Dealing with the ‘Double-Whammy’: Women’s Experiences of Schizophrenia and Weight Gain

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Statement of Originality

The thesis contains no material that has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent for the final version of my thesis to be made available worldwide when deposited in the University’s Digital Repository, subject to the provisions of the Copyright Act 1968.

Signed: ___________________________ Kirsti E. Haracz

Date: ______________
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Presentations and Publications Arising from the Thesis

Refereed Journal Publications:


Conference Paper Presentations:


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List of Conventions

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<td>In some cases this is for the sake of clarity, and in other cases it is for brevity.</td>
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<td>ADL</td>
<td>Activities of daily living</td>
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<td>AEE</td>
<td>Activity energy expenditure</td>
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<td>BED</td>
<td>Binge eating disorder</td>
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<td>BS</td>
<td>Binge eating symptomology</td>
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<td>BMI</td>
<td>Body mass index</td>
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<td>BPNT</td>
<td>Basic psychological needs theory</td>
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<td>CET</td>
<td>Cognitive evolution theory</td>
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<td>CHD</td>
<td>Coronary heart disease</td>
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<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
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<td>GP</td>
<td>General practitioner</td>
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<td>IDF</td>
<td>International Diabetes Federation</td>
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<td>MI</td>
<td>Myocardial infarction</td>
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<td>OIT</td>
<td>Organismic Interaction Theory</td>
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<td>OR</td>
<td>Odds ratio</td>
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<td>PAL</td>
<td>Physical activity level</td>
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<tr>
<td>SDT</td>
<td>Self Determination Theory</td>
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<tr>
<td>SMI</td>
<td>Severe mental illness</td>
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<td>SMR</td>
<td>Standardised mortality ratio</td>
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<td>SSDs</td>
<td>Schizophrenia spectrum disorders</td>
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<td>TIA</td>
<td>Transient ischaemic attack</td>
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<td>TTM</td>
<td>Transtheoretical Model of Health Behaviour Change</td>
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Abstract

In this study I explored the experience of women diagnosed with schizophrenia spectrum disorders (SSDs) of managing their weight and what they thought had, or would support them to do this more effectively. I carried out the study according to the principles of constructivist grounded theory. Participants in the study were women, who had been diagnosed with SSDs, were not acutely unwell, and were able to give informed consent. I recruited the participants through community mental health rehabilitation services in the Hunter Region of New South Wales. Data was generated through in-depth, semi-structured interviews. Each of the 11 women who participated in my study engaged in between one and three interviews over a two-year period. I carried out data analysis alongside the data generation, with each process informing the other. Data analysis involved a two-stage coding process characteristic of grounded theory. I also employed other analytical tools including writing analytical memos, constant comparison, theoretical sorting and storyline.

The findings of the study comprise a theoretical framework that has four components. The first component is the basic social problem that was shared by all of the participants in the study. Labelled using the words of one of the participants, the double-whammy describes the women’s experience of weight gain, often resulting in obesity, as a second whammy that came along with the diagnosis and treatment of their SSD and brought with it additional challenges. The remaining three components comprise the basic social process, which was the women’s response to the double-whammy. This response centres on the core category of doing as much as I can. This category includes the women’s engagement in what they saw as doing the right things, in a somewhat cyclical process of starting to do it on more than one occasion due to the challenges of sticking with it. They also described an ongoing process of adjusting expectations, both in terms of their engagement in doing the right things, and the outcomes they expected to achieve. The women’s ability to do what they saw as necessary to manage their weight fluctuated in response to a range of mediating factors, which formed the second category in the basic social process. These mediating factors included, knowing about the potential for weight gain and how to address it, mental
health and wellbeing, and practical issues such as living on a limited income and prioritising managing their weight among competing demands. The final component of the findings was the facilitating factors that the women thought had helped, or would help them to manage their weight. These included, talking about it, having a plan, and having someone to do it with.

This study is significant in that it provides insight into the experience of women, who are generally underrepresented in research about SSDs. The study also provides a longitudinal and holistic perspective that has not been present in existing research. Based on the findings above I suggest that interventions to address weight gain and obesity for women with SSDs should: be integrated with interventions for mental health, commence concurrently with treatment for their SSD, be long term, be flexible and individualised, support development of competence in associated activities, address environmental and contextual factors, and happen in the context of supportive relationships. These suggestions have implications for mental health service providers including addressing culture and attitudes and developing knowledge and skills among staff and allocating sufficient resources to enable obesity to be effectively addressed in mental health services. Implications for occupational therapy include validation of occupation centred practice in this field given the identification of developing competence in associated activities as one of the core elements of interventions to address weight gain and obesity in women with SSDs.
Chapter 1  Introduction

1.1 Overview of the Chapter

The focus of this study is on the experiences of women who have been diagnosed with schizophrenia spectrum disorders (SSDs), of managing their weight. The term SSDs is used in this study to include those who have been diagnosed with schizophrenia and schizo-affective disorder. The grouping of these two disorders in research is common and relates to the overlap in diagnostic criteria and the fact that a significant proportion of those diagnosed with one condition will have their diagnosis changed to the other at some point, as the pattern of mood episodes becomes more apparent (American Psychiatric Association, 2013). In this chapter I provide an overview of the prevalence, diagnosis and course of illness for these disorders, their impact on the individuals diagnosed, and current treatment options. I also provide some background about the profession of occupational therapy and occupational therapy practice with people living with mental health disorders and how I, as an occupational therapist, came to explore the issues around women with SSDs managing their weight. I then give an account of the research problem, aim and questions and the research approach followed by an overview of the framework of the thesis.

1.2 Background to the Research

1.2.1 SSDs: Prevalence, Diagnosis and Course of Illness

The combined prevalence of SSDs is approximately 1% of the population with approximately 0.7% prevalence of schizophrenia and 0.3% schizo-affective disorder (American Psychiatric Association, 2013).

The diagnostic criteria for schizophrenia and schizo-affective disorder include significant similarities but also notable differences. According to version five of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), diagnosis of both conditions requires that a person must have two or more of the following symptoms for a significant portion of the time during a one month period: delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour or negative symptoms (American Psychiatric Association, 2013). In addition to the
psychotic symptoms, diagnosis of schizophrenia also rests on a reduced level of functioning in one or more major areas such as work, interpersonal relations or self-care (American Psychiatric Association, 2013). Impaired occupational functioning is not a criterion for diagnosis of schizo-affective disorder however it is frequently an issue and recognised in the DSM as an associated feature (American Psychiatric Association, 2013). The primary point of difference between the two disorders centres on whether there is a major mood episode. Schizo-affective disorder requires that there must be a major mood episode (manic or depressive), concurrent with the psychotic symptoms, however psychotic symptoms should be present for a period of at least two weeks in the absence of a major mood episode to be differentiated from bipolar disorder or depression (American Psychiatric Association, 2013). It is highlighted in the DSM-V that individuals may find that their diagnosis changes from one of these disorders to the other over time as the pattern of mood episodes becomes clearer (American Psychiatric Association, 2013).

SSDs typically develop in early adulthood, with the majority of those affected experiencing a pattern of exacerbation and remission over their lifetime. Reports regarding the outcome for those diagnosed with schizophrenia vary but it is commonly suggested that the outcome is favourable in approximately 20% of cases, with a small number of those affected experiencing complete resolution but most going on to have recurrent episodes of psychotic symptoms with varying degrees of remission in between. The prognosis for schizo-affective disorder is somewhat better than that for schizophrenia (American Psychiatric Association, 2013).

1.2.2 Impact of SSDs

Despite significant changes in treatment, which will be outlined in section 2.3 of this chapter, systematic reviews and meta analyses suggest that the proportion of people with SSDs who have a ‘good outcome’ has not increased in recent decades (Hegarty, Baldessarini, Tohen, Waternaux, & Oepen, 1994; Jaaskelainen et al., 2013; Menezes, Arenovich, & Zipursky, 2006) and people with these diagnoses continue to experience very high levels of disability and disadvantage. Of those who took part in the second Australian national survey of psychosis in 2010, only 21% were in paid employment.
compared with 72.4% of the general population, and of those in work 69% were working part time. The main source of income for 85% was a government pension, 5.2% were homeless compared to 0.5% of the general population, 22.4% felt socially isolated, a further 24.2% were lonely for company and overall only 47.4% were satisfied with their life compared to 81% of the general population (Morgan et al., 2012). The disability experienced by people living with SSDs is compounded by the sequelae of issues with functioning such as economic disadvantage, as well as stigma, discrimination and iatrogenic effects of treatment.

Schizophrenia has been described as the most disabling of all of the mental disorders (Eaton et al., 2008). Most people diagnosed with schizophrenia experience a prodromal period, where there is a deterioration in social and role functioning, prior to the onset of psychotic symptoms (McGorry, 2004). While not listed as criteria for diagnosis, cognitive deficits including declarative memory, working memory, language functions, executive functions and slow processing speed, are common in people diagnosed with schizophrenia and recognised in the DSM as features supporting diagnosis (American Psychiatric Association, 2013). These cognitive deficits, along with negative symptoms such as asociality, avolition, anhedonia, affective flattening and alogia, are often present even during periods of remission from positive symptoms and impact significantly on functional outcomes (Carbon & Correll, 2014). Other features associated with schizophrenia which may also impact on function include, dysphoric mood, disturbed sleep patterns, anxiety, abnormalities in sensory processing and social cognitive deficits (American Psychiatric Association, 2013). Occupational functioning is also often impaired in people with schizo-affective disorder, with restricted social contact and difficulties with self care commonly identified (American Psychiatric Association, 2013).

Stigma is a significant contributor to the reduced social participation and poorer wellbeing among people with SSDs. Corrigan (2000) described severe mental illness as “striking like a double edged sword” (p.49), with both the symptoms and skill deficits that arise from the illness and the societal reactions to severe mental illness impeding the person from achieving in relation to social roles and quality of life. Of the
respondents in the second Australian national survey of psychosis, 37.9 % reported having experienced stigma or discrimination in the last year and that fear or actual experience of this had stopped them doing things that they wanted to do (Morgan, et al., 2012). These findings are mirrored in the findings from an Australian national survey of mental health literacy and stigma, which found not only that there were high rates of stigma towards mental illness, but that the levels of stigma towards schizophrenia were higher than for any of the other illnesses covered in the survey (Reavley & Jorm, 2011). In their synthesis of qualitative studies concerning the subjective experiences of stigma among people with schizophrenia accessing community mental health care, Mestdagh and Hansen (2014) identified a range of impacts of stigma on daily life including: reduced social contacts, lack of privacy, others making decisions for them, insinuations or statements that they should not be involved in romantic relationships or parenting roles and unsupportive working situations.

Iatrogenic treatment effects, in particular the side effects of the medications used to treat SSDs, also contribute to poorer social participation and wellbeing. Antipsychotic medications cause a range of side effects including weight gain, sedation, hypotension, prolactin elevation and related sexual dysfunction, and anticholinergic effects (Tandon, Nasrallah, & Keshaven, 2010). Staring, Mulder, Duivenvoorden, De Haan, and Van der Gaag (2009) found, through the use of structural equation modelling on data from 114 people with a psychotic disorder, that while medication adherance was associated with less severe psychotic symptoms, which improved quality of life, it was also associated with more adverse medication side effects which lowered quality of life. The undesirable side effects of antipsychotic medications have been identified as a significant reason for people not taking their medication as prescribed, which then increases the risk of illness relapse (McCann, Boardman, Clark, & Lu, 2008).

1.2.3 SSDs and Women

There are gender differences in both the incidence and prevalence, and in how SSDs manifest. Recurrent meta-analyses have found lower incidence of schizophrenia among women with the ratio being 1.3:1 (Aleman, Kahn, & Selton, 2003) or 1.4:1
Schizoaffective disorder, however, is more common in women (American Psychiatric Association, 2013). Women are generally recognised as having what is described as a more favourable course of illness and outcome than men. This is reflected in the findings from the Australian survey of low prevalence (psychotic) disorders in which women in all diagnostic groups reported better premorbid functioning, a more benign course of illness, lower levels of disability and more integration into the community than men (Morgan, Castle, & Jablensky, 2008). Similarly, in a longitudinal study of people with SSDs followed up at five points over 15 years, Grossman, Harrow, Rosen and Fauli (2006) found that women consistently showed better functioning over time, more frequent periods of good functioning and recovery, and fewer and shorter hospitalisations. Conversely however women are more susceptible to negative side effects of antipsychotic medications, in particular weight gain, diabetes and specific cardiovascular risks (Seeman, 2009). They are also more likely to become overweight or obese than males with these disorders (Hakko et al., 2006).

Differences in the course and outcomes of the illness, and the impact of medication side effects suggest that women may also have different needs with regards treatment and support for SSDs (Kelly, 2006; Kulkarni, 1997). There is however limited research that focuses specifically on women and women are underrepresented in research, other than epidemiological studies, about SSDs (Kulkarni, 1997; Longenecker et al., 2010). This means that much of what we understand about SSDs and associated treatment is based on the experience of men, and may not necessarily translate for women (Longenecker, et al., 2010). In order to address this there needs to be research that focuses on women, or at least stratifies findings for men and women, so that we can gain a better understanding of the needs of women with these disorders and develop effective ways to meet these needs.

1.2.4 SSDs: Treatment and Recovery

Treatment for people living with SSDs has in many ways seen dramatic changes over recent decades. The introduction of antipsychotic medications in the 1950’s is cited as a turning point. Prior to the introduction of these medications standard treatment
consisted of admission to long stay psychiatric hospitals which were supposed to provide a safe and supportive environment (Tandon, et al., 2010). Even the early antipsychotic medications were reasonably effective at treating the positive and disorganising symptoms of the illnesses and are credited as a key factor in enabling the process of de-institutionalisation (Tandon, et al., 2010). Recent decades have also seen the development of a range of psychosocial and cognitive interventions such as, cognitive behavioural therapy, social skills training, family psycho-education, assertive community treatment and supported employment (McGorry, 2004). Current clinical practice guidelines identify antipsychotic medication as the cornerstone of treatment but also recommend comprehensive psychosocial interventions, such as those identified above and interventions in the social and cultural environment to provide adequate shelter, financial security, access to meaningful social roles and availability of social support (McGorry, 2004).

The approach to treatment for people with SSDs in recent years has also been shaped by the concept of recovery. The contemporary understanding of recovery in mental health originated from the consumer movement which is traced back to the 1980’s (Andresen, Oades, & Caputi, 2003). The recovery movement sought to change the negative views of what was possible for people living with mental illnesses and restore their right to self determination, a meaningful life and community participation consistent with their own goals and preferences (Davidson & Roe, 2007). There is no universally accepted definition or description of recovery although it is generally recognised as being a journey, unique to the individual, rather than an outcome. A number of conceptual models have been developed, generally from qualitative research about consumer experiences, that describe what is involved in someone being in recovery. Davidson, Rowe, Tondora, O’Connell, and Lawless (2009) identified common elements from international qualitative research studies which included: renewing hope and commitment, assuming control, incorporating the illness, managing symptoms, redefining oneself, finding ones niche in the community, being supported by others, becoming empowered, exercising citizenship and overcoming stigma.
In recent years the conceptualisation of recovery, that came from the consumer movement, has increasingly been incorporated into mental health policy and service provision guidelines. In Australia in 2013 the National Framework for Recovery Oriented Mental Health Services was released (Australian Health Ministers Advisory Council, 2013). This document draws on the research and models of recovery to provide guidance for mental health services and professionals to operate in accordance with recovery oriented principles. Recovery is seen as an individual journey, with the person living with mental illness in control, hence the role of services and mental health professionals under this approach is to support the efforts of the individual (Davidson, et al., 2009). According to the framework recovery oriented mental health services draw on the expertise of people with lived experience of mental illness as well as professional knowledge, support people to take an active role in their life, mental health and wellbeing, and to embrace their strengths and capacity for living a meaningful life of their choosing (Australian Health Ministers Advisory Council, 2013). While this guidance is for service provision it surely follows that research supporting mental health service provision should also adhere to these principles.

1.2.5 Occupational Therapy and People living with SSDs

The origins of the profession of occupational therapy can be traced back to mental health care in the moral treatment era of the late 18th and 19th centuries (Fossey, 2012; McKay, 2008). Core to moral treatment was a recognition that a lack of occupation exacerbated symptoms of mental illness and a belief that people who were housed in asylums should be encouraged to engage in a balance of daily occupations, work and leisure (Paterson, 1997). Originally lead by psychiatrists, the use of occupations in asylums was the basis of the new profession of occupational therapy which emerged in the early 20th century (Fossey, 2012; McKay, 2008).

As it’s name suggests, occupational therapy is underpinned by an understanding of occupation as a determinant of health. Participation in occupation is understood both as a human need for “mental, social and physical wellbeing and a means of restoring and maintaining health” (Fossey, 2012, p. 294). Occupation is everything that people do, and includes taking care of themselves and others, working, and enjoying leisure. It
is defined simply by Larson, Wood and Clark (2003) as “the activities that comprise our life experience and can be named in the culture” (p.16). The primary goal of most occupational therapy intervention is to “enable participation in personally and socially meaningful occupations that support health and wellbeing” (Krupa, Fossey, Anthony, Brown, & Pitts, 2009, p. 156). Occupational therapists use a range of occupation-focused models, which centre on the relationship between the person, occupation and the environment in order to understand factors affecting occupational performance and participation (Duncan, 2011). Another useful document is the Occupational Therapy Practice Framework published by the American Occupational Therapy Association which outlines both the domains and processes of occupational therapy practice (American Occupational Therapy Association, 2008). The domains, or areas in which occupational therapists are considered to have expertise are outlined in Table 1.1 below. The process of occupational therapy involves a cycle of evaluation, intervention, and outcome measurement (American Occupational Therapy Association, 2008).

Table 1.1: Occupational Therapy Practice Framework: Aspects of Occupational Therapy’s Domain (American Occupational Therapy Association, 2008)

<table>
<thead>
<tr>
<th>Areas of Occupation</th>
<th>Client Factors</th>
<th>Performance Skills</th>
<th>Performance Patterns</th>
<th>Context and Environment</th>
<th>Activity Demands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activities of daily living (ADL)</td>
<td>Values, beliefs and spirituality</td>
<td>Sensory perceptual skills</td>
<td>Habits</td>
<td>Cultural</td>
<td>Objects used and their properties</td>
</tr>
<tr>
<td>Rest and sleep</td>
<td>Body functions</td>
<td>Motor and praxis skills</td>
<td>Routines</td>
<td>Personal</td>
<td>Space demands</td>
</tr>
<tr>
<td>Education</td>
<td>Body structures</td>
<td>Emotional regulation skills</td>
<td>Roles</td>
<td>Physical</td>
<td>Social demands</td>
</tr>
<tr>
<td>Work</td>
<td></td>
<td>Cognitive skills</td>
<td>Rituals</td>
<td>Social</td>
<td>Sequencing and timing</td>
</tr>
<tr>
<td>Play</td>
<td></td>
<td>Communication skills</td>
<td></td>
<td>Temporal</td>
<td>Required actions</td>
</tr>
<tr>
<td>Leisure</td>
<td></td>
<td>and social skills</td>
<td></td>
<td>Virtual</td>
<td>Required body functions</td>
</tr>
<tr>
<td>Social Participation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Required body structures</td>
</tr>
</tbody>
</table>

Occupational therapists continue to be employed in significant numbers in mental health settings, and in Australia are employed in public mental health services, non-government organisations and private sector services, covering the spectrum from primary care, to acute services and longer term rehabilitation services (Fossey, 2012). Occupational therapy evaluation generally involves gaining an understanding of the patterning of a person’s occupations and identifying issues that impact on performance.
and participation (Fossey, 2012). Occupational therapists then use a range of interventions to address identified issues including: collaborative problem solving, occupational analysis, time use planning, modification of activities and/or environment to enable participation, development of strengths and skills for occupational performance and interventions that target underlying performance problems such as cognitive deficits to build capacity for occupation (Fossey, 2012; Krupa, et al., 2009).

My interest in the topic of this study developed during my years of practice as an occupational therapist in mental health settings. During my clinical career I worked both in inpatient and community based mental health services, in acute care and rehabilitation and across both the public and private sectors in England and Australia. I worked in the field of mental health for much of my career between graduating as an occupational therapist in 1993 and commencing my academic career in 2006. During this time I noticed the people I worked with gained significant amounts of weight. I also noticed that their weight increasingly became part of our conversations about their occupational issues, either in terms of it’s impact on their ability to do things, or it being something that they wanted to change. This led me to look at the research to try to understand more about the issue and what could be done to address it. As I discuss in more depth in the next chapter, I found a good deal of research evidence that supported my observations regarding the increasing prevalence of overweight and obesity among people with SSDs and some research regarding the impact this had on individuals in terms of their physical health, mental health and wellbeing. There was little evidence however for successful interventions or indicating what the occupational therapy role might be in addressing this issue. I also noted that there was almost no research that explored this issue from the perspective of people living with SSDs.

1.2.6 Occupational Therapy, Obesity and Health Promotion

Having not been able to find much literature regarding the role of occupational therapy in addressing weight gain and obesity in people with SSDs I looked to the wider occupational therapy literature for some direction. I reviewed the literature regarding occupational therapy and obesity and then the broader literature regarding occupational therapy and health promotion. In both cases I found very little had been
published at the time I was commencing my PhD studies although the literature in both of these fields, while still small, has grown exponentially during the time I have been working on this project. While little of this literature focuses on people with mental illness, let alone specifically on people with SSDs, it is helpful in developing a framework for understanding how occupational therapists might approach the issue with that population.

There is a steadily growing body of publications about the role of occupational therapy in addressing the issue of obesity. When I began searching for evidence regarding occupational therapy interventions for obesity I found very little. This is reflected in the American Occupational Therapy Association’s position statement on obesity published in 2007 (American Occupational Therapy Association, 2007) which, although it advocated strongly for an occupational therapy role, and outlined possible interventions, was only supported by two references about obesity from the occupational therapy literature. By the time I conducted an integrative literature review into occupational therapy and obesity in 2012 (Haracz, Ryan, Hazelton, & James, 2013) there were a total of 22 articles (published between 2002 and 2012) that were suitable for inclusion; 12 quantitative or mixed method research articles, two qualitative research articles and eight theoretical articles. Most (15) of the articles were focused on children and young people, with only two about people with mental illness. Interventions described in the review primarily focused on increasing physical activity and to a lesser extent modifying dietary intake but there was strong evidence of an occupation focused approach and recognition of the need to consider the interaction between the person, environment and occupation in supporting sustainable behaviour change (Haracz, et al., 2013). Interventions described in the articles included in the review spanned all three levels of health promotion as described by Scriven and Atwal (2004), and four of the five action items from the Ottawa Charter for Health Promotion (World Health Organisation, 1986). It is worth noting that only three of the papers in this review were research studies reporting outcomes of interventions with the others being cross sectional studies exploring needs of particular population groups, so much of the content of the review was based on discussion and recommendations for practice rather than study findings. In the two years following the completion of that review
the number of articles published about occupational therapy and obesity almost doubled, albeit with much of the new research also focusing on children.

The alignment of the principles of occupational therapy and health promotion, and the potential for occupational therapy in this arena has long been recognised. Scriven and Atwal (2004) trace the discussion of health promotion in occupational therapy literature back to the 1960’s. Others, such as Wilcock (2006), suggest that it is embedded in the roots of the profession with the recognition of the influence of occupation on health and wellbeing. The American Practice Framework (American Occupational Therapy Association, 2008) includes health management and maintenance within the domains of concern of occupational therapy, and health promotion and prevention as occupational therapy intervention approaches. Despite this recognition of the alignment between health promotion and occupational therapy, respondents to a number of surveys of occupational therapists report little involvement in health promotion activities in the usual course of their work (Holmberg & Ringsberg, 2014; Quick, Harman, Morgan, & Stagnitti, 2010; Turcotte, Carrier, Desrosiers, & Levasseur, 2015). The barriers respondents in the above studies identified to incorporating health promotion into their practice included a lack of confidence on the part of occupational therapists regarding their role, as well as organisational limitations which also reflected a lack of understanding of the potential contribution of occupational therapy to health promotion.

1.3 Research Problem

Weight gain and obesity are well documented as growing problems that impact on the health and wellbeing of people living with SSDs, who already face high levels of disability and disadvantage. Women with SSDs experience even greater levels of overweight and obesity and associated health issues than men. Women are likely to have different experiences and needs to men, and are under-represented in the existing research. There is, as yet, little evidence for effective means of addressing weight gain and obesity in this population and, despite the move towards a recovery oriented approach in health service delivery, little research that explores the issue from the perspective of people living with SSDs. While occupational therapy, with its focus on
the relationship between occupation and health and wellbeing, and alignment with the principles of health promotion, would appear well placed to help address the issue, there is little published to indicate the nature of such a contribution.

1.4 Research Aim and Questions

My aim therefore in conducting this research was to gain an understanding of the experiences of women living with SSDs, of managing their weight.

The specific questions I sought to answer were:

1. What was the women’s experience of managing their weight prior to and following their diagnosis with a SSD?
2. What factors influenced their ability to manage their weight?
3. What support had they, or did they think they would find helpful in managing their weight?

1.5 Significance

This is the only study to date that specifically explores the experience of women living with SSDs of managing their weight. The focus on women is important as it recognises the documented differences in experiences of men and women with SSDs and the potential for women to have different needs. As I identified earlier, much of the existing research is dominated by the experience of men, and may not transfer to women. This study has the potential to contribute to the development of more effective strategies to address the issue of weight gain and obesity in this population through drawing on the knowledge of those with lived experience of the issue. While drawing on the expertise that comes with lived experience is a core feature of the contemporary recovery orientation in mental health, there has been limited research of this type conducted into this issue to date. The longitudinal nature of this study adds a dimension that is not present in the small amount of existing research, which is all based on single encounters with study participants. In addition, the exploration in this study of what participants had done or were doing, and what they thought would be or had found helpful, differentiates it from the existing research which tends to focus on barriers to meeting public health guidance. Contextualising the findings in existing,
mental health recovery, health behaviour change and occupational therapy theory and research, assists in providing direction for further research and practice.

1.6 Research Approach

I chose to carry out this research using a qualitative approach, employing constructivist grounded theory methodology. A qualitative research approach is recognised as being well suited to exploring issues about which little is known, or that are complex and changing, or when the aim is to gain a detailed understanding of that issue, all of which are the case with this study. In addition the adoption of a qualitative approach was also consistent with my goal of understanding the issue from the perspective of the research participants and my desire to carry out the research in a manner that allowed participants to help shape the findings of the research (Creswell, 2013; Richards & Morse, 2007). Philosophically my approach to the research is underpinned by the constructivist paradigm, which views realities as multiple, contextual, intangible and socially constructed (Broido & Manning, 2002; Charmaz, 2000; Schwandt, 1994, 2000). This position is consistent both with the philosophical underpinnings of the profession of occupational therapy and the principles of recovery, which inform contemporary mental health practice. Because I was seeking to understand a process, that of women with SSDs managing their weight, I chose to use grounded theory methodology. Grounded theory is a qualitative methodology that enables researchers to develop explanations of social processes. This is achieved through a systematic process of inductive analysis of data that is generated from the participants’ experience of the issue being explored (Charmaz, 2000; Creswell, 2007; Fassinger, 2005; Wuest, 2007). Grounded theory is widely used in health research and has been identified as useful for developing understanding of health service users perspectives of a particular issue, how they manage that issue and what might be done, which is essentially the focus of this study (Crooks, 2001; McCann & Clark, 2003a; McCann & Clark, 2003b; Richards & Morse, 2007).

