

PERCEPTIONS OF PERSONS WITH SCHIZOPHRENIA RELATING TO
THEIR WEIGHT

by

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A thesis submitted to the School of Nursing
In conformity with the requirements for
the degree of Master of Science

Queen's University
Kingston, Ontario, Canada

(May, 2009)

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Abstract

Purpose

The purpose of this study is to examine weight and lifestyle among persons with schizophrenia from their perspectives. Two specific research questions are addressed:

- 1: What are the perceptions of persons with schizophrenia related to their weight?
- 2: What are the experiences of persons with schizophrenia in maintaining a healthy lifestyle?

Methods

A qualitative, constructivist research design is used to guide the study. Unstructured interviews are the method of data collection and analysis is done using constant comparison.

A purposive sample of 18 participants was obtained from an Outpatient Psychiatric Unit.

Findings

Three themes, Normal Life Thrown a Curve Ball, Weight Management as Complex, and Today's Experiences Shape Tomorrow's Outcomes, were identified by the participants. Weight management was seen as a complex and difficult phenomenon; however, participants were optimistic about their ability to achieve a healthy weight in the future. Individual strategies, support and education were identified as essential weight management components.

Conclusions

The perceptions identified in this study further our understanding of the complexity of weight management, and can be used to design future weight loss interventions better tailored to this population.

Acknowledgements

I have been privileged to work with a distinguished thesis supervisory committee. They have each contributed to this work. Dr. Cynthia Baker, as my thesis supervisor, has expanded my understanding of qualitative research methods and research involving persons with schizophrenia. She has a remarkable ability to synthesize self-report data and tease out themes. My hope is that my future work can be as insightful. I have also learnt a great deal from Dr. Diane Buchanan's expertise in research with participants with mental illness. Dr. Margaret Harrison, a guru in mixed methods research, has contributed greatly to the final draft of this thesis and has provided me with guidance on graduate studies in general. I look forward to working with her throughout my PhD studies.

Thank you to the participants who took the time to be a part of this study. Without their interest and willingness to discuss their weight with me, this thesis would not have been possible.

Giuseppe Borracci, a Registered Nurse working in the Psychiatric Outpatient Clinic at the Royal Ottawa Mental Health Centre in Ottawa, Ontario was incredibly helpful in facilitating access to potential participants and encouraging recruited persons to take part in the study. His support throughout the recruitment and data collection process was extraordinary. Dr. Nancy Brookes, also from the Royal Ottawa Mental Health Centre, provided me with tremendous insight into the ethics process at the hospital and acted as my internal contact person so that I was able obtain ethics approval – thank you. I would like to acknowledge my family, and thank them for their support over the past two years. My mom Kim, my dad Dave, and Chris were particularly kind as they tirelessly read and edited each draft of this thesis, without (much) complaint.

Finally, the financial support provided by the Queen's Graduate Award and the RS McLaughlin Fellowship was greatly appreciated.

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Chapter 1

Introduction

Weight gain appears to be a major challenge for persons with schizophrenia who are being treated with atypical antipsychotic medication. Introduced in the 1990's, these drugs are effective in controlling many symptoms of schizophrenia, and cause less extrapyramidal side effects than existing medicine. However, it has been demonstrated that they induce substantial weight gain and are associated with increased metabolic syndrome, cardiovascular disease, and other obesity related conditions (Kaplan, 2004). Furthermore, there is evidence that weight gain itself may affect quality of life and medication compliance in this population, as obese persons with schizophrenia are 2.5 times less likely to adhere to prescribed pharmacological treatment, than those without weight problems (Mauri et al., 2006). Unfortunately, the joint diagnosis of these two chronic conditions has become commonplace as 40-60% of individuals with schizophrenia are also obese (Catapano & Castle, 2004). This growing epidemic is poorly understood, yet clearly a major health concern that requires immediate attention. In order to appropriately address the issue of adverse weight gain in this population, a further understanding of their subjective experience of weight and weight management must be revealed. Thus, the purpose of this study is to investigate these phenomena from the perspective of the person with schizophrenia, using qualitative methods in the constructivist paradigm. The following specific research questions are addressed:

1. What are the perceptions of persons with schizophrenia related to their weight?
2. What are the experiences of persons with schizophrenia in maintaining a healthy lifestyle?

Chapter 2

Literature Review

Schizophrenia

Schizophrenia, a long-term illness with no known cure, is considered the most disabling psychiatric ailment, and is defined in the Diagnostic and Statistical Manual of Mental Disorders IV (DSM IV-TR, 2000) as a severe psychotic disorder involving abnormal brain structure and function, presenting most frequently in combination with a life stressor, between the ages of adolescence and early adulthood. Approximately 1% of the earth's population is affected by schizophrenia and statistics indicate that 40% of persons with the illness do not receive psychiatric treatment, resulting in homelessness, incarceration, and violence (National Institute of Mental Health, 2001). Schizophrenia affects all races; however prevalence is greater in men than women.

The etymology of the term schizophrenia, which is less than 100 years old, is based on the combination of two Greek words; 'schizo' meaning split and 'phrene' meaning mind. The first written description of schizophrenia was noted in Egypt in the year 200 BC. At this point in time, it was believed that the illness was a symptom of heart or uterine disease, caused by poisons or demons. Prior to this, ancient Greek and Roman literature indicated public awareness of schizophrenia with an understanding that an imbalance of bodily humors was the root cause. In addition, Hippocrates of Greece, born in 460 BC, and considered the greatest physician of his time, believed that the 'insanity' of schizophrenia was caused by a morbid state of the liver. Over time, the understanding of schizophrenia broadened, and by the 18th century it was commonly accepted that the mental illness was caused by a disordered central nervous system. In 1887, psychiatrist Emil Kraepelin described the specific cluster of symptoms indicative of schizophrenia

as a 'mental illness', and Swiss psychiatrist, Eugene Bleuler, coined the term 'schizophrenia' and outlined the positive and negative symptoms of the illness in 1911. From the 19th century onward, extensive research has been conducted, and a common understanding exists that schizophrenia is a disease of the brain and biologically based (Schizophrenia.com, 2007).

The DSM IV-TR (2000) lists five classes of schizophrenia: Disorganized, catatonic, paranoid, residual, and undifferentiated. The symptoms of schizophrenia are identified as either positive or negative. Positive symptoms include hallucinations, delusions, and disorganization in speech and behavior. Hallucinations manifest most frequently through auditory voices, but can also involve visual, tactile, olfactory, gustatory, and somatic experiences. Delusions are mistaken beliefs about the self or the environment, regardless of contradictory evidence. They can be classified as delusions of persecution and infliction of harm, delusions of reference or conviction that public events are directly related to self, somatic delusions and belief that one's body is abnormal, thought broadcasting, and delusions of control. Negative symptoms, distorted aspects of the person by the disease, are less remarkable than positive symptoms, but just as debilitating. Often referred to as the 'four A's' of schizophrenia, they are flat affect, avolition, and anhedonia. Respectively, they encompass the absence of expression, empty verbal responses, inability to partake in goal directed activities, and lack of pleasurable experiences. Both categories compromise the ability to adequately cope with the mental illness and diminish the chance of maintaining a normal life (Kneisel, Wilson, & Trigoboff, 2004).

The illness trajectory of schizophrenia entails five phases. The premorbid phase exists when there are no signs or symptoms of the illness. The prodromal phase is entered when gradual and subtle behaviour changes such as tension, insomnia, impaired concentration, and social withdrawal are exhibited. The onset phase occurs when symptoms become recognizable, and the progressive phase involves recovery from the first psychotic episode and initial relapses. The

illness is said to be in the chronic or residual phase when multiple relapses have occurred over the span of many years (Lieberman, 2004). A diagnosis of schizophrenia is made when two or more of the following symptoms are seen for the majority of a month: Delusions, hallucinations, disorganized speech, grossly disorganized/catatonic behaviour, and negative symptoms, in conjunction with significant impairment in work, relationships, or self-care activities, significant problems for longer than 6 months, and the manifestations are not substance related or associated with another psychiatric disorder (DSM IV-TR, 2000).

Although no single cause of schizophrenia has been identified, many theories exist, including genetic predisposition, biochemical and neurostructural, organic or pathophysiologic, environmental or cultural, and perinatal theory. The genetic predisposition theory states that 10-20% of people with one immediate family member with schizophrenia will inherit the illness and 40% of people with either parent or an identical twin affected will too develop schizophrenia. Interestingly, 60% of persons with schizophrenia have no close relatives with the disease (Narasimhan & Buckley, 2005). To date, seven genes have been confirmed by scientists as associated with a heightened risk of having schizophrenia (Weinberger, 2004). Biochemical and neurostructural theory involves the idea that excessive amounts of the neurotransmitter dopamine causes overstimulation of the brain and disruption of normal cell communication, thereby causing hallucinations and delusions. Unfortunately, the cause of elevated dopamine is unknown. Structurally, scientists supporting this theory explain that abnormalities of the neurocircuitry can cause an excessive amount of unfiltered information that overwhelms the brain and leads to errors in perception, hallucinations, and delusions. (Kennedy, Pato, Bauer, Carvalho, & Pato, 1999). The organic or pathophysiologic theory is based solely on circumstantial evidence and requires further investigation. According to these theorists, functional deficits in the brain caused by stressors (infections, toxins, trauma, substances, etc...) lead to the development of schizophrenia.

(Shives, 2008). Environmental or cultural theory is based on the belief that schizophrenia results from a faulty reaction to the environment and the inability to selectively respond to multiple stimuli. Again, this theory requires more vigorous investigation. (Kolb, 1982). Finally, supporters of the perinatal theory describe oxygen deprivation or malnutrition/starvation during the first trimester of a pregnancy as causal. They believe that schizophrenia develops in the 34th or 35th week of pregnancy during which time critical brain development ensues (Sullivan, 2004).

Medication

The symptoms of schizophrenia are managed through the prescription of antipsychotic medication. The first antipsychotic, chlorpromazine, was discovered in 1952 by French psychiatrist Pierre Deniker. His 'miracle drug' stabilized psychotic symptoms to a point where persons with schizophrenia were able to live outside of psychiatric institutions (Townsend, 2008). Today, two classes of antipsychotics exist: Typical and atypical medications. Typical antipsychotics, also known as conventional or first generation drugs, include chlorpromazine, haloperidol, fluphenazine, perphenazine, prochlorperazine, thioridazine, and others. These drugs are very effective in reducing positive symptoms, yet are associated with extrapyramidal symptoms and tardive dyskinesia, and harsh side effects (Deglin & Vallerand, 2007). Atypical antipsychotics, also known as novel or second generation drugs, include ziprasidone, risperidone, quetiapine, olanzapine, aripiprazole, and others. These medications were first introduced in the United States in 1990 and came shortly thereafter to Canada. They effectively reduce psychotic symptoms with a lower propensity to cause extrapyramidal symptoms. However, they too are associated with severe side effects: Weight gain, metabolic syndrome, and endocrine changes. Generally, all antipsychotics, except aripiprazole, work as antagonists at dopamine receptors. The neurotransmitter dopamine allows for communication between cells in the brain, and an increase

of dopamine is thought to cause psychosis. Therefore, blocking the reuptake of dopamine from the blood decreases dopamine in the cells and ultimately minimizes or eliminates psychotic symptoms. Aripiprazole, on the other hand, balances dopamine levels in the brain, rather than simply decreasing them (Townsend).

