. 107). Polkinghorne also found research in his field out of touch with practical problems/issues of the field. He suggested a need to turn practice to theory when engaged in the research process.

Robert Coles’ (1989) view of narrative comes from the field of psychiatry, in which he believes the field ought to proceed in harmony with living. This harmony consisted of a shift from interview style psychiatry to conversation style. The shift is chronicled in Coles’ (1989) experience in the field through a parable further in this paper. While only viewing narrative from one discipline, Coles (1989) attempts to saturate the story of the person involved from that single disciplinary view. Coles (1989) rejects the notion of seeing just the behaviours of a person suggesting the need to look at the whole story, thus a biographical text is created – narrative.

In *The Call of Stories* by Robert Coles (1989), Robert shares a story from his beginnings as a young psychiatrist with a young boy named Phil. Phil was a boy with polio admitted to the hospital, both parents were deceased, he lived with his widowed grandmother, had no siblings, and two uncles lived thousands of miles away. When Robert started working with Phil he was frustrated as interviews with Phil were not going his way. Often Phil would refuse to engage in interviews since Robert would decline to answer personal questions Phil posed to him. Upon reflection and with help from his wife and colleague Robert discovered his approach of gathering information about Phil was ineffective. There was no connection, no flow. Robert needed to change his approach from an interview to a conversation style. Phil became comfortable

discussing his own personal life when he heard about Robert's life story. This change brought Robert closer to understanding Phil's story. Narrative for Coles (1989) is a conversation, a sharing of information back and forth, allowing for similar experiences and events to bring people closer together.

Laurel Richardson (1990) explores the definition of narrative in her article on narrative and sociology:

Narrative displays the goals and intentions of human actors; it makes individuals, cultures, societies, and historical epochs comprehensible as wholes; it humanizes time; and it allows us to contemplate the effects of our actions, and to alter the directions of our lives (p. 117).

Narrative is human experiences organized in sequenced meaningful episodes (Polkinghorne, 1988). Richardson (1990) describes narrative as "both a mode of reasoning and a mode of representation. People can "apprehend" the world narratively and people can "tell" about the world narratively" (p. 118).

The narrative becomes part of the recovery (Roe & Davidson, 2005). Roe and Davidson discuss how the narrative perspective opens up new understandings of how persons diagnosed with a mental disability respond to and experience the onset. This process of narrative may shed light on barriers that were unknown to the person prior to engaging in the study, and perhaps the removal of some barriers may spring from this new awareness.

Roe and Davidson (2005) identified five categories (p. 92) of results they have found in previous studies using narrative with persons with schizophrenia, which include:



1. Participants separated their “healthy” self from their “ill” self.
2. The healthy self-remained a subject, whereas the illness became an object.
3. The object (illness) was perceived as actively trying to influence the subject as well.
4. Narrator became the protagonist in the story; had control over the events and actions.
5. A capacity to integrate self and illness, to combine the different categories into a coherent whole.

When discussing schizophrenia, Roe and Davidson (2005) state:

narrative is one of the few tools available that enable the person to weave back together a sense of who she is that both incorporates and yet extends beyond who she used to be prior to illness and who she has become due to illness (p. 93).

Narrative has the ability to “highlight both the individuality and the complexity of a life” (McCormach, 2000, p. 282). Schizophrenia must not define them. I must not define them. The use of narrative in this research must continue to ask questions. Asking and listening to the narrators will be the ongoing construction of their identity during this research journey. I experienced the narrators in the moments of time and space in which I journeyed with them. Research in dementia care, support, and services by Dupuis et al. (2012) around creating authentic partnerships will allow for a more meaningful conversation with the narrators. For Dupuis et al. (2012) authentic partnerships “are absolutely necessary for social action and changing perceptions and misunderstanding of dementia” (p. 444). I see the strength of authentic partnerships in research with persons with schizophrenia and with narrative inquiry. The

authentic partnership approach would provide shared learning to occur between the narrator and myself. “Through shared dialogue and critical reflection, personal and professional assumptions were challenged in a non-threatening manner as diverse stakeholder groups learned from one another” (Dupuis et al., 2012, p. 249). What did I learn about myself from being immersed in this journey? How did I come to understand the narrators? How did I come to understand schizophrenia? Through continuing to ask questions in my research by reflecting, my work not only become mine “but will better reflect the mutual process involved in the construction of meaning portrayed in our stories” (Dupuis, 1999, p. 61).

## **Narrators**

*Journal Note - November 27<sup>th</sup>2013*

*I was called into the Ethics department to meet with the manager presiding over my application. Wow, what an intense meeting that was. I didn't really think twice about what would be said or what would be discussed. I guess I just assumed that they had some basic questions. This was not the case. They didn't really understand my answers on the application form, especially the procedures section. Apparently it was too academic for them to read. It needs to be more in lay terms as she stated over and over again. “I am not an expert” was her response to my phrasing and use of words in my application. She is not the expert in all fields so the more basic the information, the better. That's fine, I could expand more on what specifically I want to do, how I would do it, where, and when. What I have issue with is that she wants me to label and add the potential risk associated when doing research with people with schizophrenia. Was it my fault though? I added a section about exclusion criteria regarding active psychosis. What was that for? How could I really believe that that information would be useful? It's not what I think... right? I wonder why I wrote that in the first place, but now she has that in her head and she needs me to explain how I would deal with potential dangerous situations. I don't want to bring the negative narratives into the ethics application as a representation of the people I intend to work with. I also do not understand why my supervisor was not called into the meeting as well. There were two ethics staff members and me in the room. It's also amazing how the Ethics department requires lay language – they seem so disconnected to the Recreation and Leisure department. What about the progressions of qualitative research? What steps are people in the Ethics department doing to update their knowledge about different types of research designs? Narrative is*

*common in our department, I'm not the first person to propose such research, so what is it? How can my peers doing quantitative research fly by me in the research process? Even when discussing some things with them, they would try to relate it back to seemingly quantitative terms. Why are those terms okay, but when I use my qualitative terms, I'm asked to put it in more lay terms? I don't want to label the narrators. I'm feeling pressure to do so, or this process could take longer. Ugh! So many ropes to jump through, changes to me as a researcher and person that they want of me! Also, why are they asking me about my safety? That wasn't even in the application form! Who cares if it's private or public space to conduct the conversations? These human beings are participating in this study because they want to! They are not forced to tell me their story because of the agency, they want to do it for themselves, to better the lives of others and give to the research community. In fact, with their help I hope to really challenge the dominant discourse I find the Ethics department wanting/endorsing. Sue has been really great about this process/issue. She wants to attend any more meetings they drag me to and has taken the time and energy to help edit the application forms. Sara has also been a great supporter of me and keeping the potential narrators aware of the barriers I'm facing right now. I was afraid of scaring or discouraging them because of this long process. I don't think I would have the patience they do if I was in their shoes! Lisbeth was a little shocked to hear about the snags with ethics but has encouraged me to write about it! This is what I'm doing now!*

For this study, I contacted three persons living in the community who have been diagnosed with schizophrenia or schizoaffective disorder, to complete a recorded conversation as well as *walk-a-bouts* of co-constructing conversations in their communities. Walk-a-bouts of engagement in the community has been adapted from the work done by Angrosino (1994) work title *On the Bus with Vonnie Lee*. In the journeys Angrosino took with Vonnie Lee on the bus, Angrosino (1994) saw that Vonnie Lee was “telling his life story without specific prompts, did so in the form of bus routes” (p. 22). What Angrosino (1994) learned from being with Vonnie Lee in the community was that Vonnie Lee was challenging the dominant narratives that exist about him and his past. Vonnie Lee's actions during the walk-a-bouts were a counter-narrative to the negative and dominant Vonnie Lee image that came about during the interview. The walk-a-bouts with Vonnie Lee were seen as an act of self-creation (Angrosino, 1994), which deepened

the narrative of Vonnie Lee by being cued in the community and different locations that continued that conversation of his story. According to Angrosino (1994) the walk-a-bouts “demonstrates the desirability of contextualizing the autobiographical interview within the ongoing life experience of the subject rather than treating it as a retrospective review” (p. 25).

The narrators were contacted through a local community mental health agency in [City B] that adapts a recovery process and practices. The [local mental health housing agency] is an example of an agency that adapts a recovery-orientated philosophy that serves persons with a mental health disability living in the community. Another agency is the *Canadian Mental Health Association – Grand River Branch* that provides services to persons who have ongoing and significant mental health disabilities living in the community.

The selection of the three narrators was in collaboration of a mental health professional [recreation therapist] at a community mental health agency [local mental health housing agency]. There were two female narrators and one male narrator. All narrators were white, on Ontario Disability Support Program (ODSP), and had been living in the community for several years at the time of the study. Inclusion criteria included a person who is: over the age of 18, formally diagnosed as having a schizophrenia spectrum disorder according to American Psychological Association (2013), and living in a community-based setting. The male narrator, Ryan, lives with his parents, is in his late thirties, single, and originally from the [City A]. One female narrator, Tina, is living on her own with the support from the [local mental health housing agency], in her forties, and in a committed relationship. Whitney, another female narrator, also lives on her own with support from the [local mental health housing agency], divorced, a mother to one daughter, and has one cat.

Through narrative inquiry the narrators in this study may have gained a sense of (or heightened their already existing) empowerment as they develop and recall positive experiences and events from their past. However, the very opposite may have occurred in that the self-narrative calls upon negative experiences or events in the person's life, which could lead to lower levels of self-esteem or empowerment. Awareness that this may have occurred was important in maintaining the best possible outcome for the three narrators involved. The study explored stories of differences in the community it represents; therefore collaboration with the [local mental health housing agency] in the selection of the three narrators with more diverse stories provided richer personal experiences and narratives.

Informed consent form (see Appendix A) to participant in the study were provided to each narrator as well as the letter of introduction (see Appendix B). Narrators were also informed (written in the informed consent form and verbally) that they were free to leave the study at any time if they felt the need to discontinue for any reason, which will not impact their relationship with the [local mental health housing agency] in which they are associated with. During the walk-a-bouts, the narrators also had the choice to stop or ask me to leave if ever they ever felt the need to do so. No narrators dropped out of the study or asked to leave the study at any time during the meetings. Privacy was respected during the research journey with the walk-a-bouts, where journeying with each narrator in some of the leisure/community activities can be an intimate moment for the narrator, therefore confidentiality was stressed. Pseudonyms were assigned to each narrator (Ryan, Tina, and Whitney).

### **Data Collection: Conversations, Walk-a-bouts, and Reflective Journaling**

*Journal Note - Jan. 10<sup>th</sup> 2014*

*I showed up early, not because I wanted to but because I couldn't sleep through the night. I'm nervous yet confident. This is the most prepared I have been for anything before. [Recreation therapist] made my experience so easy and comforting. It's exactly what I needed and maybe she was able to see that. I was given space, both in the sense of control over the environment and emotional space to complete this process today. The electricity was out at the agency so I lost a bit of control over my environment, but it created a feeling of chaos, which oddly enough I'm used to from my childhood. I was given a room that was used as a boardroom – huge, dark, and cold. I was then to use my skills to transform this space into a warm, open and comfortable space for the participants and myself. I met my first potential participant Whitney soon after arriving. She was early and prepared, as [recreation therapist] indicated she would always be. We walked from the front, down the hallway to the boardroom in the back. We sat next to each other and I tried to remember to keep an open posture. I started to discuss myself a bit, my education background, my previous experience in mental health services. I tried to humanize the research process, show Whitney that I'm a person with genuine interest in creating a better system. I added that my family has experience (and will always experience) with mental health illnesses. Whitney was quiet at first, but I didn't expect anything else from the first meeting, plus it was 8:45 in the morning on a Friday no less. After briefly explaining my past interests in education and mental health services, I went into expectations of this study. I wanted to go over the major aspects at least twice to make sure there wouldn't be any confusion because I'm not exactly sure what [recreation therapist] had told her about the study or about me. Whitney didn't really have any questions but did seem interested in participating, especially if it could help others in similar experiences as her or people with schizophrenia. I read out the informed consent items as she didn't have her reading glasses with her. She only had one concern that [recreation therapist] had already informed me about as it may be difficult contacting Whitney because she doesn't have a phone or email account. I would have to make appointments with her each week, which I did today for the following week. [Recreation therapist] mentioned that she is very reliable so I can expect that she shows up and is punctual about her appointments.*

*The next potential participant was Tina and we sat down around 9:20 in the morning. We were given 10 minutes to do our initial conversation and find out enough information that she understands what the fuck I'm doing there. Tina looked as though she is in her late 40s. Tina appeared to have flat affect, the kind of face that I expected but also dreaded. I didn't want to be "that university guy." I tried the same approach on Tina as I did on Whitney. Tina seemed more interested in the helping others aspect of the study and wanted more information regarding that. She had more contact information and seemed easier to get a hold of. Tina also booked another appointment for the following week. I can't believe this is happening so fast! Even though ethics took 2 months to get clearance I'm still shocked that the process is moving forward to this point.*

*After I finished up with Tina, the group of clients going snowshoeing headed for the door. There must have been 18 of us altogether for the activity. It was scary to be the outsider on this trip and also the “university guy.” I would have actually preferred if Sara didn’t make an association of me with the university, it was an identity that comes with a lot of expectation and baggage. In the case of being introduced, I would have even likened to be associated as a recreation therapist... who would have guessed I would choose that! Off we went, in four car loads to a local park to do the hike, I travelled with two clients and one staff member – no one directly linked with my study. We arrive and I’m still hesitant about my participation in this activity. It’s a long 8km hike with people (potential participants included) I just met. I try to give space for Whitney and Tina, I don’t want them to feel as I am invading too much into their leisure activity right away. I become separated from Whitney during the walk but manage to group myself near Tina. I begin to form a relationship by picking up on the spaces we are both placed in. We discuss her history with animals, she laughed at some of the school kids remarks of how it looked like we were “walking on tennis racquets.” She also laughed at her clumsiness of which she fell three times at the end of the walk – perhaps it was because her bad hips comment she made to [recreation therapist] at the beginning of the walk. Other than that the hike was an adventure for me – it changed my attitude and feelings so by the end of the walk I was less nervous and scared, and more excited and at ease. We even did some stretching at the end! How does participating in the leisure activities affect me as a researcher?*

*Another potential participant was going on the hike as well but was meeting us there. Ryan was actually the leader of the hike and seemed to have done it before. It was a bit awkward to meet up with Ryan as everyone was around, he didn’t know who I was, and the hike was about to begin! I certainly didn’t want my identity to be known as a researcher looking for subjects for my study. Looking back, I should have taken control over the situation and introduced myself the way I wanted. At the end of the trip/hike I approached Ryan, as [recreation therapist] already mentioned during one of the stops that Ryan needs to talk to me before leaving. It wasn’t ideal way of meeting or to discuss the research project but it did leave me with an opening to talk. So, after the stretching we locked eyes and moved towards each other. While everyone else piled into the cars to head back I made a quick pitch to what the study is about. I gave him the letter of introduction and an informed consent form with my contact information on it so he can contact me if he is interested in the study. I don’t think it was a great way of approaching it and I’m not confident he will contact me. I guess we will have to see how the next few weeks unfold, but my first impression on Ryan was a bust to say the least.*

Stein and Mankowski (2004) developed a qualitative research framework of conducting studies in community psychology that could be applied for this particular research. The

framework consists of four acts: asking, witnessing, interpreting, and knowing. Stein and Mankowski (2004) found that the framework is appropriate for schizophrenia in particular as they completed research project on families who had experience with schizophrenia. This framework has been applied to this study of the three narrators who experience schizophrenia. The first section of the framework, *asking*, was achieved through conversations both audio recorded and during the walk-a-bouts with the narrators. *Witnessing* is the second section of the framework which was achieved through engagement with the narrators in the community (walk-a-bouts). I created written “field notes” immediately after the community activity/event at a local coffee shop so that it was less distracting for the narrators. The third section of the framework is *interpreting*. This section is a co-construction of the narratives of each narrator in this study. Ellis and Berger (2003) discuss a way of co-constructing during the interviewing called reflexive dyadic interviewing. Reflexive dyadic interviewing involves me as the researcher to reciprocate the disclosure of personal details and experiences of my life. These experiences or details that I share will not be directly related to the experience of schizophrenia; however I shared some past experiences I have working in the mental health field and shared some of my own ways of constructing identity and community. According to Ellis and Berger (2003) this reciprocal desire allows for the creation of a final product that has “cognitive and emotional reflections of the researcher, which add context and layers to the story being told about the narrators” (p.162). Specific attention of identity and community in the stories had been highlighted in the interpreting section to continue the purpose of this research and its guiding research questions. The last section is *knowing*. Devine & Sylvester (2005) define knowledge as “contingent and ambiguous, a cultural and historical product formed by and filtered through the beliefs, attitudes, and actions of people and time” (p. 85). In this section, my reflective journaling written before,



during, and after interactions with the narrators contributed to the knowing as described above. Specific attention has been placed on the contexts in which data are collected and interpreted as Vonnie Lee's self-creation discussed in Angrosino (1994).

Data collection of conversations and reflexive notes will take place at the narrators choosing of both time and place. There was between six to seven meetings with each narrator, depending on the availability of each narrator:

1. introduced myself and the study (introduction letter, informed consent form),
2. continued to build a trusting, authentic relationship by engaging with the narrator in a community setting of their choosing,
3. a conversation with the narrator (audio recorded),
4. engagements with the narrator in a community setting,
5. second community setting (if applicable),
6. third community setting (if applicable),
7. debrief of the study, thoughts of participation in study (feedback form).

Expanding on the additional lens of postmodern thought discussed earlier, Fontana (2003) explored some trends in postmodern interviewing that break away from the modernized interviewing style of interviewer and participant. In exploring the postmodern trends, Fontana (2003) examines the boundaries between the researcher and participant where a blurring of power is seen. The power shifts the modern interview into a conversation (reciprocal relationship) as discussed by Coles (1989). One audio-recorded conversation took place during one of the meetings with each conversation lasting between 45 minutes to 60 minutes. The conversation explored the narratives of each narrator by asking questions (see Appendix D) such

as: Can you start by describing what a typical day is like for you? If you were to tell someone the story of your life, how would it go? What has your life been like over the past 10 years? Further exploration of the narratives occurred during the walk-a-bouts with each narrator by the trends discussed during the recorded conversation.

As I prepared for the conversations with the narrators, I designed a chart that contained each of the dominant narratives presented in the literature. Beside each narrative I included where I would hear them in the conversations (audio-recorded session, walk-a-bouts, or both) I had with the narrators, questions I could ask that were related to the narratives, and a brief description of the dominant narratives. This allowed me to feel prepared about what I was going to hear during the conversations – to keep me on track.

Smith (2003) stated, “In the context of narrative analysis, the “data” of interviews are first and foremost the ways in which a person has reconstructed the past to negotiate an ever-fluid process of identity construction” (p. 216). I represented my engagement with the narrator’s during the walk-a-bouts in the form of reflexive notes. These notes of the experience are one of the primary tools of narrative inquiry research (Connelly & Clandinin, 1990). The notes were also based on many fragmented experiences of the narrators in the community as experienced with the researcher. Connelly and Clandinin (1990) suggest two forms of recording notes in the community: passive and active. Passive recording suggest that events or activities of the narrator are recorded without the researchers interpretation. Active recording suggest that participation on the researchers part is considered, and the events could be reconstructed with the researchers interpretation. Emphasis for this study was placed on active recording as I found that my co-construction of the walk-a-bouts cannot be a passive experience, of which I brought myself into each aspect of the interpretation. Reflexive notes were helpful for recording each narrator’s

experiences (or lack of) with their communities by exploring where and how the place or experience interacts with the narrators. It highlighted some of the multiple ways the narrators identities are showcased and portrayed 'in the now' as seen in Angrosino's (1994) work with Vonnie Lee. The reflexive notes also viewed some of the complex and diverse communities that the narrator places themselves in or around. Reflexive notes were also used to provide deep levels of experiences of schizophrenia in the narratives which added more details of the narrator's life stories. The notes also captured informal moments that developed in the actual settings (community) that the study explored. These informal moments were highlighted by the lack of require language and were seen as experiences and expressions of emotions, thoughts, and knowledge. This furthered an understanding of the co-construction of identity and community. Also the engagement with each narrator highlighted the resistance and negotiation of identities of the narrators.

During the final meetings with each narrator I started to give more notice (verbally reminders) to each narrator of how their participation in the research study was ending. There was a chance that I started to become a part of the narrator's community or community experience (Hutchison & McGill, 1992), therefore more reminders and constantly bring up the end date was in place for total transparently of study objectives and timelines to reduce risk of harm to the narrators. The study was exploratory in nature, not comparative, meaning I did not directly compare the three narratives between each other; however similar experiences and characters are addressed. A timeline of two months was used to complete the data collection study. At the last meeting, each narrator was given a feedback form with contact information of the researcher and research facility if need be. I also stated that I would provide each narrator a

copy of the summary of results for their own use. The expected timeline I informed each narrator was by August 31<sup>st</sup> 2014.

Keeping a reflective journal of pre, during, and post interactions with the narrators added to the knowing of this research project. The journaling allowed me to reflect on what I was aiming to explore, how to achieve it, and what challenges came up during the research process. One example is writing about the experience of obtaining ethics clearance. This was an intense process that angered me due to the nature of labelling and pathologizing persons with schizophrenia in a naïve way of causing no harm to the narrators. What I felt was that I was continuing a dominant narrative that I was not comfortable endorsing and what this research study goes against. When looking at the different dimensions of doing research with persons with a disability, one lacking dimension that MacBeth (2010) discussed was the “reflexive accounts of the role of the researcher, their relationship with research participants and their experiences throughout the research process” (p. 481). Ortlipp (2008) discusses her own use of reflective journaling when starting her PhD program that impacted her research design, her concerns with the interpretive crisis, the way she approached interviewing, and how to ‘deal’ with researcher baggage. By starting a reflective journal in the conceptualizing phase of her research idea Ortlipp (2008) was able to see the changes that were made to the research design along the way and to “clarify [her] research aims and approach where I asked, explored, and answered questions about what I could know” (p. 699). Ortlipp (2008) continues “I began to see the relevance and suitability of this reflective writing process for the way I was conceptualising my study and enacting my research as an individual with particular personal experiences, desires, and ways of looking at the world” (p.700). Upon reflection of the importance of keeping a

reflexive journal, MacBeth (2010) shares how the process is an attempt to contribute to change, in which case my study will hopefully achieve as well.