1.6.1 Recruiting Participants

I recruited participants from three community based mental health rehabilitation services in the Hunter Region of New South Wales, via the staff who worked as care-
coordinators in these services. Sampling was initially purposive, using predetermined criteria to identify people with experience of the issue (Charmaz, 2006; McCann & Clark, 2003a). As the study progressed I moved to theoretical sampling, which is characteristic of grounded theory methodology and aims at gathering data to further develop concepts that arise as analysis progresses (Charmaz, 2000, 2006; Fassinger, 2005).

1.6.2 Generating Data
The primary means I chose for generating data was through in-depth semi-structured interviews. The interviews were guided by a list of topics but I used this list flexibly so that I was able to ask the participants about their experiences in a conversational manner. I chose to use semi-structured interviews as they are recognised for their effectiveness in gaining an understanding of participants’ experiences from their perspective (Birks & Mills, 2011; Kvale & Brinkman, 2009). I chose to conduct multiple interviews, where possible, in order to provide more opportunity to develop the relationships and trust with the participants, and thereby potentially the depth of the information provided; to provide a longitudinal view, and also to provide opportunities for the participants to review and help shape the emerging analysis.

1.6.3 Analysing Data
I used NVivo QSR software to store all of the data and for most of the data analysis procedures. I analysed the data using the two levels of coding associated with constructivist grounded theory; initial coding which involves labelling sections of data, and focused coding which involves identifying and using more significant codes to sort the remainder of the data (Charmaz, 2006). I also made use of the constant comparison method and the analytical tool of memo writing, both characteristic of grounded theory methodology, in my analysis. The final processes that enabled me to bring together the concepts from data analysis into a coherent explanation were theoretical sorting and coding, and writing the storyline.

1.7 Overview of the Thesis
This thesis is presented in nine chapters, the contents of which are outlined below.
In this initial chapter I provide the background and significance of the study. I begin with an overview of the nature of SSDs, their impact on the individuals diagnosed, and what is generally involved in treatment. I also provide background information about occupational therapy, its history, current place in mental health services and evidence regarding occupational therapy scope of practice in addressing obesity and health promotion. I then identify the research problem, aims and questions and provide a brief overview of the research approach. The chapter concludes with an overview of the framework of the thesis.

In the second chapter I provide a review and synthesis of existing research regarding weight gain and obesity and management of this in people living with SSDs. I begin with the research regarding the prevalence of overweight and obesity in people with SSDs and the impact on physical health, mental health, quality of life and functional capacity. I then consider the research regarding factors that contribute to weight gain and the increased prevalence of overweight and obesity in this population. Finally I look at the existing evidence for interventions to address the issue, and the contributions of occupational therapy.

The third chapter is where I describe the research approach. I begin with the philosophical and methodological frameworks that underpin the study and my reasons for selecting these. I then describe the procedures involved in carrying out the study including reviewing the literature, sampling and recruiting participants, generating and analysing data and the strategies I employed to strengthen the trustworthiness of the findings. Finally I describe the ethical issues I considered in carrying out this study and how I addressed these.

I use the next four chapters to present the findings of the study. I contextualise the concepts presented in the findings in a discussion of the existing research.

In chapter four I describe the basic social problem shared by the women who participated in the study. Labelled using the words of one of the participants, the double-whammy describes the women’s experience of significant weight gain as a second whammy that came with their diagnosis of a SSD and brought with it
additional challenges. Following this I provide an overview of the whole theory of the women’s experience of dealing with the double-whammy, the components of which are described in more detail in the following three chapters.

I describe the core category and basic social process of doing as much as I can in chapter five. This is essentially the women’s response to the double-whammy and comprises four aspects, which are described in the sub-categories of, doing the right things, adjusting expectations, starting to do it, and, sticking with it.

The women’s ability to do what they saw as necessary to manage their weight fluctuated in response to mediating factors, which I describe in chapter six. The three categories of mediating factors are described in the sub-categories of knowing, mental health and wellbeing, and having a plan.

The final component of the findings comprises the things the women had found, or thought would, support them to be more able to do what they needed to do to manage their weight. I present the three categories of these facilitating factors in chapter seven. They include, talking about it, someone to do it with, and having a plan.

Chapter eight is the discussion of the findings. In this chapter I position the findings in relation to other relevant theories, including the core elements of models of mental health recovery, and health behaviour change theories more commonly used for addressing weight gain and obesity. I then consider the implications of the findings, first for mental health services and then more specifically for the profession of occupational therapy operating within these services.

In chapter nine, which is the final chapter of the thesis I provide a summary of the major findings of the study and consider the limitations and significance of these before making recommendations for practice and further research.

A reference list and appendices are provided at the end of the thesis.

1.8 Summary

My aim in conducting this research was to develop an explanation that accounts for the experience of women living with SSDs of managing their weight. I chose to conduct the
research according to the principles of constructivist grounded theory which is recognised as a useful approach in health research to developing understanding of consumers’ experience of an issue and how they deal with it. By conducting up to three interviews with participants over a two year period I was able to gain a longitudinal perspective of their experience, and provide opportunities for participants to have input into the data analysis and final shape of the findings. The findings provide an account of the women’s perception of their weight gain and its association with their diagnosis of a SSD, their response in terms of their actions to try to manage their weight, factors that affected their ability to carry out those actions and things that they had found, or thought would be helpful. When I examined these findings in the context of existing research and theory in mental health recovery, health behaviour change and occupational therapy they provided some clear direction for further research and practice to more effectively support women living with SSDs to manage their weight.
Chapter 2  Literature Review

2.1 Overview of the Chapter

In this chapter I present the findings of the preliminary literature review I carried out when I commenced this research, which I have updated and added to as the project progressed. My aim in conducting this literature review, consistent with constructivist grounded theory methodology, was to develop sensitising concepts which helped shape the aim and methodological approach for the study. In this chapter I provide a critical overview of key bodies of research. I begin the chapter with definitions of obesity and its prevalence in society. I then discuss the research evidence regarding the increased prevalence of obesity among people with SSDs relative to the general population and the effects of this which include: increased rates of a range of medical conditions and lower life expectancy, poorer mental health outcomes and quality of life, and reduced functional capacity. I go on to review the research regarding the factors that contribute to the increased prevalence of obesity in this population including the side effects of medications prescribed to treat SSDs and the lifestyle risk factors of low rates of physical activity and poor diet. I then consider the current evidence base for interventions to address this issue and the contribution of occupational therapy. Finally I review the small amount of existing research that examines the views and experiences of people with SSDs regarding this issue.

2.2 Defining Obesity as a Public Health Issue

Overweight and obesity are significant public health issues, with rates increasing year on year (Ng et al., 2013). The World Health Organisation (WHO) defines obesity as “excess fat accumulation that may impair health” (WHO, 2012). Body mass index (BMI) cut-offs are the most commonly used population level measure of obesity. The criteria for overweight according to the WHO, is a BMI ≥ 25 and for obesity is a BMI ≥ 30. A limitation of this approach to defining overweight and obesity is that BMI does not distinguish between weight associated with muscle and weight associated with fat. The other way that obesity is measured is via waist circumference, which is much more clearly correlated with fat and with the health impacts of obesity (World Health Organisation, 2000). When measured this way it is termed central obesity or abdominal
obesity. There are different cut off points for waist circumference for central obesity in men and women, and in different populations globally. In Caucasian men and women the cut offs are 94cm and 80cm respectively (World Health Organisation, 2000). Adults who are overweight or obese are significantly more likely to have a range of health conditions including type two diabetes, high blood pressure and ischaemic heart disease (Cameron et al., 2009; Janssen, Katzmarzyk, & Ross, 2002). The proportion of Australian adults with a BMI in the overweight or obese range grew from 56.3% in 1995 to 62.8% in 2011, with 27.5% being obese (Australian Bureau of Statistics, 2013).

2.3 Weight Gain and Obesity in People with SSDs

People with SSDs are significantly more likely to have obesity than the general population. A summary of studies reporting obesity prevalence, according to BMI, in this population can be found in Table 2.1. Obesity prevalence among samples of people with SSDs under psychiatric care, both inpatient and outpatient, is reported as up to three times that found in general population comparison groups (Loh, Meyer, & Leckband, 2008; Tirupati & Chua, 2007). Some of the variation in the comparison rates can be attributed to the means by which the data is gathered, for example Tirupati and Chua (2007) compared researcher recorded measurements of a sample of people with SSDs to population statistics from a national survey where the measurements were self-reported. In addition the general population comparison data is some years older than that collected from the study population, which would cause an over-estimation of the difference, as the rate of obesity has risen steadily in recent years. Studies with contemporaneous clinical and general population samples, and the same means of gathering measures of weight and height for both groups tend to report somewhat lower, albeit still significant differences (Loh, et al., 2008; Saarni et al., 2009). Rates of abdominal obesity are even higher than obesity according to BMI cut offs. Abdominal obesity was present in 82% of respondents in the second Australian national survey of psychosis (Galletly et al., 2012).

Where gender comparisons have been made, women with SSDs have been found to have higher prevalence of obesity than men with SSDs, and higher prevalence relative to their general population counterparts than men. In their investigation of metabolic
syndrome among 430 people with SSDs, DeHert et al. (2006) found that significantly more female participants (29.1%), than males (14.0%), had obesity. Similarly in the second Australian national survey of psychosis 52.5% of women were living with obesity compared to 42.4% of men (Galletly, et al., 2012). Filik et al. (2006) and Limosin, Gasquet, Leguay, Azorin, and Rouillon (2008) found that not only was the rate of obesity higher among women than men with schizophrenia, but the rate relative to the general population was also higher. These findings are consistent with those of Hakko et al. (2006) who found in a population based birth cohort study, that women with psychotic disorders were 3.6 times as likely than women in the general population to change their BMI category from under or normal weight to overweight or obese between the ages of 15 and 31, while the likelihood for men with psychotic disorders was only 2.4 times that for men in the general population.

**Table 2.1 Prevalence of Obesity in People with SSDs**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Male SSD %</th>
<th>Male Population %</th>
<th>Female SSD %</th>
<th>Female Population %</th>
<th>Total SSD %</th>
<th>Total Population %</th>
</tr>
</thead>
<tbody>
<tr>
<td>De Hert et al. (2006)</td>
<td>14.0%</td>
<td>-</td>
<td>29.1%</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Filik et al. (2006)</td>
<td>28.7%</td>
<td>13.6%</td>
<td>50.6%</td>
<td>16.6%</td>
<td>46.4%</td>
<td>-</td>
</tr>
<tr>
<td>Galletly et al. (2012)</td>
<td>42.4%</td>
<td>-</td>
<td>52.5%</td>
<td>-</td>
<td>46.4%</td>
<td>-</td>
</tr>
<tr>
<td>Limosin et al. (2008)</td>
<td>13%</td>
<td>12%</td>
<td>22%</td>
<td>13%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Loh et al. (2008)</td>
<td>-</td>
<td>46%</td>
<td>-</td>
<td>18%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Morgan et al. (2014)</td>
<td>-</td>
<td>47.4%</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Paton, Esop, Young, and Taylor (2004)</td>
<td>51%</td>
<td>35%</td>
<td>78%</td>
<td>27%</td>
<td>33%</td>
<td>OR 1.5</td>
</tr>
<tr>
<td>Saarni et al. (2009)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>OR 2.3</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Subashini, et al. (2011)</td>
<td>-</td>
<td>59.2%</td>
<td>-</td>
<td>44.7%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Tirupati &amp; Chua (2007)</td>
<td>-</td>
<td>59%</td>
<td>-</td>
<td>20.8%</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

*OR = Odds Ratio

**2.4 Impact of Obesity in People with SSDs**

**2.4.1 Physical Health**

People with SSDs experience high levels of co-morbid physical illness. They are more likely than their general population counterparts to report current illness (Leas, 2004), and are also more likely to have multiple medical conditions (Sokal et al., 2004).
Participants (n=1424) with SSDs in a long term drug trial had an average of 2.2 medical conditions, 58% had at least one condition and 9% had four or more conditions (Chwastiak et al., 2006). People with SSDs are also more likely to have chronic conditions. Carney, Jones and Woolsen (2006), in a retrospective analysis of longitudinal administrative claims data from a health insurance provider, found that people with SSDs were more likely to have one or more chronic medical conditions compared to controls. Over 33% of the people with SSDs in that study had three or more conditions which was nearly three times the number of controls with the same number of conditions (Carney, et al., 2006). This pattern of increased physical health problems compared to general population controls has also been found in those with first episode psychosis with Samele et al. (2007) reporting an odds ratio (OR) of 2.85. Only one study made gender comparisons: Chwastiak et al. (2006) found that women had a significantly greater number of medical conditions than men.

Much of the comorbidity with somatic conditions in people with SSDs is with so-called lifestyle medical conditions, which are those conditions associated with the way a person lives. In a study by Dixon, Prostrado, Delahunty, Fischer and Lehman (1999) 65% of participants reported at least one lifestyle medical condition, and 36% had more than one condition. Perhaps unsurprisingly, given the higher prevalence of obesity in this population, many of the chronic health conditions associated with obesity are also more prevalent among people with SSDs (Miller, Paschall, & Svendsen, 2006).

**Metabolic Syndrome**

Metabolic syndrome describes a cluster of heart attack risk factors (International Diabetes Federation (IDF), 2005). For a person to be diagnosed with metabolic syndrome they must have central obesity, plus any two of: raised triglycerides, reduced HDL cholesterol, raised blood pressure or raised fasting plasma glucose (IDF, 2005). Given that obesity is considered a core diagnostic feature it is unsurprising that the prevalence of metabolic syndrome has been found to be significantly higher among people with SSDs than the general population. Table 2.2 provides a summary of studies of prevalence of metabolic syndrome in people with SSDs.
Most studies of the overall prevalence of metabolic disorder report rates in people with SSDs of between two and three times that of the general population comparison group (Cohn, Prud’homme, Streiner, Kamch, & Remington, 2004; De Hert, et al., 2006; Galletly, et al., 2012; Saari et al., 2005; Tirupati & Chua, 2007). A higher rate of four times the general population was reported by Heiskanen, Niskanen, Lyytikainen, Saarinen, and Hintikka (2003), however the sample size was very small (n=35). A population survey by Suvisaari et al. (2007) found a rate of only 1.2 times the controls.

Table 2.2: Prevalence of Metabolic Syndrome in People with SSDs

<table>
<thead>
<tr>
<th>Reference</th>
<th>Male SSD</th>
<th>Female SSD</th>
<th>Total SSD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arango et al. (2008)</td>
<td>23.6%</td>
<td>27.2%</td>
<td>24.6%</td>
</tr>
<tr>
<td>Cohn et al. (2004)</td>
<td>42.6%</td>
<td>24%</td>
<td>48.5%</td>
</tr>
<tr>
<td>DeHert et al. (2006)</td>
<td>ATP-III 28%</td>
<td>ATP-III 29.1%</td>
<td>ATP-III 28.4%</td>
</tr>
<tr>
<td></td>
<td>ATP-III A 30.5%</td>
<td>ATP-III A 35.8%</td>
<td>ATP-III A 32.3%</td>
</tr>
<tr>
<td>Galletly et al. (2012)</td>
<td>IDF -34.1%</td>
<td>IDF 39.7%</td>
<td>IDF 36%</td>
</tr>
<tr>
<td>Heiskanen et al. (2003)</td>
<td>47%</td>
<td>11-17%</td>
<td>25%</td>
</tr>
<tr>
<td>McEvoy et al. (2005)</td>
<td>ATP-III 36%</td>
<td>ATP-III 51.6%</td>
<td>ATP-III 40.9%</td>
</tr>
<tr>
<td>Saari et al. (2005)</td>
<td>AHA 36.6%</td>
<td>AHA 54.2%</td>
<td>AHA 42.7%</td>
</tr>
<tr>
<td>Subashini et al. (2011)</td>
<td>19%</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>Suvisaari et al. (2007)</td>
<td>34%</td>
<td>24%</td>
<td></td>
</tr>
<tr>
<td>Tirupati and Chua (2007)</td>
<td>36.2%</td>
<td>30.1%</td>
<td></td>
</tr>
</tbody>
</table>

In most studies where gender comparisons were made, women with SSDs were found to have higher prevalence of metabolic syndrome than men, and higher prevalence relative to their population counterparts than men with SSDs (Cohn, et al., 2004; De Hert, et al., 2006; Galletly, et al., 2012; McEvoy, et al., 2005). Only the study by Arango et al. (2008) found no significant gender difference. The presence of metabolic syndrome is associated with other health issues also found to be more prevalent in people with SSDs such as type II diabetes and cardiovascular disease.
**Type II Diabetes**

As with metabolic disorder, the prevalence of type II diabetes has been found to be significantly higher among people with SSDs than in the general population. Table 2.3 provides a summary of studies of prevalence of type II diabetes in people with SSDs.

There is significant variability in the reported prevalence of diabetes in people with SSDs but most studies place the odds ratio at approximately two or more. Much of the variation can be explained by the different methods used to gather the prevalence data. The lowest odds ratios are reported in studies using self-report measures (Sokal, et al., 2004), or health insurance claims data (Curkendall, Jingping, Glasser, Stang, & Jones, 2004; Enger, Weatherby, Reynolds, Glasser, & Walker, 2004; Hsu, Chien, Lin, Chou, & Chou, 2011). These studies, which generally report odds ratios of approximately two, rely on diabetes having been diagnosed, and the individuals either recognising that they had this disorder or receiving treatment for it. Studies that screened for diabetes, and therefore picked it up whether the individual was aware of or receiving treatment for it or not, report much higher odds ratios (Cohen, Stolk, Grobbee, & Gispen-De Wied, 2006; Cohn, et al., 2004; Suvisaari, Perala, Saarni, et al., 2008). The rates reported are also impacted by whether the comparison groups were matched for age, as incidence of diabetes increases with age. This is illustrated by the findings of Cohen, Dekker, Peen, and Gispen-De Wied (2006) who reported an odds ratio of 1.89 overall, but much higher for particular age brackets, OR:13.29 in 30-39 year olds and OR:6.74 in 40-49 year olds.

A number of studies found significantly higher rates of diabetes among women than men with SSD (Goff et al., 2005; Suvisaari, Perala, Saarni, et al., 2008). Dixon et al. (2000) reported that the women in their study were 2.1 times as likely to have type II diabetes as the men.
Table 2.3: Prevalence of Type II Diabetes in People with SSDs

<table>
<thead>
<tr>
<th>Reference</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SSD Population</td>
<td>SSD Population</td>
<td>SSD Population</td>
</tr>
<tr>
<td>Cohen et al. (2006)</td>
<td>9% 30-39 yrs 3.8%</td>
<td>4.9% 40-49 yrs 9.3%</td>
<td>4.9%</td>
</tr>
<tr>
<td>Cohen et al. (2006)</td>
<td>14.5% 30-39 yrs 0.3%</td>
<td>1.5% 40-49 yrs 1.5%</td>
<td>1.5%</td>
</tr>
<tr>
<td>Cohn et al. (2004)</td>
<td>18% 30-39 yrs 0.3%</td>
<td>6.4% 40-49 yrs 1.5%</td>
<td>6.4%</td>
</tr>
<tr>
<td>Curkendall et al. (2004)</td>
<td>OR 1.9 30-39 yrs 0.3%</td>
<td>18-44 yrs 1.2% 40-49 yrs 1.5%</td>
<td>18-44 yrs 1.2%</td>
</tr>
<tr>
<td>Dixon et al. (2000)</td>
<td>10.8% 30-39 yrs 0.3%</td>
<td>18-44 yrs 1.2% 45-64 yrs 6.3%</td>
<td>18-44 yrs 1.2%</td>
</tr>
<tr>
<td>Enger et al. (2004)</td>
<td>6.2% 30-39 yrs 0.3%</td>
<td>3.1% 40-49 yrs 1.5%</td>
<td>3.1%</td>
</tr>
<tr>
<td>Goff et al. (2005)</td>
<td>11% 30-39 yrs 0.3%</td>
<td>16% 40-49 yrs 1.5%</td>
<td>3%</td>
</tr>
<tr>
<td>Sokal et al. (2004)</td>
<td>OR 1.98 30-39 yrs 0.3%</td>
<td>18-44 yrs 1.2% 40-49 yrs 1.5%</td>
<td>18-44 yrs 1.2%</td>
</tr>
<tr>
<td>Subashini et al. (2011)</td>
<td>15.3% 30-39 yrs 0.3%</td>
<td>7.3% 40-49 yrs 1.5%</td>
<td>7.3%</td>
</tr>
<tr>
<td>Suvisaari et al. (2008)</td>
<td>19% 30-39 yrs 0.3%</td>
<td>24.3% 40-49 yrs 1.5%</td>
<td>22%</td>
</tr>
<tr>
<td>Verma et al. (2009)</td>
<td>OR 4.9 30-39 yrs 0.3%</td>
<td>0.5% 40-49 yrs 1.5%</td>
<td>0.5%</td>
</tr>
</tbody>
</table>

**Cardiovascular Disease**

Research has examined the prevalence of cardiovascular disease in people with SSDs compared to the general population by calculating relative risk, measurement of actual incidence and calculation of odds ratios. Table 2.4 provides a summary of studies of prevalence of cardiovascular disease in people with SSDs.

Studies looking at the risk of coronary heart disease in people with SSDs refer to the Framingham risk which is the risk of coronary heart disease in the next ten years, calculated using an algorithm based on the presence of known risk factors. Four such studies were identified, all of which calculated a significantly higher risk in people with SSDs than the general population (Bobes et al., 2006; Cohn, et al., 2004; Goff, et al., 2005; McCreadie, 2003).

These findings are supported by studies reporting actual prevalence of cardiovascular disease. Prevalence of most, although not all, cardiovascular conditions, was found to
be higher among people with SSDs than general population comparison groups (Enger, et al., 2004; Filik, Sipos, Kehoe, Burns, Cooper, & Stevens, 2006; Lahti et al., 2012).

Table 2.4: Risk or Prevalence of Cardiovascular Disease in People with SSDs

<table>
<thead>
<tr>
<th>Reference</th>
<th>Cardiovascular Disease Risk</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SSD Population</td>
<td>SSD Population</td>
<td>SSD Population</td>
<td></td>
</tr>
<tr>
<td>Bobes et al. (2006)</td>
<td>CHD 8.3%</td>
<td>CHD 4.5%</td>
<td>CHD risk 6.8%</td>
<td></td>
</tr>
<tr>
<td>Cohn et al. (2004)</td>
<td>CHD 8.9%</td>
<td>CHD 6.3%</td>
<td>CHD 2.6%</td>
<td>CHD risk 2.0%</td>
</tr>
<tr>
<td>Curkendall et al. (2004)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Odds Ratio</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>CHD risk 1.7/1.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Syncope 4.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>MI OR 4.81</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Arrhythmia OR 1.75</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Angina 2.45</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enger et al. (2004)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>CHD risk 4.1%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stroke risk 3.8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>TIA 2.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Filik et al. (2006)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>CHD risk 50% higher</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>than controls</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Goff et al. (2005)</td>
<td>CHD 34% &gt; controls</td>
<td>CHD risk 50%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>higher than controls</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>McCreadie (2003)</td>
<td>CHD 10.5%</td>
<td>CHD 6.4%</td>
<td>CHD risk 7%</td>
<td>CHD risk 4.1%</td>
</tr>
<tr>
<td></td>
<td>Stroke 4.2%</td>
<td>Stroke 2.3%</td>
<td>Stroke risk 3.8%</td>
<td>Stroke risk 2%</td>
</tr>
<tr>
<td>McDermott et al. (2005)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Odds Ratio</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>CAD 0.57</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>CHF 2.27</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>TIA 1.53</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Findings regarding gender differences in the prevalence of cardiovascular disease do not provide a clear picture. Only three of the studies measuring Framingham risk, and one of those measuring actual incidence, made gender comparisons. Of the studies that compared risk according to gender, one found a higher risk for women (Goff, et al.,
2005), one found a higher risk for men relative to the general population and no
difference for women (Cohn, et al., 2004), whilst one found no significant gender
difference in risk (McCreadie, 2003). Lahti et al (2012), found that not only were
hospitalisation rates for coronary heart disease higher among women than men,
mortality was markedly higher as was mortality from stroke.

2.4.2 Mortality

The impact of poor health status of people with SSDs is most starkly illustrated by the
reduced life expectancy of individuals diagnosed with these disorders (Hennekens,
Hennekens, Hollar, & Casey, 2005). Studies comparing mortality rates of people with
SSDs and the general population most often do so in terms of the standardised
mortality ratio (SMR) which gives the risk of death compared to the general population
of similar age and gender (Harris & Barraclough, 1998). Calculations of the SMR for
people with SSDs vary somewhat, but most studies have found that people with SSDs
are approximately two to three times more at risk of death than those of similar age in
the general population (Brown, Inskip, & Barraclough, 2000; Curkendall, et al., 2004;
Hoye, Jacobsen, & Hansen, 2011; Joukamaa et al., 2006; Osby, Correia, Brandt, Ekbom,
& Sparen, 2000; Suvisaari et al., 2013). The SMR for men with SSDs has generally been
found to be higher than for women (Brown, et al., 2000; Joukamaa et al., 2001; Osby, et
al., 2000; Saha, Chant, & McGrath, 2007). Some more recent studies however have
found the gap between men and women has narrowed (Hoye, et al., 2011) and in the
most recent study I located the trend was reversed (Crump, Winkleby, Sundquist, &
Sundquist, 2013). Table 2.5 provides a summary of studies of mortality rates in people
with SSDs.

Suicide is the largest single cause of death in people with SSDs (Brown, 1997;
Lawrence, Jablensky, Holman, & Pinder, 2000). The SMR due to suicide in this
population group has been calculated to be 10.8 in women and 10.7 in men (Hiroeh,
Appleby, Mortensen, & Dunn, 2001), meaning that people with SSDs are
approximately ten times more likely to die by suicide than the general population.
Startling as these figures are, suicide has been found to account for less than a third of
the excess mortality experienced by people with SSDs, while the majority is
attributable to natural causes (Brown, et al., 2000; Crump, et al., 2013; Hoang, Stewart, & Goldacre, 2011).

Table 2.5: SMR for People with SSDs

<table>
<thead>
<tr>
<th>Reference</th>
<th>SMR – All Causes</th>
<th>SMR Natural Causes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Brown et al. (2000)</td>
<td>3.54</td>
<td>2.32</td>
</tr>
<tr>
<td>Curkendall et al. (2004)</td>
<td>2.8</td>
<td></td>
</tr>
<tr>
<td>Crump et al. 2013</td>
<td></td>
<td>2.44</td>
</tr>
<tr>
<td>Enger et al. (2004)</td>
<td></td>
<td>4.4</td>
</tr>
<tr>
<td>Heila et al. (2005)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hoye et al. 2011</td>
<td>3.5</td>
<td>2.6</td>
</tr>
<tr>
<td>Joukamaa et al. (2006)</td>
<td></td>
<td>2.84</td>
</tr>
<tr>
<td>Joukamaa et al. (2001)</td>
<td></td>
<td>3.29</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lawrence et al. (2000)</td>
<td></td>
<td>1.67</td>
</tr>
<tr>
<td>Osby et al. (2000)</td>
<td>2.8</td>
<td>2.4</td>
</tr>
<tr>
<td>Saha et al. (2007)</td>
<td>3.02</td>
<td>2.37</td>
</tr>
<tr>
<td>Suvisaari et al. (2013)</td>
<td>3.03</td>
<td></td>
</tr>
</tbody>
</table>

The SMR due to natural causes is approximately two (Brown, et al., 2000; Enger, Weatherby, Reynolds, Glasser, & Walker, 1999; Osby, et al., 2000). Cardiovascular disease has been identified as the largest single natural cause of death in the studies of mortality in people with SSDs (Brown, 1997; Capasso, Lineberry, Bostwick, Decker, & St Sauver, 2008; Crump, et al., 2013; Osby, et al., 2000; Suvisaari, et al., 2013). A Swedish study that looked at changes in mortality of people with SSDs first admitted to hospital over the period 1976-1995, found an increase in SMR for all causes of death, but in particular cardiovascular disease which increased 4.7 times in men and 2.7 times in women (Osby, 2000). Longitudinal studies have found that the gap in mortality between people with SSDs and the general population has increased over time with the
increase entirely accounted for by natural causes (Hoang, et al., 2011; Hoye, et al., 2011; Nielson, Uggerby, Wallenstein Jensen, & McGrath, 2013).