There are seven chemical classes of antipsychotics of which the phenothiazines and thioxanthenes work by blocking postsynaptic dopamine receptors in the basal ganglia, hypothalamus, limbic system, brainstem, and medulla. Phenylbutylpiperadines act by blocking postsynaptic dopamine receptors in the hypothalamus, limbic system, and at reticular formation. The most notable of this class is haloperidol as it is frequently used to pacify acutely agitated persons with schizophrenia. Dihydroindolones and benzisoxazoles, the most common of which is risperidone, work through a combination of antagonism at dopamine type two (D2) and serotonin type two (5HT2) receptors. The dibenzepine class includes the regularly used medications clozapine, olanzapine, and quetiapine. Clozapine works at the dopamine type four receptors and is most active in the limbic system. Olanzapine uses a combination of dopamine and serotonin receptor antagonism, as well as action on muscarinic, histaminic, and adrenergic receptors, and quetiapine works by a combination effect on D2 and 5HT2 receptors. Finally, quinolinones (aripiprazole) act by partial agonist activity at D2 and serotonin type 1A receptors, combined with antagonist activity at serotonin type 2A receptors. (Marangell, Silver, Goff, & Yudofsky, 2003, Townsend, 2008).

Antipsychotic medications may be beneficial in controlling psychotic symptoms in persons with schizophrenia, but they are not without drawbacks. The side effects of typical and atypical antipsychotics range in severity and effect on daily life. Anticholinergic effects, such as dry mouth, blurred vision, constipation, and urinary retention occur, as well as nausea and gastrointestinal upset, skin rash, and hyper-salivation, and are primarily seen with clozapine.

These side effects are joined by orthostatic hypotension, photosensitivity, lowered seizure threshold (again primarily with clozapine), agranulocytosis (rare and presents within the first three months of treatment) and hormonal effects such as decreased libido, retrograde ejaculation, gynecomastia, and amenorrhea. Next, the most visible and debilitating side effects; extrapyramidal symptoms (EPS), tardive dyskinesia, and neuroleptic malignant syndrome (NMS), are most often seen with conventional drugs. EPS involves pseudo-parkinsonism or tremors, shuffling gait, drooling and rigidity, akinesia or muscular weakness, akathisia or continuous restlessness and fidgeting, oculogyric crisis or uncontrolled rolling of the eyes, and dystonia or involuntary muscle movements. Bizarre facial and tongue movements, stiff neck, and difficulty swallowing are seen in tardive dyskinesia, and the symptoms of NMS are increased temperature, tachycardia, tachypnea, fluctuations in blood pressure, diaphoresis, decreasing level of consciousness, and muscle rigidity. This side effect is potentially fatal and has varying times of onset (Julien, 2001, Townsend, 2008 & Shives, 2008).

Obesity

Increased weight is detrimental for all populations as obesity is a premier risk factor for various serious and life-threatening conditions. Obesity is one of the most visible and prominent chronic public health concerns in western society and is characterized by abnormal and excessive fat accumulation that is directly related to impaired health. In the general population, when energy intake (calories) is greater than energy spending (exercise), weight gain occurs. Information published by Health Canada (2006) indicates that childhood overweight and obesity has tripled in the past 25 years and that today, two out of every three Canadian adults are overweight or obese. Recent changes in society add to the obesity epidemic as many jobs are less physically demanding than in the past, and there has been an increase in passive leisure activities.

In addition, changes in food consumption, such as larger portion sizes and greater availability of convenience foods, jointly contribute to this growing epidemic. The risks associated with overweight and obesity are commonly measured using the Body Mass Index (BMI) and Waist Circumference (WC) tools. BMI is a weight to height ratio that is used to evaluate the risks associated with being over or underweight. A BMI of less than 18.4 is considered underweight, 18.5-24.9 is normal, 25-29.9 is overweight and a BMI score of 30 or more indicates obesity (Nemesure, Wu, Hennis, & Leske, 2008). Unfortunately, BMI is an imperfect measure, as highly muscular, very lean, the young and the elderly are often misplaced on the BMI spectrum. WC is used to signify risks associated with abdominal obesity, where a measure of 88 cm or larger for women and 102 cm or larger for men is linked to health problems. Conditions related to overweight and obesity includes hypertension, high blood pressure, coronary artery disease, type II diabetes, stroke, gallbladder disease, osteoarthritis, sleep apnea and other respiratory issues, certain cancers (breast, colon, endometrial), and depression (Khader, Batieha, Ajlouni, El-Khateeb, & Ajlouni, 2008).

Information published by Health Canada (2006) indicates that in order to minimize weight gain and obesity, one must moderate the amount and type of food eaten, incorporate physical activity into daily life, seek guidance from health professionals if concerned about weight, and avoid fad diets. Common experience suggests that weight management is a challenge for most persons. Unfortunately, for those with severe mental illness, this struggle is compounded by psychotic symptoms, medication side effects and a general instability of their lives.

Weight and Schizophrenia

Medication induced weight gain is a well established side effect of the treatment of schizophrenia and is believed to be primarily associated with the use of newer antipsychotic

medicines. However, increased weight has been seen as early as the 1950's, as chlorpromazine was shown to induce substantial weight gain. Unfortunately, extrapyramidal symptoms and tardive dyskinesia were also common side effects with the typical antipsychotics of this era, overshadowing the significance of weight gain (Melzer & Fleischhacker, 2001).

Casey and Zorn (2001), in a published review of antipsychotic-induced weight gain, concluded that clozapine was the first atypical antipsychotic associated with significant adverse weight gain. They also conducted a ten week study that compared the weight gain propensity of clozapine and haloperidol. It showed that more weight was gained with clozapine (11.7lbs) versus haloperidol (1.5lbs). Also of note, the patients treated with clozapine continued to gain weight through to a one year follow-up appointment. In addition, their study indicated that clozapine and olanzapine are the greatest perpetrators of increased weight.

A second noteworthy study, by Kurzthaler and Lfeischhacker (2001), monitored weight gain associated with atypical antipsychotic use. They showed that 20% (6 of 30) of patients on olanzapine gained more than 10% of their baseline weight in the first ten weeks of treatment. The maximum weight increase seen in their study was 10.5kg in four weeks of antipsychotic use. In their study they also described reasons why medication induced weight gain occurs:

1. Food intake regulation – Most research is based on the serotonergic system as it plays a role in food intake regulation. Antagonism and down regulation of serotonin receptors is said to be associated with medication-induced appetite changes and altered satiety, leading to an increased caloric intake and weight gain.
2. Some antipsychotics have an increased affinity for histamine receptors, which causes increased sedation and less energy expenditure. Energy intake must therefore be decreased if weight gain is to be avoided. However, it is thought that

this adaptation is seldom accomplished, resulting in weight gain associated with the use of these medications.

3. Atypical antipsychotics with anticholinergic effects have side effects such as dry mouth, and it is believed that sugary drinks, high in calories, are used to quench this thirst, thereby increasing daily caloric intake and weight.
4. Endocrine effects – Leptin, a hormone associated with obesity, has serum levels directly related to BMI and body fat.

The biological mechanisms by which antipsychotic induced weight gain occurs were also examined by McIntyre, Mancini, and Basile (2001). They illustrated three factors that affect weight for patients treated with these drugs; serotonin antagonism alters satiety, increased histamine affinity causes both increased appetite, and decreased insulin sensitivity, due to elevated prolactin levels.

As previously mentioned, the atypical antipsychotic medications olanzapine and clozapine, are most associated with substantial weight gain, when compared to risperidone, quetiapine, and other novel antipsychotics. Recently, two new atypical antipsychotic medications; aripiprazole and ziprasidone, have been approved for use in Canada. These drugs are said to be weight neutral (McQuade, et al., 2004). Although no studies were found using ziprasidone, aripiprazole was used in a large, 26 week, multicentre, randomized, double-blind trial conducted in 2004 that looked at patients with schizophrenia who were in an acute relapse requiring hospitalization. Significant weight gain was defined as an increase of greater than or equal to seven percent of baseline weight. Three hundred and seventeen persons with schizophrenia were randomly assigned to two treatment groups; aripiprazole (N=156) and olanzapine (N=161). The study results indicated that 37% of those treated with olanzapine gained a significant amount of weight, defined as a 7% increase, as compared to only 14% in the aripiprazole treatment group.

By week 26, a mean weight gain of 4.23kg was seen with olanzapine, versus a mean weight *loss* of 1.37kg with aripiprazole (McQuade, et al.).

Weight gain may be the most obvious side effect of atypical antipsychotic medications, however metabolic syndrome and hyperglycemia are also serious complications experienced by persons with schizophrenia who are using these drugs. Heiskanen, Niskanen, Lyytikainen, Saarinen, and Hintikka (2003) studied metabolic syndrome in patients with schizophrenia. They described metabolic syndrome as an ‘enigmatic’ disorder that has five major features; disturbed glucose metabolism, disturbed insulin metabolism or impaired glucose tolerance, obesity, dyslipidemia, and hypertension. It is a risk factor for type II diabetes and cardiovascular disease. Their study group consisted of 35 outpatients with chronic schizophrenia who were being treated with antipsychotic medication. The participants were assessed for metabolic syndrome in order to establish prevalence of the illness in this population. Of the 35 participants, 37% were found to have metabolic syndrome.

Hyperglycemia associated with the use of atypical antipsychotics was summarized by Lindenmayer, Nathan, and Smith in their 2001 report. They concluded that a relationship exists between serum glucose levels and treatment with atypical antipsychotic medications. They indicated that this relationship is not dose dependent and is reversible with cessation of medication use. They outlined several reasons for which hyperglycemia is common in persons with schizophrenia; decreased sensitivity to insulin (independent of antipsychotic use), increased insulin resistance related to antipsychotic use, and effects of atypical antipsychotics on serotonin receptors, among others. An extensive literature base is available today on the topic of weight gain in persons with schizophrenia; however the subjective experience of weight for this population is much less researched.

A pilot study published in 2008 evaluated the accuracy of body image perception in persons with schizophrenia and was conducted by Loh, Meyer, and Leckband. They found that the participants were significantly more likely to be obese and to underestimate their body size than the mentally healthy population. This study also indicated that persons with schizophrenia, nevertheless, expressed a desire to engage in weight loss activities, a finding co-supported by Strassnig, Brar, and Ganguli's (2005) study on body weight perception and dieting practices in persons with schizophrenia living in the community. The latter concluded that overweight and obese females with schizophrenia wanted to lose weight and undertook extreme measures to reach this goal, including skipping meals or neglecting to eat entirely, diet pills, laxatives, and self-inflicted purging methods. Interestingly, Meyer's (2002) pilot study had a contradictory finding, in that obese patients with schizophrenia were aware of their weight, but not concerned about it and were unwilling to take action to remedy the problem. It should be noted that the sample in the latter study was drawn from an inpatient population in whom psychotic symptoms are usually more intense than among outpatients living in the community. As the evidence clearly indicates, weight management is difficult for the mentally ill population. However, in order to fully grasp the depth of their needs, their perception of weight and weight management is required.

The only article found describing weight among persons with schizophrenia from their perspectives was published in 2006 by Weissman, Moot, and Essock. They conducted focus groups to explore the experience and knowledge of weight gain with veterans having a diagnosis of schizophrenia or schizoaffective disorder. They found that weight was important to their participants and that they frequently monitored their weight. The two main reasons found for wanting to manage their weight were aesthetic purposes and to minimize medical complications.

Their results suggest that persons with schizophrenia are concerned about weight gain and are interested in weight management.

Age and Gender

There is little information available identifying whether or not gender and age affect the risk for medication-induced weight gain. Some evidence exists, however, indicating that atypical antipsychotic medication may induce greater weight gain in women than in men, as well as more severe weight gain in younger as opposed to older individuals. Unfortunately, few gender and age-focused studies are present in the literature, and research that has been conducted appears to provide conflicting conclusions (Gentile, 2006).