With use of writing in a reflective journal after each interaction with the narrators, more contextual and personal understandings of how the stories shape my knowledge of what was being said and how I bring my own values and beliefs into the research are highlighted. For Ortlipp (2008) the “exploratory and reflective journal writing allowed me to map my growing and changing understanding of my role as researcher, interviewer, and interpreter of the data generated via interviews, and to record decisions made and theoretical justification for the decisions” (p. 703).

## **Data Analysis**

Descriptive narrative research outlined by Polkinghorne (1988) will be useful in understanding the key concepts in this study by providing sequences of events which can be important to trace the process of deinstitutionalization for some people. Descriptive *narrative analysis* also provides the “story he or she uses to interpret others’ actions and which functions to inform the understanding of his or her own action in normal contexts” (Polkinghorne, 1988, p. 162). Descriptive narratives often come from oral forms such as an interview or conversation. I used all fragmented information (stories) that each narrator shared and found the primary story (or stories) that related to the purpose of this study (Polkinghorne, 1988). The findings from this narrative analysis are found in Chapter Three. The audio-recorded conversations were transcribed verbatim by the researcher. The transcripts as well as the reflexive and walk-a-bout notes were used to deepen the experiences of each narrative. Each narrative consisted of the audio-recorded conversation transcript, reflexive notes taken about the research process and

notes taken immediately following the walk-a-bouts. The narratives are placed in chronological order to build in the characters, settings, and plots with ease for readers.

Polkinghorne (1988) also states that the researcher needs to “reach” above the level of the sentence, to develop a grammar for narrative discourse (*analysis of narrative*, see Chapter Four). An analysis of the narrative was used to understand key concepts particularly related to identity construction. However, using a postmodern framework to analysis of narrative, I reexamined the textual claims to authority of the narratives I hear and see of the narrators. Similar to the authoritative medical model approach to health care, I as a researcher was aware of my own position of “authority”. Kincheloe and McLaren (2005) state “no pristine interpretation exists – indeed, no methodology, social or educational theory, or discursive form can claim a privileged position that enables the production of authoritative knowledge” (p. 311). Polkinghorne (1988) states that the “analysis of narrative data does not follow an algorithmic outline, but moves between the original data and the emerging description of the pattern (the hermeneutic circle)” (p. 177). Each story is filled with a great deal of context by the conversations and field notes in textual forms. It is important to highlight some of the narratives discussed in chapter one in the narrators stories in my role as a gatherer of information.

Adapting Roe’s (1994) data analysis of the narrative process, I have used this process as a guide. Roe’s four steps have been shaped to focus on schizophrenia. The meta-narrative does not fit with my study so will be exempted from my data analysis process. The following four steps of Roe’s (1994) work include:

1. Identify the accepted and traditional stories and narratives that dominate persons with schizophrenia.

2. Identify the existence of non-dominant narratives (counter stories and non-stories) of persons with schizophrenia.
3. Compare all stories (dominant, counter, and non) to come up with a meta-narrative.
4. From creation of a meta-narrative, determine if and/or it affects the lives of persons with schizophrenia.

The process Roe (1994) has laid out is very linear. After identifying the narratives presented by the narrators, there were moments of crystallization (non-linear, reflection) of the analysis process. These moments of crystallization occurred by going back and forth between the transcripts, reflection notes from the walk-a-bouts, and my reflexive notes about the research process. Also, I was able to step back and talk more about the narratives as a whole with my supervisor that led to a deeper understanding of what the key aspects of each narrative said. Having to tell my supervisor of the three narratives I heard made me more aware of how I was going to share the narratives in this document. The sharing needed as much detail so that a reader would follow the stories. While this crystallization did not lead to a meta-narrative, it did allow me to look at some of the things that were not said. According to Roe (1994) non-stories are those that do not hold traditional structure of a beginning, middle, and end. These non-stories stand alone and are not about identity or community but added to the development of an authentic, reciprocal relationship with the narrators.

Due to the personal nature of sharing such stories of mental health and illness, struggles, pain, and fear to name a few, there is a potential for discomfort in sharing these narratives and also when reading them when the summary of results have been circulated. When sharing the summary of results with the narrators, they could be in a different state of mind/being and re-

experiencing the stories may cause discomfort or concern. Reinforcement at the beginning of the study about some of the expectations and experiences that may occur is important for the safety of the narrators and also gives some insight into what the significance of participating in the study had on each of them. A letter of introduction to the study, me as a researcher, a little about the department and my supervisor Dr. Susan Arai, and a brief description of the University of Waterloo was handed to each narrator. An informed consent form was also handed to each narrator during the first meeting. Debriefing with each narrator of the experience of sharing their stories aimed to cause as little risk to the persons as possible as well as provide contact information if they had any questions or concerns. A copy of the summary of results is given to each narrator in person by the author unless requested otherwise.

Richardson (1990) states that few researchers have “explicitly analyzed and articulated how individual’s narrated experiences of daily time are linked to larger social structures, linking the personal to the public” (p. 125). The construction of a social world is created in the process of telling a story. However, the notion of generalizability (or a meta-narrative) of the narrator’s stories in this study has been cautioned due to the complexity of the schizophrenia spectrum, temporality, and the community the person resides.

## **Reflexivity**

As seen throughout this paper my reflexivity as the researcher and author is included to outline subjective experiences and histories that have impacted my ability to co-construct and interpret the life stories of the narrators. Creswell (2009) defines reflexivity as a researcher’s, “biases, values, and personal background, such as gender, history, culture, and socioeconomic status, that may shape their interpretations formed during a study” (p. 177). With narrative research, and with Coles (1989) view on the narrative process, I will share my stories with the



narrators, and in some ways become a part of the experiences – certainly during the walk-a-bouts. I have formed, reformed, struggled with, resisted, negotiated, and accepted multiple identities that I have felt I belonged to at specific times over my life so far. I most often identify as a homosexual which means I have been through negotiations and resistance of this identity in and around my communities through the years. I have also moved around quite a bit, been exposed to many different cultures, communities, and groups of people in a more physical sense of community but I have also belonged to online and virtual communities that exists using the internet. Depending on where I lived and worked, communities have taken various forms and sizes from rural to urban and familiar to the unfamiliar.

The study has however, drawn upon on the narratives of the three narrators who experience schizophrenia, instead of my experiences unrelated to schizophrenia. As seen as an important aspect of a story, experience, or event, my own experiences or stories have helped shape the overall narratives of the narrators by allowing of an authentic partnership between myself and the narrators. However, as Creswell (2009) indicates, awareness of the researcher's personal background that could impact the interpretation of the narratives and could impact the narrative the researcher shares with the narrators. Negotiating what stories, personal information, and other information a researcher shares with the narrators must be consciously considered as relevant to what the purpose of the study entails.

My history working with persons with schizophrenia has been short but extremely powerful. I was introduced to schizophrenia when working as a recreation therapist on a community mental health treatment team. The complexity and challenges I faced as a practitioner in developing strategies and techniques for treatment had a lasting effect on the way I heard and understood mental health. Some individuals I worked with were newly diagnosed

with schizophrenia or schizoaffective disorder – a few were around my age. I have no direct connection to schizophrenia through family or friends; however, personally, I have felt very touched by some of the people with whom I have worked. I have always been a stronger supporter of community integration and inclusion for all people with a mental health disability. At times I have seen how this label of “mentally ill” has made it difficult for persons to gain full inclusion and acceptance into communities, especially rural settings. That being said, growing up in a small community has also shaped my idea of how caring, supportive citizens can work together to create positive change for the well-being of all members belonging to that community. I also think hearing and co-constructing their stories will test my ability to convey a representation of the people I work with and push me to different, unfamiliar boundaries. My reflections on my strengths and weaknesses, and my own humanity have been a critical aspect of this research project before I endeavor fully into it.

My strong attitudes and feelings toward animal care played a role in how I used brought in and controlled my personal biases. During a walk-a-bout at a horse stable, a place I would never go to in my leisure time, I was overwhelmed at times of my strong emotions of animal cruelty. I have never been a supporter of animals used to the sole purposes of human need or enjoyment. I tend to stay away from zoos, marine parks, or circuses. I had a similar feeling during my years as a recreation therapist where we would volunteer with the clients at a local humane society. Seeing animals locked in cages leaves chills flowing down my spine. However, as I saw and heard the excitement from the clients at the humane society and of Whitney at the horse stable (during a walk-a-bout), I knew how important that experience was to them. I was looking at the situation through broken glasses which distorted my vision of what was actually happening. The horses were giving affection and love to Whitney, just as she was giving love

and affection back. As I read through Whitney's narrative I saw how little she had opportunities to have experiences like visiting the horse stables in her life. Who was I to deny her of that peace? I learned that at times I needed to take off my broken glasses and open my ears and heart.

### **Assessing Quality of Narrative Studies**

Rappaport (1993) claims that narratives and life stories contain structural features such as event sequences arranged in specific contexts. The narratives allow community members a glimpse of what and how community came to be for certain stigmatized members. To explore the stories in more depth, Connelly and Clandinin (1990) call for writers to frequently move back and forward several times in the writing process. Researchers do not always get the stories right however as we may "misunderstand or misinterpret the people we are trying to understand, but the goal of such work is to understand what their stories mean to them" (Rappaport, 1993, pp. 248-249). While lending ideas from a postmodern framework, we as researchers will challenge the use of traditional representation. St. Pierre (in Richardson & St. Pierre, 2005) explores this idea of *postrepresentation* that involves not asking questions of "who are they narrators?" or "what do they mean?" but rather ask "what else might writing do except mean?" (pp. 971-972). There are four criteria sections that Richardson (in Richardson & St. Pierre, 2005) claims can apply to postmodern studies. The following are the four criteria outlined by Richardson (p. 964):

1. Substantive contribution – will hearing and writing the narratives of each narrator in this study contribute to our understanding (as a community and as human beings) of social life for that person.
2. Aesthetic merit – are the stories and narratives shaped in a way that invite others to read and attempt to understand the complexity of the stories.

3. Reflexivity – will the author have awareness of themselves and of the community to be both a producer and a product of the final text?
4. Impact – how does the study move me, affect me, and what does it drive me to do afterwards or during.

Credibility in the study will use a number of different techniques; however representation has been counter to the traditional notions of truth and credibility. As mentioned above, developing a trusting relationship with the narrator is an important factor during this study. Asking the narrators to listen to their narrative (presented during walk-a-bouts) is another technique used in qualitative research (Creswell, 2009). Hearing the narratives can authenticate one's own story, sometimes a reploting of the story (Richardson, 1990). This was accomplished during follow-up conversations through the different walk-a-bouts with each narrator. Richardson (1990) discusses the idea of “(re)narrativizing” as a way of reconstructing a person's biography, allowing different meanings and systems of meanings to develop. This was seen during a follow-up discussion with Tina when I asked to clarify what the main purpose of attending the walking groups heard during the audio-recorded conversation when at a walk-a-bout with Tina. She made it clear that her participation was driven by a social need rather than a physical need that was heard more during the audio-recorded conversation. This realization was only accomplished through Tina hearing her own narrative through my words.

These issues of quality will be considered throughout the study as it unfolds. In Chapter Five I return to discuss these issues for assessing quality of the narrative.

## Chapter Three: Narratives of Ryan, Tina, and Whitney

The following narratives consist mostly from the audio-recorded conversation that each narrator had. The sequence of each narrative has been arranged in chronological order to capture the stories in an easy-to-read manner. The narratives did not present themselves in chronological order during the audio-recorded conversations, as the questions were not placed in an order. For readers of these narratives, chronological order allows for insight into the lives of the narrators.

At the beginning of each narrative I use my own voice to describe in detail about how each narrative unfolded. My voice is italicized to make distinguishable from the narrators voice. Also embedded in the narratives are my reflection notes from the walk-a-bouts and my self-reflexivity notes from the research experience, both which are italicized. My voice during the audio-recorded conversations also played a part in setting up the stories that were heard by giving context to why the narrators shared certain aspects of their life. These sections are marked by using my name (Devan) as the author of those words.

The characters presented throughout the narratives of Ryan (see Appendix E), Tina (see Appendix F), and Whitney (see Appendix G) are expanded on how each character's played a role in the overall life of the narrators. The characters are introduced to you in order of impact in each narrator's story. Characters are also identified as a protagonist, an antagonist, both or not identified as either (due to lack of information known about how the character is involved in the narrator's life).

### Ryan

*Of the three narrators, Ryan's narrative was the most polished. He has given many public talks and has scripted his story in a way that has been practiced. His narrative quite often*

*resembled a scripted dialogue that Ryan would have to educate others. When talking about his daily routine, Ryan used words such as goal setting, educate ourselves, and co-facilitating. The language Ryan used seems to be picked up from the health service groups and programs in which Ryan has participated.*

### **Ryan's Narrative**

Well I guess I would say that I had a normal childhood. I was born I lived on a street called [Johnson Street] when I was really little and I moved to [Smith] street. Near [Palace] and [Bagot] in [City A], I lived there until I was 7 and I moved to the house I live to now when I was 7 so I've been there for 30 years. I lived in [City A] my whole life. I have an older brother yup, and a younger sister. All three of us live in [City A], we are pretty lucky that way. My sister likes to apply for jobs all over the place but she is still here. We are pretty close. My brother is 14 months older than me so we grew up going to the same school and having a lot of the same friends. And my sister she's a bit younger but uhh I used to counsel at [summer camp] which is a Y camp and my sister would always go for a month while I worked there so I knew her pretty well from that. And I used to babysitter her when I was little. I am about 4 years older than what she is. So we are pretty close now too.

*As a child Ryan played soccer and baseball – summer sports. His mother didn't like driving in the snow/winter and since his father was working all the time, Ryan wasn't able to play in winter sports like hockey.*

I had lots of friends in school. Got good grades. Umm ya and umm I got along with people pretty well umm my parents got divorced when I was young so my dad moved away so I umm he moved to [City H] first and we were suppose to visit every second weekend so I started to see him every second weekend. He actually got transferred to [City G] so I visited him there for years. But then he moved back to [City H]. Umm growing up I worked for my parents they

had a small business. Uhh in the ceramic business, they sold decal, like you get a mug and there's like a logo on the mug. That's a decal so they used to sell those. Umm to decorate a pot, as well as clay. And in high school I was on the wrestling team, I was actually on the wrestling team in grade 7 and 8.

So I did really well I went to OFSA for my school. That was pretty cool. I got voted uhh rookie of the year for the wrestling team. So umm in high school everything was pretty good, I used to hang out with my friends on the weekends when I wasn't with my dad so we would party or go out smoke cigarettes and starting drinking and started smoking marijuana and doing stupid stuff like LSD and magic mushrooms. Ya with them.

I walk[ed] before I was ever like I used to walk home from school in high school which is like three kilometer walk and after school I would go out for coffee with friends sometimes and walk home from there which is like five kilometers.

I was 18 turning 19. I think it was grade 13. It probably started at the beginning of the year because at first I didn't really remember when it started but I remember that I wasn't doing well in math which was usually one of my best courses so that was the beginning of grade 13 in '94. There was so many symptoms it just didn't fit with the mental illness. I was tired all the time you know, instead of going out with friends after school I would go home and nap. Then I would wake up and then do my homework then fall asleep and before I knew it was morning and I was just exhausted. I had a lot of symptoms like I was tired I had headaches, my back hurt, everything just I had physical pain everywhere, felt like swollen glands and ya I really didn't know what was going on, no one knew what was wrong with me but my parents noticed that something was up because my grades were slipping especially in math. I had an

algebra/geometry I actually got a 53 in that class so I barely passed and my average had always been 76 all through high school so we didn't really know what was wrong so I was trying to do stuff that would help so I went to the chiropractor and the chiropractor sent me to a nutritional consultant and they thought it was maybe diet. So I turned 19 the next February and it was just sort of was getting worse from then because at first I could deal with the voices I could get the homework done, I passed all my classes and I graduated but it just gradually went downhill from there for a while. I had actually went tree planting for a summer and I think I got beaver fever when I was up there so. Beaver fever umm beavers have like a parasite in their poops so if you drink water that the beavers swim in you can get sick it's like kinda like having the flu for like you know like a month or two or whatever. ya I guess it can be kinda scary I guess I didn't have it that bad. But uhh ya so all the other symptoms like being tired and all that I just thought I had beaver fever you know, it's not mental illness at all.

I don't know if it was because I didn't get help or if schizophrenia just affects people that way, I'm not really sure but it got worse and worse until I was actually diagnosed with I was 21. It was actually by my acupuncturist. She was a medical doctor in China but because she couldn't speak English very well she couldn't practice here so she was an acupuncturist here. She actually told my mom she opened up Chinese to English Medical dictionary and pointed out schizophrenia so which was weird, that the doctors didn't really know what was wrong with me

I have always liked walking and it was actually my acupuncturist actually got me back into the walk. I didn't know she diagnosed me with schizophrenia because she told my mom but I found out later but. She told me that if things got bad I could just go out for a walk so my voices were bad even if it was the middle of the night I would go out and walk around my neighbourhood try to clear my head a bit so.



Devan- and it always seem to work?

Ryan- It does ya. It did then too.

But ya so I was diagnosed and things got a bit worse for a while and then I ended up in the hospital because my parents phoned the police because I was really agitated one day. It was over a stupid argument about my mom wanted to wash my clothes but I said they were already clean but I smoked in my room and she wanted to wash them because they smelt like smoke so I kinda flipped out. And uhh she actually called the police and then lied to them that I had grabbed her arm and uhh and then they took me to the hospital at the local [hospital] site or [A-Block] and I was admitted there and they got me on medication and uhh they said I wasn't really getting better so they deemed me as being schizop... resistant... wait let me think what to call... umm treatment resistant schizophrenia. So they put me on a medication called Clozapine

At first I really did resist it. I didn't really know what schizophrenia was but I knew that I didn't want to have schizophrenia, umm I realize that in the news, like growing up in the news you know like Paul Bernado who has schizophrenia and was a murderer so that kinda you know in my head that people with schizophrenia are crazy or they are insane and umm so I had an aunt that was adoptive and she had schizophrenia. My family always said that she was crazy so like I knew her and she seemed normal enough but she just didn't really cope well and umm I didn't really want to be anything like her or admit that I was anything like her but uhh umm I didn't admit it at first I didn't really know anything about schizophrenia, I didn't know what psychotic meant. I didn't know what a break from reality was or a delusion was or umm ya I really didn't know and I didn't want to accept it and it wasn't until after I got out of the hospital that I did accept that I had schizophrenia.

That's what I thought that I was the only one and my self-esteem was really low. You know I thought people just didn't like me anymore. That was really hard, I thought I wasn't good at anything anymore. Mostly because my voices would keep me awake at night and I was just really tired and cranky and moody and. I had a lot of anxiety. Sort of wish I listened to my mom because she wanted me to go to [Support Centre]. So if I had done that, I would have been way ahead of where I am now. I guess I needed the diagnosis from psychiatrist and medication and that so. Ya, well, you gotta be in the right state to hear it I guess. I thought I actually needed to hit bottom before it could better. So before I was in the hospital I hit bottom and then was ready to try and get better.

So like I had been diagnosed and they kept trying to tell me I had schizophrenia, my family doctor kept saying I had schizophrenia, I didn't want to listen so my life kinda ended. I stopped talking to people I spent all my time in my room. I really lost all my friends from high school, they really didn't understand. They honestly thought that my problem was I wasn't partying enough, or that I was partying too much and all my problems were drugs and alcohol. You know you explain to your friends after a party you feel like crap and they are like "oh have a beer" so I really don't see a lot of friends from high school a lot. I have a best friend, we have been in class since grade 7 together so we've known each other since pre-school. Yeah, he used to come over and see how I was doing and called me once a month and so. I was really close with his family, I went to [high school] but I had to take the bus into school and he lived like a two minute walk from there so I used to go to his house after school to do homework with him so I was always hanging out with him and his family. So he's still around and I see him when I can. So I kinda lost most of my friends. My parents would go to work, I would like watch TV then I had jobs when this was going on too, I was working at a local factory. It's a warehouse they sell

fasteners, nuts and bolts, and screws, rivets and that. And then I quit that job to go tree planting I think and then after I got back from tree planting I got a job ummm I was in another warehouse in [City B] called basic stoppers and they sold like paper and stationary and stuff too, and uhh ya I you know, I really wasn't really talking to others and I don't know how I made it. I was exhausted you know, I was amazed that I could actually still walk I was so tired.

So for me, when I wasn't well for me it was hearing a lot of voices, I would hear voices like they would wake me up in the middle of the night or umm they would talk to me all day or whatever. That was probably the worst part of my symptoms ummm because when I heard voices it was 24 hours a day and umm they tended to keep me awake so I couldn't sleep and then uhh the voices keeping me awake I would be more tired which would make the voices even worse. But personally ummm that also the schizophrenia that made me really paranoid I wouldn't trust people or I thought that people were out to get me so uhh ya before I got help I actually had to teach myself how to block out the voices cause they got so bad that I couldn't even read in my head. You know if I wanted to read I had to read out loud to myself and I just felt it was too much effort to read at all so umm often I would listen to the radio to block out my voices or turn the TV up really loud but my parents would get upset. You know if I was listening to the radio in the middle of the night or whatever so I had to figure out how to block them out on my own. So at first I just did anything, you know, talk to myself or hide under the covers and then one day as I was hiding under the covers I realized that that was working because I was listening to myself breathe when I was under there. And the sound of my breath sort of distant the voices and at first it didn't block them out it just made them a lot quieter so they weren't as loud and then I learned how [to] deep breathe and block them out so they keep getting quieter and

then there would be times when silence and I couldn't hear voices at all. So for me that was a big breakthrough and that was before medication and before I was in the hospital.