The other way that the difference in mortality between people with SSDs and the general population is reported is in terms of life expectancy in years. Studies have reported the life expectancy of people with SSDs to be reduced by between 10 and 25 years (Crump, et al., 2013; Laursen, Nordentoft, & Mortensen, 2014; Laurson, 2011; Nielson, et al., 2013). As well as reduced life expectancy, the high rates of obesity and poor physical health status of people with SSDs has been linked to poorer mental health outcomes, medication non-adherence, lower quality of life and reduced functional capacity.

### 2.4.3 Mental Health

The number of medical co-morbidities has been found to be significantly associated with the overall severity of psychopathology, and in particular the severity of positive symptoms and depressive symptoms in people with SSDs (Chwastiak, et al., 2006; Dixon, et al., 1999; Jeste, Gladsjo, Lindamer, & Lacro, 1996). Arango (2008) found that individuals with SSDs and metabolic syndrome had more severe symptoms, both positive and negative, than those with SSDs who did not have metabolic syndrome. The nature of the studies does not however allow for the determination of causality.

While weight gain has been identified as the most distressing adverse effect of treatment with antipsychotic medications, particularly for women (Fakhoury, Wright, & Wallace, 2001), it has also been associated with treatment efficacy. Greater treatment emergent weight gain has been found to correlate with greater improvements in mental state and more effective response to antipsychotic medications (Ascher-Svanum, Stensland, Kinon, & Tollefson, 2005; Bai et al., 2006).

### 2.4.4 Medication Adherence

Weight gain and embarrassment about weight gain have been identified as the side effects of antipsychotic medications that cause the most distress, particularly among women (Covell et al., 2007; Fakhoury, et al., 2001). Similarly, distress with weight gain appeared to be the mediating psychological variable in a study of the impact of obesity
on adherence with antipsychotic medication (Weiden, Mackell, & McDonnell, 2004). In a survey of community dwelling people with SSDs in America, Weiden et al. (2004) found that those with obesity were 2.5 times as likely to be not taking their medication. The association was linear, with people who were in the overweight range being less likely than those who were in the obese range, but more likely than those who had weight in the normal range to be non-adherent. In a trial in the USA, which was set up to examine issues regarding novel antipsychotics and their effectiveness, only 26% of participants finished the 18 month study on the medication they were originally prescribed. Weight gain was one of the factors associated with discontinuation and was found to be more common in the medications associated with higher degrees of weight gain (Manschreck & Boshes, 2007).

2.4.5 Quality of Life

Weight gain and obesity have both been found to be associated with poorer perceptions of quality of life among people with SSDs. Allison, McKell and McDonnell (2003) found that weight gain was associated with lower quality of life, specifically poorer quality of life, general health and vitality. Similarly, Hofer et al. (2004) found that weight gain was negatively correlated with general life satisfaction, affect and self-esteem. Quality of life in people with SSDs has been found to be linked with both BMI and waist circumference (Faulkner, Cohn, Remington, & Irving, 2007), with perceptions of quality of life declining across the BMI categories from healthy to obese (Kolotkin et al., 2008; Strassnig, Singh Brar, & Ganguli, 2003a).

Comorbidity with medical conditions is also associated with lower quality of life in people with SSDs. The number of medical co-morbidities has been found to negatively correlate with quality of life scores (Chwastiak, et al., 2006). The presence of specific comorbidities also reduces quality of life. Dickerson et al. (2008) found that participants with SSDs and diabetes reported less subjective satisfaction with health related quality of life than those with SSDs but without diabetes.
2.4.6 Functional Capacity

It is perhaps unsurprising that obesity and associated comorbidity have been found to be associated with reduced physical capacity in people with SSDs (Strassnig, Brar, & Ganguli, 2011). Obesity has been found to lead to disability independently of SSDs via both intrinsic (such as anthropometrics and body composition) and external (related to comorbidities) determinants (Capodaglio et al., 2013). People with SSDs have been found to have significantly impaired physical functioning compared to the general population and those with other psychiatric diagnoses (Chafetz, White, Collins-Bride, Nickens, & Cooper, 2006). In a qualitative study exploring the experience of women aging with SSDs one of the categories in the findings was the impact of declining physical abilities on participants’ ability to do things. The difficulties reported, including weakness and balance difficulties, pain in extremities, cardio respiratory and bladder control problems, were somewhat surprising given the relative youth of the study sample (average age 54, range 47-65 years) (Pentland, Miscio, Eastabrook, & Krupa, 2003).

In addition to the impact on physical capacity, obesity and associated co-morbidity have also been associated with reduced cognitive functioning in people with SSDs. Having a BMI in the obese range has been found to correlate with poorer cognitive functioning (Abdul Rashid et al., 2013; Friedman et al., 2010). In addition studies have found poorer cognitive performance in people with SSDs who have medical co-morbidities relate to obesity such as metabolic disorder (Li, Zhan, Rao, & Zhang, 2014; Lindenmayer et al., 2012), and type II diabetes (Dickinson, Gold, Dickerson, Medoff, & Dixon, 2008; Takayanagi, Cascella, Sawa, & Eaton, 2012). There also appears to be a correlation between the number of medical comorbidities and the level of neurocognitive impairment (Chwastiak, et al., 2006).

2.5 Causes of Obesity in People with SSDs

The issue of weight gain and obesity in people with SSDs is a complex one and while a number of contributing factors have been identified causal mechanisms are far from clear. Much of the research exploring this has focused on the impact of side effects of
medications used to treat these disorders, in particular antipsychotic medications, and lifestyle risk factors of diet and physical activity.

2.5.1 Medication Side Effects

Medication side effects are undoubtedly a factor contributing to the high prevalence of overweight and obesity among people with SSDs. In a survey of people taking at least one antipsychotic medication, the side effects that were most commonly reported were weight gain/hunger, tiredness/lethargy, and lack of co-ordination of muscle problems (Cascade, Kalali, Mehra, & Meyer, 2010). Numerous studies and recurrent systematic reviews have found significant weight gain is associated with most antipsychotic medications (Allison et al., 1999; McIntyre et al., 2003; Taylor & McAskill, 2000; Wetterling, 2001). The degree and rate of weight gain are generally greater with the more recent ‘atypical’ or ‘second generation’ antipsychotics, although there is variation between different versions of these medications (Parsons et al., 2009; Rummel-Kluge et al., 2010). A longitudinal observational case-control study using national hospital discharge data found that over the period 1988-2002, spanning time prior to the introduction of atypical antipsychotics, to them accounting for 86% of all antipsychotic prescriptions, there was a 12.6% increase in obesity among people with schizophrenia and schizo-affective disorder compared to 2.6% in those without these disorders (Reist et al., 2007). Weight gain has been found to occur quite rapidly following the commencement of antipsychotic medication with significant increases in BMI and waist circumference found in as little as four weeks (Tarricone et al., 2008). While short term studies suggest that the initial rapid weight gain may be followed by a plateau, reviews have found evidence for continuing weight gain over longer periods (McCloughen & Foster, 2011; Wetterling, 2001).

The mechanisms by which antipsychotic medications cause this weight gain are not clearly understood. A literature review found evidence for a range of possible contributing effects including, disruption of carbohydrate and lipid metabolism, peripheral insulin resistance leading to type II diabetes, increased appetite and enhanced energy consumption and non specific effects such as sedation and reduced motor activity (Baptista, Kin, Beaulieu, & Baptista, 2002). It has also been found that
characteristics of the individual, such as age, baseline BMI and gender impact on the amount of weight gain that is experienced (Bushe, Slooff, Haddad, & Karagianis, 2013; Strassnig, Miewald, Keshaven, & Ganguli, 2007; Verma, Liew, Subramaniam, & Poon, 2009). Of particular relevance to this study is the finding that women are more susceptible to weight gain as a side effect of antipsychotic medication (Seeman, 2009; Strassnig, et al., 2007; Verma, Liew, et al., 2009).

While the evidence that side effects of antipsychotic medications contribute to weight gain and the disproportionately high levels of obesity in people living with SSDs is compelling, they are not the only factor. Weight gain and associated medical conditions such as diabetes were observed in people with SSDs before the advent of these medications (Barnett et al., 2007). People diagnosed with SSDs who are drug naïve or drug free have also been found to have higher rates of obesity and diabetes than general population comparison groups (Allison et al., 2009; Thakore, Mann, Vlahos, Martin, & Reznek, 2002). Research into weight gain, obesity and associated poor physical health of people with schizophrenia also suggests a link with lifestyle factors, specifically low levels of physical activity and poor dietary intake.

### 2.5.2 Physical Activity Levels

There is a relatively limited body of research that examines the physical activity levels in people living with SSDs. The research that exists is however fairly consistent in its findings that people living with SSDs have lower levels of physical activity than are recommended for good health and are less likely to meet the recommended levels than general population comparison groups.

People living with SSDs have been found in repeated studies to meet a variety of criteria for being sedentary, and to be more sedentary than general population or healthy control comparison groups (Bassillos, Judd, & Pattison, 2014; Galletly, et al., 2012). One criterion for being sedentary is taking on average less than 5000 steps per day (Tudor-Locke & Bassett, 2004). In their study using pedometers with outpatients with SSDs Beebe and Harris (2013) found that the participants averaged between 2384 and 4399 steps per day. Other studies have looked at the proportion of waking time that is spent in sedentary activities, which are defined as involving sitting, reclining or
lying and expending less than 1.5 times the metabolic rate. Participants with SSDs in a study by Janney et al. (2013) spent 81% of their waking hours in such activities. The proportion of time spent engaged in sedentary activities is significantly greater among people with SSDs than the general population (Roick et al., 2007; Soundy et al., 2013). Finally a study that measured total energy expenditure (TEE) and activity energy expenditure (AEE) using double labelled water, and based on these readings calculated the physical activity level (PAL) of a group of men with schizophrenia (Sharpe, Stedman, Byrne, Wishart, & Hills, 2006). According to the World Health Authority a PAL of 1.5 or less is sedentary. Therefore the average PAL of 1.39 among participants in the study by Sharpe et al. (2006) also supports the suggestion that people with SSDs are sedentary.

In addition to spending more time engaged in sedentary activities, existing research suggests that people with SSDs also have low levels of engagement in physical activity. Most studies that have investigated this phenomenon have found that people with SSDs have lower overall participation in physical activity than general population or healthy controls (Brown, Birtwistle, Roe, & Thompson, 1999; Lindamer et al., 2008). An exception is the study by McLeod, Campbell and Hesketh (2011) in which participants with SSDs were as likely to meet the recommendations for the amount of physical activity as the general population. However, in this study, as in others that distinguished between different categories of physical activity, people with SSDs were more likely to report walking or low intensity physical activity than vigorous or high intensity activity (McLeod, et al., 2011; Roick, et al., 2007; Soundy, et al., 2013). They have also been found to be more likely to report doing no exercise at all (Archie et al., 2007; Davidson et al., 2001; Roick, et al., 2007).

2.5.3 Diet

As with physical activity there is only a small body of research into the diet of people living with SSDs. Much of what does exist, however, suggests that this population is less likely to meet guidelines for healthy eating than general population comparison groups. They have been found to have lower consumption of fruit and vegetables (Brown, et al., 1999; Dipasquale et al., 2013; McCreadie et al., 1998; Simonelli-Munoz et
In addition their diets have generally been found to be higher in fat and sugar (Brown, et al., 1999; Dipasquale, et al., 2013; Ratliff et al., 2012). Similarly, Samele et al. (2007) found that those with first episode psychosis were more likely to consume a high fat, fast food diet than matched community controls.

Not all comparisons found people with SSDs to have less healthy diets than the general population. Strassnig, Singh Brar, and Ganguli (2003b) found that the participants in their study with SSDs did not make different dietary choices than the general population, gaining the same proportions of calories from fat, protein and carbohydrates although they ate more overall than the general population comparison group. Henderson et al. (2006) found that the group with SSDs consumed less total fat than the general population comparison group in their study. Some of the variation in findings of studies of diet habits may be attributable to the different methods of data collection employed. For example, Henderson et al. (2006) used a four day dietary record, whereas Strassnig et al. (2003b) employed a 24 hour recall, while others such as Simonelli-Munoz et al. (2012) used survey tools.

Only two of the studies identified made gender comparisons, however these indicated that the diet of women with schizophrenia was less healthy than that of men. In particular they were found to have a higher consumption of fat (Archie, et al., 2007; Strassnig, Singh Brar, et al., 2003b).

2.6 Addressing Obesity in People with SSDs

2.6.1 The Evidence Base for Clinical Interventions

The role of both medication side effects and lifestyle risk factors in the increased rates of obesity in people with SSDs has lead researchers to explore the potential of pharmacological and behavioural interventions to address the issue. Several systematic reviews comparing pharmacological and non-pharmacological interventions found there was insufficient evidence to support the use of adjunct medication for weight loss (Birt, 2003; Faulkner, Cohn, & Remington, 2007; Faulkner & Cohn, 2006; Faulkner, Soundy, & Lloyd, 2003). Faulkner and Cohn (2006) did suggest that this might be the final course of action for those who do not respond to behavioural interventions.
Whitney, Procyshyn, Frederickson and Barr (2015) however, suggested that while there was modest evidence of some benefit from some pharmacological interventions they each had side effects that needed to be considered. While there was some support in these reviews for the effectiveness of non-pharmacological interventions this was limited.

Systematic reviews and meta-analyses of randomised controlled trials have found that there is some evidence, albeit limited, for the effectiveness of behavioural interventions to prevent or treat weight gain in people with SSDs. Several reviews in recent years have found statistically significant differences between intervention and control groups for weight, and BMI (Alvarez-Jimenez, Hetrick, Gonzalez-Blanch, Gleeson, & McGorry, 2008; Bonfioli, Berti, Goss, Muraro, & Burti, 2012; Caemmerer, Correll, & Maayan, 2012; Lowe & Lubos, 2008). It is important to note however that in those reviews that report changes in bodyweight or BMI from baseline, the size of these changes were consistently below even the lowest threshold (5% of baseline), identified as being clinically significant. There is also a lack of evidence for the weight loss being maintained as most of the studies included in the reviews did not include follow-up, and where follow-up did occur the duration was relatively short at between two and three months (Alvarez-Jimenez, et al., 2008; Bonfioli, et al., 2012; Caemmerer, et al., 2012). This is significant as even those who are most successful in achieving weight loss struggle to maintain this over time. This is illustrated by the findings of a study of lifetime members of Weight Watchers among whom only 26.5% maintained weight loss of at least 5% of baseline for one year and only 16.2% at five years (Lowe, Kral, & Miller-Kovach, 2008). It was also not possible to discern what type of interventions included in the reviews were more beneficial due to the variability and overlap of what was reported (Alvarez-Jimenez, et al., 2008; Caemmerer, et al., 2012; Lowe & Lubos, 2008).

The need for further research to determine effective approaches to managing this far-reaching problem is advocated in all of the systematic reviews to date. While the authors of these reviews call for more randomised controlled trials with increased
numbers, longer interventions and duration of follow-up, there is also a need for other research to inform the development of appropriate approaches.

2.6.2 Occupational Therapy Intervention

Despite the apparent fit between health promotion and occupational therapy and the increasing body of research regarding the profession’s role in addressing obesity discussed in the previous chapter, there is little evidence of occupational therapy involvement in intervention trials to address weight gain and obesity in people with SSDs. A series of articles described the development and trial of the RENEW program which was delivered to groups of participants by a multi-disciplinary team that included an occupational therapist (Brown, Goetz, & Hamera, 2011; Brown, Goetz, Hamera, & Gajewski, 2014; Brown, Goetz, Van Sciver, Sullivan, & Hamera, 2006). The program involved education and experiential learning in physical activity, nutrition and healthy lifestyles. In a small pilot study, Bacon, Farnworth and Boyd (2012) provided access to, and instruction in the use of, the Nintendo Wii Fit to people at risk of obesity in a secure mental health facility. Three other papers described interventions involving occupational therapists (Lloyd & Sullivan, 2003; Lloyd, Sullivan, Lucas, & King, 2003; Pendlebury, Bushe, Wildgust, & Holt, 2007). In all three cases the articles were descriptive of clinical programs rather than research trials. Two papers described programs that involved psycho-education about diet and exercise and an exercise program (Lloyd & Sullivan, 2003; Lloyd, et al., 2003). While these were described as health promotion or lifestyle, rather than weight loss programs, weight loss was the key outcome reported. The program implemented by Pendlebury et al. (2007) was a weight loss group which involved education and weekly weighing of participants. The interventions described in these articles are consistent with those represented in the wider evidence base. However, while these papers give some insight into the type of interventions occupational therapists may be involved in, they do not provide detail on the specific contribution of the occupational therapists to these programs.

Recommendations regarding the focus of occupational therapy interventions in this area are made in a small number of related, but not intervention based, studies. In two studies exploring occupational therapists’ experiences of addressing issues of diet with
people with severe mental illnesses (SMI), the role was described as centreing on supporting people with SMI to integrate guidance on healthy eating into their daily lives, largely through development of skills (Mahony, Haracz, & Williams, 2012; Williams, Magin, Sultana, & Haracz, in press). Similarly, Carson, Blake, Saunders and O’Brien (2013), based on their findings of the factors influencing food choices in people with SMI, suggested that occupational therapists focus on skill development to support capability and self-efficacy in tasks such as grocery shopping, meal planning and preparation and strategies to enable people with SMI to integrate changes into their daily lives. The theme of facilitating the integration of changes in daily routines was also picked up on by Northey and Barnett (2012) in relation to increasing physical activity participation.

2.6.3 Views and Experiences of People with SSDs

A key factor in determining effective long term actions to address their issues with weight gain and obesity must surely be the views of people with SSDs themselves (Connolly & Kelly, 2005). This position can be argued on the basis of the principles of the contemporary recovery approach to mental health practice, which values the expertise of people with lived experience. In addition there is also considerable research evidence that people living with SSDs have different views regarding their needs and priorities in terms of both goals and services (Bridges et al., 2011; Fischer, Shumway, & Owen, 2002; Foldemo, Ek, & Bogren, 2004; Meddings & Perkins, 2002). Allison et al. (2009) also point to the need to consider the motivational, cognitive, social and resource deficits that individuals in this treatment population often encounter.

There has been to date limited research exploring these experiences and opinions. A small number of studies have been carried out in recent years, which provide some insights, but these are dominated by male participants and focus on a specific aspect of the issue, such as participation in physical activity, or the impact of the weight gain.

Existing studies suggest that people with SSDs are aware of issues with their weight, and that those who are living with overweight or obesity generally want to lose weight and have made some effort to do so. Strassnig, Brar and Ganguli (2005) found a significant correlation between self-perception of being overweight and BMI in a
sample of 143 people with SSDs. There were, however, significant gender trends, with males significantly more likely to misclassify their weight status as lower than females. This may account for the finding by Loh et al. (2008) that participants with SSDs who had obesity were more likely to underestimate their body size than controls, as 90% of the study participants were male. In each of the studies above there was also a correlation between increased body weight and both the desire to lose weight and having taken some action to try to lose weight in the past (Loh, et al., 2008; Strassnig, et al., 2005). There is little in these studies however regarding the nature of the participants’ experience of weight gain and their efforts to manage it.

Two qualitative studies exploring the experience of weight gain in people living with SSDs have also found that participants wanted to lose weight and had made some attempts to do so (Tham, Jones, Chamberlain, & Castle, 2007; Vandyk & Baker, 2012). It should be noted that both of these studies were dominated by male participants; 15 of the 18 participants in the study by VanDyk and Baker (2012) and 32 of the 42 participants in the study by Tham, Jones, Chamberlain and Castle (2007) were men. The findings in the study by Usher, Park and Foster (2013), which had more women participants, focused on the negative impact of the weight gain and the struggle to deal with this. In all of these studies findings suggested that participants found weight management a challenge and experienced little success from their efforts.

Barriers to participation in regular physical activity by people with SSDs have also been explored in a small number of qualitative studies, again with mostly male participants (Bassillos, et al., 2014; McDevitt, Snyder, Miller, & Wilbur, 2006; Rastad, Martin, & Åsenlöf, 2014). The barriers identified include challenges that would be shared by members of the general population such as immediate negative outcomes (like pain and discomfort), disinterest, or bodyweight, as well as some that are specific to people living with SSDs such as symptoms of their illness and medication side effects. A range of social factors such as lack of resources and social support were also identified.

Only one study to date has looked at the whole issue of managing weight gain from the perspective of people with SSDs. Xiao, Baker and Oyewumi (2012) interviewed
people newly diagnosed with SSDs to develop an explanation of the psychosocial processes influencing their weight management. They identified a range of barriers to weight management including lack of resources, lack of structure, the rapidity of the weight gain, hunger and perceived lack of support. Participants responded initially to the weight gain by discontinuing medications, then choosing low calorie foods and walking as exercise before moving towards weight acceptance and giving up on weight management. The participants in this study were almost all male (14 of 16) and were interviewed only once following their first episode of illness so findings may not apply to women living with SSDs or represent the experiences and perceptions of those who have been living with their illness for a longer period of time.

2.7 Summary

People living with SSDs experience higher rates of obesity than the general population (Galletly, et al., 2012). This undoubtedly contributes to high levels of co-morbidity, and increased rates of obesity related disorders such as cardiovascular disease, metabolic syndrome and diabetes (Galletly, et al., 2012; Lahti, et al., 2012; Suvisaari, Perala, Saami, et al., 2008). People living with SSDs also have reduced life expectancy compared to the general population (Laursen, et al., 2014), which is to a large degree due to increased mortality from natural causes, in particular those associated with obesity (Crump, et al., 2013). In addition to higher rates of mortality, obesity and related co-morbidity in people with SSDs have been associated with poorer mental health outcomes (Dixon, Goldberg, Lehman, & McNary, 2001), reduced medication compliance (Weiden, et al., 2004), reduced quality of life (Strassnig, Singh Brar, et al., 2003a), and poorer functioning (Abdul Rashid, et al., 2013).

Weight gain is a recognised side effect of most of the medications used to treat SSDs (Allison, et al., 1999). This is recognised as contributing to the high rates of obesity among this population (Reist, et al., 2007). However research has also suggested that people living with SSDs have higher levels of lifestyle risk factors than the general population, in particular more sedentary lifestyles and less healthy diets (Dipasquale, et al., 2013; Soundy, et al., 2013).
Despite the evidence of increased lifestyle risk factors for obesity in people with SSDs there is not yet a strong evidence base for improving outcomes in this area. Systematic reviews have found evidence of statistically significant differences in weight outcomes between experimental and control groups in randomised controlled trials of behavioural programs, which include various combinations of diet, exercise and behaviour change interventions (Bonfioli, et al., 2012; Caemmerer, et al., 2012). The changes in weight that are reported are generally not sufficient to be considered clinically significant and there is little evidence for maintenance. There is also little evidence in the literature of occupational therapy interventions to address weight gain and obesity in people with SSDs. There are reports of trials involving occupational therapists in delivering multidisciplinary interventions but the specific role of the occupational therapist is not clear (Brown, et al., 2014).

In line with the core principles of recovery, the expertise of people with lived experience should surely be helping to inform the development of interventions to assist people with SSDs to participate in activities to manage their weight. These perspectives have been largely absent from the research until the emergence of a small number of studies in the last few years. Those investigations that have taken place indicate that people with schizophrenia are aware of the issue of obesity and desire to manage their weight more effectively. However due to a variety of factors, both environmental and related to their illness, many people living with SSDs appear to have difficulty initiating and maintaining these actions.
Chapter 3  Research Approach

3.1 Overview of the Chapter

In this chapter I describe the research approach for this study, including the underpinning philosophy, research design and specific methods. I begin by describing the philosophical and methodological frameworks that underpin the study and my decision making around selecting these. I then describe the procedures involved in carrying out the study. Finally I discuss the ethical and quality issues.

3.2 Determining an Approach to Conducting the Study

My broad aim in embarking on this study was to make a contribution by improving understanding of the issues around weight gain and obesity that may inform more effective approaches to helping women living with SSDs address these issues. The process of refining the research aim and questions, and determining the approach to conducting the research, was informed by an examination not only of the existing research as discussed in the previous chapter, but also by my own world view. Creswell (2014) suggests that in planning a study researchers need to think through the philosophical world view they bring to the study, the research design that is related to this world view and the specific methods of research that translate this into practice.

3.2.1 Positioning Myself in Relation to the Research

Creswell (2013) suggests that the first phase in the research process involves the researcher considering what they bring to the project. At the time of embarking on this research I had been working as an occupational therapist for approximately thirteen years, much of this time in the mental health field. My world-view and more specifically my view of the issue at the centre of this study, and how it should be explored, were therefore informed both by the philosophical underpinnings of occupational therapy and the principles of a recovery approach to mental health care.

As an occupational therapist my practice is underpinned by the philosophy of occupational therapy. Hooper and Wood (2014) define philosophy as “(1) a conscious framework of assumptions and beliefs that guides actions and (2) as a mode of thinking that actively relies on the framework for processing ideas and decisions”
They describe the philosophy of occupational therapy in terms of ontology, epistemology and axiology; or what is real, what is knowledge and what is right to do (Hooper & Wood, 2014), which is helpful when considering how to approach research. In occupational therapy ontology centres on the nature of humans, as occupational beings who are interconnected with their environment, and the role of human occupation in changing health over time. Knowledge in occupational therapy centres on occupation, and is viewed as being tentative, fluid and contingent. As such the approach to practice in occupational therapy is collaborative (or client-centred), occupation focused, and context specific. These tenets very much informed the specific focus for this project, as well as the choices I made regarding how the research would be conducted.

My world-view is also shaped by the principles of recovery that inform contemporary mental health policy and service provision. In particular the valuing of the expertise of people with lived-experience (Australian Health Ministers Advisory Council, 2013), suggested to me a need to approach this project in a way that would enable learning from the lived experience of the women with SSDs with regards to managing their weight.

### 3.2.2 Identifying with the Constructivist Paradigm

My philosophical position, as described above, is most closely aligned with the constructivist paradigm. A paradigm is a world view or basic belief system which informs the research process (Broido & Manning, 2002; Guba & Lincoln, 1994). Broadly speaking, the constructivist paradigm asserts that human beings construct rather than discover knowledge. Explanations for experiences are continuously devised and modified through language, interaction and shared experiences with others (Schwandt, 2000). Researchers operating under the constructivist paradigm seek to develop a theory or pattern to explain the meanings others have about the world (Creswell, 2014).

This was consistent with my aim in carrying out this project, which was to understand how women with SSDs perceive and engage in activities to manage their weight. There was also a good fit between the ontology, epistemology, and methodology of the constructivist paradigm and my philosophical framework.
The constructivist paradigm has a relativist ontology that focuses on how people experience and make sense of the world. Other paradigms such as the positivist and post-positivist view reality as singular, governed by natural laws and able to be discovered (Broido & Manning, 2002; Guba & Lincoln, 1994). In contrast, the constructivist paradigm views realities as multiple, contextual, intangible and socially constructed (Broido & Manning, 2002; Charmaz, 2000; Schwandt, 1994, 2000). As well as holding personal resonance for me this latter view is also consistent with the ontology of occupational therapy and the principles of recovery.