Lifestyle

Lifestyle factors such as low income, lack of exercise, and poor eating habits, associated with schizophrenia may aggravate the tendency for medication induced weight gain. Nutrition choices and exercise routines must therefore be balanced in order to avoid excess weight gain and obesity (Goldberg, 2003). Lifestyle, which plays an important role in the maintenance of a healthy weight, is often disorganized and unstable in people suffering from severe mental illness, aggravating the propensity to gain weight. This issue may be further compounded by symptom related factors such as low energy and psychomotor retardation that are associated with the disorder (Mauri et al., 2006). Furthermore, many persons with schizophrenia have low incomes or are unemployed due to the illness. Low socioeconomic status is associated with intake of low cost and high calorie foods; processed meals and 'junk foods', that facilitate poor nutrition and weight gain (Gentile, 2006). Specific lifestyle and illness factors of schizophrenia, contributing to weight gain, are not clearly examined in the literature and a greater understanding of what challenges are

faced by this population must be established in order to address the co-morbid risk of obesity and schizophrenia.

Interventions

Pharmacological agents, cognitive-behavioral therapy, and individual counseling have been used in an attempt to reduce or prevent weight gain among persons with schizophrenia who are taking atypical antipsychotic medication. A systematic review of interventions to reduce weight gain in schizophrenia was published in the Cochrane Database in 2008, which indicated the unsuccessful nature of current weight management techniques. This synthesis summarized the main treatment and maintenance articles regarding weight and schizophrenia. They concluded that modest weight loss can be achieved with select interventions, however few studies were used and those that were had small sample sizes and short durations of study. They also concluded that more rigorous weight management interventions are necessary (Faulkner, Cohn, & Remington, 2008).

Pharmacological management has involved the use of anorexic agents, diet pills, as well as others. These drugs work by suppressing appetite, regulating glucose, and decreasing gastric acid secretions thereby aiding the weight loss process (Graham, Gu, Lieberman, Harp, & Perkins, 2005, Henderson, 2005, Birt, 2003). Nonetheless, further knowledge is required as the exact mechanism of action for these drugs is unknown. Additionally, very little evidence exists to indicate the safety of these drugs for people with schizophrenia. In fact, these drugs have been shown to potentially exacerbate psychotic symptoms (Birt). These findings highlight the importance of developing non-pharmacological interventions for weight management that are possible and successful in this vulnerable population.

Cognitive-behavioral programs are often used as treatment options for overweight and obese persons in the general population. These structured interventions focus primarily on lifestyle modification involving the adaptation of healthier eating and physical activity. Long-term behavior change is influenced by the participants' motivation, self-evaluation, knowledge, beliefs, and ability to set goals and expectations (Teixeira et al., 2006). The 2005 Encyclopedia of Human Nutrition outlines three factors that must be present for an individual to partake in effective weight-loss practices: treatment is indicated, treatment is safe, and the person is ready and motivated to lose weight. As previously stated, illness characteristics of schizophrenia, such as decreased motivation and poor insight may impede the success of cognitive-behavioral programs adapted from the general population. It is therefore essential that weight loss interventions, designed specifically for this population, be created.

Excess body weight creates serious health risks among individuals with schizophrenia. However, evidence suggests that even moderate weight loss can lead to considerable health benefits such as less cardiac strain (Strassnig, Jaspreet, & Ganguli, 2005). Unfortunately, no nutrition guidelines exist for the management of weight gain in this population, but preliminary suggestions identified by Birt (2003) include drinking non-caloric or low caloric beverages, avoiding alcohol, moderating intake of simple carbohydrates, increasing consumption of fresh, non-starchy fruits and vegetable, and partaking in moderate physical activity as defined by 30 minutes of cardiovascular exercise 3 times per week. Although the necessity to control weight in persons with schizophrenia is recognized in the literature, currently no established weight loss interventions exist specifically for this population (Vreeland et al. 2003). Interventions which have been implemented have not been studied in randomized or controlled trials, and only a few pilot studies have elaborated on the feasibility of implementing a lifestyle modification intervention in this group of people. In addition to these problems, none of the programs identified in the literature are based on what individuals with schizophrenia recognize as helpful

measures to manage their weight, and only one qualitative study was found examining their subjective experience with weight management.

Individual counseling primarily at the onset of the symptoms of schizophrenia has been briefly discussed in the literature. Glassman (2002) suggests that screening be done preceding prescription of atypical antipsychotics and that risks versus benefits of all medications, for each individual, are considered a priori. The 2006 Compendium of Pharmaceuticals and Specialties (CPS) states that all people treated with second generation antipsychotics should be monitored for symptoms of altered metabolic state and weight gain. Contact with a dietician is also highly recommended in the literature, yet whether it is realistic to mandate continuous monitoring and dietician counsel is unclear, as access to services is often difficult for the mentally ill (O'Keefe et al., 2003). In order to effectively help these individuals attain optimal health, professionals must better understand how obesity and schizophrenia are related, the role of atypical antipsychotic medications, and what perceptions are currently held by these individuals regarding their weight management experience.

Schizophrenia and Qualitative Research

It is well noted in the literature that persons with schizophrenia have altered cognition as compared to the mentally healthy population. These cognitive deficits often include poor insight about the disease during periods when psychotic symptoms exacerbate (Zanello, Perrig, & Huguélet, 2006, Warman, Lysaker, & Martin, 2007, Ko, Yeh, Hsu, Chung, & Yen, 2006). However, self report data are often successfully collected in research studies involving persons with schizophrenia and evidence suggests that their narratives offer a good representation of their lived experience, provided intense positive symptoms are absent (Lysaker, France, Hunter, & Davis, 2005). A 2007 study by El-Mallakh used grounded theory to establish self-care behaviors

for persons with the co-morbidities of schizophrenia and diabetes. The findings of their study were derived from in-depth interviews and successfully described subjective facilitators and barriers to engaging in appropriate diabetic self-care. As illustrated, life experiences are best recounted by the person living in a particular situation and the cognitive changes present in persons with schizophrenia do not distort their ability to participate in qualitative research, nor their precision in relaying their own lived experiences.

Action must be taken in order to address the growing concern of obesity and resulting illnesses in people enduring the chronic mental disorder of schizophrenia. Although weight management is fundamentally an individual process involving lifestyle choices and self-motivation, little attention has been paid to the perceptions of persons with schizophrenia regarding weight gain. It is essential to understand the weight challenges facing them if medication induced weight gain is to be prevented or reduced through lifestyle choices and behavioral regimens. The study of weight, as seen from the perception of persons with schizophrenia, is an essential starting point needed if adequate weight management measures are to be a reality in the future.

Chapter 3

Methods

Methodology

To gain insight into how persons with schizophrenia perceive and understand their weight, a qualitative methodology was used. Qualitative research best explores the nature and reality of a phenomenon from the perspective of an individual or group (Kumar, 2005, Morse & Field, 1995). The ideal methodology to guide this type of investigation is constructivism, as it is designed to elicit an understanding of complex worlds of experience from the viewpoint of a target population and allows for the exploration of how these individuals independently and communally interpret their worlds (Schwandt, 1997).

The theoretical underpinnings of the constructivist paradigm entail a relativist ontology and a transactional or subjectivist epistemology. A relativist ontology is characterized by the assumption that there are multiple constructed realities; a transactional epistemology refers to the assumption that understanding of a given phenomenon is co-created by the interaction of the researcher and the participant in the study (Denzin & Lincoln, 2005). Researchers utilizing constructivism do not attempt to portray absolute truth, as this approach is founded on the assumption that no single objective reality exists (Lincoln & Guba, 1985). Therefore, I created a reconstruction of the collective constructed realities of the individuals living this common experience, as reality is “derived from community consensus regarding what is ‘real’, what is useful, and what has meaning” (Denzin & Lincoln, 2005, p.197).

When using constructivism, a hermeneutic and dialectical methodology is adopted (Denzin & Lincoln, 2005). Hermeneutics is the act of interpretation and an approach to data analysis that emphasizes that prior understanding of a phenomenon configures the interpretive

process (Appleton & King, 1997, Schwandt, 1997). Dialectical logic involves bringing forth conflicting thoughts and perspectives of a phenomenon of interest, by seeking out convergent and divergent ideas, from the study participants (Appleton & King, 1997, Denzin & Lincoln, 2005).

As a constructivist investigator I utilized the natural setting of the phenomenon and acted as the data collection instrument. The use of a human instrument allowed for the integration of tacit and propositional information, leading to a more comprehensive grasp of the research phenomenon (Appleton & King, 1997). The objective of the present study was therefore to create a reconstruction of the constructed experiences of weight for individuals with a diagnosis of schizophrenia.

Sampling

As the goal of qualitative research is a greater understanding of a phenomenon, purposeful sampling is often used in constructivist studies. In this method, participants are selected for the purpose of describing a phenomenon or situation that they have personally experienced (Streubert, Speziale & Carpenter, 2007). Recruitment was therefore focused and selection of participants was dependent on their ability to enhance the richness of information gathered and increase the probability that numerous multiple realities would be unveiled. Data collection and data analysis were conducted simultaneously and the emerging analysis drove sampling of participants and of data collected from participants. Four characteristics of sampling are described by Lincoln and Guba (1985) and were employed in this study. First, the sampling design was emergent with no a priori specification of sample size. Second, the sample was selected serially, meaning that each participant was chosen only after the previous participant had been interviewed and their data had been analyzed. Participants were recruited for their ability to extend information already attained, their ability to provide contrasting information, and their ability to fill a knowledge gap. Thirdly, I the researcher constructed preliminary understandings

regarding the phenomena, so that sampling could be adjusted to focus on these areas. Finally, selection of participants was continued until there was saturation of data and no new information from participants altered the reconstruction being developed. Both male and female participants were recruited for the study, although an even representation was not attained. Participants who identified themselves as underweight, normal weight and overweight were included in the sample, as well as persons at varying points of care. Participants' recovery stage ranged from newly discharged, to active day hospital members, to infrequently followed outpatients. The end number of recruited participants for the present study was 18, 15 of whom were male and three female.

The 18 participants recruited for this study met four inclusion criteria: 1) Able to speak and read English, 2) eighteen years or older, 3) DSM IV diagnosis of schizophrenia or schizoaffective disorder, and 4) not acutely psychotic at time of interview.

Procedure

Recruitment procedure

Participants were recruited from a psychiatric outpatient clinic at a hospital in Ottawa, Ontario. Recruitment was a collaborative effort between the nursing staff and me, in which I participated in several day hospital education groups, with the consent of the clients and outpatient department, in order to familiarize myself with the clients and tell them about the study. I provided the outpatient nurse with inclusion and exclusion criteria for the study and he helped to identify members who were appropriate for the study. These persons were then approached by the nurse and provided with a brief summary of the study and asked if they were interested in participating. If the response was yes, their contact information was provided to me and I then approached the potential participant, as soon as possible in person or by telephone, and

provided a more complete description of the study process. If they agreed to participate, they signed a consent form (refer to appendix A), received a copy, and an initial interview was scheduled at the convenience of both the participant and me.

Data collection

A constructivist inquirer utilizes qualitative methods of data collection. In-depth interviews and documentary evidence are considered flexible strategies for gathering data in a natural setting (Appleton & King, 1997). The present study engaged in the following data collection strategies: Unstructured interviews and medical record review.