And uhh I got fired from that job for being late and then after that I got my welfare and I got kicked off because I live with my parents and then my mom wrote a letter to the Canadian Mental Health Association that uhh I actually read the letter but she didn't know. Umm then a worker came by and helped me get on disability and so I admitted that I had a mental illness and when I was on disability it was good but I just quit leaving the house I didn't go you know I had my interact cards so I didn't go to the bank and I kinda went downhill until my parents had my arrested and put me to [A-Block]. That's sort of when I started to get my life back so. Ya after being in the hospital I was here for four months and then [City D] for seven months. For me I didn't really talk a lot to my family back then, I was just a little mad for sending me to the hospital and I was worried about going home, I actually stayed longer than I should have in the hospital because I was worried that if I went home and get in another fight with my mom and then I just end up back in the hospital again anyway.

Things started slowing getting better for me so. I needed a blood test for this and I said fine and they took a lot of blood from me and whatever and the meds starting working and I started to come out of it and I was starting to get better and they sent me to [City D] cause I was at [A-Block] for four months and the average stay there was about 6 weeks or something. So they sent me to [City D] and I was in [City D] for seven months. My family used to visit me here in town and they actually would visit around once a week in [City D]. Umm they put me on a medication called Seroquel and it actually helped with my social anxiety that I had too so and actually I was started to get better before I was out of the hospital.

They said that medications take 6 to 8 weeks to kick in and people are in hospital now for 14 days, and in the hospital I didn't realize that people are around and they wouldn't be there and then they would be back and I was confused about until I got to [City D] and realized they were discharged and then were back already so. I was in the hospital they put me on meds that helped me sleep really, so I was well rested and it helped get rid of the voices that I had too.

The side effects of the meds I'm on are like fatigue and low energy but when I was in [City D] there were two nurses that would wake us up in the morning and take us out for walks around the grounds in [City D]. It was really good for me so I was like walking so that totally helped out with the side effects of the medication you going out for a walk you, some fresh air, our rec. therapist came on the walks too sometimes.

I was always very popular in the hospital because my mom visited so much. I made a lot of new friends even in the hospital and since then and so a lot of my friends have schizophrenia and they are doing really well too. There a myth out there that people with schizophrenia don't get better which isn't true at all.

I remember one day I had to do my laundry in [City D] so I walking around in my pajamas and one of the guy said "ohh your in pajamas, what's wrong? What did they do to you? What happened?" and I said I'm just doing my laundry. Ya so my parents were very popular here and in [City D] when they would come to visit, everyone would want to talk to them and be like "Oh Rob you have visitors, your parents are here!" and so that was good too, sorta helped me patch things up with my parents and, I was in [City D] over mother's day which was the first time I left on a pass to go to a pizza restaurant in [City D] for mother's day with my family. Sorta regained my life you know. It was kinda like having to start over again since when I wasn't well

I was like I'm gonna keep going I'm gonna keep doing this, keep getting jobs and keep going out and then I got so tired you know it just got easier to start over and uhh so I that was hard too.

Well personally I know a lot, a lot of my friends have schizophrenia and the one thing I noticed even in the hospitals that people with schizophrenia are so different, you know. They are not like typically this is what people with schizophrenia is like. To know them they are all so different and if they hadn't told me they had schizophrenia I really wouldn't have known.

I actually, this is a great story. Because when I was in [City D] Psychiatric I had a rec. therapist there whose job it was to drive people cause back before this was back in 2002, that uhh they didn't have long term mental health beds in [City A] so they sent people to [City D]. So when I was there it was this rec. therapist job to drive us back to [City A] to uhh I guess people where going on day passes and that to visit family but uhh I wasn't on a pass. He actually got me connected with [Support Centre] it was actually called [City B region self-help] back then. And he got me connected to a group called [social centre] and we used to go hang out. We would go bowling or plain glass gallery and coffees and stuff like that.

And I was discharged December of 2002 and moved back with my parents, by the time I was released I was a lot like I was before I developed schizophrenia. I was more social I got out of the house and stuff, I wasn't home in my room all the time. Actually talking to people again and making friends again so it was about 5 years or so when I was well I was out of the hospital since 2002. In December it will be 12 years.

The hospital for me was sort of like a journey of healing it was when the healing started so I realized there were people in there who were way more messed up than I was and they would get up every day and go to breakfast and sit around not doing much and you know those

actually something going on there, I don't know if the staff realize this but people with mental illness talk to each other so they know a lot about other people's mental illnesses and all that too. That's where the peer support started.

And it was through that I was years later that I started volunteering with [local mental health housing agency] but the rec. therapist was one of the keys in my recovery because he drove me into town and got me connected into the community and that so. And uhh the girl at [Garden Place], I had a worker when I was released from [City D], the community outreach treatment team and uhh I knew a guy from the social club who volunteered at the [volunteer centre] at the garden so I kinda got connected that way. That was back in 2003. I started volunteering at the [volunteer centre]. It was just in the summers back then but now it's all year round because they have a heated green house. So ya I actually got involved in a, I went to a program called [Ravenclaw] which my worker from [City A] got my involved, which was a day treatment program.

So for part of the day I think it was three days a week, for part of the day I would just talk about mental illness and educate ourselves and set goals for the rest of the week and all that and uhh we played cards Tuesday afternoons and went bowling on Thursday afternoons and then the program closed down so I uhh started running the games group at the [Support Centre].

And there's a bunch of us at the bowling group that kept that going too. But it's a separate thing that we just do on our own that's not part of any organization. So the games group was the first thing I started volunteering at the [Support Centre]. And then I started running the, well co-facilitated, the schizophrenia support group called [Winterfell] and then I took it over as the head volunteer and so

So that was 2007. I started volunteering with the games group and schizophrenia support group in 2007.

*I noticed the leadership skills of Ryan during the snowshoeing event I attended. Ryan was actually the leader of the hike and seemed to have done it before. He was leading the group, knew the route, and had the interest in the group and hiking to take on this challenge.*

I guess it depends on which day of the week. But a typical day I usually get up ummm before 9 if I can. Depending on what I have to do for the day. Ummm I brush my teeth and eat breakfast make coffee. Breakfast is usually yogurt. And there's days I get up earlier because on Mondays I volunteer with the green house at the [volunteer centre]. It's called the [Garden Place] I've been volunteering there since 2003. So they have a nice heated green house where they grow micro greens all year round.

And the other day I used to get up earlier. For the Friday afternoon hike by [local mental health housing agency]. So I usually get up around 8 for that too. So a typical day umm so there's days I volunteer, I volunteer usually two to three days a week. Ummm and uhh I also do uhh training for the walk. I'm in training for the half marathon in May. So Saturday mornings I get up about 8:30 and go out and do some power walking. Usually about that time its 12 to 15 kms so I am gradually getting closer to 21 kms which is a half marathon. So I do that Saturday mornings. Sunday mornings I get up and go to yoga with my mom and yoga instructors. Ummm and after that I usually eat lunch around the same time every day. I sometimes eat at [local café] which is a café run by the [volunteer centre]. And Tuesdays I usually grab a coffee and an egg and cheese English muffin at [coffee café] before I go to my games group which is where I volunteer during the week which is every Tuesday. And uhh on the 1<sup>st</sup> or, 2<sup>nd</sup>, and 4<sup>th</sup> Wednesday of the month I run the schizophrenia support group at the [Support Centre].



So that's from 1 until 2 pm. And the afternoon on Saturdays I go to Jazz, my parents had the [local Jazz club] at the legion in [City B] on [Rebecca] Street. So umm so a lot of the time in the winter I have to shovel, like today I started off my day with shoveling, I got everything all nice and by the time I was done it already snowed

I don't mind winter. I don't really mind snow, but I don't like to shovel it all the time. So and in the summer I usually spend a part of my weekend gardening to at home. I live with my parents, I pay rent. So I have my own room there and I do my own like shopping and stuff. I lived in the house for the past 30 years. Ya I do various chores for part of my rent too and pay for groceries. I get along with my parents very well. I didn't always but I do now.

I have a lot of support umm a lot of the time it was workers or people at the hospital, people at the [Support Centre], but I found that a lot of people accepted that people do get better. So they encouraged me to keep going and keep doing what I'm doing and uhh you know keep taking my meds if they still work right. uhhm I have a lot of family support and support from my best friend and his family and people at the [volunteer centre], they are really open, learning more about mental illness, they have a psychiatric outreach program there, so a lot of them know about that. Umm ya they are just, I find a lot of people are really willing to accept mental health issues and even schizophrenia. I don't tell people I have schizophrenia but if they ask I will tell them. Umm ya. I've met a lot of cool people. Umm the woman that used to run uhh [City B self-help] so the [Support Centre] and she was friends with my mom too. So I guess that early on when I didn't want to listen to my mom, my mom would just call up her and then she would ask me, she's the one that got me to volunteer for the schizophrenia support groups.

I had no idea it was my mom, ha. My mom seems to know everyone so. When I wasn't well she uh tried all of the committees and groups that focus on mental illness. Trying to get help for me. She is actually the family navigator at [A-Block]. The people who visit people in the psych ward get to talk to my mom about how to help. This is how to discharge and medication and questions they have about that.

I always had peer support, it was going to happen. You know people with mental health issues were going to talk even to their friends, about problems they were having or they've been feeling. But a lot of the times their sharing in a way that isn't safe but with [local mental health housing agency], what our [Support Centre], it's a safe community that you can trust people that aren't going to go and tell everyone, that you are going to commit suicide or something like that.

I guess there is different types of community but for me, the community that I am a part of is the mental health community which consists of my workers, people with lived experience, umm, family, friends, and that sort of thing. Umm you know volunteering that people don't care if you have a mental illness as long as you work hard. It's like a lot of people who have development delay are capable of working and some of them work really hard. And uhh ya. They are in a community that is inclusive that includes everyone, regardless of where they come from or how they may think or all that so. Community to me is where I volunteer its ahh where I spend my leisure time, umm yea, you know the people that accept mental illness and the people are just really ignorant. And even within my community there's people in other communities but I don't really interact with them I might say hi to them on the street or something. Some of them know my name but I don't really think we are part of the same community. ya cause there are obviously the high school community who I know from the city bus and I wouldn't really talk to them unless I was in school and talking to them in class about my recovery from mental illness.

So there's lots of that community with the teachers who aren't always popular with their students but the students like my presentation and ask lots of questions. Ya cause my dad who lives in [City I] umm he had, really didn't know what to think at first when I wasn't well. Umm he didn't really know how to be supportive or anything but he's actually getting better, he's trying much harder now. He has learned to be more supportive, so there is always that community of people. Ya so I think that more people are learning about mental illness, the Bell Let's Talk thing just happened and uhh there's some people on TV and CTV, they had a special on Let's Talk, and Margaret Trudeau who I heard speak last year has bi-polar. I think the mental health community is getting much bigger. There was always for lots of workers but [it] seemed like the people with mental health issues didn't want to be involved but they are getting more and more involved. Getting more activities and realizing self-help isn't stupid as you know our therapy.

I actually belong to a group called [We Are People] and people with various mental health issues that uh, umm we go into schools and tell our stories and uhh when I went to the Summit for Mental Health and Addictions, I met some people there about my age who were from [City H] and I was telling them about this [We Are People] thing and "hey we don't have anything like that in [City H]" you know. I didn't follow up on it but you know but it's great you go and tell people your story and that was pretty cool at the conference. There were various speakers when I was there and one guy that was there was the co-founder of Second Cup coffee place and he had addiction issues. Umm he talked about starting Second Cup and they were just selling coffee and they decided they were going to have samples and then give people sample coffee you know so you got a coffee and it turned into you know this big uhh coffee shop and this guy has so many problems like I couldn't believe he started something like Second Cup and

you know the problem is he has addictions you know he's not stupid. A lot of my friends with schizophrenia are smart.

I feel much better. Part of the past couple of years I sort of got my confidence back. I can actually talk to people without thinking about what I said was stupid. I have a lot more friends, I'm a lot more active in the community. Umm actually connected with a friend from high school probably about 2009 or around then who had been diagnosed with bi-polar and I was like, he emailed me and found my information because I was in an article in the paper with my family and uhh ya it was kind of anxious about meeting him again because wasn't sure if I had anything to talk to him about because it had been so long but it went well. We went and played pool and chit chatted for a while so caught up on things. I'm actually more comfortable speaking to people and hanging out with people. More comfortable giving support, supporting someone that so many people come to my group and are depressed or whatever so I try to be supportive and help them what they are going through. So getting more confident umm. Doing more public speaking so that's getting a lot easier. When I first did public speaking I was terrified ha. I had a lot of anxiety but I am sort of over that, I don't really get nervous much. I mean in the morning I get up and I feel a little bit nervous, but as soon as I get to the school I am over that.

I started, not sure what year I started but might have been 2008 and uhh yea I'm not sure how many I do a year but I did three in January. So I usually do one a month for the school year. A lot of the times they're not until the end of the semester that we get another talk to them. The more comfortable I am answering questions from students, which is usually about hearing voices. They are really curious about that. Usually grade 11 students. We get people in class who are going through stuff with friends, going through stuff with families.

I was meaning to say that I actually belong to a group called [Fighting Stigma]. So we do stand-up comedy just to make fun of the mental health system and. Make light of mental health. We have a group here. It actually started with a guy from [Canadian province] named [John Doe]. He's a counselor and has depression and he was a comedian I don't know if he was a successfully but now he is successfully comedian. He makes all these jokes about mental health. So he trained us on Skype, in 2010. We did a 5 minute comedy set. I did that quite a bit, it's kinda been slow the past year or so but he has groups all over the world. He had a group recently started in [foreign country] so. I have your email, if we have a show I'll let you know. We had a show in October at the [Waterloo Theatre]. Kind of a fundraiser for [Brilliant Minds]. That's another thing, [Brilliant Minds] is part of the [Support Centre], healing through the arts organization. I am the chair of the local chapter of [Brilliant Minds].

*When we (Ryan, myself, other walkers, and the recreation therapist) arrived at the indoor walking track, the recreation therapist pulled Ryan aside to ask if he would feel comfortable teaching anyone who was willing to learn about speed walking. He was kind of put on the spot, but he keeps being encouraged into leadership positions by the recreation therapist and perhaps other staff. He seems to take it on quite well though. He does a lot of stuff on his own. A few walkers were interested in learning more about speed walking and Ryan took the time to teach them.*

*Ryan has done more for his community than most people I know. He is a leader, a role model, and has been both a productive consumer and facilitator. I'm in awe of all the organizations he is/has been a part of and continues to challenge what he is involved in.*

*Ryan uses his leisure to belong to his community. He describes that he lost a lot going into the hospital but gained a community through his mental disability. The leisure gave Ryan purpose, sense of worth, and a chance to excel at something. Where does Ryan get his strong desire for physical activity/fitness since he wasn't strongly involved as a child? Is it because those activities keep him actively involved in his community?*

## **Tina**

*Tina's narrative was originally fragmented in a way that made it difficult to understand as a reader. Consequently, Tina's narrative took more time and effort to order it in a*

*chronological sequence. The sequence of events she discussed was inconsistent to the topic she was talking about. One example of this in her narrative was when she was discussing her childhood as a tomboy and then preceded to mention her father committed suicide. "I was the tomboy. I would climb trees and stuff. And get into trouble a lot and umm, and then as I was around 8 or 9 my dad, he committed suicide." It was a shock to hear such a change of pace when listening to her account of her father's death as a casual statement of fact. Overall it was difficult to piece together events in Tina's narrative. It took time to move her stories around. I did enjoy Tina's company as she is friendly, humorous, and kind. She has a relative ease about herself that she carries, packed behind a somewhat anxious exterior. She somewhat reminds me of my mother.*

### **Tina's Narrative**

When I was younger, I grew up as a wild child. Very active outside with friends, hung out with the boys, I was the tomboy. Would climb trees and stuff. And get into trouble a lot and ummm, and then as I was around 8 or 9 my dad he committed suicide. Like I would hang out with boys and they would get in trouble like break windows and stuff like that so I was into little bits of stuff like that. I don't know if it was that my mom told me about my father, like he robbed stores and stuff. And he was in jail for a couple times for robbery and that. So I was aggressive when I was younger. It's been moving up to high school I got really, really shy. I had a lot of anxiety, panic attacks and stuff like that so I would uhh skip school, and uhmm eventually fail back down to grade 9 twice, and eventually kicked out of school because of my time off school. I just couldn't catch up anymore even though I was very smart. I remember getting A+ in math tests and stuff like that.

*While discussing school Tina mentioned how difficult it was to go to class with her high anxiety. She would often skip class to avoid those strong feelings. She said there wasn't any support and only received counseling at the age of 18.*

Skipping in school I fell behind too far that I just couldn't do it anymore so I was kicked out at 16 [years old] so I was made to get a job which is naturally you have to, if you don't go to school you gotta get a job and you can't sit around so I worked at the mink ranch so that was hard on me. I think that was the first time I tried suicide but nobody found out, nobody ever knew about it, so I never said anything. And then uhmm when I was, so after that I didn't work for another two year until I was 18, I was forced to go into the hospital by my mom because I wouldn't leave the home very often. I would just go to [City J] and back, like at the cottage, but I wouldn't do a lot of things with the family, go down to the beach, I would hide a lot in my, in the trailer stuff from anxiety I had panic attacks. But I didn't realize what was going on with myself I just thought you know I'm phobic I must have agoraphobia but I never did it was real bad anxiety, panic attacks. So then I was put in the hospital for 2 months and had help and got out of there and got a job and worked at several different jobs and I ended up getting fired at all the jobs because I don't know if it was my illness or not but I would mess up on the job, do different things on the job that I never had trouble getting up and getting to the job, I was always there. It was just keeping the job, I would screw up on the jobs and stuff like that where I would get fired. So I went through so many jobs and got depressed and suicidal from getting fired and that so.

He [Tina's father] was on medications but I never ever knew why he was on medications until I turned 18-19 and that's when I found out uhh he had schizophrenia. And that's about the time I got sick so umm, I uhh he committed suicide so I didn't really know he had it until I was in the hospital then I found out he had it and sooo I... I can't, forget about what we were talking about now, hahahahaha.

Devan- So your father was 26 when...

Tina- 28

Devan- 28, and you were 8?

Tina- I was about 8 or 9

Devan- And so how did that affect, the family dynamic with your mom and...

Tina- Oh they were already separated. She had to separate from him because he was very abusive to her. And he, he drank a lot and took drugs and stuff, and he beat her, like he was very aggressive beating her. I would see all of that stuff and ummm but uhh he died and it's kind of a relief for me. Even though I flipped out when I found out he died, I was so upset, I couldn't believe it. But uhh it's 'cause he used to hit me too like when I peed my pants when I was a little girl he really welt me one, and my mom would get mad at that. She didn't like him doing that but she couldn't stop him so it kind of was a relief that he kind of moved out of the house because he was so aggressive. And ummm then after that I was more outgoing with friends and a wild child like I said. I hanged out with friends outside and just uhh get away everything, trouble and you know stuff like that.

*Tina's mother now lives in [City J] in a trailer by the lake. Her mother was a cook at the [local university] for a number of years and took an early retirement. Tina has a brother and sister that live outside the [City A] area (one lives in [City K]) and has a nephew and a niece.*

I used to do it [sing] all the time but I don't do it anymore, my voice is kind of gone now that I am older and I haven't been practicing but I used to sing a lot and write a lot, lyrics, and I do my songs on stage, win money and prizes and ummm, it was fun. I have a book, 15 songs I have recorded songs I recorded, all originals, cassettes and CD's, a rock CD I did. And umm lots



of country songs, and pop, all types of music. Not just one type of. And that's about it for that.  
Yup.

The first time they didn't diagnose with schizophrenia.

Devan- they just said high anxiety?

Tina- Uhh ya, the second time I was in [hospital] for 2 months that's when they diagnosed me. I was about 19-18. Well 19 ya. So I was 19 diagnosed as schizophrenia. And uhh can't remember anymore.

I knew, when I was 18 they told me that my dad had it [schizophrenia], which I never had it, I was always wondered if I was going to get it. And when I did get sick I knew right away that's what it was. So I asked my mom. I said, "did dad have schizophrenia?" because I forget they told me in the hospital when I was 18, and she said, "nooo he never had that." I said, "then why did he take pills what were they for?" And she just said "they were for his nerves." So I got her to phone my Aunt Harriet, his sister to find out and she hung up on my mom. And then she finally phoned back and said, "ya he had it." And my mom was shocked because she never ever knew, all those years that he had ever had an illness, of schizophrenia. She knew he was on pills but she always thought it was just for uhh nerves but she never understood in those days, a lot of people didn't understand in those days that, and the medications aren't always good for I don't know. Ummm, but uhh ya I was 19 when I was diagnosed with it. And then at uhh didn't go good with me, I was upset. I thought, you know, "Why? Why did this have to happen to me?" And uhh but I lived with it and I was in and out of hospital for lot of times, with suicide. And just uhhmm I'm trying to get better on medications that never had bad side effects because I suffer from side effects for several years with my eyes. Which made me home, like a home person

again anxiety, where I wouldn't want to go out anymore again. So I stayed in the home for years. Moved from place to place and still stayed in and would avoid going shopping, and if anything I would go to the corner store and buy all my groceries even though it was expensive. I was too afraid to go into a big shopping centre where there were people. Because of my eyes like they used to blink so much I think it was called tardive dyskinesia, I think it was I'm not sure if that was exactly what it was. But one of the doctors I had told me it was. And there was never a cure for that for me with the old medications. Because I never start new medications until I had the new doctor, Dr. Kenneth. The older doctor never knew the new medications he even told me, but I don't know the new medications and he just knew the old medications. So I knew I had to switch doctors so I did and that's when I had Dr. Kenneth and he really dug me out of a hole, out of a uhh my anxiety, the vision cleared up, I could see again, then I got my drivers [license] back. I had my license all the time, but I promised I would never drive that way. So when I got my vision back permanently, uhh, he said I could drive again, I was so happy I wanted to start life again, and uhh I would date again. Finally met Bob and uhh we've been together for 11 years and ya Dr. Kenneth he's awesome. He really dug me out of a lot that I uhh was in for some many years of my life. I get to see him tomorrow, once a month to get my medications and stuff and see that I'm okay. And uhh so that's how it all happened. And uhh I haven't been in the hospital since I was 28 or 27, 27, 28 something like that. He's an awesome doctor, he's the only one that got me the way I should really be.