The relationship between the researcher and participants, and what can be known, under the constructivist paradigm is transactional and subjectivist (Guba & Lincoln, 1994). Researchers adopting a positivist or post-positivist position aim to remain separate from study participants and adopt procedures to avoid having any influence on the findings (Broido & Manning, 2002; Guba & Lincoln, 1994). Constructivism by contrast views knowledge as being constructed through collaboration between the researcher and participants (Charmaz, 2000; Guba & Lincoln, 1994; Schwandt, 2000). Rather than seeking to avoid influencing the findings, the researcher recognises that their own values and experiences as well as those of the participants will shape the research and acknowledge this (Broido & Manning, 2002; Creswell, 2007). There are strong parallels with the principles of client-centred practice and collaboration which are at the centre both of occupational therapy philosophy and the recovery approach in mental health care (Hooper & Wood, 2014; Sumsion, 2000).

Researchers operating under the constructivist paradigm employ methodologies to help them understand their world (Creswell, 2007; Schwandt, 1994). As opposed to positivist or post-positivist researchers who begin with a theory to be tested, constructivists seek to generate a theory or explanation based on the shared understanding constructed with participants in the research process (Creswell, 2007). This is achieved through methods that involve interaction with participants in order to elicit their constructions and processes to distil these into a shared construction (Guba & Lincoln, 1994). Therefore, having identified with a constructivist paradigm it seemed
most appropriate to consider a qualitative methodology to answer my research question.

3.2.3 Adopting a Qualitative Approach

Qualitative is one of two broad categories of approaches to conducting research and is generally defined in terms of the nature of the questions it is suitable for addressing and the methods used for data gathering and analysis. The definition by Creswell (2014) below provides a clear account of these elements:

- an approach for exploring and understanding the meaning individuals and groups ascribe to a social or human problem. The process of research involves emerging questions and procedures, data typically collected in the participants setting, data analysis typically building from particulars to general themes, and the researcher making interpretations of the data (p.4).

Many of the indicators for the suitability of qualitative research apply to my study such as: to explore an issue about which there is little known; when an issue is complex or changing; or we want a complex and detailed understanding of an issue; when we want to hear participant’s voices, understand a process from their perspective and reduce the power differential usually present in researcher/participant relationships (Creswell, 2013; Richards & Morse, 2007).

Qualitative methods are widely used in occupational therapy research and are increasingly recognised in the wider evidence base for health care. Qualitative research is recognised as underpinning much of the knowledge that informs occupational therapy practice (Lysack, Luborsky, & Dillaway, 2006). It is recognised as compatible with the profession both in terms of its ability to address many of the questions that are relevant to our practice and its consistency with our philosophy (Hammell, 2001). The contribution of qualitative research to the evidence base for health care is increasingly being recognised, in particular it’s value in illuminating the experience of living and coping with chronic illness and the development of approaches to rehabilitation and self-management (Carpenter & Suto, 2008; Grypdonck, 2006).

Having identified that a qualitative approach would be most appropriate I now needed to identify a specific methodology. Qualitative research is ‘an umbrella term’ for a number of interrelated research methodologies (Carpenter & Suto, 2008; Fossey,
Harvey, McDermott, & Davidson, 2002, p. 717). While identification of a qualitative approach suggests particular data gathering and analysis techniques, or ‘methods’, a ‘methodology’ provides a logic for selecting, justifying and understanding the methods used in a particular study (Carter & Little, 2007). Identification and application of a recognised methodology therefore assists in enhancing rigor and facilitating evaluation of the study (Creswell, 2013). The nature of the research aim, or question is a key factor in determining which of the qualitative research methodologies is most appropriate for a particular study.

### 3.2.4 Choosing Grounded Theory Methodology

As my research question had a focus on a particular process; that of women with SSD managing their weight, and the aim was to develop an explanation of this process, grounded theory was the most appropriate methodology to employ. Grounded theory is a qualitative research methodology that supports researchers to develop mid-range theories that explain human behaviour in social contexts (Charmaz, 2000; Creswell, 2007; Wuest, 2007). It is characterised by systematic guidelines for inductive analysis of data that is collected from participants on the basis of their experience of the issue under investigation (Charmaz, 2000; Fassinger, 2005). This results in the generation of theories that are ‘grounded’ in the data. The focus on theory generation as opposed to rich description also differentiates grounded theory from other qualitative research methods (Creswell, 2007; Walker & Myrick, 2006).

Grounded theory methodology is widely used in health research and has been identified as a useful methodology for occupational therapy (Stanley & Cheek, 2003), and occupational science (Nayar, 2012). In particular it has been identified as a useful methodology for gaining an understanding of users of health services regarding a particular issue, the way they manage that issue and what might be done (Crooks, 2001; McCann & Clark, 2003a; Richards & Morse, 2007). Grounded theory has been specifically identified as being useful for studying the experience of people with chronic illness (Charmaz, 1990; Strauss & Corbin, 1998), and women’s health issues (Crooks, 2001). In addition it has been successfully employed by researchers investigating other aspects of experience of people with SSDs such as early psychosis
Grounded theory methodology was first proposed by two American social scientists, Barney Glaser and Anselm Strauss, in 1967 based on their collaboration researching dying in hospitals (Bryant & Charmaz, 2007a; Charmaz, 2006; Glaser & Strauss, 1967). In developing grounded theory Glaser and Strauss sought to address what they saw as major problems with sociology research at the time (Bryant & Charmaz, 2007b). This largely centred on what they termed as ‘the embarrassing gap between theory and empirical research’ (Glaser & Strauss, 1967). Research at the time was dominated by the positivist paradigm and the use of quantitative methods to verify a small number of ‘grand theories’, which were logically derived (Bryant & Charmaz, 2007a; Charmaz, 2000, 2006). Qualitative research, which Glaser and Strauss saw as the means of generating theory, was viewed by many of their contemporaries as being ‘unsystematic’, ‘impressionistic’ or ‘exploratory’ and was generally only used in the preparation stages of quantitative research (Charmaz, 2000, 2006; Glaser & Strauss, 1967; Walker & Myrick, 2006). In developing Grounded Theory, Glaser and Strauss sought to develop a methodology that facilitated theory development from empirical data (Charmaz, 2000, 2006). They also sought to move qualitative research from lower level descriptive studies to those with explanatory power (Charmaz, 2006). In doing this, and to legitimise this method, they incorporated some of what were seen as the strengths of quantitative research, that is logic, rigour and systematic analysis (Walker & Myrick, 2006).

Grounded theory has undergone much development since it was originally proposed by Glaser and Strauss nearly five decades ago (Dey, 2004). Contemporary commentators generally recognise three major schools of grounded theory, the Glaserian school, the Strauss and Corbin school and the Constructivist school (Bryant & Charmaz, 2007b; Hood, 2007). Researchers using a grounded theory methodology are expected to clearly identify which of the Schools guide their work (O’Connor, Netting, & Thomas, 2008; Wuest, 2007). While Glaser and Strauss both continued to develop and write about grounded theory throughout their careers, they did so
separately from the 1970’s. Glaser is considered by most, including himself, to have stayed fairly close to the original iteration, and this school is referred to as the Glaserian, or original Glaser and Strauss school (Charmaz, 2006). Strauss on the other hand went on to work with Juliet Corbin and made several alterations. These included new analytic procedures and a greater emphasis on verification, resulting in a second School known as the Strauss and Corbin school (Charmaz, 2006; Walker & Myrick, 2006).

Both the Glaserian and the Strauss and Corbin schools of grounded theory are seen to be aligned with the post-positivist paradigm (Charmaz, 2000; Hall & Callery, 2001). Both assume an external, objective reality and thus data are ‘discovered’ (Charmaz, 2000). In order to most accurately discover this reality, researchers in the post positivist tradition followed procedures designed to increase objectivity (O’Connor, Netting, et al., 2008). Such procedures in the earlier versions of grounded theory include, delaying review of the literature until after data collection and researchers setting aside any prior knowledge of the issue under study. Because of these assumptions, data were seen as existing in an objective reality, neither the social context, the relationship between the researcher and participants, or any other processes involved in the production of data were considered (Bryant & Charmaz, 2007b; Charmaz, 2006). The goal was to produce context free but modifiable theoretical statements that accurately reflected the objective reality. Epistemology also influences methodology selection and hence I was drawn to the more recent versions of grounded theory which are more consistent with the epistemology of the constructivist paradigm (Carter & Little, 2007).

**Constructivist Grounded Theory**

Constructivist grounded theory retains the core procedures of the original grounded theory (O’Connor, Netting, et al., 2008). The differences from the other two schools centre on the view of reality and consequently the role of the researcher and their approach to carrying out the procedures as well as the nature of the theory produced. Constructivist grounded theory, consistent with the constructivist paradigm, takes a relativist position, accepting the existence of multiple social realities (Charmaz, 2000; Guba & Lincoln, 1994). These realities are considered socially constructed and
influenced by context. As such, the data in constructivist grounded theory are seen to be constructed via the actions and interactions of those involved in the research setting, rather than discovered as part of an external reality.

The researcher is thus seen not as a neutral observer, but an active participant in the research process, whose decisions shape both process and product (Bryant & Charmaz, 2007b; Charmaz, 2000, 2006). The expectation that the researcher should disregard prior knowledge of the issue under investigation, or avoid review of the literature is removed. Instead it is accepted that researchers will bring such knowledge to a study. This knowledge is referred to as sensitising concepts and is seen as useful as a starting position for the research (Charmaz, 2006). Recognition of the researcher as being actively involved in the construction of the data necessitates a reflexive approach in constructivist grounded theory that was not present in the two earlier versions (Charmaz, 2006; Mills, Bonner, & Francis, 2006). Reflexivity involves the researcher attempting to become aware of their presuppositions and how they influence the decisions they make in constructing the research.

The view of data as being co-constructed by the researcher and participants also has implications for the nature of the relationship that exists between these parties. The participant is seen as an expert in their experience and an equal contributor in the construction of the data. Researchers need to be conscious of developing a relationship that will support this reciprocity (Mills, et al., 2006). Implicit in this relationship is the need to be aware of power imbalances, articulate these and attempt to address them. In addition researchers using this methodology will seek to employ procedures to involve the participant beyond the initial data gathering, this may involve member checking, whereby the outcomes of different stages of the data analysis may be presented to participants to check that it fits with their experience.

The grounded theories produced following the constructivist school are therefore seen as an interpretive understanding of the studied world rather than an exact picture of it (Charmaz, 2006; O’Connor, Netting, et al., 2008). While generalisations are made, these are seen as limited and tentative rather than universal, and the importance of context is recognised when determining whether theories are applicable.
3.3 Procedures – Carrying Out the Study

Due to the inductive nature of constructivist grounded theory, the procedures involved do not occur in a linear sequence. Sampling, data collection and analysis occur simultaneously throughout most of the life of a grounded theory study, with each process informing and refining the other (Bryant & Charmaz, 2007b). Data analysis begins as soon as the first data are collected, and sampling and data collection continue until analysis suggests that no further data is required. The interrelationships between these processes as they occurred in my study are illustrated in Figure 3.1. However, for ease of explanation, I will describe the procedures in the order in which they first occurred within the study.

![Diagram of interrelationships between research processes](image)

Figure 3.1: Interrelationships Between Research Processes in My Study

3.3.1 Literature Review

Literature reviews, and specifically when in the research process they should be conducted, are one of the points of difference between the earlier and more recent constructivist versions of grounded theory. Earlier versions suggested that the literature review should not be conducted until the end of the research process, to
avoid the researcher being influenced by preconceived ideas (Wuest, 2007). More recent authors recognise the practical need for a literature review to be conducted at the beginning of a project for the purpose of satisfying ethics committees and review boards (Wuest, 2007). In addition, under the constructivist version of the methodology an early literature review is seen as helpful in developing sensitising concepts, or ideas to structure the early data collection (Charmaz, 2006; McCann & Clark, 2003a).

I conducted a preliminary literature review when I embarked on the project, which I have updated and added to as the project progressed. My initial aim in searching and reviewing the literature was to refine my research aim, develop an initial framework for the interviews and formulate a rationale for conducting the research in order to gain ethical approval. I was therefore looking to understand the scope of the issue in terms of what was already published, and to identify the gaps or discrepancies in the existing research. As the study progressed and I was developing categories through the analysis process I went back to the literature to explore the concepts in these categories that may not have been part of my original literature review. Reviewing the literature at this stage helped in refining these categories. I also turned to the literature during the later stages of analysis when considering the overall theoretical framework for the study. Finally I used the literature to contextualise the findings when writing up the research for dissemination.

3.3.2 Sampling and Recruiting Participants

I employed two different sampling strategies in this study. I began with purposive sampling and then as data analysis progressed and concepts began to emerge I began to use theoretical sampling. This progression in sampling strategy from purposive to theoretical is characteristic of grounded theory methodology (Draucker, Martsolf, Ross, & Rusk, 2007; Fassinger, 2005). In this section I describe how I implemented both purposive and theoretical sampling as well as describing the recruitment sites, recruitment process and the demographics of the women who participated in the study.
**Initial Purposive Sampling**

The aim of initial sampling in grounded theory is to provide data that enables the researcher to determine the broad scope of the issue being explored and begin to establish concepts around which theoretical sampling can then be targeted (Birks & Mills, 2011; Morse, 2007). Purposive sampling, which is generally employed as the initial sampling strategy in grounded theory, entails developing a set of predetermined criteria to facilitate recruitment of participants with experience of the issue (Charmaz, 2006; McCann & Clark, 2003b). I chose the criteria for this study based on a combination of pragmatic and ethical considerations. To be included in the study participants needed to be: women; living with a diagnosis of a SSD; over the age of 18; able to speak English; give informed consent; and not acutely unwell. The first two criteria were determined to meet the need for the participants to have experience of the issue being investigated. As the study was about the experiences of women with SSDs then it was necessary for all participants to be women with SSDs. The requirement for participants to be over the age of 18 was also determined in order that those participating in the study have experience of the issue being explored. Females generally have a later onset of SSDs and it was determined that women over 18 would be more likely to have an established diagnosis. The requirement for participants to be able to speak English was pragmatic. Because data generation was to occur via in-depth interviews, and I only speak English, this criterion was set so that the participants would be more likely to be able to effectively engage in the interview process. Finally, the criteria regarding being able to give informed consent, and not being acutely unwell, were determined on ethical grounds and are discussed in more depth in section 3.6 of this chapter.

In order to meet my aim of gaining a broad overview of the issue I also adopted a maximum variation approach to sampling to include participants with a wide range of experience of the issue (Fassinger, 2005; Morse, 2007). I began by identifying different parameters that may affect the women’s experience of managing their weight. These included age, time since diagnosis, educational level, level of support required, or independence with activities of daily living, whether they were living alone or with others, whether they were a mother, whether they were working or studying or
neither. I then sought to include participants with varied characteristics in relation to each of these factors. I achieved this by monitoring the characteristics of each participant who joined the study, and asking the case managers who were the agents of recruitment to identify potential participants who had the characteristics that I was yet to gain in my sample. For example, the first two participants to join the study were Elizabeth and Faith, neither of these were working or studying so I asked the recruiters to identify people who were – and each of the next three participants were either studying or working or both. Similarly, all of the first seven participants were under 40 years of age so I asked for some older participants, and the following four participants who joined the study were older.

**Theoretical Sampling**

Following the preliminary analysis of the first data, I began to use theoretical sampling. Theoretical sampling is identified as one of the core defining features of grounded theory methodology (Charmaz, 2006; Fassinger, 2005). The aim of theoretical sampling is to gather data to explore ideas and questions that arise during data analysis, to develop concepts and categories and the relationships between them (Charmaz, 2000, 2006; Wuest, 2007). Theoretical sampling may involve any of a number of strategies, all of which I employed in this study. These strategies include: recruiting new participants, modification of interview schedules, revisiting earlier participants with new questions or revisiting data that has already been collected (Charmaz, 2000, 2006; Wuest, 2007).

*Recruiting New Participants*

Recruiting new participants with specific characteristics or experiences that may enable them to contribute data that will help to further develop categories is perhaps the most obvious strategy of theoretical sampling. While I used this strategy it was the one I used least.

*Modification of Interview Schedules*

From the beginning of the project I made notes in my research diary following the analysis of each interview, of questions that I thought needed exploring more, or patterns that seemed to be arising that I wanted to follow up. On the basis of this I
would add additional probes or questions to explore these issues in subsequent interviews. An early example of this is, after the first two interviews it was beginning to be apparent that the participants’ attitudes, experiences and actions in relation to their weight changed over the course of their illness and recovery, on the basis of this I chose to follow this up more explicitly in the interviews that followed.

**Revisiting Earlier Participants with New Questions**

This strategy was built into my procedures for conducting follow-up, (second and third interviews), with participants. One of the foci of these follow-up interviews was the generation of more data in relation to the emerging categories, some of which may not have been addressed in the initial, or earlier interviews with some of the participants. More detail regarding these interviews can be found below in section 3.3 of this chapter.

**Revisiting Data that has Already Been Collected**

Again this strategy was built into my procedures to some extent in the early stages of coding. As detailed in section 3.4 of this chapter, after coding a new interview I would review the coding list and then go back to the earlier transcripts and re-code using any new codes that had been added. Later when I was developing categories and writing about these in memos I would go back to interviews that had been conducted before the particular category was developed and code for that category and its associated properties and dimensions.

**Sample Size**

The sample size in grounded theory research is not determined prior to the commencement of the study but through the data analysis process and based on an assessment that theoretical saturation has been reached. Charmaz (2006) suggests that theoretical saturation is reached when all of the categories are saturated. How one judges that saturation has been reached is a point of some debate in the literature with Morse (2007) questioning whether it can ever be achieved. Dey (1999) suggests that theoretical sufficiency is a better fit for grounded theory. Saturation of categories or theoretical sufficiency is generally agreed to occur when the researcher makes a judgement that there is sufficient support for a category to provide a coherent and
explicable account of an experience (Green et al., 2007; Morse, 2007). In this study I conducted a total of 24 interviews with 11 participants. I found that by the time I was analysing data from the final few interviews I was not finding anything that was providing new theoretical insights, and I had a good amount of data from a range of participants to support the existing categories and their associated properties and dimensions.

**Sites**

I recruited participants from three community based mental health rehabilitation services in the Hunter Region of New South Wales (NSW). The Hunter Region is located 130 kilometres north of Sydney in NSW. It covers 31,011 square kilometres and includes 11 local government areas. Newcastle, which is the regional centre and Lake Macquarie have 54.8% of the population for the region and are mostly urban while the remainder of the local government areas are rural or semi-rural.

The three services from which I recruited were located in Newcastle, Lake Macquarie and Maitland, which allowed me to recruit participants from both urban and rural or semi-rural areas. I chose to recruit from the community rehabilitation services, known as ‘Supported Recovery Services’. These services were staffed by clinicians from a range of professional backgrounds including; medicine, nursing, psychology, social work and occupational therapy. Referral criteria required that consumers who accessed these services were aged between 18 and 65, had a diagnosed mental illness and were not acutely mentally unwell. Recruiting from these services gave me the best opportunity to access participants who met the criteria for the study.

**Recruiting Participants**

Recruitment for the study commenced in July 2009 and proceeded throughout 2010 and 2011. Recruitment of study participants occurred via the staff, working as care co-ordinators, in the community rehabilitation teams. Prior to the commencement of the study I visited each of the sites and made a presentation to the care co-ordinators regarding the purpose of the study and the criteria for participation. During these presentations I enlisted their assistance to recruit participants by identifying suitable people within their own caseloads and approaching them.
The care co-ordinators approached women who were clients of the service and met the criteria for the study. They provided these women with the participant information statements (Appendix I) and consent forms (Appendix II). Those women who were willing to participate completed consent forms, which included their phone numbers and addresses and returned these to me in the pre-paid envelopes that I had provided.

When I received a consent form I contacted the participant by phone to confirm their willingness to participate and to arrange a first interview. All of the women who completed the consent form agreed to participate in this first interview. I arranged follow-up interviews similarly by contacting the participants by phone to confirm their willingness to participate in another interview. In some cases when I contacted the women for follow-up interviews they had relocated to another area and were no longer able to participate in the study. I remained in dialogue with the care co-ordinators regarding the ongoing recruitment until I did not require any more participants.

**Participants**

Eleven women living with SSDs participated in this study. Table 3.1 provides demographic details of each of the participants using pseudonyms. Further information is contained in the participant portraits in Appendix III. The women reflect a range of ages and experiences. Gaye did not provide her age or the duration of time she had been living with her illness. The other ten women ranged in age from 24 to 61 years, with a mean age of 36 years. Seven of the ten women were under the age of forty so the median age was 32. They had been living with their diagnosis of a SSD for between 2 and 32 years, with the mean duration being 14 years and the median 12 years. Their age at diagnosis ranged from 14 to 30 years with the mean and median both being 22 years.

The women’s experience of their illness and recovery varied greatly with some experiencing numerous and frequent admissions to hospital while one of the women had only one admission. Some experienced ongoing distress, as a result of positive symptoms, while others experienced few positive symptoms or were not distressed by those they did experience. As well as their diagnosis of SSD many of the women were, or had at some time, also been living with another mental health issue. Five of the
women also reported having a diagnosis of depression and being treated for this concurrently with their SSD. Three of the women had histories of substance misuse, two had used illicit drugs and one used alcohol, although all reported that they were not using at the time of their participation in this study.

Table 3.1 Demographic Profile of Participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Years since diagnosis</th>
<th>Other mental health issues</th>
<th>Education Level</th>
<th>Current work or study</th>
<th>Income</th>
<th>Accommodation</th>
<th>Lives With</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abbie</td>
<td>32</td>
<td>12</td>
<td>Depression</td>
<td>Tertiary</td>
<td>Study</td>
<td>DSP</td>
<td>D.o.H</td>
<td>Alone</td>
</tr>
<tr>
<td>Danika</td>
<td>28</td>
<td>10</td>
<td>No</td>
<td>Year 10</td>
<td>Work and Study</td>
<td>DSP/Pay</td>
<td>Housing Association</td>
<td>Alone</td>
</tr>
<tr>
<td>Elizabeth</td>
<td>29</td>
<td>13</td>
<td>Depression</td>
<td>Year 10</td>
<td>No</td>
<td>DSP</td>
<td>D.o.H</td>
<td>Alone</td>
</tr>
<tr>
<td>Emily</td>
<td>61</td>
<td>32</td>
<td>Depression</td>
<td>Tertiary</td>
<td>No</td>
<td>DSP</td>
<td>Retirement Village</td>
<td>Alone</td>
</tr>
<tr>
<td>Faith</td>
<td>37</td>
<td>11</td>
<td>Substance Use</td>
<td>Year 11</td>
<td>No</td>
<td>DSP</td>
<td>D.o.H</td>
<td>Father</td>
</tr>
<tr>
<td>Gaye</td>
<td>*</td>
<td>*</td>
<td>ADD, Depression, Substance Use</td>
<td>*</td>
<td>No</td>
<td>DSP</td>
<td>*</td>
<td>Alone</td>
</tr>
<tr>
<td>Isobel</td>
<td>31</td>
<td>10</td>
<td>No</td>
<td>Year 10</td>
<td>No</td>
<td>DSP</td>
<td>Private Rental</td>
<td>Mother</td>
</tr>
<tr>
<td>Karen</td>
<td>49</td>
<td>19</td>
<td>Alcoholism Depression</td>
<td>Tertiary</td>
<td>Work and Study</td>
<td>DSP/Pay</td>
<td>D.o.H</td>
<td>Alone</td>
</tr>
<tr>
<td>Mary</td>
<td>26</td>
<td>4</td>
<td>No</td>
<td>Tertiary</td>
<td>Study</td>
<td>DSP</td>
<td>Private Rental</td>
<td>Flatmates</td>
</tr>
<tr>
<td>Nette</td>
<td>45</td>
<td>31</td>
<td>No</td>
<td>Year 9</td>
<td>No</td>
<td>DSP</td>
<td>Housing Association</td>
<td>Alone</td>
</tr>
<tr>
<td>Nuela</td>
<td>24</td>
<td>2</td>
<td>No</td>
<td>Tertiary</td>
<td>No</td>
<td>DSP</td>
<td>Privately owned</td>
<td>Parents</td>
</tr>
</tbody>
</table>

*Information not provided

The women described varying degrees of social support and engagement with services. All were receiving, at minimum, care co-ordination and support from a health professional in the community mental health rehabilitation team. For some this was the only mental health service or disability support they received. Others accessed a range of services including home care, out-reach mental health and disability support, supported employment, peer support groups and drop in centres.
Most of the women relied on their Disability Support Pension for their income although two supplemented this with earnings from part time or casual employment. Most of the women had completed high school at least to year ten. Five had commenced tertiary education although only one had completed a tertiary qualification. Four of the women were studying at TAFE during the time of the study.

Seven, of the women lived alone. Three lived with one or both parents, one shared with flatmates and two were living with partners at different times during their involvement in the study. Two of the women had babies during the time they were involved in the study. Two others had adult children and grandchildren. The other seven had not had any children.

### 3.3.3 Generating Data

While grounded theory methodology has very well defined analytic processes, data may be generated by a range of techniques according to what is most suitable to the individual study (Henwood & Pidgeon, 2003). I have consciously used the term ‘generating’ rather than ‘collecting’ or ‘gathering’ data as this is more consistent with the constructivist paradigm where the researcher engages with the participants to produce the data (Birks & Mills, 2011). I chose to use in-depth semi structured interviews as the primary means of data generation in this study. Additional data were generated through the field notes I wrote after each of the interviews and the reflective diary I kept throughout the process.

**Choosing In-Depth Semi-Structured Interviews**

In-depth interviews are defined by Taylor and Bogdan (1998) as “repeated face-to-face encounters between the researcher and informants directed towards understanding the informants’ perspectives on their lives, experiences and situations, as expressed in their own words” (p.88). The degree of ‘structure’ in research interviews describes the complexity of the interview guide and the rigidity with which this is used in the interview process. Brinkman (2013) suggests that the distinction between structured, semi-structured, and unstructured should be thought of as a continuum. Semi-structured interviews are generally guided by a list of topics with suggested questions...
which can be used flexibly which is consistent with the conversational style appropriate for in-depth interviewing (Minichiello, Aroni, & Hays, 2008).

I chose to use in-depth semi-structured interviews, as this approach to data generation is consistent with the aim, underpinning theoretical framework and methodology for this study. My aim in conducting this study was to understand both the experience and the actions of women living with schizophrenia with regards to managing their weight. Interviews are the most effective means of gaining an understanding of the individuals experience from their perspective (Birks & Mills, 2011; Kvale & Brinkman, 2009). In addition, in-depth interviews are identified as the most appropriate means to gain understanding of events which cannot be directly observed by the interviewer and Minichiello et al. (2008) highlight their value in understanding “action and patterns of living” (p.66). This approach is consistent with the ‘traveller’ metaphor for the interviewer adopting a constructivist approach to research (Buetow, 2013; Kvale & Brinkman, 2009). In this metaphor the ‘interview and analysis are intertwined phases of knowledge construction’ and the interviewer ‘walks with the locals’, asking them questions about their experience of their world in a conversational manner (Kvale & Brinkman, 2009, p. 48). In depth interviews are conducted in a conversational style, which involves both the researcher and interviewer contributing to the process of establishing meanings (Minichiello, Aroni, & Hays, 2008). Semi structured interviews have been identified as the most commonly employed data collection method in grounded theory studies (Birks & Mills, 2011). In describing the benefits of semi-structured interviews over the more or less structured options Brinkman (2013) highlights that they are flexible enough to follow what is deemed to be important by the interviewee but at the same time allow the interviewer some control in focusing on what they see as important to the project. Charmaz (2003, 2006) suggests that this combination of ‘flexibility’ and ‘control’ means that this type of interview fits well with grounded theory methodology.