Unstructured interviews are typically used in constructivist research. They provide greater breadth of information than other types of interviews (Denzin & Lincoln, 2005) and allow for a thick description and clarification of the experience of interest, while engaging the participant in a peer-like discussion (Swanson, 1986, Lincoln & Guba, 1985). The interviews were held in an office at the outpatient clinic in a hospital in Ottawa, Ontario, at a pre-specified time. The participants were asked open-ended questions regarding their mental illness and their experience with their weight and lifestyle. They were asked to divulge personal information regarding nutrition habits, income, social support, and health beliefs. The interviews lasted an average of 50 minutes and were done in single sessions, although each participant was offered the option of splitting the sessions depending on his or her comfort and convenience. Participants were given the opportunity to ask questions at any time. The interviews were audio taped, with the permission of the participant, by two tape recorders and written notes were taken after the interview, as well as during the review of the audio tapes. The tapes were transcribed verbatim and will be stored in a locked file cabinet, with a numeric code as the sole identifier, for a period of 5 years following the completion of the Master's thesis. The transcriptions have been removed of all identifying information, save a numeric code.

The participant's medical records were used to access demographic information including age, gender, onset of schizophrenia, co-morbidities, medication history, and current weight (refer to appendix B).

Data Analysis Strategy

Data analysis in a constructivist inquiry is an emergent, inductive, and interpretive process. As noted, data collection and analysis occurred concurrently, using the methods of unitizing, categorizing, and constant comparison as outlined by Lincoln and Guba (1985). As each interview took place, the data obtained from the interview was coded in a process referred to as unitizing; the assignment of a precise description to the piece of information that is capable of being independently interpreted. After the identification of units, I began the formation of categories. Categorizing is a process by which groupings of previously unitized data are created in order to "provide descriptive and inferential information about the context or setting from which the units were derived" (Lincoln & Guba, 1985, p. 203). Specific quotes from the transcripts were linked to the categories using a colour coding schema.

Constant comparison is a method of data analysis that was first proposed by Glaser and Strauss (1967) as part of their grounded theory methodology. In this study, constant comparison was used in the analysis of data. This approach features the assignment and reassignment of data to units and units to categories, and every piece of data was continuously compared with every other piece of data. This back and forth assessment allowed for both refinement of units and categories in an ongoing manner. Throughout this process, memo writing occurred in order to discover properties inherent in each piece of information and in each category. The memo writing involved taking notes about all categories so that a developmental history was created from the set of memos, and an inclusive, practical, and universally applicable definition was defined for each category of units (Glaser & Strauss, 1967). This process continued until all units of data

were coded and classified and no new categories emerged, thus data saturation was reached (Lincoln & Guba, 1985).

Trustworthiness

Lincoln and Guba's (1985) four criteria of credibility, dependability, confirmability, and transferability were followed to ensure the rigor of this study. Credibility, established by implementing activities that increased the probability that credible findings were found, was accomplished by prolonged exposure in the field, as well as the use of member checks to review the final reconstruction. Time was spent, prior to recruitment, at the day hospital, in order to establish a rapport with the potential participants and to extend information regarding the study. Member checks were done with two participants of the study. They were met separately at a local coffee shop and provided an outline of the themes found and had an opportunity to clarify and ask questions of the final reconstruction. Although no new information was found, the participants reiterated the influence of weight gain on possible medication non compliance, as well as the negative effect and frustration felt with the inability to adequately manage their weight. Dependability is a criterion that was met once the findings were deemed credible by the member checks (Streubert Speziale & Carpenter, 2007) and is based on how well the reconstruction reflects their reality. Here, verbatim quotations from the participants are interspersed throughout the findings. This enhances dependability as it shows that their words support the construction revealed by the researcher. Confirmability was used as a measure of evaluating the research process. This criterion was met by executing high quality interviews, having only one interviewer, by memo writing, and by keeping a detailed audit trail of the study. Finally, transferability, the probability that the reconstruction will have meaning to other persons with schizophrenia living in a similar situation, is enhanced by giving a thick description of the population and of the experience of weight as it was perceived by them.

Ethics

Informed consent was obtained from each participating individual and consent forms were signed, dated, and witnessed. The original copy was kept in a separate locked study file and a second copy was provided to each participant. The consent form included the following study aspects; goal of the study, specific nature of participation throughout the study period, risks and benefits associated with participating, and contact information in case of concerns (refer to appendix A).

Participants recruited for this study were stable, or only exhibiting mild psychosis. If at the time of the interview, it was felt that the participant was experiencing acute symptoms of their mental illness, it was arranged that I would contact the day hospital nurse as soon as possible for appropriate follow-up. If a psychiatric emergency was to occur, the participant was to be referred directly to the nearest acute care hospital, at which I am an employee.

Although no emergency situations occurred, one participant, who's data was not included into the findings of this study, was experiencing obvious signs of psychosis that were evident within the first few minutes of the interview. Upon this realization, I terminated the interview and asked the participant if he would mind coming with me to see the day hospital nurse. Appropriate follow-up ensued with the help of this nurse.

In the initial interviews participants asked questions related to the treatment of their illness. I felt it was important to address their questions, but did not want to sacrifice the integrity of data collection, so would answer briefly and return to the question after the interview. Once this trend became apparent to me, I began informing the participants prior to beginning the interview that if they had questions unrelated to the study topic, or if they wished to discuss other matters, that I would be happy to speak with them after the completion of the interview. If I was

unable to adequately address their needs, I referred them to the day hospital nurse for further discussion. Fortunately, including the case discussed above, only three participants required this type of follow-up. One participant had concerns regarding his medications since his psychiatrist had been recently decreased his dosages, while the other was questioning his current level of alcohol consumption. In both instances, the day hospital nurse was readily available and took immediate action in addressing their concerns.

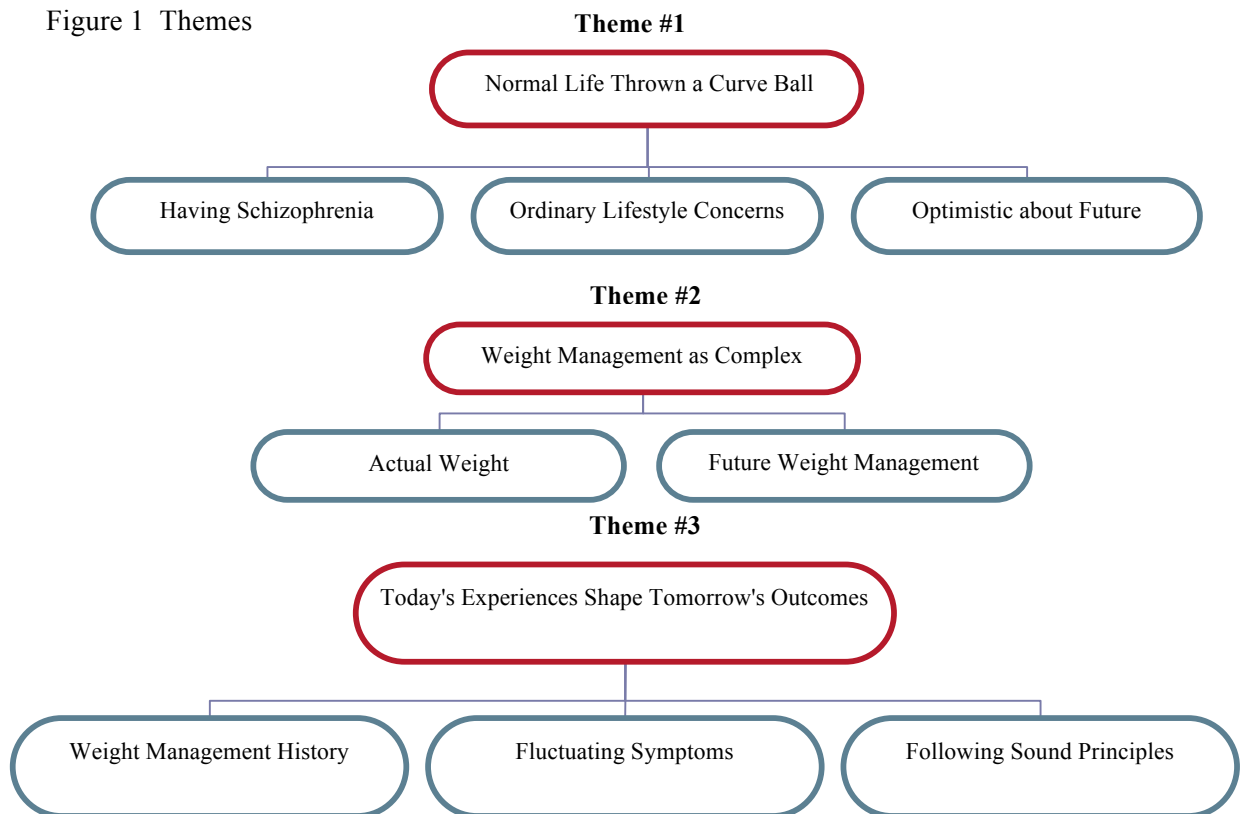
Ethics approval was obtained from both the Queen's Research Ethics Board, as well as the Research Ethics Board at the participating hospital.

Chapter 4

Findings

There was a great deal of interest among the outpatient clients regarding this study. Recruitment efforts were tremendously successful. All approached clients agreed to participate and only one was refused due to active psychotic symptoms. The phenomena of weight and lifestyle are described with the help of three themes; a normal life thrown a curve ball, weight management as complex and today's experiences shape tomorrow's outcomes. As figure 1 illustrates, each theme has a number of sub-themes with the first set consisting of having schizophrenia, ordinary lifestyle concerns, and optimistic about future; the second being actual weight and future weight management, and the third including weight management history, fluctuating symptoms, and following sound principles.

Figure 1 Themes



In order to best reconstruct their story, verbatim quotations are laced throughout the descriptive results with references in parentheses to the case number of the participant being quoted. Prior to the description of their experience of weight, a depiction of socio-demographic, medical, and weight related characteristics of the participants is provided to lay the foundation for an understanding of their perspectives regarding weight and weight management.

Description of Participants

Of the 18 participants, 15 were male and three female. Only two participants were in an intimate relationship, one being married. The average age was 45 years and varied from 31 to 64 years. Three participants held part-time jobs while the rest were unemployed. All 18 relied on Ontario Disability Support Program (ODSP) for their primary income. Twelve participants lived in their own home either alone or with family/roommates; while the remaining six resided in supportive housing/group homes.

Ten participants had a DSM IV-TR, axis one, diagnosis of schizophrenia, with the remaining eight having a diagnosis of schizoaffective disorder. Six suffered from an additional psychiatric illness, most commonly anxiety. Co-morbid medical issues were seen in 14 of the 18 participants, and many suffered from multiple physical conditions including diabetes, hypertension, high cholesterol, arthritis, and others.

Psychotropic medications were taken by all participants, with every participant taking atypical antipsychotic drugs. Seven were also taking conventional antipsychotics and three had taken them in the past. Mood stabilizers were used by seven participants, and nine more reported taking further pills, most often for medical issues (see table 1). Only six of the 18 participants were smokers, with one actively using nicotine replacement therapy.