I am very comfortable with myself now. I accept it [schizophrenia], and it doesn't bother me anymore that, well people never really made fun of me like when I had it, my family. I always thought people would say, you know, schizo, this and that, but you know what, I had a lot of good friends and uhh family and they never threw things in my face like that. And I grew up

with people understanding me. I am glad I have the family that I have because they stuck with me through a lot of silly things like suicide attempts and stuff. They stuck with me and they never uhh gave up on me. So I can accept it now and also meeting people with the same illness with mental health has made me stronger person, and ummm it's made me accepted into society that we have mental health and people that understand the illness today, the worst it used to be closed in like you know. Years ago people never talked about it much now I hear it so much in the news, on TV and the radio, mental health week and mental health this and that, and even the news. When I see the university students on the news, where uhh summer can be suicidal, I thought oh my god, it's an epidemic with illness, it doesn't matter if its schizophrenia or not. I mean there's so much anxiety and stress for everybody. I always think there's I think everybody in the world has something wrong whether it's mental or physical, or whatever and I accept everybody and, and so I everybody's that I've known has accept me, so I feel good about myself now. And I don't hide it umm, I don't make it a big show when I meet friends. I'm schizophrenic how are you? Ha ha you know I just uhh if they ask what's wrong or something, I say, "what do you mean?" If they push on I say, "oh I have an illness I don't know if that has anything." And then I will mention it and like I mentioned it to a couple of people at [coffee shop] that I hang out with and they said "ohh I didn't know you had that, I would have never known." You know. And they don't give me a hard time and they treat me as anyone else and they talk to me like anybody else. Which I enjoy, I like a conversation of people everyday uhh, that don't judge me. You know. I feel more calmer with that and more uhh accepted so.

I have a little bit of anxiety but it's usually when there's appointments or people I don't know yet that I have to meet like the other anxieties have died down a lot from the medications and uhh going forward to do those things just pushing myself to do them. The anxiety overcomes

itself after a while. It's not very bad, panic attacks like I used to have. It's just bits of anxiety when I first met someone knew like you. I first met you [Devan] I was a little anxious, but I think that's just normal, the normal anxiety that everybody has. I am not anxious now or anything. And I uhh just get that way if there's a big event like a wedding or just normal like anybody else. I was anxious, very anxious, going to the walking groups, but once I pushed myself to go, like I said I overcame it in no time.

Meredith, she works here [Service worker], she comes to see me once a month, she is coming on Friday. And uhh she talks me about entering groups and stuff so I have been its good. Dr. Kenneth, he counsels me and uhh gives me my meds and stuff so I mean, there's a lot of people that uhh just get me out, doing things. And things on my own I do, ummm. So ya, that's about it.

I get up, I do my appointments. I do what I have to do. And uhh I get things done now.

Devan- But before it was just too...

Tina- Depressing it was lethargic, it was just nothing, no going nowhere, doing nothing, empty. Anxious and depressing and just I don't know.

A typically day is making sure I get my appointments all done. And umm. Walking with groups like Monday, Wednesday, and every second Fridays. Ummmmm. That's about it. Uhh spending time with my boyfriend. And uhh hanging out at [coffee shop] once in a while, coffee time, the thrift stores haha. But that's about it. The main thing is just to get the things done that I have to get done in that day. Which is the appointments and stuff that are very important.

I can be a morning person if I set my alarm. And sometimes I am a morning person, sometimes I am later depends if I can sleep at night because I have trouble sleeping. So lately it's been my sleeping patterns have been very well. I bought some Melatonin. And tried that out for a while. It got me back into a routine. So I stopped it after 5 days. Five evenings of Melatonin. And I am back on track again. So I thought that would help me with my sleeping problems.

Devan- ya, is it just too much energy at night?

Tina- Ya, it's anxiety and energy. Stuff like that.

Devan- do you sleep better umm when you go for the walks? So Monday nights and Wednesday nights? Do you feel like you sleep better then?

Tina- ya that helps. It helps. But sometimes when my energy levels high it doesn't matter if I walk or not I have trouble sleeping. Wake up in the night, have night sweats and stuff. And I found out it was from the diabetes off Dr. Oz. Ha ha ya, Dr. Oz mentioned that sleeping disorder with diabetes and sweats and I wake up with sweats in the night. And it is exactly to a tee and I think that's my problem is my diabetes. That's why I have trouble sleeping. Yup, it's so many seconds for that. I fit to a tee, that pattern. So that's what I discovered.

I like Dr. Phil and ummm, TLC channel, I like the true stories about people and ummm American Idol, once in a while and that's on during the week. And that's about it. The news.

I think just the walking group for now, because I am working on my weight. My blood sugar levels with my diabetes and that. That's really important to me right now is my physical health, more than anything right now. Umm eventually down the road I could see probably going

to different little groups and stuff. I will see about that but uhh as for now just the exercise is very important for me.

Tonight's a group [walking group] a 6:30 pm at the [local running store]. Wednesday night. So that's good, every Wednesday night, five kilometers, I like it, it's good. We do all different walks, all around the city of [City B] like as far as we can get. Within an hour or something.

*Tina wanted to make clear that the walking group was to push her out of her shyness.  
Being social was the reason she joined the walking group.*

Devan- Ya, umm what has the relationship with Bob been like over the past 11 years that you've been dating him?

Tina- Uhhmmm \*sigh\* it's been good, I love him, so much. I never think I love anybody like him before that much that I'd could see myself with him forever, I don't know what I would do without him. He always tells me he loves me. He doesn't know what he would do without me. We are like twins, only he's a guy and I'm a girl. We like everything the same and... Ya, best friends, lovers, just I don't know, we just love each other so much and we understand each other a lot. He can hear anything and I can hear anything and that's so great that he accepts me. And I really accept him. He has a brain injury, and I, we don't know exactly what his illness is but it could possible schizophrenia. Uhh he, we, I got him to see a psychiatrist and he has a family doctor now, I got him a family doctor because he never had all that. And he was in an accident, a brain injury accident. He was going to the brain injury group. I even got him into the group here. But he couldn't he keep appointments much and he needs help but I mean he's got a doctor now and a psychiatrist but he uhh doesn't like to join in things. He doesn't keep, he's basically what

I was like, anxiety and he says he gets anxious when he goes places and panic attacks or whatever, I don't see him as getting panic attacks but he feels that way. And uhh, ya he's just like the old me, which I'm trying to get him like the me today. You know, and he's getting out of some of that with the appointments with psychiatrist and the doctors. And uhh umm. I tried to help him as much as I can, like I care for him so much I want him to get help. Like get him into what he's missing, what I had. He doesn't like a lot of people he doesn't like a lot of walking, things like that. He's eating not good, like he's overweight, I'm trying to get him to watch his weight and that but we are there for each other, we are there for support, like couples should be. And I care for him a lot, so I'd like him to get further help. But he just doesn't want to continue to get the help. I think he's a procrastinator, kind of lazy that way, which I wish he wasn't but he is. And I love him hahaha. We used to bike ride but now he doesn't even want to so I don't know.

*Tina gets bored with television but mentioned she is a home body as of late. That's how she spends most of her time with Bob, even in the summer – they like to just stay in. Tina mentioned she wants to spend her Saturday nights at the local YMCA. She feels like she is too old for the bar scene.*

I live alone. I'm in housing, and I live on my own and uhh, and he [Bob] has housing. And uhh we've been together for 11 years. And I don't live with him because he's a smoker and I can't live with that.

I used to smoke but I quit about 11 years ago, I used to smoke 2 large packs a day and I quit cold turkey. Back then it was \$58 a carton for du Maurier king size light. I don't know what it is today for a carton

Devan- seems to be always be going up though

Tina- ya, that's good

Devan- hahaha

Tina- hahahaha, I'm glad. I wish everybody would quit. To each is to own. Expensive, it stinks. I used to smoke 2 large packs a day. I quit smoking at the same time as I quit drinking alcohol, which, I was never much of a drinker. So I thought I would leave it instead of take it, because I didn't need it anyways and I am on medications so why bother. And then I lost 22 pounds all at the same time at Christmas. I took a class for diabetes at the uhh at the [City A] hospital, and uhh I learned about diabetes and that, and they all came into the same time I was quitting everything so it worked out great and I am all.

Devan- So what does your life like now would you say? Today, what would you say your life is like?

Tina- Its better. Uhhmm I still get racing thoughts but I can more or less handle it now, control it better. Like through, ya walking, walking and swimming like in the summer time I go to many swims. I'll drive down to the pond and go swimming, like in [Village A]. Free swims [sponsored by local coffee shop], sometimes they have that, I take advantage of that haha and then my mom, she lives up at the beach so I go up there sometimes and go swim up there at the lake and uhhmm. Just more outgoing and uhh, uhh can talk better too, I noticed that my talking is better, I just don't say a couple words and look away. I can have a normal conversation the way I should be. Umm that's much better, umm like today.



My relationship with my family is very good, they love me, I love them. They support me and the things with mental health. My mom and my sister is very excited about me doing this [research project]. She said, "Tina that's great" and I went to my aunt and uncles, Rick and Donna and uhh Rick's like "wow Tina that's great", I was there on the weekend, they invited me over. Bob and I ran into them at [clothing store]. "Come on over tonight", it was Saturday night and I said "alright." So we went over and I mentioned it to my aunt and uncle and they said "ohh well that's awesome you know, you are really doing well" and uhh, my family, uhh my mom and my sister and brother they all uhh ummm they think I've living pretty good now, because my mom always worried about me, where I lived and stuff, and now that I am living in housing I have support through mental health and housing and stuff like that. Uhh she feels safer hahaha. I guess she always says "I worry about you so much but now that the way you are living today and you're doing very well, I don't worry as much" haha. And uhh ya so they're all accepted, acceptable of everything now that I do and it's the right decision and that uhh they're happy for me. So and they see me as doing better than how I used to be. You know the sicken days and now they see me as different now.

*Tina was interested in helping others and wanted more information about the study at the beginning. I asked Tina how she felt participating in this project and she mentioned that if it helped people with schizophrenia then she would feel good. I asked her how she felt her story could help and I think that threw her off a bit, she was unsure about what her story could mean to others.*

## **Whitney**

*Whitney was very open about the fact that she finds pain and heartache in dredging up the past as she often done in the self-help and addiction groups; however, she was able to discuss her past in detail. With very few prompts or questions, she led the discussion of her*

*narrative as if it has been told many times. There were also some noticeable things not being said, or talked about further. When discussing her marriage and eventual divorce there appeared to be gaps in describing what transpired towards the end of her short marriage. Her transitions between topics were at times short and rushed. Whitney did say she no longer dwells on the past and perhaps if she was taking control of her narrative, she was going to talk about what she wanted to talk about. "My past had neglect and abuse and things like that and that I was rehashing it and putting blame and then blame on myself and guilt and shame. I just found that wasn't working. So I rather live in the now."*

### **Whitney's Narrative**

*Whitney's childhood seemed to give her positive feelings, especially discussing her experiences with horses. Her father worked at a beef cattle farm for a number of years, her mother trained, showed, and cared for horses and also worked part-time as a bartender. As Whitney moved into her teens, the family moved to their own farm with a specialty in training and showing horses. Whitney was very involved in the horses and discussed one horse Boo being of significance. She was the one who would hold Boo when he was a young colt to domesticate the horse and also show dominance as the leader or head of the group. She had Boo for two years until he was sold and left Whitney's life forever. She described this process as "devastating" and "heartbreaking" for her. Her mother offered her little consoling and with a tough love approach, told Whitney, "this was the way things are." Whitney never had another experience with a horse as she did with Boo. Whitney also mentioned a spiritual connection to horses. I feel this might also be with other animals because she has had at least two cats in her life. She discussed her interests in computers, math (100% in high school), and working for a real estate agency here in [City A]. She attended [the local college] for a number of years. She has had many jobs here and there; I don't think she has had a career. Whitney also went to [the local University] as well but I was not sure if she finished. Whitney worked in [City C] for a few years as well but always lived here in [City A]. During her years at [the local college], she was forced to live in a women's shelter for a few months. She described this as life threatening. She would have black eyes and had to fight people off her because "I had money and they didn't."*

I got married in 1989 while I was working in [City C]. And umm (pause) there in, we, ended up working there until 1991 and by then I was pregnant and umm I ended up getting a job

in [City A] for a number of years, uhh as a computer programmer. And I went on maternity leave, my daughter was born in uh 1992. And umm we, after a year when I went back to work after she was born umm, my ex-husband decided that he wasn't happy in his job that he wanted to do his life dream which was pig farming. And umm he, he hadn't earned very much money he was, he was working as a pig farmer so he was earning minimal wage and mean while I was earning about 40 to 50 thousand dollars a year and saving up thousands of dollars a year in my RSPs. Well he said to me "I'm fed up with this, I want to be a pig farmer" and I think what brought it on was the fact that his older brother was given a farm by his parents. And so he was jealous and he said "I want a farm, I want a farm now!" and so he said "I'm gonna go farm with you or not" so I decided I don't want to break up the marriage so I guess I will go with him. So we ended up finding a farm to lease umm an hour west of [City D], in a place called [City F]. And umm it actually it was the worst thing we could have done, umm we looked at the place when the power was off so we used flashlights and didn't discover all the things wrong with it, which we should have had someone come with us, to view it with us, but he was high and mighty that he wanted to do it on his own. And, and his parents had told him "well if you wait two more years, we will give you a farm too or give you payment for a farm." And he said "no I want it now, I don't want it in two years." So we went and I put all my RSPs into the farm. Umm so he couldn't have done it without me because he had no money. And umm we ended up with a, I think it was 5 acres of, there was, uhh, there was an old farm house, a five bedroom farm house that was heated by wood stove. And that area there's no wells, there's no ground water, so you have to use your fishing ponds. So we had two huge irrigation ponds which were filled up by putting a sub pump in the drainage system and filling up that way and then pigs have to have water that's equivalent, pigs have to eat what humans eat, he has to be drug free and uhhm it has

to be sterile and like, just the same, they have the same stomach as humans. Umm so the water had to be treated with hydrogen peroxide because of the, it wasn't like, just drinking pond water would have poisoned them. So when I was in the hospital umm we used to the hydrogen peroxide pump for the water and anyway we started out, we built our own pens for the pigs, the barns were there, there were five barns and two silos. And umm we ended up having to do a lot of maintenance, we ended up with welding machines, my husband taught me how to weld. And I did the construction and umm we had to do our own plumbing or else we would have had to hire a plumber so I knew how to do plumbing. And umm uhhh for the first, well actually the first year he ended up getting injured, he had an old injury from a motor cycle accident from when he was a teenager. And he [had] broken his leg, and I could see it broken out, so he had to be in a traction for a long time. So anyways his leg was fragile and he ended up getting injured on the farm, something fell on his leg and he ended up in hospital again for a month! And we had just gotten the pigs, and I had no idea how to do, to run the farm, so my dad came and stayed with me for two weeks while my husband was in the hospital. And umm I had to run the farm. And that was hard and so, I mean, and my dad went home and my husband came back home from the hospital and umm, ya, we, we were running the farm and we had this big garden, I had a big garden and, in the fields and umm we decided that we were losing money because of that time in the 1990s umm pig farmers were very expensive, and you didn't make money unless you inherited the farm. We were trying to make it on our own, so he ended up taking a job off the farm, umm, at a, a tobacco and garden vegetable farm and working days and I was running the farm. He taught me how to do everything, he taught me how to do the breeding, umm we were using artificial insemination for the breeding so I was using like microscope and test tubes and things like that. Umm he taught me how to do the processing of the piglets when they are two

days old, you clip their teeth, you clip their tail, you give them their injections, you castrate them. Umm he taught me how to be a midwife. Umm the only thing I couldn't do on my own was the transportation. Umm like sorting the pigs out and sending them to market. But I ended up being the one to drive the truck and trailer to the market. Umm to drop them off at the market and umm, so I learned how to drive the, there was the, big jeep truck and uhh a great big stop trailer. And I ended up learning how to drive that too. And but the time 1995 came around, the end of 1995 uh we lost all our money and we were living off the food bank but we were still, we still had enough money coming in from the pigs to feed the pigs but that was it. We didn't have enough money for anything else. And so we ended up in a fight one night and he assaulted me. And I called my girlfriend and asked her if I could come over but by the time I got to her place she had called the police and told them that he had assaulted me. And he ended up going to jail and uhhm I never saw him again after that. He left the farm completely, he left the pigs with me, so I ended up, my lawyer advised me to call the bank and tell them what was happening and the bank took the farm from me. I ended up moving into town with my daughter. Umm and living on welfare. And uhh at the time I was very depressed and getting upset all the time about separation so, my physician arranged for my daughter to go into daycare for free. And so during the days she was in daycare I only had to take care of her at night. After a couple years of living like that we decided, I decided it was better, I couldn't find a job and out there, there were no jobs, there was no job training program or anything. So I ended up moving back to [City A] in 1997. And my daughter started school, she actually started school out there, she started in junior kindergarten and then she came here to [City A] and she started taking French Immersion.

When I got sick I was sick for two weeks at home, and I didn't know what was wrong, I knew something was wrong but I didn't know what. Umm I wasn't taking care of her and I

wasn't taking care of myself but she was 13, so somehow I must have given her money or something but she was managing to cook her own meals and get herself to school and everything and then, I finally decided I couldn't stay at home anymore, I thought something was wrong. So I told her "find a place to go" so she contacted one of her friends and they took her in and then I went to the hospital after she found a place to go. Umm my experience at the hospital was umm, I took myself to the hospital and in the taxi, and the doctor on call decided that there was nothing wrong with me. And she was gonna send me home and I said "I can't go home, like I have no food, I haven't been taking care of myself." Umm I have been up, I was up 24 hours a day, I was, I was actually communing with the angels, they were teaching me how to fly hahaha. Umm I would lie on my bed and I would be in the s... (demonstrates a flapping of her arms, like wings) flap my wings and I would, people were talking to me and the TV would talk to me and the radio would talk to me and I would hear things like this was a neighbor downstairs and in the apartment down the stairs, I could hear them and it was like they were talking to me through the, the floor. And umm so I told the doctors "well I, I don't know why you won't let me in" and they said "this isn't a hotel, we're not here to take care of you" and umm so that was at [City B hospital] so she kicked me out of there. And I got a taxi and took myself to [City A hospital], which doesn't have a psych ward but at least they admitted me to Emergency. Umm because I started my actions again, like flying with the angels and then they recognized, the nurse recognized that and said "ya, that's psychosis." And so they took me in the emergency ward and they ended up having to tie me down and inject me with Haldol I think it was. Umm and uhh they kept me overnight in the emergency ward and then the next morning they sent me by police car back to [City A hospital]. And the same doctor was on and she said the same thing again, she said "no, there's nothing wrong with you, you just got it, it's all in your mind you can, you don't

need to be like this, you can take care of yourself” and I said “well I can’t go home like, there is something wrong, I know there is” and, “but I don’t know what it is” and she, so she found me a place at [City E] Hospital, they had an opening in one of their, in their ward. Umm so I went to [City E] Hospital and I was there for a week and the doctor there said he didn’t have the facilities to treat me. So they sent me to [City D]. And I was in [City D] for a month and while I was there I was doing my, all my actions like and I was reading my bible and, and I was definitely in psychosis that I umm, I couldn’t sleep. Umm and they were very angry about that, that I couldn’t sleep so they would try to prescribe me sleeping medications, I said “I’ve never taken sleeping medication, I don’t want to take sleeping medication” cause I knew it was addictive. So they were very angry with me, that they ended up tying me down because I would get out of bed and they said that was disturbing everybody else so at bedtime they would tie me to my bed. And umm after a month of being there and talking to the doctors there, they decided that it was all in my head, I could umm choose, I was choosing to be that way and they told me it was a behaviour problem. And so in the meantime while I was in the hospital, my parents were in contact with my landlord and he decided he was afraid of me and that he didn’t like what I was doing so he was kicking me out and I, [pause] to me it wasn’t by Landlord Tenant Act rules but because I wasn’t there to voice my opinion my parents said “okay, we will move her out” so I had nowhere to go, all my stuff was in storage. When I got back to [City A], after the month I was living in the women’s shelter at [Our Lorde Place]. And I only had the clothes on my back. I had thrown, while I was in my psychosis before I went to the hospital, one of the things that the angels had told me was that umm I needed to be free of all my possessions because where I was going I wouldn’t need anything and that God would provide for me. So I gave up many of my things, I went through all my stuff and I, I wanted to donate it but nobody take it, nobody would uhm do

the donate, like drive it to the donation place. So it ended up going into the garbage and it was things that would have been valuable, like my photo albums and stuff like that, that ended up in the dump haha. So that was frustrating and all I ended up with was the clothes on my back because I thrown out, I was told that anything old was contaminated by the devil. So I had to get everything new. So I threw everything out. And so I lived at [Our Lorde Place] for, I think I was there for a month and during that month I ended up, I didn't even have any snow boots, all I had was slippers. One day I put my slippers on and the angels had been talking to me again and said "oh you have to go home" so I thought that meant go back to my apartment where I was living. And umm so I put my slippers and my coat on and I took a taxi back to my apartment, when I got there all the people said "what are you doing here?" "We're going to get a court order for you being here" and luckily somebody talked and then someone called the police on me but the police never arrested me, they just took me back to [Our Lorde Place]. They said "no you can't come here anymore, you don't live here, you are not allowed on the property" and I said "okay" and then that was when they told me that if I went back again then there would be a court order placed against me. Umm because the people there felt threatened. Umm and umm so I ended up going into psychosis again after about a month and a half while I was staying at Mary's place. And this time I didn't come out of my room for two weeks and somebody complained that my room was smelling, well that was because I hadn't even been going to the bathroom I'd been using the, the garbage can as a toilet and umm I was reading my bible and staying up all the time and the people were banging on my doors saying "be quiet" cause they could hear me talking. And then one day they decided that there must of been something wrong because I hadn't been out of my room for two weeks. So the people that were running [Our Lorde Place] opened my door and discovered that I had no clothes on and that I had been living like that for a while. And



they decided that I had to go to the hospital again so they packed me up and took me to the hospital and they didn't even stay with me in the emergency, in the waiting room, they just dropped me off and said "put her in" hahahaha

It was a different doctor this time so they admitted me into the umm into the psych ward. And uhh I was doing my flying with the angels again so they strapped me to my bed every night and uhh I ended up fighting back a couple of times and I ended up isolation, tied to my bed. One time I managed to escape the constraints. And I was started banging on the door and I got even more punishments. And (pause) umm ended up, I stayed for a month and a half again. Umm and I made lots of friends, there were lots of other people with psychosis like mine umm, I didn't find any woman that were flying with angels but there were a lot of men that were actually flying with the angels and one of them told me that, "oh this how you're supposed to do it" and I was, I wasn't doing it right hahahaha. Ya, but it was interesting to know that I wasn't the only person like I finally felt "wow, this is actually happening" and, but I felt very comfortable in that because umm when I was flying with the angels it felt like there was somebody controlling me, like a puppet. So I wouldn't put my arms up, someone was actually pulling my arms up and making them do that. And when I walked, it felt like somebody was pulling my leg and like with a string and, and making me walk and things like that. So I walked the halls and some, sometimes if it, depends on what nurse was on duty, as to whether they would tie me down or not, but if they didn't tie me down I walked the halls all night, I never slept. Umm and they told, one of the nurses told me I was gonna die because I didn't have any sleep and I said "well, I haven't slept in months, why would I die now?" and I haven't slept in months and it was very serious to them that they thought I had to sleep. And a few times they injected me with sleep medication, I was very furious with that because umm it makes you drowsy and you can't do

anything. So umm once I got so I wasn't, once I was around other people then I seemed to be at ease with it, but they still didn't treat me well other than talking to me. They thought that psychotherapy was going to get me out of my psychosis. I can't see anybody coming out of psychosis with psychotherapy.