**Structuring the Interviews**

I chose to conduct multiple interviews with the participants in this study, where possible. This decision was prompted by the benefits of multiple sequential interviews
identified by Charmaz (2003, 2006), including the potential to foster trust and develop a stronger rapport which enables the researcher to get closer to the phenomenon under study, the ability to check things over time and thereby correct omissions in early data gathering, develop a more detailed account of the participant’s story, and to follow the participant’s path through a process. I conducted up to three interviews with each participant over a two-year time frame. Table 3.2 shows the timing of the interviews. The timing of the interviews was influenced by a range of factors including: recruitment; availability of participants, which was affected by a range of factors including episodes of illness for some, and other life events; my own availability; and the progress of the analysis. The structure of the interviews changed, from the first interview which was guided by the interview guide I established prior to the commencement of the study, to subsequent interviews which were structured around checking my interpretations of the data with the participants, filling in gaps and clarifying aspects of categories that were emerging through analysis.

Table 3.2: Timing of Interviews

<table>
<thead>
<tr>
<th>Name</th>
<th>Interview One</th>
<th>Interview Two</th>
<th>Interview Three</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abbie</td>
<td>Feb 2010</td>
<td>June 2010</td>
<td>Jan 2012</td>
</tr>
<tr>
<td>Danika</td>
<td>Feb 2010</td>
<td>May 2010</td>
<td></td>
</tr>
<tr>
<td>Elizabeth</td>
<td>July 2009</td>
<td>May 2010</td>
<td></td>
</tr>
<tr>
<td>Emily</td>
<td>Oct 2011</td>
<td>Feb 2012</td>
<td></td>
</tr>
<tr>
<td>Faith</td>
<td>Dec 2009</td>
<td>May 2010</td>
<td>Nov 2011</td>
</tr>
<tr>
<td>Gaye</td>
<td>June 2010</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Isobel</td>
<td>April 2010</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Karen</td>
<td>June 2010</td>
<td>July 2011</td>
<td>Nov 2011</td>
</tr>
<tr>
<td>Mary</td>
<td>Feb 2010</td>
<td>August 2010</td>
<td>Dec 2011</td>
</tr>
<tr>
<td>Nette</td>
<td>June 2010</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nuela</td>
<td>April 2010</td>
<td>June 2010</td>
<td>March 2012</td>
</tr>
</tbody>
</table>

First Interviews

Prior to commencing the study I developed an interview guide that I used in the first interviews with each of the participants. Guides for semi-structured interviews generally contain an outline of the topics to be covered and possible questions but without fixed wording or order (Kvale & Brinkman, 2009; Minichiello, et al., 2008). The
guide acts as an aide memoir to help the researcher focus on topics that may be important to the study (Minichiello, Madison, Hays, & Parmenter, 2004). I constructed the initial interview guide based on a review of the literature, and my experience working as an occupational therapist with women living with SSD. I chose to structure the guide according to the ‘funnel’ method described by Minichiello et al. (2008) which involves starting with more general questions, designed to begin the informant thinking about the topic in more general terms and to allow time for rapport building before focusing in on more specific questions. I also gave attention to the characteristics of interviews specific to constructivist grounded theory (Creswell, 2007).

The guide began with general questions about the women and their lives designed to facilitate the beginning development of rapport and also to begin to establish context for the data specific to the issue under investigation. Close rapport with respondents is identified as essential for research seeking to develop understanding (Fontana & Frey, 1994). The initial question was a broad: ‘Can you begin by telling me a little about yourself?’ This was designed to establish with the participant that I was interested in them as a person, and gave them the opportunity to identify factors they were willing, and saw as important, to share about themselves. I then followed up with specific probes regarding contextual factors that I had identified might be important, if these were not covered in the participants response to the initial question. This is reflective of the constructivist approach which emphasises the importance of locating data in context (Charmaz, 2003).

The questions designed to address the interview topic moved from a broad focus on the nature of health, to the specifics of the women’s beliefs and actions related to managing their weight. As suggested by Charmaz (2003), I tried to formulate questions that explored the interview topic but also fitted the participants experience. I began by asking the women what they thought being healthy meant, what aspects of health were important to them, how important they thought body weight was and how they thought having schizophrenia had affected their health. I then moved on to the things they did to manage or improve their health and then more specifically the things they did to manage their bodyweight and any unmet needs in relation to this.
Finally I focused in on the activities known to mediate against overweight such as their participation in exercise and how they managed their diet. I also asked what advice they would give to a woman newly diagnosed with schizophrenia regarding managing her weight and what advice they would give to health professionals about providing services to help women with schizophrenia manage their weight. As well as the broad questions I had a number of possible probes identified to gather more detailed information. A copy of the initial interview guide can be found in Appendix IV. As suggested by Charmaz (2006), I found that having a well-planned interview guide with questions and optional prompts helped my confidence, particularly in the early interviews, and enabled me to concentrate on what informants were saying.

While the interview guide was an invaluable support I was also wary of the potential for it to limit the information gathered and therefore the need to not be too reliant on it, to be flexible with its use within an interview and to review and modify it in the light of ongoing analysis (Minichiello, et al., 2008). So, while it was helpful to have the guide to check I was covering things that I had identified as important I did not necessarily ask the questions in the exact order that they appeared on the guide, or using the precise wording. This enabled me to follow the flow of the conversation and to pick up on things that appeared important to the informants. In some cases these were things that I had anticipated and may have missed if I had stuck rigidly to the interview schedule (Minichiello, et al., 2004). An example of this was comfort eating, which had not come up at all in my initial literature review, and had not been something I had been aware of in my work, and so it hadn’t occurred to me to include it in the interview guide. Yet, when Abbie spoke of it in her first interview she suggested that it was a critical factor in both her initial weight gain and her ongoing difficulty in managing her weight. As well as being flexible in the use of the guide during each of the interviews, I modified the guide between interviews to include new issues that arose and concepts that developed through ongoing analysis (Birks & Mills, 2011). For example, picking up on the importance with which Abbie invested the issue of comfort eating, I included questions about this in subsequent interviews, and found that most of the women identified with this behaviour and believed it was a significant factor in their weight gain.
Follow-up Interviews

Follow-up interviews were structured around taking my synthesis and interpretation of the earlier interview/s back to the participants for confirmation, clarification and to gather further information to develop categories. This process reflects the principles of member checking which is widely recognised as valuable in enhancing the quality of qualitative research, specifically the credibility of the findings. Member checking involves providing the participants with the transcript of the interview, and/or the interpretations of the data, to review and provide comment on (Minichiello, et al., 2008). Proponents of constructivist grounded theory argue that member checking is subsumed into the process of concurrent data collection and analysis and theoretical sampling that is characteristic of the methodology (Birks & Mills, 2011; Charmaz, 2006).

Early follow-up interviews focused more on gaining the participants’ feedback on my identification and summary of the important aspects of what had been discussed in the interviews, whether they agreed with these, and giving them the opportunity to clarify, or add detail. My research plan and ethics application included the option for participants to receive a copy of the transcript of their interviews to check for accuracy, add to, and delete content from, as is usual practice with member checking. Given the length of the transcripts however I was concerned that the participants would not engage with this process, which indeed soon proved to be the case. While I continued to offer this throughout the study most participants declined the option of receiving the transcript and of those who did receive it few returned it with any comment. In order to provide a more accessible means of the participants commenting on the information that had been generated, I formulated a summary of the content of the initial interview. The participants were provided a copy of this summary, which was usually about three pages. They had the option of reading the summary themselves, or having me read it to them. The follow up interview was structured around the summary with me asking questions regarding how well they thought it accounted for their experience and any suggestions for how this could be improved, updates regarding what had happened or changed in the time since the last interview, and further information to fill out the account. I planned the questions for each of the interviews with reference to the initial interview guide and any questions that had not
been fully addressed, aspects that were unclear, and issues that may have arisen in interviews with other participants since their interview. An example of an early summary and associated prompt questions can be found in Appendix V.

As the study progressed I changed the structure of the summaries that were used as a basis for the second and third interviews. The summary used for each individuals’ second or third interview still only contained data that was generated from their own earlier interviews but this information was organised into the categories that were emerging through the analysis of all of the participant interviews. A later summary can be found in Appendix VI.

*Interview Procedures*

I tried to organise the interviews in such a way as to cause the least amount of inconvenience to participants. I could not conduct the interviews in the participants’ homes due to restrictions placed by the university, which required two researchers to be present for home visits to people identified as having a mental illness. This was not a condition that could be met given that I was the only researcher involved in carrying out the interviews and I also felt that the presence of a second person might be intimidating for the participants and interfere with my ability to establish rapport. I opted therefore to conduct the interviews at the offices of the mental health rehabilitation services that the participants attended for regular appointments. I arranged the interviews where possible to coincide with when the participants would be attending the centre, or nearby, for another appointment. I did this to reduce the inconvenience to the participants and to avoid them incurring any expense associated with participation in the study. This strategy was particularly important due to my decision not to offer financial compensation for participation. While there is some argument for a small payment to recognise time and travel expenses it has been found that even what may seem like a small amount such as $20 can impact on the nature of participation among vulnerable populations (Cook & Nunkoosing, 2008).

I sought to create an atmosphere within each of the interviews that would enable collaborative data generation. This meant paying particular attention to establishing rapport and minimising the power differential between me, as researcher, and the
participants. At the beginning of each interview I spent time talking with the participants about the purpose of the research and the plan for the interview and checking again that they were happy to participate. I also spent time, particularly at the beginning of the first interview, but also at the others, engaging with the participants in ‘small talk’ to help to establish a comfortable environment and establish points of connection. Similar to Crooks (2001), I perceived that being a woman interviewing women I might be more readily accepted and the participants might feel more comfortable discussing issues such as their weight than they might be with a male interviewer. I was however acutely aware that I was very slim, at least at the start of the study, and despite my efforts to manage the way I dressed in order to not accentuate my thinness it was clear that some of the women were conscious of it in the early interviews. Elizabeth commented in our first interview, ‘the thing is, before I was put on anti-psychotics I was nice and thin like you’ (Elizabeth, Interview One). Similarly, Faith when talking about her preferred weight in our second interview said: ‘I don’t really want to be really thin. I don’t think – that’s not naturally my build. Like you’re quite thin, but it’s your normal – I just want to be healthy’ (Faith, Interview One).

Perhaps fortuitously I became pregnant early on in the data generation process and gained a good deal of weight. I also retained quite a bit of weight for some months after having my baby. Not only did this perhaps change how the women viewed me – not being so noticeably thin, it also gave me some more perspective and understanding of their experience. I was conscious of trying to minimise any power differential in my interactions with the participants and ensuring that they were able to help drive the construction of the data. Strategies I adopted to address this included those suggested by Charmaz (2003) of giving full attention to what the participant wants to say, even when it seems extraneous and pacing the interview to suit the participants needs. I am reasonably confident that I was successful in my attempts to create this comfortable and collaborative environment, not only based on my perceptions during the interviews but also on the basis that none of the women I asked declined the option of further interviews, and some even commented that they had found them beneficial,
‘It’s good actually sitting here talking to you about it, just the whole lot of it’ (Faith, Interview two).

**Field Notes**

After I conducted each interview I wrote detailed field notes. In these notes I tried to capture a range of things that would both help to add depth to the data collected in the interview, give some direction to how the content covered in the interview could be built on in future interviews, capture immediate analytical thoughts that arose, and reflections on how the interview went and what I might alter in the carrying out of the interview. I used these field notes in a range of ways. Firstly they provided additional data, which augmented the dialogue recorded in the interview, and as such were included in the analysis process, secondly they helped inform analysis through capturing the analytical thoughts that occurred during the interview. Frequently I would spend time working on the analysis after doing an interview, before receiving the transcript, based on these analytical thoughts – adding them to memos and testing out ideas by going back to existing data. They also helped inform theoretical sampling, and finally the ongoing development of my interview style.

**Research Journal**

Throughout the life of the project I kept a research journal which served three main purposes, a way to keep track of what I was doing in the project, both the actions and the decision making that underpinned them; a place to work through and record my reflexive thinking; and an element of the audit trail demonstrating the means by which data were transformed to findings.

The research journal served a very practical purpose in helping me keep track of what I did over the life of the project. I recorded details of all of the interviews that I conducted, the discussions with my supervisors, the data analysis actions and the reasoning that underpinned them, and reading or discussion that informed methodological decisions. This was particularly useful in maintaining coherence of the project given the extended time period over which I carried out this study and some sizeable breaks that occurred due to pressure of work, illness and having my daughter.
The record was also useful when it came to writing up the account of the methods for the thesis.

### 3.3.4 Analysing the Data

#### Managing the Data

I managed the data for the study using a combination of NVivo, word documents and notebooks. I recorded each of the interviews using a digital voice recorder. Following the interviews I saved a copy of the WMA file of the interview in NVivo and also sent it to a transcribing service. While many authors in qualitative research identify benefits of transcribing their own interviews in terms of immersion in the data, I made a judgement based on past experience that I could use other strategies that would enable me to achieve immersion without the tedium involved in transcribing. These included reviewing, checking and correcting the transcripts while listening to the audio recordings soon after receiving them. Prior to coding I conducted this reading while listening another couple of times, making notes of things that occurred to me during the process. Along with the field notes that I recorded immediately having conducted the interviews, this allowed me to add depth to the words in the transcript, for example by making observations of the emotion associated with what the participants were describing.

I used NVivo to store all of the data, and for most of the coding, I stored the interview transcripts, field notes and my research diary as well as the memos I wrote during analysis in NVivo. As I have detailed in the section below, I conducted some of the initial coding activities on paper, but also did this in parallel in NVivo and after the first few interviews I conducted this process entirely on NVivo. Later in the data analysis when I was exploring the relationships between categories and the properties and dimensions within them I often moved backwards and forwards between paper notebooks and NVivo. I found that drawing and writing facilitated my thinking about the data. Any actions taken as a result of this thinking were however managed in NVivo.
**Initial Coding**

Coding in constructivist grounded theory involves two main processes; initial coding which involves labelling sections of data, and focused coding which involves identification and use of more significant codes to sort the remainder of the data (Charmaz, 2006). The purpose of initial coding is to open up the data to enable the researcher to see beyond the individual stories of the participants, to the detail of the data, in order to be able to identify phenomena and patterns (Bazeley, 2013; Birks & Mills, 2011). Through this process the researcher identifies processes and concepts that are further explored and developed through ongoing sampling, data gathering and analysis.

I began coding immediately having received the transcription of the first interview with Elizabeth. I started coding on paper copies of the transcript. I made this decision as I wanted to be able to see the codes alongside the body of the transcript, at least in the early stages of analysis. I set up the transcript such that there was a wide margin on the left in which I documented the codes. I began coding line-by-line, which involved labelling each line in the transcript. This strategy of line-by-line coding is advocated in grounded theory research to ensure that the coding accounts for all of the data and to prevent analytical possibilities from being cut off too early (Bazeley, 2013; Charmaz, 2000).

I followed Charmaz’s (2006) approach of coding for actions and using coding labels which described actions and, where possible, were in-vivo codes. The attention to coding for actions, and using labels that describe actions fits with the focus of grounded theory on understanding processes (Charmaz, 2006). The exception to the focus on coding actions was when I was coding for context, which Bazeley (2013) identifies as important for facilitating comparison. In-vivo codes are those which use the participants’ words to describe concepts in the data (Birks & Mills, 2011). The use of in-vivo codes is advocated in constructivist grounded theory as a means of keeping the focus on the participants’ perspectives of the processes under examination (Charmaz, 2006). To facilitate keeping my focus on actions, and on the participants perspective I
asked myself the broad question, ‘What is happening here?’ when examining each line of data.

The line-by-line coding of the first interview generated a long list of codes (134) which prompted me to look at ways of managing the coding so that I could keep track of what I was coding and how. The potential for generating a large variety and volume of codes through initial coding is documented in the methodological literature (Bazeley, 2013; Charmaz, 2006). Birks and Mills (2011) highlight the potential for novice researchers to feel overwhelmed by long lists of codes and the value of organising to assist in calming this. The following quote from my research journal at this time reflects my experience of this,

I feel my coding could be more systematic (in terms of how I name my codes). I am going through line by line and being systematic in that way but have a large code list already which is difficult to navigate as it is so long and I can’t remember how I coded each item. I wonder if I can come up with a more ordered way of deriving the codes? Or whether this is some of the ‘messiness’ of research that I will have to get used to.

My first action to address this was to review the list of codes for instances where two codes were essentially coding the same concept and where this occurred collapsing the two codes into one code. After I did this, the list was reduced to 109 codes. I then organised the codes into a tentative series of categories. My aim in doing this was not to be identifying conceptual categories that would be part of the final theory but to group similar items together to make it easier to find codes when coding subsequent interviews as suggested by Bazeley (2013). An excerpt of the list of open codes from Elizabeth’s first interview is available in Appendix VII. The early categories are available in Appendix VIII. I continued this process of reviewing the code list for duplication and sorting codes into categories after I coded each interview.

**Focused Coding**

The second level of coding in constructivist grounded theory is focused coding. The purpose of focused coding is to move the analysis towards the formation of analytic categories and determine the relationship between these categories. While I talked about forming categories in the above section on initial coding, those were just about
grouping like things together. Focused coding begins when the researcher starts to see patterns in the codes generated through open coding that can provide some analytical direction (Charmaz, 2006). Focused coding is different from open coding both in terms of the nature and function of the codes. Focused codes are more “directed, selective and conceptual” than open codes and are used to sort and explain larger segments of data (Charmaz, 2006, p. 57).

In focused coding the first step is recognising which of the codes are more salient to the process under investigation, and which of these might have some potential as categories. Appendix IX contains the early focused coding for this study. In some cases I used existing codes, which were raised to the level of categories, whereas in other cases I came up with new category labels, which brought together a number of existing codes. Alongside this coding process I was continuing to write memos, which helped me in determining the subcategories, properties and dimensions of the categories and the relationships of these to each other.

**Writing Memos**

Memo writing is described as a fundamental process in grounded theory which enables the researcher to move from data to the more abstract concepts that form the theory (Birks & Mills, 2011; Charmaz, 2006). Memos are analytical notes that grounded theory researchers write to develop ideas that arise in data analysis. They are the place where the researcher documents comparisons and defines the properties and dimensions of the categories, identifies gaps in the data and questions for further exploration, and explores the relationships between categories (Charmaz, 2006).

I began writing memos from very early in my study, exploring ideas that arose from the data. Initially the memos were quite short, but I built on these as the analysis proceeded. I found that writing the memos not only served as a way of recording the ideas, but indeed the process of writing them helped in forming and refining my analytical ideas. Ultimately the memos formed the foundation of the findings that are presented in this thesis.
An example of the development of ideas in memos is the progression from my early memo on generating ideas, to what became the category of talking about it, which is one of the facilitating factors. Early in the study I wrote a memo called ‘generating ideas’ (see Appendix X) that recorded my observations regarding interviews with two of the earlier participants Elizabeth and Faith, that the women seemed to be generating ideas of what they wanted to do to manage their weight through talking to me. I added to this memo after each of these interviews when I observed this phenomenon. Later I developed a memo, called talking about it, (Appendix XI) which involved broader discussion by the women of their perceptions of their experiences of talking with others about their efforts and how this impacted on their ability to manage their weight. Within this memo I discussed the common experience that it was helpful having the opportunity to talk about things, and that this was often most helpful when the women themselves were generating ideas, as in the earlier memo. Through ongoing analysis the code of talking about it became one of the sub categories of facilitating factors. The concept of ‘generating ideas’, became a component of the property education and advice, and the value of talking about it to maintaining motivation became the property, keeping it on the agenda.

**Constant Comparison**

Constant comparison is another strategy that is synonymous with grounded theory methodology. Initially this involves comparing incident with incident in the data, which results in the generation of initial codes (Birks & Mills, 2011). Having created the initial codes I continued to compare incident to incident but also compared the codes with each other, in the process of refining the code list as described in the section on initial coding above. I also compared codes with data, through the process of coding subsequent interviews and going back and recoding earlier interviews using the revised coding lists. In moving to focused coding, as described above, I was comparing codes with codes, codes with emerging categories, and again going back and comparing these with data. I continued this process of comparing units of analysis with other units of analysis and with the data until the final theory was complete.
I also found that the narrative summaries that I developed for each of the women in the study were really useful for comparison. As the analysis developed these summaries reflected the emerging categories and I was able to describe how each of the categories was reflected in each participant’s data, and to compare the account of each category between the different women. This reflects one of the two strategies identified by Richards and Morse (2007) for identifying process in grounded theory studies, identifying the trajectory or course of events in each participant’s story and contrasting major events to identify patterns, emotional responses, behavioural strategies, antecedents and consequences.

**Theoretical Integration**

Theoretical integration refers to the process of bringing together the concepts developed during data analysis to create a theory that has explanatory power in relation to the issue under study (Birks & Mills, 2011). While the entire process of data gathering and analysis are working towards this goal, there are two strategies that I used that are identified as the final strategies in the analysis process that specifically address theoretical integration, storyline and theoretical sorting and coding (Birks & Mills, 2011). Again, while these are the last processes to commence in data analysis, I began to use these processes alongside the other data analysis strategies from the time that the first categories began to appear.

**Storyline**

I found writing the story of what was emerging in the analysis a very useful process and did this in different ways from early on in the data analysis process for a range of purposes. The first storyline I wrote was in May 2010 based on the analysis of interview one with the first seven participants. This story can be found in Appendix XII. I revisited this process as the analysis progressed and found it useful both in terms of developing and recording my ideas. As I described in the section on follow-up interviews, I structured the summaries of each participant’s data, which were the foundations of these interviews according to the emerging storyline with the associated categories. I continued to review these summaries, even after the final interview with each participant, and these were very useful in helping me put together the
explanation for each of the categories in such a way as to account for the spectrum of experience of the participants.

**Theoretical Sorting and Coding**

Theoretical sorting involves looking at how the categories relate to each other and is also helpful in determining the core category. This can be done in a variety of ways, using diagrams, or moving pieces of paper or printouts of memos on a table, or post it notes on a wall. I used a combination of drawing diagrams and writing the names of categories on pieces of paper and moving these about to determine how they related to each other.

**3.3.5 Trustworthiness**

It is well recognised that the quality of qualitative research is judged by different criteria than that of quantitative research. There is less agreement however on the precise criteria by which the quality of qualitative studies should be judged. Even within the literature on grounded theory there are a range of views regarding the precise factors that should be considered. In deciding which criteria to address in considering the quality of my research I followed Charmaz’s (2006) suggestion to also consider disciplinary influences. Qualitative researchers within the discipline of occupational therapy, and those reviewing qualitative research within the field commonly make use of the guidelines such as those put forward by McMaster University (Letts et al., 2007). The McMaster guidelines consider the four elements of trustworthiness: credibility, dependability, transferability and confirmability suggested by Guba (1981) and expanded on for occupational therapy by Krefting (1991). More broadly, quality in qualitative research is underpinned by reflexivity.

**Reflexivity**

All of the strategies that I used to enhance the trustworthiness of this study were underpinned by reflexivity. In line with the constructivist paradigm I recognised that I occupied a central role in this research, determining the aim of the research, the methods that were used and how they were employed, and interpreting the data (Carpenter & Suto, 2008). As such my own experiences and views would of course influence and shape the research. Finlay (2002) defines reflexivity as “thoughtful,
conscious self-awareness” and suggests that reflective analysis in research involves “continual evaluation of subjective responses, inter-subjective dynamics and the research process” (p.532). While not all proponents of grounded theory research agree on the value of reflexivity (Glaser, 2001) it is generally seen as important by those operating under a constructivist paradigm (Birks & Mills, 2011; Charmaz, 2006; Gardner, Fedoruk, & McCutcheon, 2013).

I adopted a reflexive approach throughout the life of the project. As discussed in section 1.2 of this chapter, I examined my own ‘world view’ when I was developing the plan for the research and the role of my various experiences and associated views on determining my interest in the topic, and the means by which I decided to carry out the study. A key focus of reflexivity, particularly under a constructivist paradigm is the dynamics of the relationship between the researcher and participants (Birks & Mills, 2011; Finlay, 2002). I discuss my thoughts regarding my role in this relationship and my efforts to reduce the power differential in section 1.3.3.3 above. I captured my reflexive thinking in my field notes, research journal, and analytic memos, which are described in more detail in the sections pertaining to these activities above. I also found it valuable to discuss my reflexive analysis with my supervisors on a regular basis.

**Credibility**

Credibility refers to the degree to which the explanation of the phenomenon that is rendered in the findings would be recognisable, or seen as plausible by the participants, and the degree to which others, having read the findings would recognise it when they encountered it (Carpenter & Suto, 2008; Cooney, 2011). The primary means by which I enhanced the credibility of this study were through generation of data over a prolonged period and from a range of participants; the involvement of participants in processes that are consistent with member checking; and through the adoption of a reflexive approach throughout the study.

Prolonged engagement with participants contributes to credibility by allowing for the development of greater rapport and opportunities for the researcher to observe and verify recurring patterns (Krefting, 1991). Data were generated in this study over a period of just over two years. I interviewed eight participants twice and five of the
participants three times over that two-year period. The interval between interviews with an individual participant varied from three to 18 months. I used the second and third interviews with participants as an opportunity for member checking. I shared the data, and my interpretations of it, and later the concepts that were developing through analysis with the participants to ensure that I was accurately capturing their views and experiences (Krefting, 1991). I described these processes in more detail in section 3.3 of this chapter.

My reflexive approach also helped me to keep attention on maintaining the credibility of the study. Through recording my thoughts and feelings, questions and ideas, and discussing these with my supervisors I was able to maintain awareness of my own thinking and feeling about the processes and the explanations that were being generated, and to make sure that these did not dominate those that I was hearing from the participants. Keeping track of processes in my research journal also assisted me to maintain attention on following grounded theory procedures, which assisted with keeping the theory grounded in the data. Memos helped with maintaining the link between the data and the concepts that were developing, and helped keep it close to the participants’ experience, which is also related to the dependability of the research.

**Dependability**

Dependability relates to the consistency between the data and the findings. The main means of ensuring this aspect of trustworthiness are the maintenance of an audit trail, and peer review. I primarily maintained an audit trail, which is an explanation and record of all of the decisions and actions taken in the research, through my research journal, which is described in section 3.3, and excerpts of which I have included throughout this chapter. I also kept records of the data analysis as it progressed through exporting and saving code lists and later through saving a new version of the Nvivo file each time I worked on the data analysis. Peer review was conducted regularly throughout the process with my supervisors. In the early stages of the project this involved discussing my coding and the logic of this with them. Later we used my writing of the storyline, the participants’ stories and memos of emerging categories and their relationships with each other for peer review. The focus of these discussions was
on making sure that there was a clear, strong logic and link between the data, the coding and the concepts that came from this data.

**Transferability**

Transferability refers to the measure of applicability of qualitative findings into contexts outside of the study situation which is determined by the similarity between the two contexts (Krefting, 1991). Lincoln and Guba (1985), suggest that rather than providing an index of transferability it is the researchers responsibility to provide adequate information about the participants and setting so that others may make transferability judgements. To facilitate the reader’s judgement about transferability I have provided a description of the research sites and an overview of the general characteristics of the participants in section 3.2 of this chapter. More detail regarding each of the participants is also contained in the descriptive portraits in Appendix III.