Table 1 Current Medications Prescribed for Each Participant

Medication-Atypical	Medication-Conventional	Medication-Mood Stabilizer	Medication-Other
Seroquel	None	Effexor	None
Zuclopenthixol Deconate IM	None	Epival	Cogentin
Seroquel	None	None	None
Zyprexa, Seroquel	Flupenthixol Depot	None	None
Seroquel, Risperidone, Risperidal Consta IM	Clozapine - past	None	None
Seroquel	Clozapine	None	Procyclidine
Riperdal Consta IM	Clozapine - past	Lithium, Epival, Topamax	Ditropan, Metformin, Celexa, Ativan
Risperdal Consta, Seroquel	None	Epival	None
Fluvoxamine, Zyprexa	None	None	Cogentin, Ranitidine, Ativan, Colace
Zyprexa, Seroquel	Haldol	None	None
Seroquel, zyprexa, risperidone	Clozapine	None	None
Risperdal Consta, Seroquel	None	None	None
Risperidal, Seroquel	Nozinan -past	None	Clonazepam
Risperdal Consta	None	Epival	Celexa, Cogentin
Risperdal Consta	Pipothiazine Palmitate	None	Cogentin
Risperdal Consta	None	Epival	Cogentin, Ativan
Risperidone, seroquel, aripriprazole	Flupenthixol Depot	None	Ativan
Zyprexa	Flupenthixol Depot	Valproic acid	None

Fourteen of the 18 participants reported that weight was a concern for them; however upon investigator observation, all participants but one appeared to be carrying moderate to large amounts of excess body fat as evidenced by an obviously disproportioned waist to hip ratio. The average actual weight for the study participants was 93.97kg (97.79kg-male, 90.15kg-female), ranging from 68.18kg to 181.36kg.. Thirteen of the 18 participants stated that they wanted, however, to lose weight and the average desired weight loss was 20.96kg (20.70kg-male, 21.21kg-female), with a range from 0.00kg to 56.36kg. One participants desired to gain weight as he felt he was substantially underweight, which appeared to be accurate (See table 2).

Table 2 Current Weight and Weight Concerns of Each Participant

Is Weight a Concern?	Current Weight (kg)	Self-Identified Ideal Weight (kg)	Desired Weight Loss(kg)	Appears to be a healthy weight
Yes	111.36	68.18	43.18	No
No	84.09	84.09	0.00	No
Yes	95.45	84.09	11.36	No
Yes	68.18	86.36	18.18 (gain)	No
Yes	79.55	79.55	0.00	No
Yes	86.36	63.64	22.73	No
Yes	181.36	125.00	56.36	No
Yes	109.55	90.91	18.36	No
Yes	105.55	90.91	14.55	No
No	106.82	106.82	0.00	No
Yes	77.27	52.27	25.00	No
Yes	90.91	77.27	13.64	No
Yes	106.82	90.91	15.91	No
Yes	80.91	79.55	1.36	Yes
Yes	90.91	90.91	0.00	No
Yes	97.73	90.91	6.82	No
No	75.91	75.91	0.00	No
No	88.64	88.86	0.00	No

Overview of Findings

The participants of this study described relatively normal childhood, adolescent, and young adult development. However, their normal existence was interrupted by an unexpected challenge; the onset and diagnosis of schizophrenia. They described how their life was thrown into upheaval, and how schizophrenia became the forefront of their life while ill. Fortunately,

with the initiation of treatment, the participants reported that their illnesses slowly stabilized. This stability allowed for a certain re-connection to their life and society. Participants, however, were then faced with dual challenges; those imposed by everyday life, and a life-long management of their symptoms of schizophrenia. Interestingly, most seemed to have or stated they had come to terms with their diagnosis and understood its permanent impact on their lives. This acceptance was integral to their ability to envision a future of mental, emotional, physical, and financial health. Though their reality was shaped by the underlying characteristics of schizophrenia, they reported being able to take this into consideration, and aspired to achieve the same type of goals one would expect among the mentally well population. The goal of attaining a healthy weight was paramount for the participants of the study, and is an example of a common aim experienced by both mentally well and mentally ill persons. Participants identified weight management as challenging in itself, without the added barrier of medication-induced weight gain; an obstacle imposed on them by their illness. As a result, they perceived their weight management as complex, and believed that their ability to adequately manage their weight, in the future, depends on both individual strategies and support. Individual strategies that were described as beneficial were healthy eating and exercise, and the support received included both informational and social or professional. Even though participants identified these key ingredients for successful weight management, they re-iterated the complexity of the phenomenon and explained that a long-term commitment was involved, often with many small successes and failures along the way. Past experiences were also felt to shape weight realities in the future. Furthermore, as this population deals with a diagnosis of schizophrenia that involves treatment shown to further complicate weight management, the participants felt that a combination of their past experiences with weight and their past experiences with fluctuating symptoms and relapses would influence their future weight management. Despite the chaos schizophrenia imposed on their lives and their view that

weight management is complex, participants were optimistic for their future and believed that applying sound weight management principles in the present, would allow them to achieve a higher level of health and better weight management in the future.

Normal Life Thrown a Curve Ball

During the interviews, participants provided a thick description of their lives with schizophrenia, the major context for them in their experiences with weight and weight management. From their perspectives, their hopes, dreams, and expectations are and have been essentially normal. Life, however, threw them a curve ball in the form of an unpredictable, difficult illness that tends to be poorly understood by friends and family. Here, a reconstruction of their experience with schizophrenia, as well as their lifestyle, is presented with the help of three subthemes; Having Schizophrenia, Ordinary Lifestyle concerns, and Optimistic Expectations for the Future.

Having Schizophrenia

Schizophrenia is classified as a major mental illness and has the ability to greatly alter a life. When asked to describe the experience of having a diagnosis of schizophrenia, all 18 participants eagerly testified to the negative impact on their lives; “It’s horrible, it’s really horrible. I used to have really high goals for myself, and you know I have enough trouble right now doing my laundry in one day (6)”. Shattered ambitions, frustration with symptoms and treatment, as well as the necessity to continuously adapt to the elements of the illness, “I’ve worked around it and done things and I work around it all the time (17)”, were the predominant complaints voiced by the participants. Several noted, though, that as their medication regimen was refined and tailored to their needs, life with schizophrenia had become easier, “... she put me

on the Consta and it changed my whole life. I'm not on a mood stabilizer now so I'm really healthier, probably the healthiest I've ever been... (14)". Each illness narrative had a unique plot; however the underlying tale summarized a normal life thrown a curveball. For most, the challenge of adequately functioning in society, their difficulties in maintaining relationships, and the stigma of their illness, lead to the social isolation so often endured by those with pervasive mental illness.

Participants described the social difficulties they had experienced because of their symptoms in considerable detail. One noted, for instance:

... I used to have trouble at work because I'd be in people's houses and I'd be talking to myself and I'd be laughing and laughing and laughing and what's going on with him because I'd be in the corner laughing hammering in smooth nails or something like that and I'd be laughing my ass off and no one would know why (4).

He continued saying: "...I was always busy in my mind by myself, I was having a hard time going to bars and socializing because I was always talking to someone else in my head (4)".

Many were well aware of the negative impact of their behaviour on others. As one participant said "I've done things that are embarrassing that I wish I had never done, the type of worry I put my family through, seeing my life kind of not materialize into what I had hoped it would be (11)". Participants noted that the chaos inflicted by the onset of schizophrenia is often the greatest strain on family and friends, "Well it was really tough on them when I was in the hospital a lot in my twenties. I was in and out of the hospital in my twenties every two to three months and it was tough on them because they heard a lot

of the bad things that were happening or that I was doing to myself or that were happening to me (10)".

Participants noted that the stigma associated with schizophrenia was not lost on their families and friends, who sometimes saw them as "violent or weird (8)". As one explained, "Um, a lot of my friends are stand offish when I tell them about my schizophrenia because they know about my past and the things that I've done (4)". Their illness was also met with a lack of acceptance, "My brother on the hand is more skeptical, he doesn't believe that I have an illness, he's sort of in denial (8)", and halted communication so that "It doesn't get talked about all that much (6)". Unfortunately, this lack of understanding left many participants with the sense that they suffered without the support of loved ones, "It's kind of shit. I suffered and they don't give a damn. (12)". The majority of the participants reported less than satisfactory relationships with pre-illness friends and family, creating a social network largely reliant on professionals, "I'm basically by myself except for my doctors and (nurse) and the people at ODSP office, they'll talk to me when I need to. (17)".

Although the reality of "if they know I had schizophrenia then they wouldn't care about me (11)" existed for the vast majority of the participants, some indicated that improvements in social relations can occur; "For the longest time my mom wouldn't talk to me because she didn't understand the illness, but she's come around since then and we're working on our relationship again. (3)". For those that have salvaged relationships, education and "...research to learn more about the illness so she has come to terms with it... (18)", appear to be key ingredients for the change. The desire to repair and acquire social contacts is important to those with schizophrenia and although bonds between fellow clients offer companionship, many participants craved intimate connections as well; "I don't have that great of a support system, like I don't have a

girlfriend or anything, and I'd really like one. (8)". Though the inability to empathize with someone suffering from schizophrenia can cause family and friends to shy away from the individual, participants adamantly reported the importance of relationships with others, as one middle-aged male noted, for instance, that "...to be single and have friends. Girlfriends, female and male friends (12)" was greatly important to him.

Ordinary Lifestyle Concerns

With any chronic illness, life includes challenges atop the normal stresses of day to day existence. Nevertheless, the participants of this study perceived their lifestyle concerns as relatively ordinary. They focused on managing the daily components of eating right, exercising, sleep/energy, and money. These tasks are described below.

Eating right. Participants identified food choices as an important lifestyle element they were concerned about. One stressed this saying "Just eat the right things, that's the most important thing (14)". The daily activities of cooking and grocery shopping, if done independently, allows for considerable autonomy over the food eaten by an individual. Ten of the 18 participants reported having ownership over these tasks. The remaining eight participants received their food and groceries with the aid of another. The cooking, for the latter group, was done jointly by themselves and other group home or family members, or prepared by group home chefs or the meals on wheels program. Groceries were provided to a few of the group homes in which the participants resided, however almost all participants indicated that they were responsible for their own snacks. The food bank and donations were often utilized.

While they believed in eating the right food, some felt their diet included fast foods and shouldn't, others were concerned that their diet included too much junk food and canned food. For one, eating the right food was a vegetarian diet which he followed. Ingestion of foods at

particular times of the day, as well as the addition or avoidance of certain elements in their diet, were also techniques used by many of the participants to maintain what they considered to be proper nutrition. Many participants, for instance, described abiding by an eating schedule in which three patterns in particular were showcased; eating five to six small meals per day, eating three to four moderate meals per day, and eating one large meal with the option of an additional snack if possible.

Exercising. Exercise is an integral component in weight management, a fact well known to the participants of this study. A hundred percent of the group indicated that they want to, or know they should, engage in physical activity “Right now as it stands, the only exercise I’m getting is with the walking, which is good, but I’d like to maybe include a little bit more with that. Maybe another 20 (minutes) to half an hour a day of some type of cardio and maybe some weights with it (3)”. Although the actual percentage of persons who said they actively incorporate regular exercise into their life is slightly lower, only two participants reported no structured exercise regime, and a sole participant described himself as non-active. Of those who were active, most partook in low intensity exercise in the form of walking, with a few who described high intensity work-outs, multiple times per week, involving weight resistant training and more vigorous forms of cardiovascular exertion. Interestingly, if participants described their exercise efforts as limited, they attributed this to three common issues; medication side effects, physical ailments, and medication-induced lack of motivation.

Sleep and energy. Participants described their everyday life as affected either by their sleep patterns, energy levels or both. Sleeping habits vary widely among individuals, as was the case among the study participants. Many factors affecting their sleep, however, were affected by their illness, the most pervasive of these described were medications and medication scheduling.

“...the medication I’m on, they knock you out a bit” was a common thread shared by many of the study participants, along with schizophrenia-related side effects such as fatigue, insomnia, and emotional factors; as one participant noted “negativity, I don’t feel comfortable with myself... I don’t like being by myself in my room to fall asleep. (11)”. Grogginess or tiredness felt in the morning by many of the participants was another illness related issue that had repercussions on their daily functioning. One participant who felt “Very groggy, oh very groggy, (it’s) the hardest time of the day for me (9)” explained that he “really struggles with that and I think if it wasn’t for that I’d have more confidence in myself to manage my day (9)”. Others described experiencing periods of diminished energy in the morning, afternoon, or throughout the day. For instance, one participant who reported difficulty accomplishing tasks in the morning stated; “It takes me a little while to get going in the morning. It normally takes me a couple hours to get going. (18)”. Nevertheless, energy levels were perceived to be stable throughout the day among 11 participants.