Devan- So you weren't on any medications?

Whitney- Nope, no medications.

So I was still like, having the angels were very comforting, I know I wasn't alone. And umm there was always somebody to talk to. So I was always talking and listening and, and the thing was when I was umm reading my bible, if I was reading my bible and the, in the reading room, then people would walk around me and say "oh she thinks she's Job" or "oh she thinks she's Joshua" hahahaha. And they didn't even look at my book, they just knew, and they would be right about what chapter I was on. Like it was like they were psychic haha. So and that was one of the things that had happened to me before I actually got really sick, was that I believed that people could read my mind. And umm so it was actually very comforting umm but they ended up letting me go after a month because I stopped flying with the angels. Umm and so they just said "you're fine so you can go home" so I went home and this time [Our Lorde Place] won't even take me, they said "no you've, you've had your full time, your only allowed to come here so many months." Umm so I ended up, I was allowed to stay until I found another place but I had to find a place right away. So I found a room in a basement apartment umm but it was a brand new room but it was an old house and they hadn't done it properly. So in the summer the room started to sweat and it got moldy so I ended up only staying there for a month because one day I came home and there was this mold all over and I could smell it and I know it makes you

sick so I told people that at AA that I was going to be homeless very soon because my apartment was like that and so there was this guy that I knew, he went to AA, but he also went to self-help and he had seen me at self-help and he said "I've got a room, you can move in with me" so I ended up moving in with him. And it wasn't clean, except for my room, my room was clean because I cleaned it but I mean the rest of the house wasn't clean. It was uhh a bookstore as well as a house. And he turned it, all the rooms, and the books and the sofa, there was no living room, the kitchen had no fridge, it had a stove and a microwave, but no fridge. And so I couldn't even buy groceries and bring them home to make dinner. Umm and (pause) at that time, the second time I came out of the hospital they gave me a uhh um an outreach worker. Who came and saw me and she saw me in public umm, about once every two weeks. Just to keep an eye on me umm, and so anyway this guy that I was living with, he would take me to umm to AA meetings, and we lived right across the road from St. John's kitchen so he showed me, I didn't know where it was, I had never heard of it before and he showed me where it was and he told me "ya just come here and you can get your food here" so I would go there. Eat my meals at lunch time and in the winter time at night umm they have the [food centre] program so he would, he had a car and he would drive me to [food centre], we would go to [food centre] together. And for a while that's what I was doing. So, it wasn't comfortable, I had my own TV and I had my bed, so I was able to uhh, like anytime I, if I was at home I was in bed because there was no living room. And there was nothing else to do. Uhh and then in the, in August that year I ended up flying with the angels again, and went back to the hospital for two weeks and I think they tried getting me on something, I can't remember. But I only took it while I was in the hospital. I didn't end up taking it when I went home. And umm, ummm so I was, so that's how they were able to get, I was only in the hospital for two weeks because the medication took effect and then I went home and then I

was fine again for a while and then I, in November that year umm I went, I started, I knew I was having symptoms again so I think I took myself to the hospital and I think I walked to the hospital that time. And the doctor there remembered me and admitted me but they told me that they didn't have enough room for me that they were going to put me on meds and then, I couldn't stay in the hospital so they put me in respite. And I went to respite for two weeks. And at that time they finally connected me to [local mental health housing agency] and they got me a worker.

And they umm, so I was at that time for a while I was still seeing the outreach worker and the [local mental health housing agency] worker because they were worried that I would go back and again because I had been in so many times. So they wanted to make sure that I didn't go back in. but they also, [local mental health housing agency] came and inspected my home because that's one of the things, the support that they do. And then they discovered that I was living in mess, squalor of a house, that all I had was a room and no kitchen so they put me on the waiting list for housing. And umm it was a year and a half that I was living there before I got my apartment. Umm so I was on olanzapine and that was working, I was, I didn't have any more stints in the hospital after a while. And umm then three years later for some reason, I don't remember why, but I started hearing the angels again and they told me that the medication was wrong that it was going to hurt me, that I should stop taking it. So I did. And I ended up in the hospital again. Umm and I was flying with the angels and I ended up this time when I ended up in the hospital, it felt like it was even, I spent even more time in solitary and more time tied up. And because they would put me on the olanzapine and then my angels would tell me "no it's going to hurt you" so I would go off it again. So I ended up in the hospital four times in three months. And that was the time when every time umm I went in the hospital, my mother had to

come and get my cat. And then the second time I went in the hospital, it was Christmas, I came out Christmas Eve and my parents picked me up on Christmas day and took me to their house and wanted me to stay for a week and they had my cat. And umm their house is, my Dad's a hoarder so their house is very cluttered and it's not comfortable, it's never been comfortable. Uhh it feels like there's an evil presence there because of it being so dirty. And so I spent most of my time in bed and after two days the only time I would come out was umm at meal time. So my dad freaked out and said "that's not, that's unacceptable behaviour, we're not putting up with that" so they brought me back to [City A] with my cat. And uhh told me that I better uhh pull up my shirt-tails, or whatever it is, better get my act together and like smarten up. Umm and umm then I ended up going back in the hospital again and my mom came and got my cat and this time she ended up, somebody from the hospital called her and so she came down while I was in emergency and she started freaking out at me and said "why you doing this to us, what's your problem, haven't you got anything better to do then be in the hospital and doing this to us" and umm, I ended up in the hospital for another month and that time they decided that they would put me on the Community Treatment Program and with uhm, Risperdal the injections. And so I had a Community Treatment Order and they kept me in the hospital for a month just to make sure that the injections were working. But umm they decided that was the better way because then I couldn't go off my pills, haha. I'm on the minimal dose and for the longest term, I get three weeks, I get 25 mg every three weeks. So, but that's the least they can give me. Umm so I, for two years I was on the Community Treatment Order and now I'm on the, I'm on self, self-control I have to go by myself. But umm I definitely, I know that if it was pills I'd definitely would stop taking them again because I felt comfortable being where I was, even though I wasn't

able to function out in community, I still felt [more] comfortable being around the angels then I did being out in the community.

I usually wake up around 7:30 ummm I don't use an alarm clock I just naturally wake up. Sometimes I get up earlier and have to go the bathroom and I just don't go back to bed but most days 7:30 and umm I watch a DVD till about 9 o'clock and then I get myself ready and ummm walk downtown most of the things I do are downtown so it's about 6 or 7 blocks. I walk downtown and go to [restaurant] at the market and get my coffee and muffin and then I go to [Support Centre] and if there's a group gonna be on they usually don't start until 11 so most days I go and there's a reading room. Recovery materials to read so I just go in the reading room and find something to read and actually there's lots of books there but some of them are specific to certain diagnoses so I don't read them. I have read a lot of self-help books and spiritual books and I actually probably gonna have to start to funding their library because its community funded. Because I have lot of their books and I am having trouble finding a new book. There's actually one that I ordered from the library because it's \$25 to buy and I had seen it new but I haven't seen what it's about so I am going to get it and read it, and from the library and if I like it then I will buy it for the library for the self-help library. So I umm... when I used to go there a few years ago umm there's a reception area and I used to sit in the reception area and keep the reception person comfortable but they found that they don't want that to be a drop in area. Umm so they restricted it and said that I couldn't sit there anymore and I had to go to the meeting room if I wanted to be there. Umm so that was a bit of frustrating because ummm my doctor... my psychiatrist told me that I need to get out every day, so that I don't isolate, and [Support Centre] is the only place that I know of where there's somewhere to go that there are people that could check on me. Just to know that I am doing okay. Umm ya so I go there and then I would go to a

group at 11 o'clock until 12 and ummm then I go to lunch at [local café] that's inexpensive vegetarian. And umm then usually unless there's something special going on I usually end up going home after that and umm I have a nap for about an hour and then ummm I get up and watch another DVD and if it's still daylight by the time I am done that DVD then I read for a little while and I only read until it gets dark because my living room doesn't have any light. I have a lamp but it only takes old light bulbs, it doesn't take the new light bulbs so I have to invest in a new lamp to get one that takes the new light bulbs. And so I don't uhh then after that if I stay up I watch another DVD if not then I go... sometimes I just have a microwave dinner while I am watching DVD or if I am energetic then I get up and go out to Subway and get a sub at [food chain] for dinner. Umm and then usually I am in bed by 5 or 6. And sleep right through the night.

*As she discussed her cooking tendencies, or really lack of she opened up about her dislike of cooking for one, but it wasn't felt with contempt. She started talking about cooking in a very positive way, as a way she felt a sense of worth and responsibility within her family as she grew up. Cooking, sewing, and other chores were a collective thing to do, therefore they gave her purpose. Cooking for one now doesn't really produce the same feelings for her and I'm not sure she was a big fan of leftovers.*

It's [the self-help groups] called the [Support Centre] and its part of CMHA, umm they [Support Centre] is run by facilitators who either are employees or peers or and if the facilitators are employees they always have a background of some sort of mental health issue when they are employed there. And umm the peer support workers are people who are interested in umm in the group that have had the actually experience of that, of whatever that diagnosis is. If it is a recovery group they usually live on at the onsite facilitators and ummm so they would be the recovery group would be, the [Support Centre] is for people with mental health or umm other cognitive disabilities or addiction issues. And umm the sometimes we have people who are

family members of people with issues so we have a wide range of people that go there. Ummm I'm not sure how many people I know because umm every week the groups are just choice, you can go if you want, you don't have to go every week and so some weeks I see 10 people some weeks I see 20 people so.

Devan- How long have you been going there for?

Umm I discovered [Support Centre] actually before I got my diagnosis with schizophrenia I was, I was already on disability and I needed to fill my days so I went to the CMHA and they told me about [Support Centre]. Umm so that was in 2004 I think. And I started going just in order to boost my self-esteem and I think there was a self-esteem group at the time, and relationship group at the time. 'Cause at the time I was in, I wasn't in a romantic relationship but I was in ummm, I had a couple of friends that I felt I needed to improve my relationships with them. Umm, so I took a group, and I have since, they don't have the self-esteem group anymore and I stopped going to the relationship group because I find sometimes it ends up being a whining session and that's not what I am there for. I am there to help, or to help myself, but I am not there to listen to people whine. So sometimes I end up, if I do go and it turns into a whine session then I end up leaving, because I don't want it to affect my peace.

It's [Whitney's peace] something that I have acquired since going to [Support Centre] and I'm not exactly sure what it is but before I was diagnosed with schizophrenia I had major depression. I was never suicidal but I was always into the, "why is this happen to me? Oh God, why has God do this to me?" Umm I just had a bad attitude about things. And I after my sister died it all just seemed to go away. Umm, so then I started reading self-help books and they were teaching me about, like one of the groups I go to is loneliness, enduring loneliness and coping.



And umm through reading some of the self-help groups and some of the things we talked about at the loneliness group I realized it's just a temporary issue to being alone and being lonely its temporary, it's going to be fixed the next time I see people. So I don't need to bring it into my life and I no longer dwell on it and I can be alone, by myself, and not have a deal about it. 'Cause I used to be that, "oh my god what am I going to do? I'm all by myself umm I need people around me" and stuff like that and it's just some of the other things I have studied like spirituality and umm and I think hardly too because I since my some of my experiences with schizophrenia included umm needing the angels and speaking with God and at that time they told me that the bible was true, that I should read it and I was never raised with the bible uhh I think my mother read it to me a few times like to read the parables. But we never went to church so it wasn't something I was being exposed to, so I was in my schizophrenia, psychosis, I read the bible from cover to cover, twice. And absorbed it, and then it felt to me like there was somebody there with me, trying to help me with it and belief it. And I believe now that many of the things I never, like probably did happen, they're not just fables and old wives tales to keep people in line that they actually did happen and things like that. Umm that has brought me to sorta calmness and peace that I find my days, I don't react with anxiety anymore. Unless something is really troubling me then I don't I don't find my moods go up and down and, and vary, I find them very stable and, and I'm able to deal with things umm. Things don't bother me uhh when I was in my depression I used to be in tears quite a lot. Uhm I haven't, I haven't found that I needed to be in tears, I don't even feel like, like it's necessary. And it's not like I'm, I'm not stopping my feelings, I'm just uhh, relaxed. And part of it too is that I don't get into the uhh umm, when I was working I was I was very much very anxious about my work and that I had to do well and do well for my uhh, superiors and if I wanted to get a pay raise I had to do well, and that all caused emotional

stress. And umm now that I am not working I'm finding myself so much more relaxed and I never want to go back to that because umm it was just a rat race and it was very demanding and stressful. And I would put, a lot of times I was putting the stress on myself that if I couldn't get something done by the deadline time then, then I would uhh freak out. And I don't do that anymore, I don't, I don't get upset, I don't find that I got any umm hatred or angry issues anymore, and I used to. I used to hold grudges and umm, take things personal and I don't do that anymore.

It's [Whitney's peace] been gradual, started then. And it's been gradual and I've come to now that sometimes there's a couple of people that call me the guru, and that's a big thing because umm I don't identify with it. But I do see there are times when umm something does affect me and that I realize how calm my life is compared to what it used to be, that if umm, and but I am able to deal with whatever it is that's affecting me, too. I'm able to umm, this past summer there was a situation umm, with ODSP that umm they discovered that I had saved too much money. So what they do is that they claw back. And they deduct it from your check. Well they told me that it was going to be 5% so I assumed it was going to be 5% of the total. Which was going to be more than half my cheque, hahaha. And uh for a month and a half I was starting to get really anxious because they weren't getting back to me and answer my questions. And I talked to a few people and said "no that's not true, there's no way they can do you'd be without housing or whatever" if they did that. So they just said calm down like, take it easy, don't worry about it. So I did, I took their advice and I calmed down about it and then I eventually found out that it was 5% of my cheque, which is only \$50 hahahaha. But the thing is I owe it for the rest of my life haha. So it's not a big deal, but I also brought it to me the fact that umm there are some of those things that I can't control. I just don't aggravate over them.

Devan- Ya, and so you mentioned that some people refer to you as a guru...

Whitney- Mhm

Devan- Are those people the [Support Centre] group?

Whitney- Yes

Devan- Okay

Whitney- Umm they are people especially the new comers that are straight out of the hospital umm. Or they have uhh there's a few people that have uhh a lot of emotional issues. And their like "oh I wish I was as calm like you" or "how can you not take it personally" and stuff like that.

Devan- So they heard your story and I guess they want to be where you are?

Whitney- Ya

Devan- So in a sense you are kinda like a peer umm peer specialist

Whitney- Ya

Devan- Ya, do you feel like a peer specialist?

Whitney- Umm, sometimes. Umm sometimes I do.

Devan- Ya

I feel like my, my knowledge is gone through to and I also I got some (inaudible) peace because umm before I had my diagnosis um I was drinking and using marijuana and those were parts of my life that umm were a crutch. And then in 2005 one day my daughter told me that um

she didn't like the way I was when I was drinking and drugging, and so I quit drinking on June 30<sup>th</sup> 2005. And I quit using marijuana on November 1<sup>st</sup> 2005. And actually that was only a couple of months before my diagnosis so the doctors that told [me] my use of marijuana could have attributed to my psychosis because it was a daily habit, it wasn't a lot but it was one, one joint a day and that was supposedly could have built up enough TCH that it could have affected me. And I did that for about 7 or 8 years. But through that, the quitting, and after I got my diagnosis I started going to Alcoholics Anonymous and Narcotics Anonymous and I went through the twelve step program and I actually did those two groups umm AA is available through the city umm many times a day. So I was uh like uh Alcoholics Addicts that (starts to laugh) Anonymous I was an addict, I was going to the groups like non-stop, after one group stopped I would travel to the next group and go to it and, and just keep on going and going so that attributed to my peace I think to because it, one of their statements is a lot of high power into your life. And um that was something that, it was, I found it spiritual going there, they, people understood what I was going through and since then, actually the past few years, I haven't gone back to AA or NA. Umm although I still believe in their ethics umm, I have found that after a while, hearing the stories of people that were just out of addictions was very hard because it would bring back memories and I found it too hard to go because it was actually harder to stay... I never did relapse but it was harder to stay thinking clean when I was going in and hearing the stories all the time about "oh this is how bad it is" or whatever. So I decided not to go and for me that's a good choice that I've gone through the program but I don't umm, I don't dwell on my past. And that's another thing that has gotten me my peace is that I don't, I live in the now. Umm I don't dwell on the past and what's happened to me and I believe those are choices and that's what made me who I am today, is the choices that I have made. And I also don't dwell on the

future, putting expectations into my minds so that if something doesn't happen then I am not devastated. So like, that's part of, there's one of the girls that's what she called that parable like living in the now because she's always rehashing the past "well this happened, so this is why I do this" and it's like an excuse. And that's what it used to be for me was, that my past had neglect and abuse and things like that and that I was rehashing it and putting blame and then blame on myself and guilt and shame. And I just found that wasn't working, so I rather live in the now.

Devan- Do you have a sense of community now?

Whitney- I do

Devan- Ya

Ya but I still feel like umm, I felt like a wasn't alone, I actually when I was, when I was in my psychosis, I was really upset that one time and one of the angels told me "well I'll always be with you Whitney, I'll always be holding your hand, I'll always be taking care of you, even if you can't hear me, I'm still there" so umm, that was to me very comforting. And umm...

*When we were at the horse stable Whitney mentioned she doesn't have any people in her life she would consider a close friend. She mentioned she feels a sense of peace and enjoyment when at the horse stable. Whitney also mentioned a desire to volunteer at the Humane Society, however because it's not on a bus route that is accessible to her, so that activity isn't possible.*

Devan- Do you feel like you, you can't reach that connection with people in your community now? That you have with the angels?

Whitney- Ya because it's like a soul mate thing and uhh I don't have that connection anymore.

*Whitney said she hasn't seen her parents in four years and her younger sister (who she constantly fought with) in five years. Her sister lives in [City C] and her parents live one hour north of [City B].*

Devan- Right. Is umm you mentioned the peace before, is that because the angels told you that they would always be with you holding your hands?

I think, I think that's part of it. Ya, and it also, it's come to me that umm the world is such a spiritual place for us, before I didn't even know that, before I had my psychosis I didn't know it was such a spiritual place I umm. I feel comfort around nature, I feel comfort around animals, I feel a connection to people. And I never did before. And it's, it used to be scary thinking "oh my God I'm going to die" or something like that. And now I'm not afraid because I know that there is something out there.

Devan- Ya, well you mentioned the animals and how you um you spend a lot of time with, well now that I know you spent time with pig's haha.

Whitney- Ya ha ha.

Devan- And horses, and ya I definitely feel that same way around animals too.

Whitney- Mhm

Devan- Just, it's a different kind of connection that you can't get with, with the some humans, ya.

Ya and the pigs are very smart. The pigs are more trainable than dogs too, they would know, and actually one of the things I had to do is cleaning the pens and we had two boars and my ex-husband was terrified of them because he was afraid, he'd seen people get mauled by boars. And he said "never turn your back on them" so I never had turned my back on them but

for some reason I think it's because I was doing the artificial insemination collection. That anytime they saw the blonde coming by they were like "oh ya! There's the blonde!" hahaha because uhh we would use, I was use a sow to tease the, but I would do the collection.