**Confirmability**

The criterion of confirmability relates to the neutrality, not of the researcher but of the data (Guba, 1981). The strategies used in this study to address confirmability include the documenting of process and decision points in the research journal, peer review of decision making by my supervisors, member checking regarding my interpretation of the data and reflexive analysis, all of which contribute to the other aspects of trustworthiness and have been discussed above.

**3.3.6 Ethical Considerations**

In developing this study I considered the principles of merit and integrity, justice, beneficence and respect as outlined in the National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council, Australian Research Council, & Australian Vice Chancellors’ Committee, 2007). The study gained ethical approval from the Human Research Ethics Committee of Hunter New England Health (approval number 09/09/18/5.11) and the Human Research Ethics Committee of the University of Newcastle (approval number H-2009-0132).
**Merit and Integrity**

To have merit and integrity a research study must have, a sound theoretical basis, the potential to provide useful outcomes, and be conducted using appropriate methods by suitably qualified and experienced researchers (National Health and Medical Research Council, et al., 2007). In developing the study I conducted a thorough examination of existing research which enabled me to specifically target a gap in the evidence and determine the potential benefits of an understanding of the experiences of women with SSD in managing their weight, which is outlined in chapter two of this thesis. I also determined the most appropriate research design and methods to achieve the aims of the study, as discussed in chapter three. These aspects were subject to peer review as part of the ethical review process, during my confirmation at the end of the first year (equivalent) of my PhD studies and through presentations at national conferences. My competence for carrying out the procedures involved in conducting the study was developed through training as part of a Masters Degree, experience in conducting qualitative research as part of that degree and on other occasions and guided reading and support from my supervisors, all of whom are established researchers and have considerable experience with qualitative methods.

**Justice**

The concept of justice in research relates to fairness in the recruitment and selection of research participants and reporting of outcomes (National Health and Medical Research Council, et al., 2007). In section 3.2 of this chapter I outlined the sampling and recruitment strategies and provided a rationale for the selection criteria for the study. In the following chapters I will report the findings of the study. These findings have and will continue to be reported at conferences and in peer-reviewed publications to facilitate access and scrutiny.

**Beneficence**

The principle of beneficence requires assessment of the potential risk of harm and benefits of the research, further assessment that the benefit outweighs the potential for harm, and actions to minimise the risk of harm or discomfort to participants (National Health and Medical Research Council, et al., 2007). The risk of participants...
experiencing any harm as a result of participating in this research was considered by the researcher to be very low, although there was some possibility that they may experience some psychological harm or distress during the interviews due perhaps to discussing information that they felt embarrassed or upset about. A number of actions were taken in relation to this possibility. First the possibility was communicated to the participants in the information statement, along with a description of the types of issues that would be discussed in the interview, so that participants were aware when they gave consent. Secondly, procedures were determined for any occurrence of a participant showing signs of distress, and these were also outlined in the information statement. The procedures included me suspending the interview but staying with the person, and where necessary assisting them to gain support from their usual support network. This only occurred on one occasion, in my first interview with Mary. She became tearful when talking about her frustration with not being able to manage her weight. I suspended the interview and stayed with Mary. She soon recovered and expressed that she wished to continue with the interview although I had given her the option to stop. After the interview I stayed with Mary for the few minutes between our interview and her scheduled appointment with her care co-ordinator. Finally I took the position at all times that the comfort of the participants would take precedence over data collection. Participants were not pressured to discuss issues about which they indicated they would prefer not to disclose or which appeared to cause them distress. Other than the incident with Mary, described above, there were no further occasions where this issue arose.

Respect

The criterion of respect involves making sure that all interactions are underpinned by a recognition of the value of every human being (National Health and Medical Research Council, et al., 2007). As well as abiding by the principles of merit and integrity, justice and beneficence, respect requires consideration of issues such as consent, privacy and confidentiality.
**Consent**

The principle of respect requires that due consideration be given at all stages of the research to the capacity of humans to make their own decisions, and where this capacity is impaired that steps are taken to either empower people or provide protection where necessary (National Health and Medical Research Council, et al., 2007). Throughout this project I took measures to make sure that individuals were provided with the necessary information to make informed decisions about consent, and that only those with the capacity to give informed consent were included. The inclusion criteria for the study were designed to preclude those who were unable to give consent as a result of the impact of their mental illness. This included people whose capacity may be temporarily impaired due to an acute episode of illness, or those whose capacity was impaired on a more long term basis as indicated by them being under protection of a guardian order for such decision making. The care co-ordinators who provided information about the study to potential participants were asked not to provide the information to people who did not meet the requirement of being able to give consent. Recruitment occurred via the care co-ordinators, who had no involvement in the study, to avoid participants feeling any pressure to participate. I only contacted participants after receiving their signed consent form. I continued to establish ongoing consent on each encounter, making sure that I explained what would be involved and giving participants the opportunity to ask questions before making their decision to continue to give their consent. I did this on each occasion when I phoned to arrange an interview, at the commencement of each of the interviews, and at the end of first and second interviews to determine participants consent for me to contact them for an additional interview. Participants were informed in the information statement that they could withdraw their consent at any time, and withdraw their data from the study, without any adverse consequences.

**Privacy and Confidentiality**

Respect also involves taking measures to protect the privacy and confidentiality of the participants. In this study I de-identified all of the interview data. I asked participants to nominate a name that they would like to be used to label their data in the study. I referred to the participants by this pseudonym in the interviews and in any reporting
of the data. All data is stored with the pseudonym and any identifying information linking individuals to pseudonyms is stored separately. As well as using a pseudonym to refer to the participant I removed names of other people whom the participants referred to, writing instead their relationship such as friend, cousin, doctor. I also removed any names of locations or organisations that could potentially help identify the participant. I stored all computerised data on password protected computers and hard copies in a locked cabinet and I have been the only one to access this data.

3.4 Summary

The research approach that I adopted for this study was underpinned by the constructivist paradigm, which fit with my aim of developing a theory to explain the meanings women with SSD have about managing their weight. I used constructivist grounded theory, which is a qualitative research methodology with a strong precedent in health research, and more specifically in investigating the experiences and needs of people with chronic illness, including schizophrenia, in managing a range of issues. I have in this chapter provided a detailed account of how I carried out the various processes involved in grounded theory research for this study, from the selection and recruitment of participants, through data generation and analysis, and illustrated these processes with examples from my records. My intention in doing this was to provide a clear account of the means by which the data was transformed to produce the findings, which I will detail in the next four chapters.
Chapter 4  The Double-Whammy

4.1 Overview of the Chapter

This is the first of four chapters in which I describe the findings of the study. In each chapter I discuss a component of the theory dealing with the double whammy. I describe the concepts that make up each of these components of the theory and illustrate them with quotes from the women who took part in the study. I also discuss these concepts in relation to the existing published research. In this chapter I describe the basic social-psychological problem that was shared by the women who participated in this study, the ‘double-whammy’. A ‘double-whammy’ is defined in the concise Oxford Dictionary (2008) as a twofold blow or setback. Nuela used this phrase when discussing discrimination,

I think there’s a bit of discrimination against large people and there’s also discrimination against people who disclose that they have a mental illness. So having both of them, being a fat person with a mental illness, yeah that’s like a double whammy (Nuela, Interview One).

The concept of the double whammy fits well with the participants’ experience that significant weight gain was a second ‘whammy’ that came with their SSD and brought with it additional challenges. The problem is made up of two components. I just piled on the weight, describes how the women, who generally did not have weight issues prior to their illness, gained significant amounts of weight following their diagnosis which they attributed to their illness and it’s treatment and which led to overweight and in many cases obesity. It’s impacting on my health, describes the women’s concern about their weight and the problems that they were already experiencing, or anticipated they might, as a result of the excess weight. These included physical health problems, reduced functional capacity and additional mental health problems. Having described the double-whammy in some detail, I then provide an overview of the whole theory, dealing with the double-whammy, the components of which are then described in more detail in the following three chapters.

4.2 I Just Piled on the Weight

Gaining weight, becoming overweight or obese, and having difficulty losing weight were all issues that the women in this study associated with the diagnosis and
treatment of their mental illness. They generally did not have any of these issues prior to having a SSD, as suggested by Karen in the quote below:

Before I took medication for my schizophrenia I never had a weight problem. I wasn’t skinny or anything but I was just average. Then as soon as I started taking medication my weight just, I’ve always had a weight problem ever since (Karen, Interview one).

Mary was the only participant who had any issues with her weight prior to the onset of her illness. She reported that she ‘did struggle with my weight as a child’ (Mary, Interview three). She did however describe having gained control of her weight in her teenage years and had been wearing size 12 clothing until she had become unwell in her early twenties. None of the other women recalled being overweight prior to their illness. Some described themselves as having been ‘slim’ or ‘skinny’, while others described their pre-diagnosis weight as having been, ‘average’, ‘normal’, or ‘healthy’. All of the women described gaining large amounts of weight after commencing treatment for their SSD. Some described the amount gained in kilograms with the range being from 30 to 40 kilograms. Isobel reported, ‘I was 91 kilos. So I – I’ve always been hovering around 62 kilos, so I put on a lot of weight, nearly 30 kilos’ (Isobel, Interview one), while Faith said, ‘I’ve put on 40 kilos in recovery and I’ve got to lose it. I was 65, I’m about 106’ (Faith, Interview one). Others described their weight gain in terms of increase in clothing size with the most dramatic being Abbie who went from a size 12 to size 26 and Mary who said, ‘I went from a size 12 to about –yeah, like a size 20’ (Mary, Interview three).

4.2.1 Gaining a lot of Weight in a Short Amount of Time

Generally the weight gain occurred over a relatively short period of time following their initial diagnosis and commencing treatment. ‘Because I put on a lot of weight at the beginning when I first took medication’ (Karen, Interview one). Abbie described her experience of gaining weight following the hospital admission for her first episode of schizophrenia, ‘It came on really quickly. I’m not sure exactly how long it took for me to get from a size 12 to a size 26. It could have been a year, a year and a half maybe’ (Abbie, Interview three).

The phenomenon of rapid and significant weight gain in the early period following diagnosis and commencement of antipsychotic medication, particularly the
contemporary ‘atypical’ antipsychotics is well recognised. Participants in the qualitative study exploring the experience of antipsychotic weight gain by Usher et al. (2013) also reported rapid weight gain following commencement of medications with one participant reporting gaining ten kilos per month in the first few months. Addington, Mansley and Addington (2003) followed 114 individuals who had experienced their first episode of psychosis over their first year of antipsychotic treatment and found that they gained an average of 12% of their original body weight within the first year of treatment, with more weight gain occurring in the first than the second six months. Even more strikingly, Tarricone et al. (2008) recorded significant increase in BMI and waist circumference in 15, previously antipsychotic naïve, study participants in only four weeks of treatment. This rapid weight gain following the commencement of treatment, and the resultant small window for recognition of the need to manage their weight has been identified by people living with SSDs as a key factor impacting on their weight management (Xiao, et al., 2012).

Emily’s experience was somewhat different, while she had experienced rapid and significant weight gain, this did not occur when she was first diagnosed but when her medication was changed after an exacerbation in her illness more than 20 years later. Emily had taken one of the older antipsychotic medications (Stelazine) from the time she was first diagnosed in 1979 and following a few years of fluctuation had remained relatively well on this medication until the death of her mother and main carer in 2009. This precipitated an exacerbation of her illness. She had been hospitalised and her medication changed to an atypical antipsychotic (Zyprexa), following which she reported, ‘the weight I’ve put on is stupendous. I used to be quite slim [55 kilograms] and now I’m 85 kilos’ (Emily, Interview one). This experience reflects the differential weight gain implications of psychotropic medications with the atypical, medications found to produce much more rapid and significant weight gain than traditional antipsychotic medications (Baptista, et al., 2002; Blin & Micallef, 2001; Theisen et al., 2001).
4.2.2 The Medication Made Me Put on Weight

The women drew a direct link between their medication and their weight gain, ‘the medication has made me put on a lot of weight’ (Mary, Interview one). They spoke of weight gain being associated with the particular antipsychotic medications that they took, ‘It’s a side effect of taking clozapine’ (Faith, Interview two), ‘Risperdal puts weight on you’ (Gaye, Interview One), ‘But the Seroquel does make you bulk on the weight’ (Nette, Interview One). This recognition of the contribution of medications to weight gain was consistent with the findings of other studies of the experiences of weight gain in people with SSD (Tham, et al., 2007; Vandyk & Baker, 2012). It is also well supported by empirical evidence, reported in numerous systematic reviews, that almost all atypical antipsychotics, do cause weight gain although the degree is variable (Haddad, 2005; Newcomer & Haupt, 2006; Parsons, et al., 2009; Rummel-Kluge, et al., 2010; Taylor & McAskill, 2000; Wetterling, 2001). As well as antipsychotic medication some of the women were also taking mood stabilisers and recognised these as also contributing to their weight. Nette stated, ‘I find the lithium bulks on the weight more than anything but it’s hard to tell with so many drugs which drug is actually doing which damage’ (Nette, Interview One). This perception is also supported by research evidence of the weight gain side effects of mood stabilising medications (Torrent et al., 2008).

It Makes Me Hungry

The primary mechanism through which the women thought the medication increased their weight was through ‘increased appetite’. These two words however do not adequately communicate the constant presence and overwhelming intensity of what the women experienced. Nuela referred to medication causing her to be, ‘disastrously hungry’ (Nuela, Interview one). Elizabeth described how when she was first taking the medication, ‘I was hungry all the time and kept wanting to go into the kitchen and get something to eat’ (Elizabeth, Interview one). Similarly Mary, who had been living with her illness for less than two years when we first met, described feeling really frustrated by the constant hungriness and was tearful as she said, ‘I just always feel hungry. I’m constantly eating ’ (Mary, Interview One). Participants in the study by Usher et al. (2013) also described being constantly hungry. The intensity of the hungriness
experienced as a side effect of medications is also portrayed in the category labelled ‘insatiable hunger’ in a qualitative study of the psychosocial factors affecting weight management in people newly diagnosed with schizophrenia (Xiao, et al., 2012). One of the participants in that study reported that there was, ‘no end to my hunger’ (Xiao, et al., 2012, p. 244). Blouin et al. (2008) found that people treated with atypical antipsychotic medications had disordered eating behaviours that appeared to develop in response to altered appetite sensations, making them more susceptible to hunger, less satiated over time after a given meal, and having higher levels of dis-inhibition associated with loss of control of food intake, than controls.

**Feeling Tired and Lethargic**

The women thought that the medication reduced their level of energy and motivation which also contributed to them gaining weight and having difficulty losing it. Nuela described feeling, ‘really zonked out tired’ (Nuela, Interview one). Karen believed that, ‘the medication also makes me a bit lacking in motivation’ (Karen, Interview one). She had come to this conclusion after making the observation that, ‘Sometimes if I forget to take my medication in the morning I’ve noticed that I have more energy that day’ (Karen, Interview one). This perception aligns with the participants in the study by Abed (2010) exploring the factors impacting on lifestyle choices in people with SSDs who identified that tiredness made it difficult for them to function during the day and interfered with their ability to engage in exercise.

**Putting up with Side Effects for Wellness**

Nuela identified that her perception that the side effects of the medication contributed to her weight gain meant that she did ‘not want to take it and I’m more likely not to take it and be medication non-compliant’ (Nuela, Interview one). This is consistent with the evidence I reported on in Chapter Two, that weight gain is identified as one of the most distressing side effects of antipsychotic medication, particularly in women, and is associated with people not taking their medication as prescribed or even stopping it altogether (Covell, et al., 2007; Fakhoury, et al., 2001; Weiden, et al., 2004). In a cross sectional study of people with psychosis in Australia, Tham et al. (2007) found that of those who thought that medication contributed to their weight gain, 64%
had considered stopping their medications, 16% had stopped on at least one occasion and 12% had stopped altogether. Similarly in a qualitative study of why people stop taking their medication, where participants had stopped for at least a year, one of the key factors in their decision making was losses experienced as a result of medication with one of those identified losses being usual body shape (Roe, Goldblatt, Baloush-Klienman, Swarbrick, & Davidson, 2009). It was interesting to note that one of the participants in the study be Roe et al reported feeling disturbed at the suggestion made to her that it might be preferable to be ‘fat and balanced’ (Roe, et al., 2009). Some of the women who participated in my study described being given the same message by their psychiatrists. Emily recalled, ‘Well my psychiatrist, Dr [name] said you’ve either got to be well and plump or sick and thin. I said I think I’ll pick well and plump’ (Emily, Interview one).

Like Emily, most of the women who participated in my study believed that the implications of not taking their medication and possibly becoming unwell were too great, and so continued to take it despite the side effects. Karen said, ‘I’d rather be taking my medication and well and a bit overweight rather than anxious’ (Karen, Interview one). This reflects the findings by Xiao et al. (2012) in their study of psychosocial influences on weight management in people with schizophrenia, that while some people stopped their medication as a strategy for losing weight others, despite not being happy with their weight gain, saw their symptoms as a greater threat. Similarly, while many of the respondents in the national psychosis survey described medication side effects impacting significantly on their everyday lives, most felt that they relieved their symptoms and took them as prescribed (Waterreus et al., 2012). Carrick et al. (2004) describe this phenomenon as an attitude of ‘sufferance’ whereby participants in their study of the experience of taking antipsychotic medication recognised that available treatments come with limitations and were prepared to put up with quite significant side effects for sufficient benefits (Carrick, et al., 2004).
4.2.3 Comfort Eating

As well as increased appetite, which they attributed to their medications, the women who participated in my study described their illness affecting their dietary intake in a more indirect manner, through their response of comfort eating. Most of the participants described comfort eating as a way of coping that was employed both in the beginning, when they were first diagnosed with their illness and in response to ups and downs, both of which are described in more detail in Chapter Six. Over eating, generally of high fat or high sugar foods, has been identified as a coping response to both acute and chronic psychological stress (Dallman, Pecoraro, & la Fleur, 2005; Rutters, Nieuwenhuizen, Lemmens, Born, & Westerterp-Plantenga, 2008). Various termed emotional eating, stress eating or comfort eating, it has been found to be more prevalent among women, and people who are obese (O’Connor, Jones, Conner, McMillen, & Ferguson, 2008).

Comfort eating was not something I asked specifically about in the early interviews as it was not been something I had come across in my initial literature review regarding weight gain and obesity in people living with SSDs. However after a couple of the women raised it without prompting I did begin to ask about it directly in later interviews. Similarly in a qualitative study looking at health eating behaviour in people with severe mental illness, Barre, Ferron, Davis, and Whitley (2011) found that although the focus of their questions was on food in the context of health some of their participants talked about it in terms of comfort and meeting emotional needs, with one of them describing it as being almost like medicine. This was reflective of Abbie’s description of ‘medicating myself with food’ (Abbie, Interview one).

I did not find any studies that specifically examined emotional eating in people with SSDs although there were two that explored the prevalence and correlates of binge eating, which may or may not occur in the context of emotional eating. Theisen et al. (2003) explored binge eating symptomology in 74 people taking clozapine or olanzapine and found that half of the total sample, and 56% of the females screened positively for binge eating symptomology. In another study that compared 40 people with schizophrenia with matched controls, 17 of the participants with schizophrenia
compared to ten of the controls had binge eating symptomology (Khazaal, Fresard, Borgeat, & Zullino, 2006). While Theisen et al. (2003) concluded that the binge eating disorder was medication induced, Khazaal, Fresard, Borgeat, and Zullino (2006) suggested that it was due to a high level of emotional vulnerability which is a predisposing factor for severe overweight and BED or BS. Elman, Borsook and Lukas (2006) suggest a neurobiological contribution to overeating in people with SSDs, specifically to do with homeostatic and reward mechanisms, which may be exacerbated by atypical antipsychotic medications. Reward mechanisms are also linked to stress, or comfort eating in the model proposed by Adam and Epel (2007) who drew on addictions literature to develop a model centring on reward circuitry in the neuro-endocrine system as mediators in the relationship between stress and eating.

The women viewed their comfort eating as a contributor to their weight gain and difficulty losing weight or maintaining weight loss. This is reflected in the comment by Faith linking the symptoms of her illness, comfort eating and weight, ‘I think not having my privacy and just eating for comfort’s hurting that, so it does make it harder to lose weight’ (Faith, Interview three). This finding is reflected in other studies of the perceptions of people living with overweight and obesity. Participants in a qualitative study looking at emic perspectives of body weight in overweight and obese women identified eating in response to stress or for emotional satiety as a key reason for them being overweight (Parker & Keim, 2004). Similarly, in a study exploring how adults in a weight management clinic explain their obesity, eating to manage emotional pain, and as a substitute for relationship were identified as key factors (Goodspeed Grant & Boersma, 2005). This perception is validated by the findings of a prospective study of 1562 employees that emotional eating was more significant in driving weight gain than other lifestyle behaviours (Koenders & van Strien, 2011). Similarly, a review of factors associated with weight loss maintenance and weight regain identified binge eating and eating in response to negative emotions and stress as risk factors for weight regain (Elfhag & Rossner, 2005).
4.2.4 Being Overweight or Obese

While not necessarily at the time of the study, all of the women who participated in my study had at some point since their diagnosis been overweight or obese. Two of the women had succeeded in losing much of the excess weight that they had gained. Danika, who had at one point reached 123 kilograms in weight, was down to 91 kilograms when we met and while she was still overweight she was, ‘pretty much nearly the weight I want to get to’ (Danika, Interview One). Similarly Isobel had managed to reduce her weight from 91 kilograms to 72 kilograms and believed that she was, ‘not overweight – too overweight’ (Isobel, Interview One). Abbie, Emily, Karen, Mary and Nuela, all described themselves as obese during the time of the study while Gaye thought she was overweight. Others were not comfortable with categorisations but used other labels to indicate that their weight was above what they considered to be Okay such as, ‘a bit porky’ (Nette, Interview One). The limited research available indicates that women with SSDs are likely to accurately self-estimate their weight status. Meyer (2002) found in a survey of chronically mentally ill inpatients that despite being significantly functionally impaired they had a good awareness of their weight gain and there was good correlation between their actual weight and their perception of their weight status. While the participants in Loh, Meyer, and Leckbands’ (2008) study tended to underestimate their weight status this may be more due to the fact that most of them were male. In the study by Strassnig, Brar, and Ganguli (2005) while both male and females who were in the obese range were aware of their weight status, only females who were in the overweight range were, with males in this range underestimating their weight. This is also consistent with a general population study that found that men did not identify themselves with being heavy even if they were objectively overweight (Grover, Keel, & Mitchell, 2003).

4.3 It’s Impacting on My Health

The women who participated in my study were generally concerned about their weight and believed that it had or would cause them additional problems as well as exacerbating some of those they were already experiencing as a result of their SSD. Abbie’s usually cheerful countenance became noticeably clouded when she talked
about her weight and she, on different occasions, referred to it as ‘a big concern’ (Abbie, Interview one) and to being ‘worried about it’ (Abbie, Interview two). Particularly in the first interview, Mary became quite upset when talking about her weight gain. She identified that this was because, ‘it’s impacting on my health in other ways’ (Mary, Interview One). The only one of the women who expressed that she did not care about her weight gain was Gaye. She was aware of her weight gain and knew that this was not ideal, ‘I don’t really manage. I’m overweight’ (Gaye, Interview One). Gaye was however very overwhelmed and distressed by the ongoing effects of her illness as well as other social factors. Her schizophrenia was poorly controlled with medication and she continued to experience distressing symptoms and recurrent admissions to hospital. She also had depression for which she was medicated, ‘but it don’t work. I’ve been on that many antidepressants it’s not funny’ (Gaye, Interview One). She described a long history of trauma including abuse as a child, domestic violence in her marriage, and ongoing problems with her son, ‘I’ve got a violent son who has got mental problems and he’s called me filthy names and he’s hard to deal with’ (Gaye, Interview One). She found that she was overwhelmed with the many challenges in her life and declared, ‘I don’t care that I’m overweight, that’s the least of my problems at the moment, it really is’ (Gaye, Interview One). This reflects the finding by Xiao et al. (2012) in their study of the psychosocial factors affecting weight management in people with schizophrenia that, despite recognising their weight gain was not desirable, some participants had decided to accept it and focus their attention on their recovery from their mental illness which they perceived as a greater threat.

4.3.1 Physical Health Problems

The women were aware of many of the health problems associated with being overweight or obese and were concerned about their vulnerability to these as is captured in Nuela’s observation that, ‘There’s lots of problems that happen when you’re too heavy or too thin, mostly with too heavy, like: diabetes, heart disease, hypertension, stroke, cancer’ (Nuela, Interview one). They spoke of wanting to lose weight to avoid these health problems. Elizabeth said, ‘That’s why I am trying to lose it because I don’t want to keep getting more health problems, because it will probably never end’ (Elizabeth, Interview two). The recognition of and concern about the health
implications of their weight by the women in this study is reflected in other qualitative studies exploring the experience and impact of antipsychotic related weight gain (Usher, et al., 2013; Vandyk & Baker, 2012). In contrast however the participants in the study by Abed (2010) were unaware that they were at higher risk of developing type II diabetes and identified lack of knowledge of physical health related issues as a factor that affected lifestyle choices. The basis for the concern expressed by the women in my study is also well supported by research, including the finding by Allison, Mackell, and McDonnell (2003) that weight gain in people with schizophrenia is associated with poorer self-reported general health, as well as research finding increased incidence of obesity related co-morbidities including: metabolic syndrome (De Hert, et al., 2006; Galletly, et al., 2012; Tirupati & Chua, 2007), type II diabetes, (Cohen, Dekker, et al., 2006; Suvisaari, Perala, Saarni, et al., 2008) and cardiovascular disease (Bobes, et al., 2006; Goff, et al., 2005).

4.3.2 Type II Diabetes

The primary physical health concern that the women in my study raised in relation to their weight was type II diabetes. Several of them had been told that they were at risk. Abbie reported, ‘My GP also said, you know, that I need to lose the weight otherwise I’d be at a very high risk of getting diabetes’ (Abbie, Interview one). Others, like Elizabeth had been diagnosed with ‘borderline diabetes’. Those who hadn’t developed type II diabetes described being very anxious to lose the weight to prevent this, ‘I really need to lose the weight because I don’t want to get diabetes’ (Abbie, Interview one).

Two of the women, both of whom had a baby either during or just before their entry to the study, did develop diabetes during the time they were involved with the study. Mary, who had her baby during the study, developed gestational diabetes. While this resolved following the birth of her son she was concerned at being at higher risk of developing type II diabetes as a result,

when I was pregnant I was diagnosed with gestational diabetes as well and I know that that - women who have gestational diabetes are at a greater chance of getting type II diabetes when they’re older. So I’ve really got to watch it now so it doesn’t turn into that (Mary, Interview X).

Nuela, whose baby was born just before she joined the study, had not developed gestational diabetes, ‘and I kind of assumed that if you don’t get diabetes in your
pregnancy you’re kind of bullet proof’ (Nuela, Interview three). She was however diagnosed with type II diabetes less than a year after her son was born, which she described as, ‘a shock’, ‘even though I had a lot of warning signs, like my weight, the doctor telling me and pre-diabetes symptoms and all that stuff’ (Nuela, Interview three). Karen also had Type II diabetes. She had been diagnosed before she entered the study, and saw her diabetes as resulting from her overweight,

I got a bit of diabetes like I take medication for diabetes, but I don’t have to take insulin or anything like that, I just have to take a pill. So I think that’s one of the side effects (Karen, Interview two).

4.3.3 Managing Day-to-Day Activities

Most of the women also described some impact of their weight on their ability to manage day-to-day activities. This was generally as a result of reduced energy levels, which Karen described below,

Yeah, it just makes me feel, it’s an effort to do things sometimes and sometimes I lack energy. They say that when you’re overweight you kind of feel sleepy and tired a lot. So I’m sure that’s related, why I feel sometimes lacking energy (Karen, Interview one).