Managing money. The ability to adequately manage finances and create a budget that allows for flexibility was a skill sought by most of the participants. With Ontario Disability Support Program (ODSP) as the primary income for all participants, money was limited. Help with budgeting from professionals and relatives eased the strain for some participants, as supplementary money for living expenses was received by a few fortunate persons, and monetary allowances dispensed to others. Reliance on free resources such as the hospital gym and the food bank to augment their financial situation was described, and budget techniques like keeping a ledger, tracking monthly spending, and allotting certain amounts of cash for specific purposes were utilized. The importance of making appropriate and educated choices when spending money was stressed by most of the study participants and one explained this, saying the following:

What we do is we look at the cost and see if we can find something that is a better buy and see if it's worth it, if it's a better buy and it's better for us we'll buy it. If it's slightly more expensive, but it's better for us we might buy it anyways. But we take, we try to ah, understand the relationship of eating well and good budgeting and try to make a decision to see if we can afford it. That's another thing to see if it's realistic for us to be able to purchase something that is good for us but that is according to our budget (9).

Although 17 of the 18 participants reported a manageable budget involving only a small amount of debt, those who smoked indicated a further strain on their resources, as one ex-substance user demonstrated "I get sixty-four dollars from them and sometimes I have to use a little more money to eat healthy, but I don't smoke anymore and I don't drink anymore so I usually have lots of money (14)".

Optimistic about Future

Despite the difficulties their illness had imposed on their lives, participants were surprisingly hopeful when looking ahead. When asked to outline where they realistically see themselves in two years, the study participants projected a more normal life within seven categories; education/work, illness, relationship, weight, lifestyle, and personal/emotional. Participants foresaw themselves as working, paid professionals, holding both part-time and full-time employment, and believed that they would be furthering their education "Well, realistically, I would like to have a part-time job and maybe go to school part-time (11)". Forecasted, were improvements in mental health involving either reduction of or maintained management of symptoms. For instance, one projected a reduction in the 'dysphoria' he experienced, saying "maybe not eliminate it (dysphoria), but diminish it so that it isn't such a focus in my life and

concentration (5)". Others expected new relationships, "... I'm going to meet a man, a good man. He doesn't have to be handsome or anything, just nice and faithful and honest. (13)". They also anticipated lifestyle improvements including new apartments, returning to old hobbies, and attaining a healthy weight. Many participants were hopeful that in two years they would have accomplished as much as possible in improving their lives and a renewed confidence in themselves as productive community members.

Interestingly when asked to describe their goals for themselves, the same seven categories emerged. Work and education goals were articulated by many participants, as well as a desired improvement in their illness course, a reduction or elimination of symptoms, and the avoidance of decompensations and hospitalizations. New and satisfying relationships were sought by participants, and many aspired to improve their lifestyle by eating a better diet, attaining a healthier weight, maintaining an exercise regime, staying sober, and having an income. They prioritized their goals and identified both short and long-term objectives, "Well, you need to prioritize them first, make a list, sit down and then prioritize them on a scale from one to ten. Ok, like, how important is this goal to me? Somewhat? Very? Very very, very much? Or you know and sort of like make a little questionnaire and at the end you can sit down and tally it up and you can see the results of which goals are the most important to you at the end of the test or whatever you are doing for yourself (3)". They also specified, that their goals need to be realistic and "grounded on reality"... (9)".

Weight Management as Complex

Participants experienced weight management as a complex phenomenon. This complexity applied both to their understandings of their actual weight and their perceptions of their future weight management. Each of these aspects are discussed here.

Actual Weight

As noted in the literature review, it is well documented that atypical antipsychotic medications are associated with weight gain. All participants described their pre-illness weight as normal, healthy, or only slightly overweight, with the exception of two who suffered from anorexia and one who has battled lifelong obesity. Most believed they had gained weight following the initiation of antipsychotic medications or while in hospital, and also attributed spikes in weight to acute phases of their illness. Three participants described the following sequences;

...he put me on some heavy amounts of Seroquel which in turn made me gain quite a bit of weight (3).

Um, well I had taken a particular med, Clozapine, for a short bit, couple of weeks or so, and it just made my appetite increase a lot and I put on about forty pounds, I'd never been that weight in my whole life (1).

Well, I went on medication when I was, I was first put on meds when I was twenty-four years old and I was about two-hundred twelve pounds and now I'm forty-one and I weigh three-hundred ninety-four pounds (7).

Thus, medications were identified as posing a tremendous influence on current weight, and participants described medication-related cravings, decreased motivation and coordination, hunger, sedation, etc... as added barriers to be overcome if they are to maintain a healthy weight.

However, the participants also identified many other factors as contributing to their current weight; eating habits, exercise routines, medications, finances, smoking, and their diet and exercise education/knowledge. Skipping meals, succumbing to cravings, and eating whenever hungry were the prime poor eating habits noted by participants. Healthy habits were said to

counter-influence their weight, and were described as eating foods from all food groups, avoiding fats and sugars, and dividing meals into smaller portions. From their perspectives, the interplay of negative and positive eating habits constituted a dietary influence over their current weight. They also identified rigorous exercise, and the lack thereof, as contributing to their current weight, along with a host of other factors such as injuries, arthritis, and lack of energy. Finances played a role in their perception of their current weight as well, as they stated that more money is required to buy healthy, non-processed foods. Finally, among the smokers, the nicotine in cigarettes was also identified as an influence on weight by stimulating their metabolism, therefore burning extra calories at rest.

Although participants expressed a gradient of reactions to their current weight including terrible, concerned, improving, comfortable, and good, the majority stated that they were “not very happy with it (6)” and wanted “to lose a lot of weight (9)”. For the few who felt comfortable or good about their weight, its stability appeared to be the major reason. One person noted, for instance, “I’ve been able to manage my weight; I don’t think I have a problem with my weight, I’ve stayed the same for two to three years now (10)”.

The concerns expressed about their current weight touched on three main categories; weight-related illnesses, esthetics, and emotional distress. High cholesterol, type 2 diabetes, aches and pains, and a history of such illnesses weighed heavily on the minds of some of the participants; especially those who were overweight “Well, I don’t want to get diabetes or have a heart attack or a stroke(8)”. Esthetically, the inability to wear choice clothing, a feeling of unattractiveness, and a general sense of “Well it makes me feel embarrassed... the way I look and the way people look at me (7)” were described. Lowered self-esteem, embarrassment, and insecurity were emotions identified in conjunction with the participants’ unmanaged weight.

Future Weight Management

As noted earlier, most had plans to alter their actual weight, and had identified a combination of weight management strategies to use. Since they perceived weight to be a complex phenomenon, they identified the need to use individual strategies combined with informational support and various types of social support systems.

Certain individual strategies were believed to be particularly beneficial in achieving weight loss such as “Curb(ing) my eating habits a bit (16)”, reducing fast foods and junk foods, eating meals more slowly, ensuring sufficient hydration, making better food choices, and having a consistent diet. Exercise, also an individual strategy, was likewise identified as important. Habits like “...more things like walking. A lot more. Instead of taking a bus somewhere, I’d walk (6)” and enhancing cardio exercise with weight training, were being planned by the study participants.

Many participants weighed the benefits of their psychiatric medications against the side effect of increased weight. Although most accepted the need for psychotropic medications in order to live relatively normal lives, they looked for strategies to modify their current medication regime in some way. One frustrated participant, for instance, stated:

Since I’ve started the injections, I’ve put on fat content, so it’s getting to be conscious. I’d like to be slim, trim, and as muscular as I can, and since I’ve started the injections, I’ve started to lose my strength... I have less energy to be active and less energy to eat properly... Hopefully I’ll be off the injections, in fact I’m speaking with the doctor and I’m hoping to be able to convince him to take me off the injections and put me back on pill form again (15).

This participant was on a Community Treatment Order and therefore unable to make medication decisions autonomously but a potentially problematic individual strategy was identified by a few

participants who wondered if discontinuing their medications altogether would help them achieve an optimal weight. One asked for instance, “Do you think if I go off the olanzapine I’ll lose weight? (7)”.

Given the complexity the study participants saw in managing weight, informational support was considered to be an important and necessary aid for them. Participants stated that in order to accomplish weight change goals and be successful in future endeavors, a person must feel equipped with the essential tools required to embark upon their objectives. The importance of receiving an adequate education about weight management was stressed numerous times in relation to their perceived ability to successfully reach and maintain weight goals. For instance, a middle-aged man explained: “Exercise AND diet and knowing your medication and how much you have to work out to make up for your medication... I’m taking olanzapine everyday, so I know that I have to work out more than I normally would just to maintain a healthy weight (10)”. Although most participants indicated that they had received weight-related education in the past, many felt further information, or reinforcement of past education, would be beneficial for their future weight management, “...learning how to eat nutritiously. We talked a lot about the food we eat, what’s good and what’s bad and what makes a difference and what doesn’t, and that helped (9)”. Generally, they sought a better understanding of how to choose, shop for, prepare, and ingest foods, and what role medication, or the discontinuation thereof, plays on weight. More specifically, many participants felt it would be constructive to have an outline of tips and techniques used by others to achieve their weight goals, thereby drawing on the experiences of their peers.

More sophisticated forms of information support were used by some, as a small portion of the participants favored accessing information through the internet or books. “I would go onto the web or something, there’s a lot you can do (8)”.

Sources of social support identified by participants to assist future weight management reflected the nature of their actual support systems. Although some reported keeping regular contact with selected friends, the vast majority of their day was spent at the hospital, with healthcare professionals in other settings, socializing with fellow clients, or alone. Four distinct categories of people were identified as sources of support in their lives: Health care professionals, peers with mental illness, family caretakers, and for some, those intertwined in their particular altered thought processes. For instance, one said of the support he felt from healthcare professionals “My symptoms are completely under control, I have no symptoms. Do you think Dr. L. (his psychiatrist) would have taken me off the clozapine if I still had symptoms? Every now and then I get suspicious, a little paranoid, but Dr. L. says that everyone gets like that... I wouldn’t go to the (emergency department), I’d wait until Monday and come see Dr. L. and tell him what’s going on (7)”. Another explained how he was supported by his peers “I have a friend (mental health consumer) who also comes over and he’s really good at computers, so he helps me and I watch and learn (3)”. A young man described the support he received from a family caretaker, his girlfriend, stating:

She has seen me at my worst with all my symptoms and stuff and she has had to do research to learn more about the illness so she has come to terms with it and knows that as long as I take my medication that I am stable, so she is always checking in with me to make sure I’m taking my medications. She’s a good support for me (18)..

All the participants felt professional experts, the first category of social support, were the most important for assistance with weight management issues. General practitioners, psychiatrists, and other healthcare professionals were mentioned, as one identified “a nutritionist or a weight loss expert... (8)”. Formal professional support programs, however, were also identified by some. The Healthy Lifestyles Program, for example, run by a physician is designed to offer obese patients education regarding nutrition, healthy food choices, exercise, and the effects of obesity. Some were already part of the program and described how it motivated them and provided a kick-start to weight loss. Furthermore, discussion among group members about successes and failures created a camaraderie and team spirit they valued. The Day Hospital that some attended also offered education and support groups tailored to unique topics, as well as occasional contact with a ‘guest expert’ in weight management. The weekly schedule helped maintain motivation and reinforced material learnt previously. Thirdly, one on ones with a dietician were utilized by some participants in an attempt to regulate their diets. These were weekly sessions for a period of three to four months that involved education and techniques such as diary writing.