The only thing I don't like is the Risperdal causes weight gain, so I have gained over 60 pounds. I gain a pound a week while I'm on Risperdal. And the doctor says there's no other injectable but the other, the nurses told me that they don't know any skinny that are on that medication. So there's nothing I can do about it. And I tried not eating and actually that wasn't good because I was eating like two meals a day and I was getting like dizzy and low sugar and stuff like that and the thing is too because of my weight gain now, umm I'm always getting told "oh you have this condition or you have that condition or you, you need to be tested for this condition" so I'm always having to go for tests and especially now that I am over 50. Supposedly there are so many more conditions that you can get when you are older. I keep having to go for tests after tests after tests and I feel like it's an invasion of privacy and I don't want those things. Like just let me be, but they say "oh you" ... when I complain and I didn't want to go for it they said "no you have to comply" and that's like well, the only thing I would like for not to happen is to gain weight but now that I have gained so much weight I'm on the risk for diabetes. And umm there's nothing I can do to reverse it because umm I've never been one to have to, like I, all my life I was skinny and I never had to make an effort to exercise I just had to live. And now they're telling me "you need to be doing two hours of exercise a day" and I'm like that's too tiring, I'm tired.

Umm it's [Whitney's life] very calm and structured. Umm (pause) it's like umm (pause) in a way it's, it's a bit sad because my daughter has decided that since she went into foster care when she was 13 and I was never able to get her out of foster care umm she's decided not to

contact me anymore. So that's a bit upsetting but I don't dwell on it and I don't uphold anything against her, it's like umm she, I know she is happy. So now she's at, she's 21 now. She's uhh in 4<sup>th</sup> year of a 5 year program at the [local university] taking [name of program] the co-op program. And she's uh, a don of her residence. So umm in a way I would like to have a relationship with her but I'm not gonna be the mom from hell and force it upon her, that, that would chase her away even more. So maybe someday she'll come back but umm right now, I pay attention to myself and umm, ya.

*I was finding myself feeling sad for Whitney when she was discussing her relationship with her daughter not wanting to be a part of her life, although Whitney felt okay with that at this point in her life. I got the sense she was really hoping her daughter would try to reignite the relationship later on but she is still at peace with her life, her relationship, and her situation right now.*



## Chapter Four: Analysis of Narratives

Further analysis of each narrative reveals that each have the experience and process of:

- being diagnosed with schizophrenia,
- a turning point,
- the idea of their life starting over, and a
- feeling of peace or acceptance.

The same analysis of each narrator reveals the dominant discourse of the experiences of schizophrenia. The idea of their life starting over indicates that each narrator thought that life had ended at some point of time. A dominant feeling of life ending, particularly around the time of diagnosis of schizophrenia, says something about the current way persons with schizophrenia are supported during that time. What needs to change to preclude a feeling of life ending for persons with schizophrenia? How do we go from diagnosis of schizophrenia to acceptance/peace in people's lives?

While this general process is found in each narrative, the exact stories are quite different from one narrative to the next. There is variation in the order in which each aspect of the process appears. For Ryan, his experiences show up in a more linear way, however Whitney's narrative moves back and forth in a fragmented style. Tina's narrative was also fragmented however the fracturing was not as in depth as Whitney's recall of her past.

For each person the turning point in their narrative differed. Turning points in Whitney's narrative occur when she lost her relationship with her daughter, her family, and her ex-husband. Whitney was shuffled around from shelter to bad living spaces. She found solace in the mental health and addiction groups by hearing other people's stories and by sharing her story with

others. She now describes that she is at a peace in her life. She describes it as a gradual process and “I’ve come to know that sometimes there’s a couple of people that call me the guru, and that’s a big thing because umm I don’t identify with it. But I do see there are times when something does affect me and that I realize how calm my life is compared to what it used to be and I am able to deal with whatever it is that’s affecting me.”

One of the major turning points in Ryan’s life was what he describes himself as the moment his life “kinda ended” as his family doctor kept saying he had schizophrenia. He had lost all of his high school friends as he isolated himself in his room and wasn’t listening to anyone in his life. He didn’t have a strong relationship with his family and during a fight over laundry with his mother he allegedly grabbed her arm and was arrested. He was admitted to the mental health unit at two different hospitals for a period of 11 months in total. During his hospitalization he said he regained his life. He states that he returned to his pre-illness life; however, I am not sure he is the same as that person. Ryan has grown from the experiences he encountered in hospital and out in the community. I think the disappearance of voices in his head made the biggest difference for Ryan. He was able to concentrate again, even though he found some help with the breathing techniques he used before medications, “for me that was a big breakthrough.” The connection to his community was where Ryan really felt like he was coming into his own. He gained a sense of belonging, a feeling that was missing in his life prior to hospitalization. He also was surrounded by positive people in his life at this time, towards the end of his hospital stay. He is very supported in the community now.

There are two turning points in Tina’s narrative one trauma related and the other in relation to schizophrenia. The first was the death of her father. Tina describes feeling relief but also shocked and sad. She was very young at the time and mentioned that after his death she

became a wild child who caused trouble and got in trouble with the law. Tina herself attempted suicide several times early in her life. The second turning point was meeting Dr. Kenneth. Tina was experiencing severe negative side effects from the medications she was on and as she switched doctors, it was Dr. Kenneth who put her on some new medications that decreased her side effects. This changed Tina's life! She was able to drive again and feel more comfortable in public settings like grocery stores. Her life started over at that moment. She stated that she was able to date again and quickly met Bob. She hasn't been in the hospital since being with Dr. Kenneth. He seemed to work well with Tina to improve her quality of life – he saw what her needs were and was able to match them to what he could provide.

In this chapter I conduct further analysis of narrative (Polkinghorne, 1988) drawing each narrative into conversation with the literature presented in Chapter Two. This involves both using the literature to shed light on the narrative, and also using each narrative to provide a critique of the literature. In so doing, we respond to the research questions that guided this research: What dominant cultural narratives play out in participants' communities? How do those narratives constrain participants' identities and positions in community? How do persons take up or challenge these constructions in their own narrative of self?

### **Whitney**

Whitney has made an effort to reach this inner peace; however there have been barriers placed along her way. She is constantly trying to be the “good consumer” of each mental health service that has presented itself to her however as we critically explore the narrative we found that the services are defective. They set Whitney up to fail, to be dependent on them, and to push her away from any kind of safe haven or home she creates. We see how Whitney would rather be in psychosis with her angels than be unable to function in the community.

### **The conundrum of the “good consumer”**

When we apply the literature, we might re-story Whitney’s narrative as follows. As Whitney was moved from place to place, the shelter she once thought of as a safe haven was now viewing her as a defective consumer. People were clear in telling her that as a defective consumer she had overstayed her welcome and needed to move on. Whitney was forced to relocate herself yet again. However this raises the question, what were the existing options for Whitney? Marcus and Westra (2012) discussed the positive correlation between existing treatment options and help-seeking skills; therefore the good consumer is one who is able to seek help when needed. Whitney moved in with a friend from Alcoholics Anonymous, but the place was not suitable for Whitney. Her standards of living were low at that time as the residence consisted of just her room, a kitchen that had no fridge, and a living room covered in books. After Whitney was discharged from the hospital for the second time she said “they gave me a uhh um an outreach worker.” It was her friend and now roommate who informed Whitney (not the outreach worker) of some of the local and free resources that were available to her such as [food centre] and [food centre #2]. What support was Whitney receiving from the outreach program? The help-seeking skills abilities that Marcus and Westra (2012) discussed seem to be presented by the consumers in Whitney’s narrative but perhaps the service providers are the ones who need to improve their knowledge about existing treatment options? What about issues of poverty that remain unaddressed in the narrative of the good consumer?

The good consumer is also one who follows doctors’ orders. Her doctor and service workers told Whitney she needed to not isolate herself and get out of the house every day. Her doctor’s orders of socialization seem to be based on the concept of social cognition being the best predictor in community function according to Pijnenborg et al. (2009). But then are good

consumers supposed to be seen and not heard? Or is a good consumer to connect with others but not staff? Whitney described being told not to socialize with the reception at the [Support Centre]. Was she being labeled as a defective consumer when asked not to be social with the receptionist? Whitney had thought she made a connection and this left her feeling frustrated and confused. She felt comfortable being at the agency so when she was told that they didn't want that area to "be a drop in area" Whitney was hurt. So then does being a good consumer mean using the "services" but knowing how to read boundaries, to know one's place? This was a place for self-help and for Whitney that involved being social. Her schedule was tightly woven around the programs and services available at different mental health agencies. The schedule usually stays the same every day "unless there's something special going on" so Whitney's quality of life depended on being accepted and welcomed in these spaces. Her community functioning relied on having the social cognition – the human ability and capacity to perceive the intentions and dispositions of others, described by Pijnenborg et al. (2009). What intentions and dispositions of workers in community mental health agencies is the good consumer supposed to read and respond to? We want to help you but only if it does not affect us? Be social, but only with those people? We will set limits and boundaries by delineating program spaces in which social interaction may occur?

### **De-pathologizing pathology**

Whitney first noticed something was wrong when her daughter was 13 years old. Whitney recalls she had been feeling sick for two weeks and left her daughter to look after herself, although she has only a vague memory of how her daughter was able to do that. This was the point in her life that she starting communicating with angels – hallucinations. She also heard other voices during this time such as her neighbours who lived on the floor below her. These

hallucinations are part of the identity as pathology and described in detail by the American Psychological Association (2013). During her hospital admissions, Whitney describes moments where she was placed on isolation, tied to her bed. These moments were often associated with flying with angels. Whitney quickly discovered that her moments with angels were more common than she thought. She made new friends in the hospitals who shared similar experiences flying with angels. This was both enlightening to hear and comforting to know she was not the only one. Whitney was receiving reinforcing information about her hallucinations from others. For Whitney, her “perception-like experiences” were being reinforced by others, countering the narrative of identity as pathology presented by the American Psychological Association (2013). She heard and flew with angels just like others had. When with the angels, Whitney never felt alone. “Always somebody to talk to... always talking and listening.” The angels were not pathological to Whitney; they were comforting at a time of distress and need.

### **Re-thinking dependency and control in the context of learning**

Whitney describes her lack of control of her life from an early age. Her mother sold her favourite horse without consoling her, her ex-husband controlled her future and finances, and later in Whitney’s life she had a lack of control over where she resided. She highlighted some aspects of self-control when she took over operation of the farm when her husband was in the hospital, and when she and her daughter moved into the city. At the farm Whitney had many responsibilities: construction, some of the plumbing, care of the garden, and feeding and transporting the pigs. These responsibilities are often placed on family members or caregivers of persons with schizophrenia according to the Government of Canada (2006). On the contrary, Whitney was doing a great deal of physical work and also financed the farm using her savings.

Her family was financially and physically dependent on Whitney which counters a narrative of dependency.

The peace Whitney describes in her narrative required a process of learning that had been unfolding over several years. “I don’t react with anxiety anymore.” This peace that Whitney describes challenges Peter’s (2000) notion of defective identity being associated with the inability to learn. Whitney talked about realizing her loneliness, anxiety, and anger were temporary issues in life that would keep occurring, and understanding that it is your reaction to them that can change. To maintain her peace, Whitney avoids certain self-help groups now if she finds “it ends up being a whining session and that’s not what I am there for.” Peter (2000) also claimed behavioural problems are often a sign of defective identity. Whitney stated she had bouts of anger and hatred however she moved past being stuck in those emotions to grow into a new self – peace. This peace has been a major turning point in Whitney’s life. “I don’t find that I got any umm hatred or angry issues anymore and I used to, I used to hold grudges and umm, take things personal and I don’t do that anymore. I also brought it to me the fact that umm there are some of those things that I can’t control. I just don’t aggravate over them.”

### **Whose discomfort and whose drug dependency are we concerned with?**

In this narrative, power and control over decision-making also comes forward in Whitney’s narrative around drug use and her struggle with addictions. This narrative is also tied to the idea of the good consumer—one who takes the drugs prescribed.

Whitney was involved in drinking and drugs in the past as a crutch so when attending the addiction groups she was not fond of speaking about her past. “It was harder to stay thinking clean when I was going in and hearing the stories all the time about ‘oh this is how bad it is’ or

whatever.” She was part of the 80% of people with schizophrenia who abuse substances (Government of Canada, 2006). Whitney knew she struggled with addictions and made decisions that helped her keep clean; however, she was also forced to face her struggle with addictions in hospital. This time it was in relation to prescription drugs. Whitney was knowledgeable about different medications and side effects and would often advocate for her rights. During one admission Whitney was up all night disturbing the staff and other patients and was told to take sleeping medications. Whitney was reluctant to take the sleeping medications due to their addictive nature and refused so they administered the medications forcefully.

A Government of Canada (2006) report states people with schizophrenia who abuse substances also show problematic behaviours such as poor recovery and violence. Did the health care system set Whitney up to fail? What other ways could have been used to respect Whitney’s wishes and help her sleep? This is an example of another loss of control for Whitney. She was standing up for her rights of not wanting to be exposed to an addictive substance as she has experience being addicted to alcohol and marijuana.

### **Deinstitutionalization – whose job is it to care?**

In Whitney’s narrative we see the lack of care highlighted. Frustrated and still unwell, Whitney left the hospital to take a taxi to another hospital in the area. At this facility they were able to provide the help Whitney needed; however, they were not able to provide longer term care for Whitney, therefore she was transferred out of the city, out of her community. Her community lacked the available resources to provide care for Whitney, which Hutchison and Potschaske (1998) addressed as a need for people with a mental health disability in the wake of deinstitutionalization. With the deinstitutionalization movement we saw the shift of dependence specialized mental health services institutions to general care provided at general hospitals (Sealy



& Whitehead, 2004) and in community. Whitney was refused care at one hospital as she states the doctor told her “this isn’t a hotel, we’re not here to take care of you.” Her former landlord claimed he was afraid of Whitney and wanted her removed from the premises. Changes to housing conditions and the availability of education discussed by Packer et al., (1997) are not only important to people living with schizophrenia but also to the community at large. This creates less dependency on mental health services and provides more opportunities for choice and selection. Whitney mentions that after a hospital admission she had linked up with a service worker at a local housing support organization. With the help of the housing support worker, Whitney was placed on a waiting list for a home that would meet her needs. However Whitney waited a year and a half for a home

### **Ideal community for who?**

In Whitney’s narrative, there is a hesitation around her sense of community. She clearly states she has little connection to people in her life and no one she would consider a close friend. Whitney does describe a strong connection to nature and animals, specifically horses and cats, which contribute to her feelings of being at peace. We see a clear lack of social connection and need for other supports. While dominant narratives focus on adequate income and social isolation (Government of Canada, 2006), Whitney’s peace is supported by other kinds of connections. Whitney mentioned she would rather be in psychosis with the angels by her side, than to be without them. “I felt comfortable being where I was, even though I wasn’t able to function out in community, I still felt comfortable being around the angels than I did being out in the community.” This notion challenges the dominant narrative that community is the ideal place/space (Sealy & Whitehead, 2004) that can accommodate Whitney’s unique needs (Warner,

2004). Whitney's level of comfort and connection to the angels is what was really important in her life.

## **Ryan**

The re-storying of Ryan's narrative was difficult since he has scripted his experiences to share with others; however when the literature is applied we can see how Ryan's battle to fight stigma continues. Ryan's narrative focuses on his acceptance and advocacy for people with a mental health disability and starting his life over. With focus we can see how Ryan's narrative challenges the quest for a cure for schizophrenia, notions of defective identity, and isolation being the plight of people with schizophrenia. He has created a sense of community that is both trusting and safe and enables Ryan to find purpose in life. He continues to strive for more, counter to the mental health literacy narrative we will explore.

### **Beyond the defective identity - weaving a path of acceptance and support**

Ryan refers to his time in hospital as a "journey of healing" where his peer support began. He counters the narrative of defective identity (American Psychological Association, 2013; Peter, 2000). As Ryan accepted his identity as a person with schizophrenia he opened himself up to using and accessing the resources presented to him, including day passes to [City A]. Ryan described that by discharge time he was back to the way he was before coming to the hospital: more social, leaving the house often, not isolating himself in his room as much, and talking to people again. While Sealy & Whitehead (2004) describe those who are defective as "too difficult" to live in the community, Ryan describes feeling like he is a valued part of society.

Ryan's early exposure to schizophrenia consisted of media reports around Paul Bernardo being a person with schizophrenia. According to Marcus and Westra (2012) we could propose that Ryan's mental health literacy was poor during his youth. Ryan admits that "at first I didn't really know anything about schizophrenia. I didn't know what psychotic meant. I didn't know what a break from reality was or a delusion was or ya I really didn't know and I didn't want to accept it." This occurred during his early experiences of schizophrenia, before his hospitalization in [City A] and [City D]. Hospitalization exposed Ryan to the different people diagnosed with schizophrenia – how different they were from him and each other. This led Ryan to have new understandings of how he views schizophrenia as more of an individualized illness rather than the more generalized notions he held early on. His earlier notions of the defective identity of schizophrenia (Paul Bernardo) were created in the health care system and then reinforced in communities (Peter, 2000).

Ryan's narrative gives us insight into a time in his experience when two dominant narratives provided him with very little in terms of how to move forward with his life. One was the idea of a cure (Schizophrenia Society of Ontario, 2013) and the other were media representations of who a person with schizophrenia is. Ryan describes that at first he thought only of Paul Bernardo and struggled how to understand himself in relation to this. Ryan's narrative gives us insight into Marcus & Westra (2012) statement that youth with mental health disabilities are less likely to receive the care they need in communities. Was Ryan given information about schizophrenia in a way that was easy to understand? Was Ryan willing to listen to what information was being presented to him? Ryan's narrative gives us insight into his process of making meaning and understanding his own experience of schizophrenia. He now views schizophrenia as a constant part (and an important part) of his identity. Ryan describes the

importance of having space to struggle (and hit rock bottom) while still having support and access to the things that determine health.

Counter to the dominant narrative of poor mental health literacy (Marcus & Westra, 2012), Ryan mentions he knows a lot about schizophrenia and educates himself frequently by attending groups and reading materials on mental health. His friends also are involved in the mental health education groups and actively involved in the mental health community. We know from the literature that communication needs to be tailored when providing mental health information to youth (Marcus and Westra, 2012). In hindsight, Ryan states that if he listened to his mother at the time where he was going through the early stages of schizophrenia he would be ahead of where he is now. We saw how communication at that time in Ryan's life was messy. He stopped listening to his mother. Ryan mentioned he thought he needed to hit bottom before he could feel better and described his time before going into hospital as hitting bottom. During this low, Ryan began to negotiate this illness. When symptoms became prominent he turned up the volume on the television to mask the voices. He took walks in attempt to clear his mind, and put a blanket over his head and tried to focus and listen to his breathing. Ryan resisted the notion that people with schizophrenia do not get better, he believes strongly that people can and do get better. Like Warner (2004), Ryan has come to understand that people do manage their symptoms. Aspects of these early strategies continue to be helpful for Ryan, while others (e.g., turning up the TV volume) are no longer necessary.

The experience of being in the hospital also opened Ryan up to seeing how different people's recovery times are and how differently they experience schizophrenia. He saw the turn-around rates of other patients – how quickly people come in and out of hospitals. “I didn't realize that people are around and they wouldn't be there and then they would be back and I was

confused about until I got to [City D] and realized they were discharged and then back already so.”

After resisting his schizophrenia identity during his youth, Ryan described that he finally accepted it and stated he could start a new life. Ryan described “[I] regained my life you know. It was kinda like having to start over again since when I wasn’t well I was like I’m gonna keep going, I’m gonna keep doing this, keep getting jobs and keep going out and then I got so tired you know, it just got easier to start over.” While Hutchison & McGill (1992) describe the importance of having an available support system in his community, Ryan’s quality of life and overall well-being were fostered when this was coupled with his acceptance of schizophrenia as part of his identity.

### **Breaking the essentializing mold—becoming his own role model and permeating bounds of a community of identity**

Counter to the dominant narrative of isolation and lack of close relationships (American Psychological Association, 2013) for persons with schizophrenia, Ryan stated he made many new friends as a patient in the hospital. Ryan experienced a sense of belonging and a community while in hospital. Hospitalization was a turning point in Ryan’s life. Ryan claimed his life was over during the early stages of his mental illness, he then states that towards the end of his hospitalization his life started over. Nurses at the [City D] hospital would often try to counter the side effects of the medications that afflicted Ryan and others with schizophrenia by waking them up and taking them on out on walks. The hospital space, a space not often associated with community, became the origin for his sense of belonging.

Ryan was breaking the strangle hold on the identity of schizophrenia once held for murderers; he was becoming his own role model in life. His stories are then shared with others (high school students, government officials at summits, etcetera's) to foster Ryan's sense of identity. Overall, Ryan's narrative is positive, hopeful, and expresses gratitude for supports he has, especially his family. Ryan spoke that he and his siblings are lucky to all live in [City A] area and to be close to each other over the years. He referred to his childhood as a normal upbringing, with lots of friends, strong family supports, and that he received good grades. This allows for positive stories to be shared around people's experiences with schizophrenia. The focus here is on hope, agency, and opportunity—key aspects of the recovery process (Ryan et al., 2012). Ryan's sense of identity is not solely based on his experiences with schizophrenia but of all the stories of his past and present he holds on to and shares with others. Ryan described how his family came to visit him regularly while in hospital, which Ryan credits as how they repaired their relationship with one another. While the American Psychological Association (2013) states the ability to have close family relationships would be reduced, Ryan rekindled his close relationship with his family. When Ryan discusses his interdependence in the community he states he does various chores around his home, pay's for his groceries, and shovels the driveway. He feels like he contributes to the family household as a productive member of the family and on a larger scale within society.

Permeating bounds of a community of identity also means moving beyond formal supports and services provided by community agencies. Ryan describes how he and his friends find a way to continue a social event community services were not able to provide. "There's a bunch of us at the bowling group that kept that going too. But it's [a] separate thing that we just do on our own that's not part of any organization." This story fits with Warner's (2004) look at

how some communities are not able to meet the needs of persons coming from an institutionalized background. In some cases there are more services in hospital than out.

### **Active negotiations of safety, trust and resistance in support**

Support is not passive and without power negotiations and implications. This is revealed if we look more closely in Ryan's narrative at what he says about his experiences of safety and trust.