Nuela also described, ‘all those fat feelings, like tired, heavy and slow’ (Nuela, Interview two). Others described lack of stamina in terms of breathlessness. Emily stated, ‘Yes, everything’s an effort. I seem to gasp for breath’ (Emily, Interview one).

These findings concur with a population survey by Morris, Koehn, Happell, Dwyer, and Moxham (2010) which found that individuals of all ages, except 18-24 years, who had obesity reported low energy levels. The women in my study described in particular how their lack of energy or stamina interfered with their mobility. They found it difficult to ‘stand in one place for a long time’ (Emily, Interview two), to ‘walk for a long time’ (Mary, Interview one) and to manage inclines and stairs, ‘I do struggle a bit with hills’ (Mary, Interview three), ‘it’s hard to get up the stairs, on to the top floor’ (Faith, Interview one). Being physically active was also affected by other aspects of carrying excess weight as described by Nuela,

There’s bits of me that wobble and jiggle and make things uncomfortable when I’m being active and even real mild activity in certain clothes can be quite unforgiving. Like the sweating and rash between the legs when you walk, sort of things. Yuk. That actually really hurts. For anyone who’s never had that, that hurts. It feels like on fire and it looks gross and it feels gross and you know it’s because your legs are too big. So mentally it feels gross (Nuela, Interview three).
Other activities were made more challenging by their body size, which made things either awkward or uncomfortable. Emily described how, ‘I can’t bend over to put my shoes on very well and things like that, because my tummy gets in the road’ (Emily, Interview two). Similarly Isobel described how, ‘hopping in and out of the car, and getting - sort of just getting up off the floor’, is easier without the excess weight (Isobel, Interview One). Participants in other studies exploring the experience of obesity also described feeling physically uncomfortable and being restricted in their ability to do things like climb stairs and go shopping (Ogden & Clementi, 2010; Vancampfort, Probst, Scheewe, et al., 2011).

There is little research regarding the impact of overweight and obesity on functional capacity in adults. A correlation has been found between overweight and obesity and reduced functional capacity, including mobility, in older adults (age ≥60), (Bannerman et al., 2002; Chen & Xuguang, 2008; Jensen & Friedman, 2002; Wee et al., 2011). Forhan, Law, Vrkljan, and Taylor (2011) explored time use in people with class III obesity and found that they spent increased amounts of time in self care and reduced time in leisure and work activities than the general population. This finding must be read with consideration that it is based on the experiences of people with severe obesity only. In a general population cohort study where weight and health related quality of life were monitored at five year intervals it was found that weight gain over two consecutive five year periods was associated with declines in physical functioning, role limitations due to physical problems, pain, general health perceptions and vitality. It is notable also that a dose response relationship was found in this study, especially among women (Milder et al., 2014). Studies of health related quality of life conducted with people with schizophrenia have shown that weight gain and high BMI are associated with poorer scores for vitality, and physical functioning and role limitations due to physical functioning (Allison, et al., 2003; Strassnig, Brar, & Ganguli, 2003; Vancampfort, Probst, Scheewe, et al., 2011). It is worth noting here also that the women who took part in my study tended to define health in terms of what they could do. This finding was reflected in a study of motivational discourses for weight loss in women in which the participants tended to see health as a means to an end, defining it in terms of what they could do rather than biomedical measures (Kwan, 2009).
4.3.4 Self Esteem and Mood

In my study, the impact of being overweight or obese that was most commonly identified and strongly felt by the women was psychological and emotional. This is consistent with a finding in the study by Lewis et al. (2010) exploring the impact of public health messages about obesity on obese adults. Despite the fact that public health messages about the impact of obesity rarely mentioned mental health, most of the female participants in that study believed that obesity was more of a risk for poor mental health outcomes than physical health outcomes. This was attributed to societal reactions to obesity rather than the obesity itself (Lewis, et al., 2010).

The women in my study talked a lot about the negative impact of their weight gain on their self-perception and self-esteem. A number of the women described feeling self conscious as a result of their weight gain. Elizabeth said ‘I just don’t even like looking at myself because of the weight I am at’ (Elizabeth, Interview one). Mary also described avoiding mirrors and cameras because of the way she looked. Like many of the women in my study Karen described a belief that, ‘my self-image probably gets affected by my overweight-ness’ (Karen, Interview three), and many, like Abbie, felt that as a result, ‘My self esteem is pretty low. I feel very bad about my body’ (Abbie, Interview one). Nuela, described feeling like her weight had more of an impact on her identity and self-esteem than her mental illness, ‘Most of the time I feel like mostly I’m a fat person rather than a person with schizophrenia’ (Nuela, Interview two). Similarly Karen described,

> I’ve got to attend to all my facets of myself and you know, like weight is just one part of it. Sometimes it’s the most debilitating part because you’re physical you know, you feel uncomfortable or you feel embarrassed with your weight. Sometimes it’s the most obvious one that people can see most (Karen, Interview one).

Participants in other studies of the experiences and effects of medication induced weight gain also described not liking the way they looked, and avoiding looking at themselves as a result of the weight gain (Usher, et al., 2013; Vandyk & Baker, 2012). Participants in these studies, as well as studies with people with obesity who didn’t have SSD have also identified the impact on their self-esteem and confidence as well as describing a range of negative emotional responses including anger, shame, anxiety, guilt and even hate (Ogden & Clementi, 2010; Usher, et al., 2013). Levels of self directed
weight bias in people with SSDs who also had obesity have been found to be the same as in the general population and are associated with poorer quality of life and negative affect (Barber, Palmese, Reutenauer, Grilo, & Tek, 2011).

The women in my study also described concerns regarding the impact of their weight on their mental health. Neula talked about the impact on mood suggesting, ‘it would definitely cause a lot of distress and depression just looking at yourself and realising that you don’t fit into what you want to look like or what someone else wants you to look like’ (Nuela, Interview three). Mary also expressed a belief that, ‘a lot of mental health problems can come from being overweight as well’ (Mary, Interview two).

There is strong evidence of an association between obesity and weight gain and reduced self-esteem, and mental disorders, in particular depression and anxiety. Half of the participants in a study of the lived experience of obesity in Australia by Thomas, Hyde, Karunaratne, Herbert and Komesaroff (2008) described poor mental health outcomes including low self esteem and depression. The correlation between obesity and poorer mental health, particularly in women, has been established by a number of population surveys (Johnston, Johnson, Leod, & Johnston, 2004; Jorm et al., 2003; Morris, et al., 2010; Scott et al., 2008). Because they were cross sectional these studies were not able to establish the direction of causation. A small number of longitudinal studies have however demonstrated that obesity leads to increased rates of depression. Roberts, Deleger, Strawbridge, and Kaplan (2003) conducted a five year, two wave, observational study of 2123 people and found that obesity at baseline was associated with a two-fold risk of depression five years later. Similarly, Kasen, Cohen, Chen, and Must (2008), in a longitudinal study of women conducted over thirty years, found that a baseline BMI of ≥30 was associated with significantly increased odds for both global anxiety disorder (OR 6.27) and major depressive disorder (OR 5.25). Finally, Herva et al. (2006), in a longitudinal study in Finland found that teenage obesity was associated with depression in adulthood (for those who were still obese).

**4.3.5 Stigma and Discrimination**

As well as diminishing their view of themselves the women who took part in my study believed that others viewed them more negatively because of their weight. Emily,
Karen and Nuela, all described a belief that other people would view them as lazy, as illustrated in Karen’s comment that, ‘Yeah like people think that you’re kind of - you eat too much chocolate or they kind of think that you’re lazy or something like that, especially they think you’re lazy’ (Karen, Interview two).

The existence of stigma and discrimination on the basis of weight is well recognised in the literature, with US survey finding that the rates were similar to those reported for racial discrimination in that country (Puhl, Andreyeva, & Brownell, 2008). Puhl et al. (2008) also found that women were at greater risk, which is reflected in qualitative studies of the experiences of overweight and obese people. Only a small proportion of the participants in the studies by Thomas et al. (2008) and Lewis et al. (2011) had not experienced stigma and discrimination and in both cases all of those participants were male. Women who kept diaries recording episodes of weight stigmatisation in a study by Seacat, Dougal and Roy (2014) reported an average of three events per person per day.

The women in my study described experiencing weight based stigma and discrimination directly through comments or missed opportunities. Mary described hearing her friends and family talking about other peoples’ weight gain and feeling, although the comments weren’t directed at her, ‘that being overweight isn’t very acceptable’ (Mary, Interview three). Abbie, had experienced comments directed to her, ‘When I spend time with my family, my nephews will joke about how fat I am and it’s terrible’ (Abbie, Interview two). Comments from spouse, family members and friends were one of the more common sources of weight stigmatisation experienced by the women in the study by Seacat et al. (2014). Nuela also believed that she had experienced discrimination on the basis of her weight and identified that in the context of work feeling, ‘like I’m not being given the chances that someone who was thinner was getting because I felt discriminated against’ (Nuela, Interview one). Participants in other studies exploring the experiences of being obese describe similar experiences of direct stigmatisation through comments, or discrimination resulting in missed opportunities as well as more indirect stigma (Lewis, et al., 2011; Parker & Keim, 2004; Thomas, Hyde, Karunaratne, Kausman, & Komesaroff, 2008).
Indirect stigma is described by Ogden and Clementi (2010) as the difficulty experienced in participating in activities because individuals are operating in a world that is designed for thinner people. This was particularly felt in the context of shopping for clothes. Participants described their discomfort with having to buy clothes in particular shops, or designated sections of shops, as described by Abbie, ‘going clothes shopping, you know, it’s sort of embarrassing because I have to go to the plus girls’ size clothes’ (Abbie, Interview two). Other participants described difficulty in buying clothes to fit. Nuela described how, ‘because of my weight, pants really don’t do up on me. Skirts ride up at the back, especially if they’re not made for bigger women’ (Nuela, Interview three). Karen described how, ‘I’d always have to think of what to wear that doesn’t make me look fat and things like that’ (Karen, Interview two). Women with obesity in other studies also described having difficulty buying clothes that they liked, or that fit and reported feeling stigmatised in the context of buying clothes (Lewis, et al., 2011; Parker & Keim, 2004; Seacat, et al., 2014).

One of the more unfortunate effects of weight related stigma and self bias is the potential for it to contribute to further weight gain through individuals avoiding activities where they perceive they are likely to encounter stigma, including exercise and engaging in comfort eating to cope with the negative emotions (Bidgood & Buckroyd, 2004; Lillis, Levin, & Hayes, 2011; Seacat, et al., 2014).

4.4 Dealing with the Double-Whammy, An Overview of the Theory

The remainder of the findings of this study comprise a theory of Dealing with the Double-Whammy, which provides an explanation of how the women manage the basic social problem of the double-whammy of SSDs and weight gain and obesity described above. A visual representation of the theory can be found in figure 4.1, and a full list of the categories, sub-categories, properties and dimensions can be found in Table 4.1.
The women’s response to the double-whammy, is described in the core category, as the basic social process of doing as much as I can. This category has four sub categories. The first sub category is doing the right things, the properties of which are the activities that the women believed to be the right things to do to manage their weight, doing exercise and adjusting their diet by cutting down and eating more healthy. Throughout the process the women engaged in adjusting expectations, which is the second sub category. Adjusting expectations involved a constant interplay between the women wanting to do more and being realistic both with regard the actions they were able to take and the outcomes they expected to achieve. The third subcategory is starting to do it, which
involved the properties of reaching the limit beyond which they were not willing to go with either their weight, or an associated factor, and deciding to act to address their weight. The women described starting to do it on more than one occasion because of the challenges of sticking with it which included keeping going with the additional activities required such as exercise, and resisting temptation to eat too much or the foods that they perceived to be contributing to their weight.

The women’s engagement in the process of doing as much as I can was impacted by a range of mediating factors, which constitute the second category in the theory. There are three sub-categories of mediating factors that impacted on each other, as well as the women’s ability to engage in the activities they saw as necessary to managing their weight. The first sub-category is, knowing. This sub-category included three properties: knowing the issue which was the degree to which the women were aware of the potential for weight gain and how much weight they were actually gaining, knowing what to do to manage their weight which included awareness of guidelines about diet and exercise and how to integrate these into their daily lives, and knowing how to do it which related to their knowledge and skills in carrying out associated tasks such as shopping for and preparing food. The second subcategory of mediating factors was mental health and wellbeing. The women found that their ability to do what they saw as necessary to manage their weight was particularly impacted in the beginning when they were first diagnosed and commenced treatment for SSD. Following that time their ability to manage their weight fluctuated in response to ups and downs, due to the episodic nature of their illness or the impact of other life events. Finally the women described the impact of practical issues, particularly the challenges of living on a limited income which necessitated watching your money, and juggling managing their weight with other priorities.
<table>
<thead>
<tr>
<th>Sub-Categories</th>
<th>Properties</th>
<th>Dimensions</th>
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<td>Doing as much as I can</td>
<td>Doing the right things</td>
<td>Doing exercise Incidental activity or exercise</td>
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<td>Weight loss as the only, or just one benefit</td>
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<td>Cutting down</td>
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<td>Making healthy choices</td>
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<td>Goals for weight loss</td>
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<td>Sticking with it</td>
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<td>wellbeing</td>
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<td>Doing what you need to survive</td>
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<td>Ups and downs</td>
<td>Symptoms, mood and life</td>
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<td>Prioritising different issues</td>
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<td>Facilitating Factors</td>
<td>Talking about it</td>
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<td>Keeping it on the agenda</td>
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The final category was facilitating factors, which included things that the women had found, or thought would, assist them in their efforts to manage their weight. The first subcategory of facilitating factors was talking about it. At its most fundamental level this involved keeping it on the agenda, by having someone with whom they regularly discussed their weight and efforts to manage it and may also involve measuring and monitoring. Other properties of talking about it included education and advice, which was helpful for filling in the details in their knowledge regarding healthy eating and exercise and providing practical suggestions for how to integrate these guidelines into their daily lives. For education and advice to be helpful it needed to occur in a context where the women felt like they were being listened to and understood. Similarly encouragement was important but praising encouragement was experienced as more helpful than pushing encouragement. The second sub-category was having a plan. This included the value of having routines, both for eating regular meals, and fitting exercise in. They also talked about the value of planning tools such as budgets, meal plans and shopping lists and the importance of having strategies to avoid behaviours that were counter to their weight loss efforts, such as avoiding temptations and managing cravings. The final sub-category described the value of having someone to do it with. The women found this helpful to get me going, providing motivation, particularly to engage in exercise, through
accountability and companionship. The other property of this sub-category was helping me out, with components tasks, particularly in relation to obtaining and preparing food, either by teaching me how, or doing it for me.

## 4.5 Summary

The women in this study described experiencing significant weight gain in the context of their diagnosis and treatment for SSDs. They attributed their weight gain primarily to the side effects of their medication and their coping strategy of comfort eating. For many of the women the weight gain had resulted in obesity and with this came additional problems such as obesity related physical health problems, reduced functional capacity and additional emotional or mental health difficulties. This linking of the onset of their weight gain with their illness, and the additional problems that they perceived came with their overweight or obesity, resulted in a perception of the double whammy, of SSDs and weight gain.

The women’s response to this weight gain is captured in the basic social process of dealing with the double-whammy, which has three categories. The process centres on the core category of doing as much as I can, which is impacted by a category of mediating factors and supported by facilitating factors. I discuss the details of each of the three categories of the process of dealing with the double whammy in the next three chapters.
Chapter 5   Doing as Much as I Can

5.1 Overview of the Chapter

In the previous chapter I described the basic social problem shared by all of the participants in this study, which was the *double-whammy* of SSDs and significant weight gain. I then gave an overview of the theory describing how the women manage this problem, which comprised the core category of *doing as much as I can*, as well as *mediating factors*, and *facilitating factors*. In this chapter I will describe in more detail the women’s response to the *double-whammy*, which is encapsulated in the core category, *doing as much as I can*, depicted in Figure 5.1 below. All of the women talked about making changes in their daily lives in an effort to manage their increasing weight. They described what they were doing as being as much as they could do in the context of the limitations and resources in their lives at any particular time. This is nicely captured by Abbie’s statement in the first interview that she was ‘doing as much as I can at the moment trying to walk more and sort out the food’ (Abbie, Interview one), and then in the third interview, ‘that’s still true. I am doing as much as I can. It’s just I’m capable of doing a bit more now’ (Abbie, Interview three). *Doing as much as I can* is made up of four subcategories: *doing the right things*, *adjusting expectations*, *starting to do it*, and *sticking with it*. In this chapter I describe each of these sub categories, and their respective properties and dimensions and relate the concepts to the existing literature.

![Figure 5.1: Doing as Much as I Can](image)
5.2 Doing the Right Things

When they talked about what they did or thought they could or should be doing to manage their weight the women all described three types of activities that they saw as the right things to do. These activities, doing exercise, cutting down, and eating more healthy, are the properties of the category, doing the right things. Regardless of the degree to which they engaged in these activities the women were confident that they were the necessary actions. When I asked her how she knew what to do Faith said, ‘I think everybody really knows what to do to lose weight. It’s just a matter of applying it’ (Faith, Interview three).

5.2.1 Doing Exercise

All of the women I spoke to identified exercise as an essential activity for weight loss and most described engaging in exercise for this purpose at some time since their diagnosis and treatment for their SSD. The perception that exercise is essential for weight loss is supported by the finding by Kruger, Blanck and Gillespie (2006) that people who were successful with weight loss and weight loss maintenance were more likely to exercise 30 minutes or more a day and add physical activity to their daily routines than those who weren’t. The property doing exercise describes the women’s past, current (at the time of the study) or planned participation in activities they described as exercise. The dimensions of this property are, incidental activity or exercise, routine, amount, and weight loss as only or just one benefit.

All of the women who reported engaging in exercise clearly described exercise for the purpose of weight loss rather than incidental activity. This finding is in contrast to much of the research describing physical activity participation among people with SSDs. Studies that have explored the nature of the physical activity in which people with SSDs engaged generally identified walking as the predominant or sole activity and concluded that this represented incidental physical activity in the context of transport rather than exercise (Bassillos, et al., 2014; Daumit et al., 2005; McLeod, Jaques, & Deane, 2009; Soundy, Faulkner, & Taylor, 2007; Ussher, Stanbury, Cheeseman, & Faulkner, 2007). Some of the women who participated in my study did identify walking, which they did in the context of transport for daily activities as their
primary form of exercise. However, they were very clear that this involved extra walking undertaken with the goal of weight loss rather than just the walking required for their transport needs. This is clearly illustrated by Elizabeth who said, ‘I tried counting some walks in with my routine, no matter where I’m going, because I’m actually trying to lose weight’ (Elizabeth, Interview one). She went on to describe examples of how she did this,

Sometimes, for example like if I go to [town], I might get off one or two stations before and then go walking up there. I’m trying to look at ways where, if there’s a full day there that I’ve got things on, I do what I can to try to get some more activity in with that (Elizabeth, Interview one).

Abbie found it difficult to motivate herself to walk just for exercise so she also chose to structure walks around a task where she might otherwise have caught a bus, ‘Like when I need something like a loaf of bread I’ll get up, go for a walk down the shops and walk back’ (Abbie, Interview One). Most of the women who described walking for exercise however did it as a discrete activity rather than in the context of travelling to and from other activities. Emily, who lived in a retirement village, said, ‘I walk twice a day all around the resort and if I’m not well enough I’ll get up and walk around the unit (Emily, Interview one). Isobel had been walking most afternoons for exercise for approximately six months when we met. She described how, ‘I do a bit of walking for at least half an hour, or a bit more’ (Isobel, Interview one). Mary also described afternoon walks on most days. In the first interview she went with her father or flatmates and at the time of the second interview, which followed the birth of her son, Mary described incorporating the walk into his daily routine, ‘we go for a walk at four o’clock every day unless it’s raining’ (Mary, Interview two). As well as walking the women also described participating in a range of other activities for exercise including swimming, going to the gym and team sports.

There was significant variation in the degree of structure in the women’s exercise routines. Abbie described her exercise routine as a ‘vague guideline, which suits me best because I don’t like much specific’ (Abbie, Interview three). She described resisting more structured routines suggested by others including her dietitian who,
wanted me to walk every day for a certain amount of time and to use a pedometer and walk so many steps. I really resisted that. I don't know why. I just didn't like it. So I felt like the freedom of being able to walk whenever I want is good (Abbie, Interview two).

Elizabeth also described doing her exercise, ‘when I can’, (Elizabeth, Interview one) rather than according to any particular routine. More commonly however the women described their routines in terms of the number of days per week that they did their exercise activities, and in some cases the time of the day. Isobel went walking in the afternoon on ‘most days’. Faith walked to the ocean baths and in the warmer weather also went for a swim in the mornings four or five times a week. Others were more specific about particular days and times, which often was associated with their exercising involving other people. Karen went swimming twice a week with her sister and met her mentor once a week for a walk, all at pre-arranged times and days. Mary’s routine was structured around her infant son. In the second interview she walked with him every day at four o’clock. In the third interview Mary had been attending the gym four or five times a week for six months. This was arranged to fit with the gym session times and the childcare arrangements for her son as described in the statement below,

Because [he’s] at day care three days, from nine till three. The problem is that the gym only - the gym closes between 12 and two so I’ve really got to try and get as soon as I - early in the morning (Mary, Interview three).

Danika was the only woman who described participating in team sports. Just prior to the first interview she had joined a softball team and she confirmed in the second interview that she had continued her involvement with the team for the entire season. This involvement comprised two sessions of exercise each week, ‘We train on Wednesday nights and play Saturday morning’ (Danika, Interview one).

As with the degree of structure in their routine, there was significant variation in the amount of exercise that the women reported engaging in. This variation occurred both between different women and in individual women at different times. The Australian guidelines for physical activity for adults and older adults at the time I was conducting this study both recommended at least 30 minutes of moderate physical activity on most days, preferably all days (Brown, Moorhead, & Marshall, 2005; Department of Health and Aged Care, 1999). These guidelines were considered the minimum levels required
to gain health benefits. Available research suggests that a significant proportion of people living with SSDs, greater than that found in the general population, report no participation in exercise. Brown, Birtwistle, Roe and Thompson (1999) in their UK survey of community dwelling people with schizophrenia found that 32% of their female participants engaged in no exercise. Daumit et al (2005) found a similar figure, of 35%, among the female participants in their American study of physical activity patterns among people with severe mental illness, half of whom had schizophrenia. Two of the women in my study, Gaye and Nette, did not report engaging in any exercise since their diagnosis and treatment for schizophrenia. Others reported variation whereby there were times that they were regularly engaging in exercise and other times when they were not. Mary for example had periods of time, described below, where she was engaging in regular exercise approaching if not meeting the recommended guidelines for physical activity. There were other times however when she was not exercising at all.

Many of the women described engaging in some episodes of exercise each week although not meeting the guidelines for doing so on most days. Karen for example described a routine she had maintained over several years of a weekly walk to the ocean baths for a swim,

> usually I try to keep that up every Sunday. That’s the thing I’ve been keeping up pretty much since I’ve lived in [suburb]. It’s not much exercise really, just going down one day a week. Walking there from my place is about a 20 minute walk and a 20 minute walk back (Karen, Interview one).

In addition to this she usually did one or two other exercise activities each week. In both the first and second interviews she described also swimming in a heated pool once a week with her sister, for, ‘half an hour. I stop after each lap so I don’t do it consecutively’ (Karen Interview one). In the second interview she was also walking,

> I meet my mentor down at [a] café in [nearby suburb] one day a week and we do a walk to [next suburb] and back, and we do that once a week even though it kills me I still do it and I know it’s good for me. So we’ve been doing that for the last two months (Karen, Interview Two).

Some of the women described exercise routines that would appear to meet the guidelines, for at least some of time they had been living with schizophrenia. Mary
described in each of the interviews doing exercise on at least four or five occasions in a week. In the first interview she said, ‘I try to exercise, go for walks, and about five times a week I do that’ (Mary, Interview one). In the second interview she reported walking every day and in the final interview she described attending a commercial gym which operated thirty minute circuit classes, four or five times a week. Danika also described having gone to the gym every day for several months with her sister a few years prior to her engagement in the study. Isobel described walking on most days. Daumit et al. (2005) found that while a higher proportion of the people with SMI in their study reported being inactive than in the general population, the same proportion were doing the recommended amount of exercise. This finding is reflected in an Australian study, which found that 49% of people with schizophrenia were doing the recommended amount of physical activity, compared to 56.6% of the general population (McLeod, et al., 2009). Despite spending similar amounts of time engaged in physical activity, the participants with schizophrenia in the study by McLeod et al. (2009) had significantly higher rates of obesity which was attributed to them spending less time engaged in vigorous exercise.

In most cases the women in my study described their primary or initial motivation for their exercise as weight loss. Many however, also identified experiencing other benefits, in particular improvements to their mental health, which they subsequently saw as reasons to engage in exercise. Faith described her swimming as being, ‘really good for me mentally and it’s really therapeutic’ (Faith, Interview three). Similarly Karen said, ‘I find that it actually helps me with my mental health doing some exercise’ (Karen, Interview two). Mary, when talking about going to the gym said, ‘I think it’s helped with my mental health as well because I always feel a lot better when I walk out of there. Yeah, it’s been good’ (Mary, Interview three). The perception by the women in my study that exercise had benefits for their mental health is consistent with findings in other qualitative studies with people with SSDs, who perceived exercise to have mental health benefits (McDevitt, et al., 2006; Soundy, et al., 2007), and the findings of a systematic review that physical activity has a beneficial effect on some attributes associated with psychological wellbeing in people with schizophrenia (Holley, Crone, Tyson, & Lovell, 2011). Participants with schizophrenia in a qualitative
study by Rastad et al. (2014) identified the immediate positive impact on how they felt, including calmer and more alert, as a motivating factor for participating in physical activity. Immediate benefits to mental health state were also identified by Vancampfort et al. (2011) who reported decreased state anxiety and psychological stress, and increased subjective wellbeing in a sample of people with SSDs after a single session of exercise (30 minutes of yoga or 20 minutes of aerobic exercise) compared to no exercise controls. A small number of studies evaluating the effect of exercise-based interventions to reduce weight in people with SSDs have also reported psychological benefits. Hutchinson, Skrinar, and Cross (1999) found that self-esteem rose significantly over time among the participants with severe psychiatric disabilities who participated in a structured exercise program over a period of 15 or 20 weeks. Beebe et al. (2005) found a decrease in both positive and negative symptoms as measured by the Positive and Negative Symptom Scale (PANSS) in participants with schizophrenia following participation in a 16 week walking program. Chen, Chen, and Huang (2009) also found an improvement in mental health status on the PANSS, as well as the Beck Depression Inventory (BDI), in people with schizophrenia who participated in their multi-modal weight control program which included exercise. They also recorded improvements in quality of life, as did Skrinar, Huxley, Hutchinson, Menninger and Glew (2005) in their 12 week exercise program. The ability of exercise to positively impact on the mental health of people with schizophrenia is also reflected in the findings of two systematic reviews of exercise as treatment for schizophrenia (Ellis, Crone, Davey, & Grogan, 2007; Gorczynski & Faulkner, 2010).

5.2.2 Cutting Down

Cutting down is one of the two ways participants talked about altering their diet as a strategy to manage their weight. They talked about cutting down in two ways. One type of cutting down was reducing the overall amount of food they consumed. The other was cutting down their consumption of particular types of foods, specifically foods that were high in fat and sugar and which they often consumed in the context of comfort eating. Cutting down was identified universally as an appropriate strategy for losing weight or preventing weight gain and most of the women described having made some efforts to
reduce their overall consumption and/or their consumption of high fat or sugar foods at some time since the onset of their illness.