The second type of support category they turned to, to alter their current weight, was peers who have lived similar experiences. As one explained, “I found it helpful to hear about other patients’ experiences and how they went about losing weight (11)” One participant was involved in Overeaters Anonymous. The program uses the twelve steps outlined in Alcoholics Anonymous including sponsors and meeting, with the addition of menu planning. This participant described tremendous success, maintained long-term, as contact with the program is continued indefinitely or until no longer required by the member.

Although there was consensus among participants that a lack of support was detrimental to weight management initiatives, they differed in whether they believed group support or one to one support was more helpful. Those who preferred group support reported that assembling together peers with a common goal allowed for targeted education and team work. The ability to communicate with others in similar situations was believed to enhance motivation and encourage continued participation. On the other hand, those who preferred to rely on one person for support reported that this provided them with the education and monitoring they needed for success. In both instances, having interaction with another was said to prolong commitment to attain the desired weight loss goal.

Today's Experiences Shape Tomorrow's Outcomes

At the same time that they were optimistic about weight management in the future, participants also believed that actions and events that occur in the present or past would influence outcomes. Most saw successful weight management as the result of an ongoing commitment to achieving a healthy weight, which can be influenced not only by what they do but also by what happens to them. They identified weight management results in the past, the fluctuating symptoms of schizophrenia, and adherence to sound weight management principles as factors that could shape weight management outcomes. In what follows, the participants' views of these phenomena are expressed.

Weight Management History

Their confidence in their ability to maintain a commitment to losing weight was bolstered if they had had weight loss success in the past. For instance, a middle aged man stated: "Well I've already lost weight so that means that I know how to lose it, I just have to be able to stick to the plan

you know (8)”. If past attempts failed or they were uncertain as to how to attain a healthy weight, they were less confident. One young woman illustrated this by saying:

I don’t really know what happened really; I can’t put my finger on it. You kind of go back to your old life... and then I’ve gained all this weight and it’s like now I feel really depressed because before I was like ‘okay, I have so much to lose’, but now it’s like ten times worse – I have so much more! (11)

Similarly, another stated: “Because I’m overweight and because well, I’m trying several ways to lose weight and it’s not coming off (7)”. Failed efforts cast a shadow over the view of future weight management, despite expectations that they would eventually be able to reach a healthy, manageable weight.

Fluctuating Symptoms

Most of the participants felt that their struggle with weight was compounded by their illness experiences. “Providing my illness doesn’t give me any complications (14) was the proviso added by one participant who was confident that he would be able to lose weight. At the same time that they held expectations of future wellness, participants were also hesitant to assume that their illness would remain stable indefinitely. Thus, they felt weight management could be jeopardized by fluctuations in their illness course despite their positive outlook. Although they described periods of time when both their illness and weight were stable, both of these were often halted by an upsurge of symptoms, “...I think I went up to 268 pounds during Easter holiday when I was in the hospital and my belly was like huge (12)”, Furthermore, as indicated earlier, well known to them was the propensity of their medications to induce weight gain. Many felt that this side effect was a major challenge, “...I’ve noticed the weight gain has been an issue since I started different medications. I think I get cravings that I wouldn’t normally have (6)”. For some

this had led to weight cycling tendencies in the past. A female participant described her struggles with medication compliance related to weight gain:

Over the years, I was discharged weighing 110 pounds; the doctor said I don't want to discharge... I said to my doctor 'you know I feel good, I'm bigger' and he said 'well don't go overboard' and sure enough there I went to 167.5 pounds and so I blamed it on my medication. So I quit my medication and went on a crazy diet and was re-admitted and again, right back to ground zero (13).

This particular participant explained that with each re-admission her baseline weight increased and described her feelings of her current weight like so: "I feel terrible. I've never been as big as I am now, and I don't see the light at the end of the tunnel you know? I'm so afraid that I will become 300 pounds one day, you know? Because I'm 235 now (13)".

Following Sound Principles

Although they recognized that instability of their illness could interfere with weight management, many believed that taking appropriate steps in the present was the way to a healthy weight in the future: "Just eat the right things, that's the most important thing (14)", "Well I advise people who don't do a lot of exercise to only have one meal plus a light snack... I think they could have a number of smaller snacks after they've had that, if they are wise (2)". The weight management principles described by the participants involved both patience and a consistent effort towards short term goals, "I would say the most important thing for me now is to have patience and to focus on the here and now (9)", "...keep on moving. Have a project and after that project is done, fix yourself another goal and all these goals will lead to something (13)". More specific diet and exercise practices were also described by them. One slightly overweight male outlined what he believed was required stating the following:

Well the rules are pretty simple, work out, do a physical workout, watch your calories, watch your fats, limit sugars. Ah, try to stick to a routine, you know have things during the day that can give you a life and that are at least half interesting. Fill your day up with things that are at least half interesting so that you can HAVE a life. If you don't have a life you can't accomplish anything. But ya, it's pretty simple, work out, eat properly, have a job, I think working a part-time job while on disability is ok and um have jobs to do and fill the rest of time up with something interesting. And getting back to weight, I think being self-motivated in enough, but people can do it with contact or without contacts, the most important thing is that you do it. Cause if you have a contact for a little while you might not always have that contact. It's important to be able to do it yourself and be committed to it (5).

Thus, participants believed their past and present experiences with weight, weight management, and their illness would greatly impact their weight in the future.

Chapter 5

Discussion

This last chapter presents a discussion of the study results. Key findings will be noted, as well as how they relate to current literature on the research phenomenon. Study limitations will be exposed, followed by implications for nursing practice and future research perspectives.

This study is only the second study exploring weight and weight management from the perspective of the individual with schizophrenia. The participants of this study revealed that these are significant concerns for them. Most were unhappy with their current weight, most appeared to be overweight (although this was not assessed objectively) and most wanted to slim down. They believed their weight is influenced by a combination of multiple lifestyle factors, as well as the use of atypical antipsychotic medications. Facilitators to weight management were outlined by the participants, and they considered weight education, diet, and exercise to be important. They understood that a deficit in one or more of these would lead to an impaired ability to achieve or maintain a healthy weight, and they believed that present actions influence weight related outcomes in the future.

Although the participants of this study were hopeful about the future despite the difficulties experienced as a result of their schizophrenia, they did identify barriers to weight management. Based on their previous experiences, they indicated that illness related factors can stand in the way of achieving weight management goals. They showcased problematic energy levels, limited finances and an inability to afford necessary healthy foods, as well as the interference of psychotic relapses, as counterproductive to successful weight management. The

construction of their experience presented in this study suggests that the weight reality for participants involved an interaction of these facilitators and barriers.

Related to the Literature

Current literature on this topic centers primarily on the tendency of atypical antipsychotics to cause weight gain and subsequent management of this weight gain. Though tremendous research has been done linking weight and schizophrenia, as well as evaluating treatment interventions, much of the literature reveals that programs designed to decrease weight are not successful in the long-term. Persons with schizophrenia appear to be unsuccessful in maintaining lifestyle changes, implemented during the studies, post completion. One reason for this may be that programs have typically been created without input from them, the consumer.

In the sole study found that outlined the perceptions of persons with schizophrenia regarding weight management, three focus groups which lasted 90 minutes were conducted with 23 male participants in the United States. The key findings from the focus groups align well with the findings of the study presented here. Weight and weight management were important concerns for people with schizophrenia, who worried about their appearance and physical health. This sample, however, also had difficulty adhering to diet and exercise plans. (Weissman, Moot, Essock, 2006). Both this study and the present study, show that weight and weight management are a serious worry for persons with schizophrenia, and pose a significant challenge for them.

A systematic review article published in the Cochrane Library in 2003 by Faulkner, Soundy, and Lloyd identified both dietary modification and exercise as important in weight loss for persons with schizophrenia. These conclusions were echoed by the participants of this study as they stated that in order to adequately manage their weight; they must partake in both proper nutrition and regular exercise. However, the present study also indicated that stable finances,

control of positive and negative symptoms, and sufficient energy are necessary for successful weight management, and that social support must be an integral part of weight management programs.

The review did not include articles on prevention of weight gain in this population, as no such articles were found using a comprehensive MEDLINE, PSYC-INFO and CINAHL search. Interestingly, the complexity with which persons with schizophrenia described weight management identifies this area as important, though not yet looked at. Perhaps preventing weight gain in persons with schizophrenia is the pivotal factor for tackling the obesity epidemic in this population.

A 2005 study conducted by Thomas, Raymondet, Charbonnel, and Vaiva, established that specific care requirements are necessary for patients with schizophrenia and diabetes. They identified key lifestyle and diet information that should be provided as health education for these patients, including weight, diet, and exercise counseling. The participants of the present study frequently highlighted the importance of weight related education and identified a lack of education as a barrier to weight management. Adequate education regarding lifestyle, diet, and exercise may benefit all patients with schizophrenia, as they are at a heightened risk for both weight gain and related co-morbidities due to medication side effects.

Some studies have suggested that weight gain may affect compliance with psychiatric medications. Perkins (2002) conducted a MEDLINE search to establish a body of literature that showcased the predictors of medication noncompliance in persons with schizophrenia. Among her findings was the influence of medication side effects, including weight gain, on adherence to medication regimes. Participants of this study did question the value of adherence to medication because of weight gain and some had stopped taking their medication in the past for this reason,

supporting her conclusion. Medications are a huge component of the management of schizophrenia. If, however, obesity and metabolic risks become severe enough to challenge medication compliance, as is suggested in the Perkins review and the study conducted here, one must hope that future weight management tactics better address the needs of this population in order to avoid increased psychotic episodes and medication compliance-related admissions stemming from adverse weight gain and metabolic syndrome.

Study Limitations

The validity of the information presented in the findings of this study is dependent on the extent of disclosure and accuracy of the study participants regarding the phenomenon of interest. Weight management is a well publicized topic, which may have influenced their recount of their weight related practices. The unfamiliarity or limited familiarity of the researcher to the participants may also have affected the truthfulness with which they described their weight reality. In addition to this, the nature of unstructured interviews, and the known cognitive and memory deficits associated with schizophrenia may have led to a failure to disclose all pertinent information, due solely to forgetfulness. Finally, the sample was drawn selectively from an outpatient population at a single hospital, and the majority of the participants were middle-aged males (N=15 male, N=3 female), signifying that caution should be used when assessing the transferability of the results to all persons with schizophrenia, as each population has distinct characteristics.