Ryan holds a great deal of trust to his mother in his treatment decisions. He even mentioned how if he listened to his mother earlier, he would be farther ahead of where he is now. Ryan discussed how his mother would talk to a woman at [Support Centre] to get Ryan to listen as Ryan would listen better to this woman than his mother from time to time. Ryan's relationship with his mother had changed from his youth to present day and with that change his support and care moved back and forth. When Ryan and his mother were fighting, he was hospitalized and arrested. As Ryan repaired that relationship with his mother, he was discharged from hospital and moved in with her.

Having choice in who scripts the story of the person with schizophrenia and who shares it is essential to feelings of safety. The mental health community is a safe space for Ryan to discuss important parts of his life. "It's a safe community that you can trust people that aren't going to go and tell everyone." It's important for Ryan to feel safe in who he shares his life with. Ryan discusses his negotiations around safety in the community:

[T]here's people in other communities but I don't really interact with them I might say hi to them on the street or something. Some of them know my name but I don't really think we are part of the same community. ya cause there are obviously the high school

community who I know from the city bus and I wouldn't really talk to them unless I was in school and talking to them in class about my recovery from mental illness.

Farone (2006) emphasized that people with schizophrenia view community as a space of security. Community integration as we heard in Ryan's narrative offers a space of feeling trust in his community. The Government of Canada (2006) found that high levels of social engagement and integration in the community lead to the development of trusting relationships between people.

At first, Ryan resists his identity as a person with schizophrenia primarily as a lack of knowledge and understandings of the mental illness. Resisting the unknown, resisting what he has little to no understanding about. His high school friends at the time didn't understand what Ryan was going through and says he lost most of his friends during that transition time. Ryan stated that his paranoia caused him to have trust issues with his friends. Insel (2010) and Aubin et al. (2009) state that negative symptoms of schizophrenia can compromise community functioning. The trusting relationship that Ryan had with his high school friends diminished due to his increase in paranoia causing Ryan to break is involvement in those relationships.

## **Tina**

Tina was on a path to repeat history. Her failed attempts of suicide, her wild child days, and her negotiations of trouble were all experiences she and her late father shared. However as we have seen in Tina's narrative there is a will and desire to change history and not repeat that cycle. We saw how determined she was to change doctors, to regain her life was a major turning point in Tina's narrative. She calls herself a "stronger person" now and I challenge anyone to



think otherwise. As literature is applied, we see how Tina's re-storying has challenged the heavy weight placed on her by her past.

### **Challenging ideas of social support – complexities of gender violence and trauma in experiences of schizophrenia**

Tina's narrative causes us to reflect more deeply on assumptions made about the nature of social support. The literature presents a dominant narrative that almost becomes a fact, that persons with schizophrenia have limited social networks (Government of Canada, 2006). In accepting this as truth we fail to see the complexity that underlies experiences of social support for people with schizophrenia and the associated inner workings of exposure to gender violence and trauma.

Drinking, drug use, and violence are described as health risks (Government of Canada, 2006) in the dominant narrative of schizophrenia. In addition, ten percent of persons with schizophrenia commit suicide (Government of Canada, 2006). These acts of violence were perpetuated by Tina's father, and were often acts of violence against Tina and her mother. Tina mentioned her father was in jail a few times for robbery and described her father's eventual suicide when she was a child. Tina started on a similar path to her father. During her childhood Tina talked about how she was a wild child breaking windows. She mentioned her suicide attempts often in her narrative, mostly during her youth, and mostly as a "silly thing." Tina described herself as an aggressive child, similar to her father's aggressive and abusive past, although when she entered high school a shy, timid, and anxiety filled Tina emerged. With the violence and trauma in the past Tina still was not able to succeed during school as she could not cope with the onslaught of panic attacks and anxiety episodes. Packer et al. (1997) describe a need for improvements in education availability and other structural interventions for greater

well-being. There were no structural interventions available to Tina at this time in her life that would have helped her succeed. She states that she did not receive counseling until the age of eighteen.

As Tina still experiences some symptoms such as racing thoughts, she mentions that she can better handle those experiences now. Instead of falling into the narrative of health risks, Tina has learned how she copes best when having those experiences. Tina is also experiencing improvements in other areas. “I noticed that my talking is better, I just don’t say a couple words and look away. I can have a normal conversation the way I should be.” Her sense of self is more present now that she is able to communicate in a way she is used to which leads to forming meaningful relationships with others. Tina had restored her confidence which she attributes to the work that Dr. Kenneth has done with her.

### **Breaking the silence, compliance, and the shame behind the defective identity**

A lot has happened in mental health awareness over the past two decades and Tina states that people are more open to talk about issues now than before. When Tina discovered she had been diagnosed with schizophrenia she was upset at first and left little room for “self-pity”. Tina notes she “lived with it” by quickly accepting it and moving forward. She now feels more comfortable accepting schizophrenia in her life and discussing it openly. While the defective identity being enforced in society (Peter, 2000), Tina is breaking the silence and challenging the defective identity. Tina also meets and talks to others with mental health illness which makes her a “stronger person.” Tina also surrounds herself with people who understand mental health issues. “I don’t hide it umm, I don’t make it a big show when I meet friends, ‘I’m schizophrenic, how are you?’ haha you know I just uhh if they ask what’s wrong or something, I say ‘what do

you mean?’ If they push on I say ‘oh I have an illness, I don’t know if that has anything [to do with it].’”

Being *dependent* on others, such as family members, pose a health risk of those involved due to an increase in financial, social, and physical responsibilities (Government of Canada, 2006). For Tina, there was health risks directly associated to her, not her family. It was more of the medications taking a toll on Tina’s quality of life than the actual diagnosis of schizophrenia. Tina states that the problems with her eyes as a side effect of the medications she was on was lowering her well-being.

So I stayed in the home for years. Moved from place to place and still stayed in and would avoid going shopping, and if anything I would go to the corner store and buy all my groceries even though it was expensive. I was too afraid to go into a big shopping centre where there were people because my eyes, like they used to blink so much I think it was called Tardive Dyskinesia.

Her doctor was older and lacked the knowledge about the new medications with fewer side effects so Tina found a new, younger doctor. Making treatment decisions based on the ability to understand enough about the disability is also referred to as mental health literacy (Marcus & Westra, 2012). Although acting for her best interest, she credits Dr. Kenneth as the one that dug her out of a hole, “So when I got my vision back permanently, uhh he [Dr. Kenneth] said I could drive again. I was so happy I wanted to start life again, and uhh I would date again.” This was a major turning point in Tina’s narrative as she let go of some built up anxiety over social experiences now that her new medications lessened her side effects and that she started to date Bob.

### **Ongoing negotiations involved in being *of* community**

Tina discussed her social isolation and not leaving her room. She actually considered she may be agoraphobic due to the high anxiety and panic attacks. Even though Tina attempted to maintain employment at a few different organizations, her mental illness would often be the root of the job failing. In the aftermath of being fired Tina would spiral into depression and thoughts of suicide ideation. This vicious cycle continued until Tina was hospitalized and diagnosed with schizophrenia. Hutchison & McGill (1992) describe the crucial peer support networks for people with a mental disability. Gerber et al. (1994) states once a person is placed in the community social skills improve. Tina's narrative reveals the negotiations with anxiety, creating routine, and igniting passion involved in being *of* community for people with schizophrenia.

While Gerber et al. (1994) states once a person is placed in the community social skills improve, Tina helps us to see that simply being in community does not lead to positive outcomes without much energy and effort on her part as she negotiates challenges of available supports, ageism, and poverty. Tina struggles with finding age appropriate activities. Tina mentioned that she wants to spend her Saturday nights at the local YMCA as she feels she is too old for the bar scene. During the walk-a-bouts Tina made many references to her age in a negative way (too old to sing, not comfortable with the bar scene, etc.). When looking at other factors like poverty (Arai & Burke, 2010), there are certain expectations of which activities are geared towards men and women around Tina's age. For many, this is the time of financial flexibility that Tina does not share.

Tina admits that she still has anxiety when attending groups or meeting new people, however that does not deter her from attending. She will push herself to go as she knows that she will overcome the anxiety and not allow herself to become the defective consumer. She is a

rather a steady, productive consumer of the mental health services offered to her. Marcus & Westra (2012) stress the importance of *routine*. Tina follows a routine everyday by focusing on what appointments and meetings she needs for her optimal treatment. Tina does describe some symptoms such as sleeping problems, diabetes, and excessive energy as current things on her mind. Her focus on her physical well-being is one of the main reasons she participates in the walking groups. Exercising is very important part of Tina's routine – an identity as good physical fitness which sits beyond the identity of schizophrenia.

A narrative of loneliness and romantic isolation is presented by the Government of Canada (2006). Negotiating passion seems to be a significant antidote to isolation and loneliness. Tina described her relationship with Bob as a significant passion:

We are like twins, only he's a guy and I'm a girl. We like everything the same and... Ya, best friends, lovers, just I don't know, we just love each other so much and we understand each other a lot. He can hear anything and I can hear anything and that's so great that he accepts me. And I really accept him.

Tina also describes success in her life through her passion in music and singing. Her accomplished singing past includes winning prizes and money at local competitions as well as producing and writing songs and CD's. I felt her passion as we discussed this topic during a walk-a-bout. These successes in people's lives should be celebrated and praised with attention and focus, rather than spending time on the illness and limitations.

## Chapter Five: Conclusion and Implications

The three narratives shared in this study have at times challenged and countered dominant narratives but also at times reinforced some dominant narratives that exist for persons with schizophrenia, but not in the way we think. We saw how Whitney was labeled as being the kind of defective consumer described in the literature but what we heard was actually her desire to comply with requests being made of her, to comply with physician's orders by engaging in services. Stories heard in this study are an important step to better understand the complexity of people's experiences and their lives. What we hear in these stories were three unique journeys of the experiences of schizophrenia, showing how schizophrenia changes each narrator's life and how each individual and his/her social worlds also shape experiences of schizophrenia.

A notion of an ideal community has been discussed by Hutchison and McGill (1992) with concepts such as relationships, inter-dependence, acceptance, services, belonging, and working together to name a few. While we acknowledge that community and community experiences varies among Tina, Whitney, and Ryan, we do see how some of the concepts discussed by Hutchison and McGill are seen in the narratives of each narrator. A notion of a community has been countered by Blackshaw's (2008) *imagined community*, where "it is a conceptual contradiction in terms because it is difficult to tell what is 'real' and what is not, and what is swinging in the hammock of imaginative supposition strung between the two parts" (p. 330). We heard this when Whitney was discussing her relationship with her angels as being of comfort to her rather than being functional in our reality. The concepts of the ideal community presented by Hutchison and McGill (1992) speak more to me as important aspects of people living the lives they wish to live, the journey that takes them from one experience to the next. The support, love, and care along the journey all have to do with the acceptance, relationships, inter-dependence,

and belonging. Perhaps the idea of community is a concept that holds on to an unrealistic picture of modern life and further validates dominant discourse.

### **Theoretical Implications**

**This study shifts focus from how schizophrenia is storied in literature, media, and communities to the perspectives of those who live with schizophrenia.** Without these perspectives we are just as lost as I was entering the health care system. Schizophrenia has been pathologized and presented from a deficit view (in terms of lack of emotional expression, motivation, and insight to name a few) as storied by the Government of Canada (2006) and the American Psychological Association (2013). The community is presented as the ideal setting and the cure (Schizophrenia Society of Ontario, 2013). The stories of Ryan, Whitney, and Tina challenge and shift these dominantly held notions of schizophrenia. Whitney's struggled with living in *the ideal* community, Ryan previously held negative ideas about schizophrenia based on media representations of Paul Bernado, and Tina was engaged in a loving relationship with her partner Bob. The three narratives bring a viewpoint often lost in the heavily medicalized (sick-healing-recovered) way we understand schizophrenia.

We saw how schizophrenia is **complex and differs from person to person**. Although there were similarities across the three narratives explored, experiences of the individuals differed greatly. Given the vast differences of schizophrenia, we hear the numerous points in their narratives when communities were not meeting the narrators' needs. For Ryan that included social groups closing leaving his social network in a fragile state. For Whitney, a lack of housing support caused her to bounce around between shelters for years. Tina's outdated medical counseling by her previous psychiatrist that led to experiences of social isolation and anxiety.

We saw that each narrative reveals **experiences of schizophrenia alongside other experiences of aging, gender violence, trauma, and poverty**. This creates significant differences in the negotiations required of the person and supports required to be *of* community. When discussing her social activities, Tina mentioned a lack of space and resources in her community that are tailored to her age. She stated that she finds it difficult to find places to be social that are outside of the bar/club scene. The narratives explored similar situations of gender, violence, aging, trauma, and poverty that Ryan, Whitney, and Tina discussed as important issues in their lives. Sensitivity to experiences alongside schizophrenia were seldom discussed in previous research which lacks deeper understanding of the persons involved. I saw how Tina discussed her age as being an issue that she was currently trying to adapt to, rather than an issue she had/has with schizophrenia.

Finally we saw **shifts in power, dependency, and control** in the narratives of Ryan, Whitney, and Tina. There were moments of dependency on others (family members, friends, etc.) but there were also moments of others being dependent on Tina, Ryan, and Whitney. The importance of mutual interdependence was heard in the narratives. Interdependence refers “to the ways in which people count on each other for mutual support and caring. It recognizes that human beings are social in nature and thrive much better in relationships with others” (Hutchison & McGill, 1992). Whitney, Tina, and Ryan describe a shift from a dependency on others to mutual interdependence with people in their lives. This shift counters dominant narratives which speak of the dependency of narrators on the health care system. It also critiques patient-focused approaches to care by critiquing a focus on only one side of a relationship. We heard how others (e.g., doctors in Whitney’s narrative) held *power-over* access to care; however, we also heard of situations where power was taken back (e.g., when Tina switched doctors). In relationships of



mutual interdependence, power is held by each person with a clear understanding of the needs and wants of persons involved.

In looking at psychiatric power, Foucault (1997) explores how some of the first therapeutic places that doctors “prescribed” for persons with a mental disability to “heal” were in nature. Nature was thought of as the healing remedy to what was known at that time as “madness”, a powerful place that could soothe the mind, relax the body, and give new life and energy to the person affected by this “madness” (Foucault, 1997, p. 42). We saw how Ryan used walking outside was an important aspect to his time spent in hospital and afterwards, but not in a prescriptive way. Whitney also connected to nature at the horse stable where her true identity was reflected in the spiritual connection she has with animals. What could Whitney do but live her life? The horse stable is a place that relaxes Whitney and also brings forth energy I felt during the walk-a-bout. Changing the social environment could involve a collaborative approach which authentically engages people as active members of the community to foster empowerment (Arai & Pedlar, 1997). In reflection in their research, Townley, Kloos, and Wright (2009) noted a lack of understanding of what the concept of community means to persons with a mental disability. We must further develop our understanding of how persons with schizophrenia understand community and choose different methods for gathering insight into those experiences (i.e., the walk-a-bouts).

The critical lens opens our eyes to the power a narrative can have on a person and a community. Whitney experienced how her community, out of fear, rejected her and banned her from her former residence. I think this is important when discussing identity and community as any claim to truth would be connected to judgments about failures and result in negative self-concepts; truth claims lead to the creation of haves and have not's. “The stories that people tell

about themselves and that are told about them are, of course, consequential for their lives and for how they are regarded in society generally” (Schneider, 2003, p. 199).

### **Methodological Implications**

Narrative inquiry is a strong approach to focusing on identity with persons with schizophrenia. Narrative has the ability to lead to identity creation as individuals reflect on the stories they share. This process happens during the conversations heard during the audio-recorded conversation and the community walk-a-bouts.

Danforth (1995) used a critical narrative methodology for those who encounter power and control struggles. Danforth’s research on children labeled “emotionally disturbed” mirrors similar struggles of power and control for persons with schizophrenia. When conducting research with persons who experience this struggle of power, we must be critical of the dominant narratives that exist. To critically challenge those dominant narratives that exist, voice of persons with schizophrenia must be heard. Narrative methodology opens space for voices of persons with schizophrenia to be heard fully, as presented in Chapter 3. As Roe and Davidson (2005) state, narrative has the ability to weave sense of self back together for persons with an illness. Critical narrative methodology has the ability to go beyond the illness, to capture the person as they wish to be seen and heard.

The walk-a-bouts allowed contextual insight into the perspective of narrators who ascribed meaning to words in a new way. The significant difference in meaning of hearing Whitney say, “I have no close connections” was able to be understood when Whitney said it at a horse stable while smiling and grooming a horse, compared to the interpretation I would have had if I heard this in a stuffy closet-like interview room. Each narrator chose the place or space

of the walk-a-bouts, usually a current leisure interest. At first I found the conversation to be about introducing me to the leisure activity, a topic that each narrator knew a great deal about. The roles changed during the walk-a-bouts, I was no longer the facilitator of the conversation – Ryan, Whitney, and Tina lead the discussions. The spaces also created a sense of enjoyment and fun, giving a relaxed ease to the research process. We were doing things that we enjoyed doing. Leisure created a comfortable space to express oneself; I felt like I could freely open myself up with conversation and I had a sense each narrator did as well, particularly because we were in their preferred leisure space.

Using principles from the authentic partnership approach (Dupuis et al., 2012) allowed me as a researcher to work toward building a trusting, reciprocal relationship for this study. This approach mirrored the social supports Ryan and Tina explored through their narratives. I found this approach was useful in focusing on the process rather than the outcomes (Dupuis et al., 2012). By focusing on the process there is space open for where the narrative to go where it needs to go and I think this could be useful for future research with persons with schizophrenia.

### **Practical Implications**

Practical applications of the narrative methodology explored by Coles (1989) and the authentic partnership approach (Dupuis et al., 2012) can be applied to the therapeutic recreation assessment process by co-constructing life stories through narratives of the person. These approaches lend to a shift from a focus on independence, outcomes, and differences in power between the client and practitioner. I presented this idea at the annual Therapeutic Recreation Ontario conference and received positive feedback to this practical approach. This shift in the way we narrate the people we work with has the ability to focus on the needs of the person, not the disabilities or pathology. When focusing on the process and not the outcomes (Dupuis et al.,

2012) we as practitioners can spend more time developing a partnership that will be of most help to the person and the team.

Struggles of power heard in the narratives provide insight into how practitioners approach care. By holding power over others, practitioners reinforce dominant narratives, which create a lack of control for those seeking care. Changing the way we think about shared roles in care rather than power over decisions made can create a better health care system. One way we can change the health care system is to use a narrative style to represent people when charting and documenting rather than focusing on the outcomes, reducing people to numbers, or only focusing on the person's limitations. There is great value in seeing and hearing the stories of people with schizophrenia.

Practitioners need to work closely with community agencies that provide support and care for persons with schizophrenia. By revisiting Hutchison and McGill's (1992) notions of ideal community we see the importance of the relations we have with the members of the community. Those connections, relationships, networking, and sharing all rely on strong communication between persons involved. Development of stronger social activities, spaces, and events that foster a sense of belonging and diversity is one way to reform policy and service provisions. Inclusion of persons with schizophrenia in the dialogue, for example the summit *Out of the Shadows at Last* (The Standing Senate Committee on Social Affairs, Science and Technology, 2006) explores gaps of services and needs of people with mental health disabilities. Actively engaging persons with schizophrenia in community development programs (i.e. social programming and events) provides insight and personal experiences otherwise missed.

## Assessing Quality

Revisiting Richardson and St. Pierre's (2005) sections for assessing quality in qualitative studies, positioned in a postmodern framework still contributed to the quality of the narratives heard in this study.

The narratives heard contributed to the understanding of the social life of each narrator. The experiences that occurred alongside schizophrenia (such as aging) provided deeper understanding to each narrator's social life. The walk-a-bout reflection notes added to this understanding by providing context to social life by continuing conversations in a leisure space.

The aesthetic merit of the narratives was sequenced in a way (chronological) in an attempt to understand the complexities of the lives of the narrators. The process of sequencing the narratives differed across the three narrators, from more disjointed stories to more polished scripts. Some of the more non-linear and disjointed stories do still appear in the narrative (Tina's discussion around her father committing suicide). This was left unchanged to show some of the ways the narrative shifted and turned during the conversation.

The inclusion of my reflexive insights into my own research process, such as the sequencing of the narratives, adds to the quality of the narratives. My reflection on my participation in the research process, that I may have become a part (product) of the narrator's communities, is also part of the quality assessment of the narratives. I am the producer of this research paper and the product of the co-construction of the narratives of Whitney, Tina, and Ryan.

Finally the impact of the study on me, and on others, is the final step in the criteria Richardson and St. Pierre (2005) discuss. My self-reflection provided me with insights into how

I grew as a person during this study, both as a practitioner and a human being. I was able to share my thoughts and held notions of schizophrenia, disability, community, and the medical framework in my journaling that allowed for a safe space to challenge my beliefs. I have added my journal notes throughout this paper and have reflected on my growth from participating in this study. I discuss how it felt going through this research process and also the steps I will take afterwards.

### **Future Research Suggestions and Discussion of Limitations**

We addressed some of the ways the narratives challenged dominant narratives, however, there are directions that future research can take. As we will explore in the limitations of this study, there is a need for advocacy and action with persons with schizophrenia. Future research could include Participatory Action Research (PAR) in communities that focus on changing the world around the needs of everyone involved. Some questions to think about are: How can a community meet the needs of people with schizophrenia? What supports need be accessible to people with schizophrenia? How can we create a community that is inclusive and understanding of people with schizophrenia? These questions bring forth narratives of experiences with schizophrenia; however, by using PAR, stories may be used to cause direct action for change.

With this research taking place over the harsh winter months of 2014, the conversations during the walk-a-bouts were dampened by the lack of energy and variety that perhaps the narrators have during warm conditions. With a greater selection of leisure activities during the summer months I could have seen more participation in activities that occur outside, instead of coffee shops or indoor spaces. Also in future research projects this could be an opportunity to have a discussion with the research participants about a selection of leisure activities that would

be available during the time of data collection. This would provide insight into each persons array of leisure engagements in community.

During the walk-a-bouts I had to rely on my memory since I choose not to audio-record the conversations in the community. I recommend having a time to debrief after the walk-a-bout with the participant to ask for clarification of what was said during the conversations. This allows for greater memory recall and allows the participant to make any changes to meanings or understandings the researcher heard.

Another limitation was my ability to remember what the narrator said during the walk-a-bouts and what to include in my reflection notes. I was unable to use direct quotes and so the stories are filtered through me, which can cause lack of understanding and bring my biases into my notes. To improve this next time I would present a copy of my walk-about notes to each narrator to clarify meaning and understanding of what was said. This process would also open up discussion of other topics including what name the narrators would want their identity to be represented as. This would improve the way we hear and give meaning to the narratives.

### **Final Reflective Note**

I am thankful for this journey I was able to experience hearing and feeling the narratives of the three brilliant and remarkable narrators. I attempted to open space to create a connection with each narrator that was scary at first, since I have never done that before. I put myself in a vulnerable situation by creating a strong connection with each person with the possibility that after this journey ends I may never see him or her again. Will they remember me and this study? I know that I will never forget what I heard and experienced over these last few months. I know I will take these stories with me wherever I go.

I have changed from embarking on this journey of research, and even from the story I shared at the beginning of this paper. I do not fear a relationship with the people I work with, I try to embrace it now. Connecting with people we work with makes all the difference in providing care. I saw a lack of connection to any form of relationship from the service providers in the story I described at the beginning of this paper. By going through this research process I choose not to disconnect from the people I work with. I want to share my story and my life as we ask persons seeking care to do. I want to be fully connected; fully present, fully aware of how my choices affect people I work with. I saw the impact of the choice to disconnect that the woman made in her engagement with the young gentleman on the bus. That is the choice I wish to avoid repeating.

My fears before embarking on this journey were not mine alone. I witnessed experiences of fear in the community by others and heard about community fear through the narratives. I am not fearful anymore. As I first met Tina I could see the fear in her eyes and hear it in her voice. She was just as fearful as I was that first day. Over time we both relaxed as we shared stories and laughs about our lives. The connection I created with Tina did not allow for fear to stay. I was conscious of my power in this partnership as my role of researcher. I also recognized and addressed Ryan, Whitney, and Tina's power during the research process. By meeting in places familiar to each narrator I adapted to their environments, in a place of comfort for Whitney, Tina, and Ryan. I avoided research jargon when having conversations. Re-reading my journal entries before the next meeting meant I could bring back topics of conversation from previous meetings that kept the flow of discussion concurrent. Fear may have shown up in the beginning, but friendship, respect, dignity, love, kindness stayed for the long haul.



Keeping a reflective journal collected my personal and professional transition through this intense journey. What I learned about myself cannot be measured or quantified but rather remembered for the place it held in me at that time. I will forever look back on this experience as one shining example of successful connection – the new standard for how we approach working with others.

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## Appendix A

### Informed Consent Form

Researcher: Devan McNeill, Department of Recreation and Leisure Studies

Thesis Advisor: Dr. Susan Arai, Associate Professor, Department of Recreation and Leisure Studies

- I have read the information presented in the letter of introduction about the study being conducted by Devan McNeill in Recreation and Leisure Studies at the University of Waterloo, under the supervision of his thesis advisor Dr. Susan Arai.
- I have had the opportunity to ask Devan any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the study without penalty at any time by advising the researchers of this decision.
- I am also aware that my information will be kept confidential and that my real name will not be used in reports and presentations. I understand that answers I provide may be used word for word; however a made up name will be used in place of my real name.
- I was informed that I may withdraw my consent at any time without penalty.
- I understand this project has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee (file #19393).
- I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact Devan McNeill at the University of Waterloo at 226-750-9880 or dmcneill@uwaterloo.ca. or his thesis advisor Dr. Susan Arai at 519-888-4567 ext. 33758 or by email at sarai@uwaterloo.ca
- I understand all of the information that has been provided to me about this research study, and I agree, of my own free will, to participate in this study.  
 YES     NO
- I agree to have my responses to the interview audio recorded.  
 YES     NO
- I agree to have the researcher, Devan, go with me into the community to continue having conversations.  
 YES     NO
- I would like to receive a summary of the research results and have included my email or mailing address below.  
 YES     NO

Email address:

Mailing address:

Participant Name (*please print*): \_\_\_\_\_  
Participant Signature: \_\_\_\_\_  
Witness Name (*please print*): \_\_\_\_\_  
Witness Signature: \_\_\_\_\_  
Date: \_\_\_\_\_

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*To be completed by researcher:*

*I have fully explained the procedures of this study to the participant.*

Researchers Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix B

### Letter of Introduction

Date: January 10<sup>th</sup> 2014

Dear: Participant

Thank you for your interest in this study titled, *Narratives of Identity and Community in Journeys with Schizophrenia*. The study will involve collecting stories of people's experiences of identity and community. The study is being carried out by Devan McNeill, a Masters student in the Department of Recreation and Leisure Studies at the University of Waterloo, under the supervision of Dr. Susan Arai. Staff from [local mental health housing agency] are helping us to connect with people who might be willing to participate. This study will provide important information about experiences of identity and community for people living with schizophrenia. The results of this study will include a summary of your story and will be made available to you at the end of the study. More information about the study appears below. By participating in the study you will receive a \$50 gift card to a grocery store or restaurant of your choice.

***How was I selected to participate in the study?*** [Recreation Therapist] is helping us to connect with people who are currently connected with [local mental health housing agency] [Recreation Therapist] has mentioned that you may be interested in taking part in our study and you have experience in the community which is diverse so as a resident of the [City A] area, we would like to have the opportunity to have a conversation and hear about your story of experiences you have had in your community.

***What will my participation involve?*** If you agree to participate I, Devan McNeill, will set up a time to meet with you and ask you about your story of experiences you have had in your community. With your permission your consent to participate and your responses to questions will be audio recorded to help to ensure that I accurately capture your words and your story. I will also ask for your permission to go with you in the community to continue our conversations about your stories, which I will be taking reflective notes from time to time. The number of times, the activities, and length of time will be discussed together during our first meeting.

***Will this affect my involvement with [local mental health housing agency]?*** If you choose not to participate or withdraw from the study this will not effect on your relationship with [local mental health housing agency] or with [recreation therapist]. Although there are no known or anticipated risks associated with participation in this study, if at any time you feel this study has raised concerns for you [recreation therapist] is available to provide referrals to services available in the community.

***Do I have to participate?*** Participation in the study is voluntary. You may refuse to answer any questions that are asked, if you wish. You can also let Devan know at any time that you wish to stop your participation in the study. We will not tell [recreation therapist] if you participate or not in our study.

***Will my information be protected?*** All information you provide will be confidential and your real name will not be used in reports and presentations. You will be given a pseudonym (made up name) that I will use when reporting the results of the study. To support the findings of the research, I may include word for word (direct) quotes from our conversations when I report on the study. In addition, paper documents and audio-recordings of our conversations will be erased at the end of the study. All information from the recorded conversations and reflective notes will be destroyed after two years.

This project, *Narratives of Identity and Community in Journeys with Schizophrenia*, has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee (file #19393). If you have any questions about this study, please feel free to contact me, Devan McNeill, at 226-750-9880 or by email at [dmcneill@uwaterloo.ca](mailto:dmcneill@uwaterloo.ca). Should you have any comments or concerns resulting from your participation in this study, you may also contact Dr. Maureen Nummelin, Director in the Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or [maureen.nummelin@uwaterloo.ca](mailto:maureen.nummelin@uwaterloo.ca).

*I look forward to talking with you!*

## Appendix C

### Feedback Form

Date

Dear

I would like to thank you for your participation in this study entitled *Narratives of Identity and Community in Journeys with Schizophrenia*. As a reminder, the purpose of this study is to explore your experiences related to identity and community through narratives.

It is my hope that our conversations provide you with an opportunity to reflect on your experiences. Data collected during our conversations will also contribute to a better understanding of identity and community for people who experience schizophrenia and how the stories of our lives are shaped by forces in society and often divide people living in community.

Please remember that any information collected about you as an individual will be kept confidential. Once all the data are collected and analyzed for this project, I hope to share this information with the research community through seminars, conferences, presentations, and journal articles. If you are interested in receiving more information regarding the results of this study, or would like a summary of the results, please provide me, Devan, with your contact information, and when the study is completed (hopefully around August 31<sup>st</sup> 2014), I will send you a copy of the information.

If you have any questions about the study, please do not hesitate to contact me by email (dmcneill@uwaterloo.ca) or by telephone (226-750-9880). You may also contact my thesis Advisor, Dr. Susan Arai at 519-888-4567 extension 33758 or by email at sarai@uwaterloo.ca. As with all University of Waterloo projects involving human participants, this project was reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee (file # 19393). Your comments or concerns resulting from your participation in this study may also be directed to Dr. Maureen Nummelin, Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

Sincerely,

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Devan McNeill  
MA Candidate  
Dept. of Recreation & Leisure Studies

---

Susan M. Arai  
Associate Professor  
Dept. of Recreation & Leisure Studies

## Appendix D

### **Sample Questions of the Interview Process**

1. Can you start by describing what a typical day is like for you?
2. If you were to tell someone the story of your life, how would it go?
3. What has your life in community been like over the past 10 years?
4. What is your life like now?



## Appendix E

### Cast of Characters in Ryan's Narrative

1. **Ryan's Mother.** She is very involved in Ryan's life and in the mental health community. Ryan and his mother didn't have the best relationship during the early stages of his illness and certainly not when he assaulted her and was arrested. However, as his mother would regularly visit Ryan in the hospital, their relationship grew. To help Ryan feel better, she was the one that introduced alternative health practitioners to him such as an acupuncturist and nutritionist. She wrote a letter to the Canadian Mental Health Association on behalf of Ryan to advocate for his rights. "My mom seems to know everyone, when I wasn't well she tried all of the committees and groups that focus on mental illness." She is the family navigator at [A-Block]. Ryan's mother is a protagonist in his narrative.
2. **Acupuncturist.** She was a medical doctor in China. Before any other doctors knew what was going on with Ryan, she was the first to diagnose Ryan with schizophrenia. She told Ryan's mom as she opened a Chinese-English dictionary and pointed to schizophrenia. She is a protagonist in Ryan's narrative. She told Ryan to walk and using alternative methods to overcome symptoms of schizophrenia. She offered to help Ryan during the first stages of his illness.
3. **Recreation therapist in [City D].** The Recreation Therapist was an important person in Ryan's initial recovery. He would drive Ryan and other patients back to the [City A] area from [City D] for day passes to connect with their communities. He is a protagonist, "he actually got me connected with [Support Centre] it was actually called [City B] region self-help back then. And he got me connected to a group called [social centre]." Ryan states that this recreation therapist was one of the keys in his recovery because he got Ryan connected into the community.
4. **Father.** Ryan's parents divorced early in Ryan's childhood, which meant he had to travel as far as [City G] to visit his father. Eventually his father moved closer to where Ryan lives and they seem to have a good relationship. He now lives in [City I]. Ryan's father is a protagonist. He noticed when Ryan's grades were slipping and knew something was wrong and offered to help Ryan. "He didn't really know how to be supportive or anything but he's actually getting better, he's trying much harder now. He has learned to be more supportive."
5. **Best friend.** Ryan's best friend has been supportive and has been there for Ryan when he needed it. They've known each other since pre-school and Ryan states that he was really close with his friend's family. This friend is a protagonist in Ryan's life and has been a constant in his life. He visits Ryan when he can.
6. **Older brother.** Fourteen months separate Ryan and his older brother who recently turned 40. They have a close relationship and growing up had a lot of the same friends in school.
7. **Younger sister.** Ryan went to a [summer camp] as a camp counselor with his sister and mentioned that the experience allowed for him to know her better. Ryan used to

babysit her when they were younger as he is four years older. “So we are pretty close now.”

8. **School friends.** Ryan would hang out with his friends when he wasn't at his dad's place and they would party with drinking, smoking, smoking marijuana, LSD, and magic mushrooms. He describes his high school friends as more antagonist than protagonist. “I really lost all my friends from high school.” They didn't really understand Ryan and his mental illness. At that stage in his life, they thought he was partying too much, or not enough when Ryan was isolating himself.
9. **Police.** The police took Ryan to the hospital after an incident with his mother. Ryan claims his mother lied to the police about him grabbing her arm during a fight.
10. **Women at Self-Help Alliance (mother knows).** Protagonist in Ryan's narrative, “she's the one that got me to volunteer for the schizophrenia support groups.” Ryan's mother knows her and would often communicate through her to ask Ryan questions because Ryan listened to her.
11. **New Friends.** Most of his friends now have schizophrenia, a mental illness, or are understanding of mental illness. Ryan defines his community as the mental health community. His new friends are protagonists. They are a bunch of guys that Ryan met at some of the groups. Even if some of the groups stop running, Ryan and his friends would organize events to keep being social, like bowling.

## Appendix F

### Cast of Characters in Tina's Narrative

1. **Father.** Tina's father was an antagonist in Tina's narrative. Tina describes he caused her to act out, become a "wild child" and get in trouble with the boys in school. He was abusive to Tina and her mother, physical beating them. Her father separated from the family early on in Tina's life, which was a relief to Tina that he was removed from the house. At the age of 28, Tina's father committed suicide. Tina was 8 or 9 years old at the time. Much later in life Tina found out her father had schizophrenia (Tina was around 18, 19) which was a big shock to her and her family. Tina's mother thought he was taking medications because of his "nerves" according to Tina. Tina also stated her father "drank a lot and took drugs and stuff."
2. **Bob.** Bob is Tina's boyfriend, partner, twin, friend, lover – they like everything the same as one another. They have been together for 11 years, soon after Tina started seeing Dr. Kenneth. Tina loves him, "I never think [sic] I love anybody like him before that much that I'd could see myself with him forever." Bob is a protagonist in Tina's story, he loves Tina very much. "We just love each other so much and we understand each other a lot." Bob has a brain injury from an accident. "He's just like the old me which I'm trying to get him like the me today." Procrastinator, lazy, overweight, he just doesn't want to continue to get the help he needs according to Tina. Bob stays in a lot, doesn't like to go out and be social in new situations. Tina states that Bob has high anxiety.
3. **Dr. Kenneth.** Dr. Kenneth changed Tina's life, for the good. Dr. Kenneth "really dug me out of a hole... he's the only one that got me the way I should really be." Dr. Kenneth was the new doctor in Tina's life who put her on medications that cleared up negative side effects that were hindering Tina's well-being and quality of life. Dr. Kenneth is a protagonist for Tina and a major character in her life and her well-being. One of the major turning points occurred after meeting Dr. Kenneth, "I was so happy I wanted to start life again." Dr. Kenneth is awesome, Tina sees him once a month. Tina credits Dr. Kenneth is one of the main reasons Tina hasn't been in the hospital since she was 27 or 28. He often counsels Tina whenever she needs it.
4. **Mother.** Tina's mother is a protagonist in Tina's life, being supportive and motherly. She often would worry about Tina when she was first going through the early stages of schizophrenia particularly around housing but feels like Tina is doing well for herself now and she doesn't worry as much. Tina's mother now lives in [City J] in a trailer by the lake. She was a cook at the [local university] for a number of years before taking early retirement. She separated from her abusive husband early on in their marriage to the delight of Tina. She was genuinely shocked to learn that her late husband had schizophrenia.
5. **Sister and Brother.** Tina's brother and sister are protagonists in Tina's narrative by supporting Tina and "the things with mental health." They are excited to hear Tina is involved in this research project (thesis). They understand Tina; however, they are not heavily discussed in Tina's narrative.

6. **Rick and Donna.** Rick and Donna are Tina's aunt and uncle on her mother's sister. They are supportive to her and Bob. Rick and Donna are protagonists in Tina's narrative and glad to hear Tina is taking part in this research study (thesis). Tina and Bob went over to Rick and Donna's house recently to have dinner.
7. **Aunt Harriet.** Aunt Harriet provided insight into Tina's father's past with schizophrenia, however kept this information secret until Tina was diagnosed with schizophrenia. When Tina's mother first called to inquire about Tina's father's past, Harriet hung up on her. Harriet is an antagonist due to her secretive nature and unwillingness to be as open about mental health as Tina is and wishes to be.
8. **Meredith.** Meredith is a service worker at the local agency, coming to see Tina once a month to talk about the groups she participates in and check up on her. Although not discussed in length, Meredith is a protagonist in Tina's life.

## Appendix G

### Cast of Characters in Whitney's Narrative

1. **Angels.** Whitney's angels taught her how to fly, would talk to Whitney, and keep her company. They would appear when Whitney was in psychosis, a sign that she needed to head to the hospital and seek treatment. "Angels were very comforting, I know I wasn't alone. And umm there was always somebody to talk to." They were actually confirmed to Whitney when she was talking to a male patient in the hospital. The male patient also saw angels and flew with them. Later on, that male patient told Whitney she wasn't doing the motions of flying right. Whitney found it extremely comforting that other people had similar experiences as her. Whitney felt like the angels used her as a puppet, that they were controlling her. So she would put her arms and legs up and the angels would use her body like on a string and making her doing things. "I'll always be with you Whitney, I'll always be holding your hand, I'll always be taking care of you, even if you can't hear me, I'm still here." The angels are both a protagonist and antagonist in Whitney's life. They are fondly spoken about by Whitney but also caused her to stop taking medications and spiral into psychosis in the community.
2. **Animals (cats and horses).** Whitney stated she has a strong, spiritual connection to animals. She was first introduced to horses at an early age where she raised a horse named Boo for the first two years of its life. When Boo was sold Whitney described that process as "devastating" and "heartbreaking" for her. Also there were moments when her mother would take her cats from Whitney as she deemed Whitney to be unsuitable to take care of animals when she can't even take care of herself. For the most part animals are protagonists in Whitney's narrative, as this spiritual connection has led in some aspect to Whitney's peace. She has been around horses, cats, and pigs to name a few. Whitney mentioned a lack of human connections at a local horse stable, however she mentioned that she is at peace in her life now. Whitney also mentioned a desire to volunteer at the Humane Society.
3. **Husband.** An antagonist in Whitney's narrative. Whitney and her ex-husband got married in 1989. They have a daughter together and owned a pig farm together during their short marriage. He was persistent on buying and owning a pig farm right away. Whitney didn't want to break up the marriage so she went through with things even though she didn't want to. They both used up all their savings to buy the farm. The farm didn't make enough money and caused a lot of financial problems for the family. One night, Whitney's ex-husband was abusive and assaulted Whitney during a fight about money issues. After being in jail following the assault arrest, he didn't speak to Whitney ever again. Whitney needed to sell the farm and go on welfare and food stamps with her daughter. He has no role in Whitney's current life or his daughter's life.
4. **Daughter.** Whitney's daughter was born in 1992. She had to manage her life at the age of 13 when Whitney went 'missing' for two weeks. Whitney stated her daughter had to cook for herself and take herself to school. Eventually she went to a friend's place to stay as Whitney self-admitted herself to a hospital. She told Whitney, her mom, that she didn't

want her doing drugs and drinking, Whitney quit both for her daughter. Her daughter is 21 now, in 4<sup>th</sup> year of a 5 year program at the [local University] taking [name of program] the co-op program. She told Whitney she doesn't want to have a relationship with her. She can be a protagonist her Whitney's future but for now she remains an antagonist that refuses to communicate with Whitney, her mother.

5. **Mother.** Whitney's mother trains, shows, and cares for horses and also worked part-time as a bartender. She is an antagonist in Whitney's life. She offered little consoling to Whitney after the loss of her first horse Boo being sold and breaking the strong connection between them. Whitney's mother also had to take Whitney's cat while she was in hospital. Then she had to pick up the cat again and when she visited Whitney in the hospital she said "why you doing this to us, what's your problem, haven't you got anything better to do then be in the hospital and doing this to us." She hasn't seen Whitney in four years.
6. **Father.** Whitney's father worked at a beef cattle farm for a number of years. He is an antagonist in Whitney's narrative as he would blame her actions on a lack of motivation and will. He freaked out at Whitney during one Christmas break because Whitney spent most of her time in her room. "That's not, that's unacceptable behavior, we're not putting up with that." Whitney mentioned that her father is a hoarder and she didn't feel comfortable at her parents' house. He hasn't seen Whitney in four years.
7. **Doctors.** Some of the doctors in Whitney's life didn't believe her at first when she tried to seek help at the hospital. "This isn't a hotel, we're not here to take care of you." This doctor at [City A hospital] wasn't supportive of Whitney's concerns and kicked her out of the Emergency room. Her second time going into the [local hospital] was with the same doctor, "no, there's nothing wrong with you, you just got it, it's all in your mind you can, you don't need to be like this, you can take care of yourself." At other hospitals such as [City E] and [City D], the doctors were better at listening to Whitney and responding to her needs. They medicated Whitney; however they would often prescribe sleeping medications because Whitney was not sleeping. Whitney didn't want to take those medications because of the addictive side effects of the sleeping pills. Some of her doctors were telling her she needs to get out every day, not to isolate herself at home. The doctors in Whitney's life have been mostly antagonist, not understanding Whitney and her needs.
8. **Service workers.** Whitney's service workers are protagonist in her life. They assist Whitney in providing housing that is stable and met her needs. They offer accessible groups and social activities that meet Whitney's needs. They have a good relationship with Whitney, and are very supportive and encouraging.
9. **Landlord.** He appeared to be afraid of Whitney. He didn't like what she was doing so he kicked her out of her place when she was in hospital. Her parents dealt with him and moved her stuff out. He is an antagonist for Whitney. She considered that home and had to live in a shelter after leaving the hospital. Tenants of the place would say to her, "No you can't come here anymore, you don't live here, you are not allowed on the property."

10. **Girlfriend.** Friend of Whitney's, opened her place to Whitney following the assault by her husband. The girlfriend is a protagonist in Whitney's life. She called the police and provided assistance to stop the violence in Whitney's life.
11. **Sister.** A lifelong antagonist, Whitney and her younger sister would constantly fight during their childhood. She currently lives in nearby [City C] and hasn't seen Whitney in five years. She participates with Whitney's mother in horse competitions in different cities.