Implications of Findings for Nursing Practice

Nurses have a responsibility to care holistically for their patients. Unfortunately, the stabilization of psychotic symptoms and the administration of medications is commonly the focus in psychiatric nursing practice, particularly during inpatient stays. The results of this study clearly

indicate that persons with schizophrenia have health concerns aside from their mental illness, including concerns regarding their weight and weight management. Nurses are in an excellent position to help alleviate the stress of adverse weight gain through the implementation of prevention and maintenance strategies. First, it is advised that nurses be aware of the distress experienced by persons with schizophrenia when they feel they are unable to control their weight. Secondly, nurses should be mindful of patients who are at points in the illness trajectory that make them vulnerable to weight gain; newly diagnosed patients, and during initiation of new atypical antipsychotic medications. Thirdly, educating patients, early in treatment, of the weight related complications of schizophrenia and associated medications may lay the foundation for further teaching exercises once the patient is no longer acutely psychotic. Many participants indicated that the weight gain they experienced was much more severe than what they had anticipated, or than what had been identified by their healthcare team. Nurses should ensure that the patient understands the amount of weight that may be gained, while reinforcing the importance of treatment, irrespective of this side effect. This initial teaching opportunity should be facilitated by inpatient psychiatric nurses. As soon as the patient is capable of participating in goal directed activities, nurses should initiate simple diet and exercise teaching, taking into account the impact of schizophrenia on cognition, attention, and memory. The participants of this study desired concrete examples and real-life solutions to weight related problems, as well as repetition, positive reinforcement, and content specific teaching, in both individual and group forums. Nurses may also help identify accessible resources for the patient regarding diet and exercise. Weight related education should begin while the patient is in hospital and be continued and expanded as they progress to outpatient status. Finally, nurses should incorporate monitoring of weight and related physical attributes into their practice, and act as a record keeper and reminder for the patient. Weight, height, BMI, and WC measures should be taken at the first

encounter with the patient and updated regularly thereafter. If the nurse notices an increase in weight and related risk factors, reinforcement of weight management material and problem solving should ensue in an attempt to prevent further deficits.

The findings of this study also highlight that persons with schizophrenia may sometimes want to, or choose to stop taking antipsychotic medications for weight related reasons. Most of the study participants associated weight gain with the initiation of atypical antipsychotic medications, and some admitted to non-adherence related to this side effect. The nurse should be aware of this potential health problem and implement both education and prevention of weight gain strategies to help avoid relapses and hospitalizations due to a failure to take antipsychotic drugs.

Recommendations for Future Research

The results of this study suggest further research is needed in many areas. Different research paths are therefore presented. The participants of this study felt that once weight had been gained, it was very difficult to regain a healthy weight. This stresses the importance of exploring ways in which weight gain in schizophrenia can be prevented, rather than simply managed after the fact. Very few articles discuss the value of weight gain prevention in any population, although many suggest it is the ideal way to tackle the obesity epidemic in both mentally well and mentally ill people. No weight gain prevention guidelines have been identified in any population, re-enforcing the need for further research in this area.

The participants also experienced strong negative emotions related to their weight gain. This suggests the call for further exploration of the connection between low-self esteem, depression, and weight gain in persons with schizophrenia.

A third area for research became evident when discussing exercise with the participants of this study. It was apparent that many different beliefs were held regarding the type and intensity of exercise needed to lose weight. It would be interesting to investigate what percentage of persons with schizophrenia, who identify themselves as active, actually undertake vigorous enough exercise to stimulate weight loss, and how this percentage may be increased.

Finally, the participants of this study indicated that they thought about or actually stopped taking their antipsychotic medications because of adverse weight gain. This suggests that evaluation research is needed to examine to what extent weight gain, as a side effect, affects medication compliance in persons taking atypical antipsychotic drugs.

Chapter 6

Conclusion

This study explored the perceptions of persons with schizophrenia regarding their weight and lifestyle. The findings of this study further our understanding of schizophrenia and weight and clearly indicate that this population is concerned with these phenomena and are motivated to attain a healthy weight. They associate medication and illness characteristics to weight gain, and at times considered altering their treatment regimes to avoid this side effect. Strategies described by the participants to counter weight gain involve individual, informational, and social support. The knowledge gained from listening to their reconstruction of their weight reality should be considered when future weight management interventions are created for this population, in order to heighten the chance of successful implementation.

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Appendix A

Consent Form

INFORMATION FORM FOR A RESEARCH STUDY

The Perceptions of Persons with Schizophrenia Relating to Their Weight

- Researchers:** Amanda Digel, BScN, R.N – Master’s of Science candidate at Queen’s University. 613-601-6822
Cynthia Baker, RN, PhD – Academic Supervisor and Director of Queen’s School of Nursing. 613-533-2669
Nancy Brookes, RN, PhD, CPMHN (C) – Nurse Scholar, ROHCG - contact person. 613-722-6521 ext 6002
- Introduction:** I am a registered nurse and a master’s student at Queens University. This study is part of the requirements for my degree. I would like to invite you to participate in my study.
Before agreeing to take part in this study, it is important that you read all of the following information. It includes details that I think you need to know to decide if you wish to take part in the study. If you have any questions, please feel free to discuss them with me or anyone else that you choose. You should not sign this form until you are sure you understand the information. All research is voluntary and you have the right to leave the study at any point.
- Purpose of the Research:** You are invited to participate in this study because you live with schizophrenia.

In this study I would like to talk with you about your weight and lifestyle, and how it affects your life. My interest is in learning from you what your experience is like.
- Description of the Research:** If you agree to participate in this study:
- Your current care will not change.
 - You will be asked to attend one or more interviews with Amanda Digel that will last a total of about 1 hour. The 1 hour can be split up into sessions depending on how long you feel comfortable talking. The interviews will be scheduled at a time and place that is convenient for you and Amanda.
 - The interviews will include questions about your weight and your lifestyle.
 - Your clinical record may be used to gather information about you and your medications.
 - Amanda Digel, with your permission, will audiotape the conversation and may make some notes.

- Up to 10 people at the Day Hospital will participate.
- You can decide not to answer any questions or can withdraw from the study at any time without giving an explanation.

Potential Harms (Injury, Discomforts or Inconvenience):

There is minimal risk, but the conversation might touch on sensitive issues around your weight and make you uncomfortable. You can choose not to answer any questions that make you uncomfortable.

Potential Benefits:

You may not get anything out of participating in the study. This is an opportunity to discuss any issues around your weight. You will also be contributing to nursing knowledge.

Protecting your Health Information:

I will use the information to understand how you experience your weight. No names will be collected; your information will be assigned a code. All the information will be grouped together with no names and nothing will identify you. Once the audio tapes have been transcribed they will be erased, and all of the study information will be kept in a locked file cabinet for 5 years and then destroyed. Consent forms will be kept in a separate locked file cabinet. This information will be published in my thesis and there may be articles in the literature and/or presentations at conferences.

Potential Costs of Participation and Reimbursement to the Participant:

The interviews will be arranged at a time and place that is convenient for both you and Amanda. You will receive bus tickets for your travel and coffee or tea and a snack will be provided for you during the interview.

Compensation for Injury:

If you suffer any injury from your participation in this study, please seek medical care as you would normally. In no way does signing this form change your legal rights nor release Amanda Digel from her legal or professional responsibilities.

Participation and withdrawal:

Participation in any study is voluntary. If you choose not to participate you and your family will continue to have access to customary care at ROHCG. If you decided to participate in this study you can change your mind without giving a reason, and you may withdraw from the study at any time without any effect on the care you and your family will receive by ROHCG.

Research Ethics Board Contact:

If you have any questions regarding your rights as a research participant, you may contact Dr. Albert Clark, Chair, Research Ethics Board (Queen's University) at 613-533-6081 during business hours, Or Dr Alan Douglass, Chair, Research Ethics Board (ROHCG) at 613-722-6521 ext 6226 during business hours.

The study protocol and consent form have been reviewed by the Queen's University Research Ethics Board as well as the Royal Ottawa Health Care Group Research Ethics Board. The Research Ethics Board may review this study as part of quality improvement and someone may contact you from the Research Ethics Board to discuss your experience in the study.

If you have any questions about your rights as a research subject or any concerns, you may contact Dr. Alan Douglass, REB Chair at 613-722-6521 ext. 6226.

Study Contacts:

Principal Investigator:

Amanda Digel, BScN, RN, MSc (c) at 613-601-6822

Or

Department Head (Academic Supervisor):

Dr. C. Baker, RN, Director, Queen's School of Nursing at 613-533-2669 -

Or

ROHCG Contact

Dr. N. Brookes, RN, Nurse Scholar at 613-722-6521 ext 6002

Code number: _____

The Perceptions of Persons with Schizophrenia Relating to Their Weight

Principal Investigator:

Amanda Digel, BScN, RN, MSc (c) at 613-601-6822

Or

Department Head (Thesis Supervisor):

Dr. C. Baker, Director, Queen's School of Nursing at 613-533-2669

Or

ROHCG Contact

Dr. N. Brookes, RN, Nurse Scholar at 613-722-6521 ext 6002

The study has been explained to me. I have had the opportunity to ask any questions I have and they have been answered to my satisfaction. I can choose not to participate. If I choose to participate, I can withdraw at any time or I may decide to not answer any question and this would not affect the care I receive now or in the future.

I still keep all my legal rights. The investigator or involved institutions are not released from their legal and professional responsibilities. I know that I may ask now, or in the future, any questions I have about the study. All study documentation on me will be kept confidential and no information will be disclosed without my permission unless required by law. I have been given sufficient time to read the above information.

I consent to participate in this study. I will receive a copy of this signed consent form.

Signature of Participant

Date

Signature of Witness (if available)

Date

Statement of Investigator:

I certify that I have explained the purpose, the objectives and the implications of the study, and have answered all of his/her questions to his/her satisfaction, and I have explained that he/she is free to end his/her participation in the study at any time without having to justify this in any way.

Signature of Principle Investigator

Date

Appendix B
Information to be Abstracted from Clinical Records

Code:

Date:

Age:

Gender:

Primary Psychiatric Diagnosis:

Other:

Medical Diagnoses:

Current Antipsychotic Medications:

Past Antipsychotic Medications (if relevant):

Current Weight:

Current Height:

Documented Weight Change (if available):

Appendix C

Information for Participants

The Perceptions of Persons with Schizophrenia Relating to Their Weight

My name is Amanda Digel and I am a registered nurse who is in a Master of Science (nursing) degree at Queen's University. For my thesis I am carrying out a research study under the supervision of Dr. Cynthia Baker. It is my intent to understand the experience of weight from the perspective of a person living with schizophrenia. I would like to have the opportunity to meet with you and talk about your weight and lifestyle.

- If you would like to be a part of my study, it will mean meeting with me for interviews lasting a total of about one hour. It can be broken into multiple meetings if you are more comfortable with that and they will be at a convenient time and place for both of us.
- All of the study information will be kept confidential and will not be seen by anyone other than myself and Dr. Baker. The final report will not have your name or any other identifier.
- It is your choice to participate or not to participate in this study.
- I will have coffee or tea for you at the interview and will compensate you for your travel expenses.

If you would like more information about the study, you can call me at 613-601-6822 or leave a message. I will be happy to answer your questions.

If you are interested in being a part of the study, please contact me or Joe so that we can provide you a consent form.

Thank you for your interest!

Sincerely,

Amanda Digel, RN, BScN, MSc (candidate)

Contacts:

Amanda Digel

Phone: 613-601-6822

Email: 2ad2@queensu.ca

Appendix D

Unstructured Interview Topics

Please note that the study design is emergent and that probes may be used to create a richer understanding of the research phenomenon. Some of these probes are listed below but others may emerge during the interviews.

1. What do you think about your weight right now?
Probes such as:
 - Have you any concerns about your weight, what would they be?
 - Have you experienced any weight changes in recent years, what would they be?
 - What, if anything, influences your weight?
 - Others
2. What do you think would be/is the best thing for you to do to maintain a weight that you feel comfortable and happy with?
Probes such as:
 - Are there things you do to lose/gain weight?
 - Can you tell me about these?
 - Others
3. Would you share with me what your life is like right now?
Can you describe a typical day?
Probes will focus on topics related to lifestyle and daily living such as:
 - nutrition
 - activities
 - ways of getting and preparing food
 - exercise
 - sleep, energy level
 - others
4. What is it like to live with a diagnosis of schizophrenia?
Probes such as:
 - How do you see yourself in 2 years?
 - How has your family/friends/others been influence by schizophrenia?
 - What goals have you set for yourself in relation to your life and schizophrenia?