The women generally thought that overeating was a contributing factor in their weight gain and saw cutting down on their overall consumption of food as appropriate. This was sometimes expressed as an aspiration, ‘I would like not eat as much’ (Mary, Interview two). Most of the women however described having made some changes to their diet in order to reduce their consumption at some time since they had been living with SSD. For some these were brief episodes. Faith reported that in the week and a half prior to our first interview she had, ‘cut down on my eating, I used to just eat and eat and eat’ (Faith, Interview one). In the later interviews however she disclosed that she had not managed to sustain this change. Others however reported more success in maintaining changes over time.

Decreasing portion sizes at meal times was a focus for some of the women. Nuela described embarking on this strategy after she stopped breastfeeding her baby in our second interview, ‘I guess I’ve started practising it a little bit at a time, like I don’t eat as much dinner and breakfast’ (Nuela, Interview two). Elizabeth reported that she often prepared meals using recipe bases, and described taking care not to eat too much of these in one sitting, ‘because they’re a very big meal, what I do is I serve it with a certain amount on the plate that’s not too much’ (Elizabeth, Interview one). She then froze the left over portions to eat at a later date. Karen talked about reducing her consumption across all three of the interviews. In the first interview she suggested that large portions were the main factor in her weight gain,

I don’t eat any junk or anything. I do all my own cooking, I hardly ever buy take away or anything because I can’t afford it but I have big helpings of things (Karen, Interview one).

She described particularly a tendency to eat a lot of potatoes, ‘I love potatoes, I’m Irish, I was born in Ireland so I love potatoes’ (Karen, Interview One). In the second interview she described having begun to try to reduce the amount she ate and reported that, ‘I’ve cut down on my potato intake. I was a real big potato eater. Most of the time I succeed in having just one potato now with my meal’ (Karen, Interview two). At the time of the third interview she talked about continuing efforts to reduce the size of her
meals, ‘I still eat a fairly large meal at night but at least it’s more disciplined’ (Karen, Interview three).

The women also reported decreasing their intake by reducing the frequency with which they ate, generally focusing on reducing snacking. Elizabeth described, ‘managing not to eat so much’ (Elizabeth, Interview one), when we first met as she had when she was first unwell, which she largely attributed to cutting down on snacks. Karen also described trying to reduce overall consumption by cutting down on snacking through the day,

Well it’s more disciplined and the snacks are more disciplined. I used to snack whenever I felt - whenever I wanted. I’d always put something in my mouth. It was like replacing a cigarette to put something in my mouth but now I have a set snack that I have in the morning and in the afternoon (Karen, Interview three).

Having identified the evenings as a time when she was prone to eating large amounts of snack foods Danika had decided to set a curfew on eating,

I try not to eat after six o’clock, from six o’clock to 12 o’clock in the night I don’t eat, even though like I’m sitting there thinking I’m hungry but I won’t eat (Danika, Interview One).

The women who took part in my study did not tend to use the risky weight loss strategies, such as skipping meals, using diet pills or over the counter weight control medication, laxatives or vomiting, that were commonly reported among the women with schizophrenia in the study by Strassnig et al. (2005).

As well as cutting down on the overall amount of food they ate, the women who participated in my study talked about cutting down on foods that they viewed as being unhealthy. In particular they identified trying to reduce their consumption of foods that were high in fat or sugar. Reducing sweet and fatty foods, as well as alcohol consumption, was the most common strategy in their successful maintenance of weight loss identified by the women in the study by Hindle and Carpenter (2011). Similarly, a reduction in the consumption of particular food types such as French fries, dairy products, high fat snacks and deserts, has been associated with people better maintaining their weight (Elfhag & Rossner, 2005). Abbie said, ‘I try to reduce the amount of times that I give into things that I know are not good for me’ (Abbie,
Interview One). Danika described resisting altogether, ‘late at night quarter past one thinking I want to go to the shop and buy some chocolate biscuits, but then I just said no, no, no, no, no. I didn’t end up getting the chocolate biscuits’ (Danika, Interview one). Elizabeth also described trying to avoid such foods altogether and used substitution, ‘in between meals, if I absolutely have to have something, I don’t always, but if I have to have something I go for fruit’ (Elizabeth, Interview one). Most however talked about having smaller amounts of these foods, ‘I might have one or two [biscuits] now, you know, but not a whole packet’ (Faith, interview one). This strategy of eating less of foods that were perceived as fattening was also identified by participants in a study exploring understanding of and barriers to healthy eating among people with serious mental illness (Barre, et al., 2011). Participants in the study by Xiao et al. (2012) also identified cutting down on certain foods, although they opted to maintain their consumption of fast foods and instant meals and concentrated their efforts instead on things like reducing the amount of sugar in their tea and choosing low fat options for things like salad dressing and diet soft drinks.

5.2.3 Eating More Healthy

The second way participants talked about altering their diet as a strategy for managing their weight was, eating more healthy. As well as reducing their consumption the participants talked about increasing the ‘healthiness’ of the food that they did eat. This strategy is consistent with the finding by Elfhag and Rossner (2005) that high quality foods and healthy eating are important to people maintaining weight loss. There were three primary aspects of eating more healthy. These were: eating fruit and vegetables, doing more cooking, and making healthy choices when purchasing foods.

Increasing their consumption of fruit and vegetables was identified by many of the women as a core element of eating more healthy. Nuela, whose control over her diet was somewhat limited by the fact that she lived with her parents, stated in the first interview, ‘I would like to increase my dietary intake of vegetables and fruit too, but mostly vegetables, although I had three pieces of fruit yesterday so that’s pretty good’ (Nuela, Interview One). Other participants talked about trying to increase their consumption, ‘I try to have lots of veggies and fruit’ (Elizabeth, interview One). Emily
described trying to, ‘eat fruit every day and vegetables two or three times a week’ (Emily, Interview one). Others reported significant changes to their diet in this respect and believed that this had helped their weight loss efforts. Isobel, who had managed to lose a significant amount of weight prior to her engagement in the study, attributed this in part to the changes she had made to her diet, which included increasing her consumption of fruit and vegetables, ‘Definitely changed my - changed what I eat. I basically now eat a lot of fruit, a lot of veg, and the right fats - I hope. Well I try’ (Isobel, Interview one).

Abbie described gradual improvements in this area throughout the time she was involved in the study. In the first interview she talked about her efforts to increase her consumption of fruit and vegetables, ‘I try. I think, okay, well at the moment it’s probably one piece of fruit a day so I’d like to improve that’ (Abbie, Interview One). In the second interview she described trying to choose fruit instead of her usual less healthy snack options, ‘I have been trying to eat bananas because they’re cheap and they’re better than a Mars Bar’ (Abbie, Interview two). By the time of the third interview Abbie reported, ‘I’m eating more vegetables and fruit now than I ever did before. I’m replacing the volume of bad things with good things. So I’m still eating the same amount, but I’m losing weight because it’s better quality’ (Abbie, Interview three).

Increasing consumption of fruit and vegetables was also a strategy of improving diet identified by the participants in the study by Barre et al. (2011).

Many of the women I spoke to reported routinely preparing most of their meals at home rather than eating out and buying takeaway. Others however identified increasing the proportion of meals they cooked at home and reducing their reliance on takeaway and convenience foods as actions to address their weight. When she had first become unwell Abbie had few food preparation skills and had survived mostly on takeaway and foods she could eat straight from the packet or tin. In the first interview Abbie described working with her case manager to increase her food preparation and along with this increase the amount of meals she cooked,
I do a big fortnightly shop and I try and sort of, maybe every second day, I might try and prepare a meal for myself. I have a goal of making it every day but it just doesn't happen (Abbie, Interview one).

At the third interview she reported that she had been cooking every second day, and had further ideas for developing her cooking at home,

Yes, that's happening. I've been cooking omelettes and stir-fries and things like that. The next thing is I really would love to learn how to bake. If I could bake some vegetables or bake a chicken or something, that would be wonderful. I'd love to be able to do that (Abbie, Interview Three).

Mary, despite feeling quite confident in her ability to prepare meals, was also eating a lot of take away food at the time of the first interview. In the second and third interviews Mary described increasing success with making changes to her diet. She was preparing more of her food at home and described with enthusiasm some of the new options she was trying for lunches, 'I've been buying like hummus and tabouli and mountain bread and ham and tomato and making up wraps and things like that' (Mary, Interview two).

The final aspect of eating more healthy, described by the participants was making healthy selections when purchasing food. Several of the participants described making the move to low fat or sugar or 'light' options when purchasing items from the supermarket. As well as changing to skim milk, Danika reported that she had begun, 'Drinking like diet coke or coke zero instead of like the full sugar drink' (Danika, Interview one). Some talked about reading the food labels to inform their choices. Isobel stated, 'I try to steer clear of the bad fats; the saturated and all the trans fats - that's not good' (Isobel, Interview one). Following her diagnosis of diabetes Nuela was particularly careful about her choices and described the process of decision making informed by the information labels on the food,

Specifically I go in the 100 - per 100 grams or per 100 millilitres and look at fat. If it says 10 or less I can keep on looking at the food. Then I move onto the other per serving and then look down onto the carbohydrates and find out how much carbohydrates are in a serving. Then I look at how much a serving is and whether that will be enough for what I think I would want right now.

So I could use Weetbix as an example. Weetbix has much less than 10 grams of fat per 100 grams so I can keep looking at it. Then I look at the carbohydrates and it probably says 17 or 15, which is
about - per two biscuits, which is about one exchange and that sounds pretty reasonable to me. I could eat two Weetbix and have a bit of skim milk on it and I could probably even put some fruit on it. That would be acceptable (Nuela, Interview three).

Participants also described trying to make healthier choices on the occasions when they did have takeaway, ‘I’m still healthy. If I go to the take-out shop, I’d have a burger, but I wouldn’t have butter, or cheese, or meat, or bacon. I’d just have an egg, basically, and salad’ (Isobel, Interview one).

5.3 Adjusting Expectations

When they were talking about their efforts to manage their weight the women described adjusting their expectations of what they could do in order to make them achievable. This was the case both for the day-to-day activities they engaged in to manage their weight and their goals for weight loss. This reflects one of the strategies identified in the stage model for weight loss success proposed by Adams (2008) derived from the experiences of women engaged in a formal weight loss program. Participants in Adams’ study identified setting realistic goals as a factor in protecting their psychological wellbeing through avoiding frustration and keeping self-efficacy intact. The two properties of the category adjusting expectations, are, being realistic and wanting to do more.

5.3.1 Being Realistic

When they were talking about their efforts to manage the weight the women drew a distinction between what they thought was ideal or desirable and the expectations they set for themselves, which they thought were more realistic. They did this, both in relation to engaging in activities to manage their weight, and their goals for weight loss.

The first context in which the women drew a comparison between the ideal and their own more realistic expectations was in relation to their day-to-day engagement in activities to manage their weight including exercise, cutting down and eating more healthy. The women talked about having realistic expectations both in terms of the way they engaged in these activities as well as how much they did.
One example of adjusting expectations in terms of the way they engaged in activities arose when the women talked about cooking more of their meals at home in their efforts to eat more healthy. Many of the women struggled with concentrating on tasks and this was frequently identified as a barrier to cooking. Abbie stated, ‘I find cooking is difficult, like, concentrating on the whole process of peeling your veggies and that kind of stuff. Like, step by step’ (Abbie, Interview one). Elizabeth also described feeling frustrated when she was trying to cook some things, ‘Because they take too long to cook. Sometimes I get impatient with it’ (Elizabeth, Interview one). In order to address their goal of preparing more meals at home so they were eating more healthy they chose, ‘to cook foods that don’t take too long to cook’ (Elizabeth, Interview one). For Elizabeth this meant making use of some pre-prepared elements such as recipe bases. Abbie described choosing meals that were quick to prepare, ‘I’ve been cooking omelettes and stir-fries and things like that’ (Abbie, Interview three). Abbie had also ‘found that sticking to a regimented diet does not work for me. So I just have to sort of only purchase healthy food and put that in the fridge and then that’s all I’ve got to eat’ (Abbie, Interview one). Others described altering how they engaged in exercise. Karen found swimming in the indoor pool, which was smaller than the ocean baths, was helpful,

> It’s easy to do and it’s only 25 metres, whereas the ocean baths is 50 metres and I always get puffed out just before it gets to the end. Whereas the 25 metres I can do that easily and then I have a rest and then I do the next thing, but the ocean bars is actually more difficult to do so that turns me off a bit (Karen, Interview two).

More commonly however the women described adjusting their expectations to make them more realistic in terms of the extent to which they engaged in the activities to manage their weight. Karen talked about her need to reduce the amount of demands in her life more generally in order to manage tasks, ‘it’s more manageable for me to have a quieter life and not to have so much in my day because then I can manage things better’ (Karen, Interview three). Others talked about having realistic expectations regarding how much exercise they were going to manage to do. In the third interview Nuela described finding it challenging to fit exercise in along with the demands of caring for her son. She described her efforts to incorporate exercise into this routine,
walking my son to one of his carers in the morning and then walking him back in a pram in the afternoon. That's twice a week and that's - I guess it takes 45 minute walk twice a day for those two days. I would rather it spread out onto every day but it's just not going to happen (Nuela, Interview three).

Danika also described a need to adjust her expectations of what exercise she could do as a result of competing demands on her time,

It’d be alright to go to the gym. Probably wake up at six, by nine be out there, shower, go to work. Something that I could do. But at the moment, my calendar is full with work, TAFE, appointments, blood tests, dentist (Danika, Interview two).

The women also talked about the importance of being realistic in relation to their efforts to cut down on their eating. In the first interview Faith described having cut down on her eating and was enthusiastic about the weight loss that she attributed to this. In response to this success she ventured to suggest, ‘I can cut down even more I think’ (Faith, Interview one). However soon after making that suggestion she recanted stating, ‘maybe not, because I do enjoy my food. It's just about eating healthy’ (Faith, Interview one).

When the women talked about their weight loss goals they also distinguished what they thought was realistic from what they thought was ideal or desirable. Nuela talked about the importance of goals being realistic, ‘I think if it's like a really way out there goal that wouldn't work, and - yeah - so it has to be pretty achievable, I think, when you’re thinking of physical goals’ (Nuela, Interview three).

Changing from overly ambitious to more realistic goals was one of the factors differentiating previous unsuccessful weight loss efforts from successful maintenance of weight loss in the study by Hindle and Carpenter (2011). Similarly in their review of factors contributing to successful weight loss maintenance, Elfhag and Rossner (2005) suggested some value in setting realistic goals as reaching a self determined weight loss goal is a good prognostic sign for maintenance. Invariably the goal weight that the women identified was heavier than the weight they had been before the onset of their illness. Emily, who weighed 85 kilograms, stated, ‘I used to be 50 [kilograms]…now I’d be happy with 60 [kilograms]’ (Emily, Interview two). Similarly, Faith stated, ‘When I
came into recovery I was 65 kilos, I think I’d like to be about 70, 75’ (Faith, interview one). Reaching their pre-diagnosis weight, while it was something the women saw as desirable, was generally also seen as being unrealistic. Abbie stated this most bluntly, ‘Okay, well I want to be a size 12 again, but I don’t think that’s going to happen’ (Abbie, Interview three). Instead the women described setting goals that they thought were more realistic.

Abbie, who was a size 22 at the time of the first interview, had a goal that remained the same throughout the study, of reaching a size 16. In the quote below she describes how she came up with that goal,

I looked around at other people and I thought, well, I probably will never get to a size 10. So what would be a realistic size for me? I just saw other people walking around and I thought well maybe a 16 would be a healthy weight size for me to be (Abbie, Interview one).

Mary also described identifying what she thought was a realistic goal,

It’s not as light as I was but I think it’s a realistic goal, so yeah I’d like to try and get down to that and I think I’d be a healthy weight if I cut - yeah. I’m not - yeah, I’m not sure how I came up with it, just that it seemed realistic and manageable (Mary, interview one).

As well as being determined by what they thought was realistic the women’s weight loss goals were also often influenced by the amount they thought they would need to lose to improve their health and wellbeing. Danika had a goal of reaching 85 to 90 kilograms, which she had identified on a computer at the chemist as being, ‘pretty much for my height, it’s the right weight for my height’ (Danika, Interview two).

Nuela wanted to reach a point where she no longer needed to take diabetes medication,

My ultimate goal is more about health right now. It’s about reducing the amount of medication I’m on to either nothing - I’m not talking about schizophrenia medication, I’m talking about the diabetes medication. So changing my amount of diabetes medication to less or even nothing (Nuela, Interview three).

Karen identified a goal in the third interview of reaching 90 kilograms, which she saw as achievable, ‘That’s not really slim but it’s a hell of a lot slimmer than I am now’
(Karen, interview three). She identified benefits in terms of physical comfort and ability to do tasks,

> When I had the hysterectomy I lost about 10 kilos and it was easier to walk and easier to stand and things like that and I thought if I can lose 10 and feel that comfortable imagine losing 40. I'd be really - things would be a real lot easier (Karen, Interview three).

As well as feeling more comfortable another practical issue that influenced weight loss goals was being able to shop in regular clothing stores. Abbie said,

> I'd like to be able to go into a shop like Jeanswest and take a pair of jeans off the rack and put them on and feel comfortable in them. That would make me feel healthy. I can't do that at the moment because I'm so big (Abbie, Interview one).

Similarly, Elizabeth reported,

> My ideal weight would probably be a size 18. Even though I'm a 22 or 23 depending on the make. I would like to get back down to a size 18 and try to stay there. All of the ladies clothes shops these days only go up to an 18 (Elizabeth, Interview one).

### 5.3.2 Wanting to do More

While the women generally felt they were doing what they could in terms of exercise and managing their diet at the points in time I spoke to them, many also expressed that they thought they should, and would like to, be doing more. While she reported making efforts to increase her physical activity, Elizabeth expressed a belief that,’ I probably don’t do as much exercise as I should be’ (Elizabeth, Interview two). Abbie consistently reported throughout her involvement in the study that she was walking for exercise to try to lose weight she also described in each interview that she thought she could, and should be doing more exercise. In the first interview she stated, ‘I’d like to exercise more’ (Abbie, Interview one). In the second interview she reported that she thought, ‘Exercise could be improved’ (Abbie, Interview two) and in the final interview, ‘something I really need to work on is more exercise (Abbie, Interview three). At the time of the final interview Abbie had been seeing a dietitian who had helped her identify a target for her exercise of, ‘an hour a day, which I'm probably doing half an hour a day and she wants me to increase that as much as I can’ (Abbie, Interview three). Some of the women described ‘more’ in terms of the duration of their
episodes of exercise, Emily thought that she probably wasn’t walking as much as she should, but believed she was doing what she could manage at the time, ‘I don’t think I walk as long as I should, I walk about 20 minutes each time. My psychiatrist said 40 minutes each time but I get a bit tired so I haven’t advanced to that yet’ (Emily, Interview one). While she was pleased with the weight loss she had achieved, Isobel expressed that she would like to be doing longer walks,

   I want to try to be going for a bit longer, maybe for an hour, even an hour-and-a-half would be something that I want to go towards. At the moment, though, I’m only doing it for half-an-hour now. I think that it would be good to do it longer (Isobel, Interview one).

Mary also expressed a belief in the first interview that she should increase the duration of her exercise sessions, ‘I would like to go further’ (Mary, Interview one). She also talked, both in this interview and the third about wanting to increase the frequency of her exercise, ‘I would like to do it [walking] more regularly, maybe every day’ (Mary, Interview one). In the final interview, Mary described that during the previous six months, while she had been going to the gym she had not been walking so often and stated, ‘I’d like to increase walking again because I think that really helps as well’ (Mary, Interview three). Nuela also talked about wanting to increase the frequency of her exercise, ‘I would also like to do a daily exercise if there was another hour in the day, I’d do that. So far it’s going in for weekly exercise’ (Nuela, Interview one).

The women also described wanting to do more in terms of managing their diet. Abbie talked about this in relation to her consumption of fruit as described above, and improving her management of her diet through eating more regular meals, in particular breakfast, ‘I hardly ever have breakfast. I know that that’s really bad for weight loss. I need to have breakfast. So at the moment I think I need to sort of organise myself a bit more’ (Abbie, Interview two). Isobel described having made significant changes to her diet to make it healthy. She thought however that there was more she could do and identified in particular that she would like to decrease her consumption of sugar,

   I put probably three heaped teaspoons in my cup, so that’s possibly, maybe 30 calories, I’d say. I count my calories, actually. Yeah, so I have four cups a day and I add up how much that is in
calories, and yeah, basically I think that it’s sugar. Sugar’s my downfall, and salt (Isobel, interview one).

5.4 Starting to do it

A critical element in doing as much as I can was the women starting to take action to manage their weight. There were two factors that were associated with the women starting to do it, which were: reaching the limit, and, deciding to act. This reflects the second stage in the theory of behaviour change in weight loss for women proposed by Berry (2004) which included: recognition of a problem, readiness to take action and decision to make change.

5.4.1 Reaching the Limit

The women described experiencing motivation to start to take action to address their weight in response to reaching some sort of limit. The limit might be in terms of behaviour. Emily described starting to take action to address her weight when she became, ‘Just fed up of being actually too lazy’ (Emily, Interview two). Similarly, Danika’s initial weight loss efforts were prompted by her sister, with whom she was living at the time, saying: ‘she didn’t want me sitting there being really big, fat and eating all this chocolate in front of my nieces. She wanted me to show my nieces that I could do it’ (Danika, Interview two).

The limit might also be in terms of how much weight they had gained. Karen described having joined weight watchers in an effort to manage her weight at a time when, ‘it was getting out of hand and I was putting on too much weight’ (Karen, Interview one). Similarly, after gaining a considerable amount of weight Isobel decided to start to act because, ‘I don’t want to get too big’ (Isobel, Interview one).

Finally the limit might be in terms of actual or potential consequences of their weight gain. Elizabeth described having reached a point where, ‘I really want to lose weight as much as I can because it’s just too uncomfortable. It’s getting to the point where it’s so uncomfortable. I’ve got to do something about it’ (Elizabeth, Interview one). Elizabeth identified an additional motivating factor as her recent diagnosis of ‘borderline diabetes’, and not wanting to develop diabetes,
So I had the first test and then it came up as borderline, so I had to go back to do pathology tests to see if I have got it. Even though I don’t have it quite yet, I still want to try to do the right thing now, whether I’ve got it or not (Elizabeth, Interview one).

Abbie had also been identified as at risk of developing diabetes and cited this as a reason she was starting to take action to lose weight, ‘I really need to lose this weight. I really need to eat better and make sure I don’t get diabetes because if I’m going to have a future of any kind, the body’s important’ (Abbie, Interview one). Nuela also identified that, while she had made efforts to address her weight on previous occasions, having been diagnosed with diabetes was a trigger for her to address her weight in earnest.

In a qualitative study exploring understanding and barriers around healthy eating among people with serious mental illness Barre, Ferron, Davis and Whitley (2011) also identified experiencing a health related event as a factor precipitating people starting to change their eating habits. The majority of participants in Hindle and Carpenter’s (2011) study of women who had successfully maintained weight loss had been motivated to lose weight for health related reasons. Health, and particularly concerns about obesity related conditions have also been identified as motivating weight loss efforts in other studies of people who were obese (Buchholz, Huffman, & McKenna, 2012; Kwan, 2009). In addition to health issues the women in Adams’ (2008) study identified physical limitations such as decreased energy or mobility, or shortness of breath, or the onset of body image concerns as the factors that stimulated action to lose weight.

5.4.2 Deciding to Act

The other factor associated with getting started was deciding to act in response to reaching the limit. The primary dimension of this property was whether the women made the decision for themselves, or others made the decision on their behalf. In many cases it was other people who identified that the women were reaching the limit and often also made the initial decision that action needed to be taken to address their weight. The women saw these contributions by others as helpful, and even necessary. Danika, whose initial weight loss efforts occurred when she was staying with her sister who,
‘pushed me to do it’ (Danika, Interview one) stated, ‘actually you need a bit of push until you get down a bit and get a bit - I guess more energy or something’ (Danika, Interview one). However their actions appeared to be more sustained and effective when they made the decision themselves. Three of the women described a shift from responding to other people’s suggestions to when they decided for themselves that they needed to take action and highlighted the importance of the ownership of this decision making. Danika achieved significant weight loss in a fairly short period of time when she was living with her sister but stated that, ‘even though my sister pushed me to do it, you really have to do it yourself’ (Danika, Interview one). She described a more recent period of weight loss that continued throughout the time that she was involved in the study. On this occasion Danika had made the decision herself to try to lose more weight and had initiated and managed to sustain involvement in exercise and some modification to her diet. Karen also described starting to take action to address her weight on several occasions in response to urging from her sisters, ‘they kind of nag me a bit about my weight, and I hate being nagged and I hate people worrying about me. So that kind of motivates me to do something about myself’ (Karen, Interview one). She found however that she did not sustain these efforts and consequently found herself, ‘always trying to start’ (Karen, interview one). In the third interview however Karen described having reached a point where she had decided for herself that she was going to address her weight,

Yeah, it’s like when you make up your mind to – keep – everything keeps heading that way like people are saying to you you’re going to – the weights not good for your health and you keep getting nagged by everyone and everyone’s telling you what’s wrong with you and everything. Eventually it hits you and you make your decision. That’s where you make your decision that you are going to work on it (Karen, Interview three).

Having taken ownership of the decision she felt more positive about her ability to be successful,

I think if I’m focused and I’m doing what I want to do not what everyone else wants me to do or my sisters or people putting pressure on me – as long as I know what I want to do and follow my, and please myself with the help of [community mental health team] and various agencies and things like that I think I can continue to keep on track (Karen, Interview three).
Two of the women described having initiated their own efforts at weight loss and had managed to sustain these for an extended period with significant success. Isobel described reaching a point where she, ‘just thought to myself I’m just going to try and start getting healthy again’ (Isobel, Interview one). Following this she modified her diet and started walking daily and had lost a significant amount of weight over a period of several months. Mary also described initiating her own efforts to lose weight during periods of wellness and in interview three had been maintaining regular attendance at the gym for six months with significant success in losing weight.

Deciding to lose weight for themselves was also a factor that the women in Hindle and Carpenter’s (2011) study identified as characterising their successful weight loss maintenance compared to previous unsuccessful attempts. Results of a meta-analysis (Koestner, Otis, Powers, Pelletier, & Gagnon, 2008) showed that autonomous motivation, where goals reflect personal interests and values, is reliably positively associated with goal progress whereas controlled motivation, where goals reflect something one feels compelled to do, is unrelated to goal progress. Teixeira et al. (2006) found that increases in intrinsic motivation for physical activities was the strongest predictor of longer term results in their 12 month follow up of a four month weight reduction program for women. Autonomous motivation was also found to be the only mediator of sustained exercise participation and weight loss among women with overweight and obesity in a randomised controlled trial of a behavioural weight loss program by Silva et al. (2011). Silva at al. (2011) posit that self motivation can become more critical over time because continued behavioural changes require overcoming new obstacles, persisting through difficult times and sustaining action when the initial impetus and reinforcers of the program are no longer available.

### 5.5 Sticking With it

The women described *starting to do it* on several occasions due to the challenge of *sticking with it*. Some of the women talked about the long-term commitment associated with achieving and maintaining weight loss. Karen stated, ‘I want to lose the weight but I know it’s going to take time’ (Karen, Interview three). Abbie attributed previous unsuccessful attempts to lack of recognition of this fact, ‘So, maybe I underestimated
how long it’s going to take to get back to a healthy weight and to keep the motivation up until I’ve lost it all’ (Abbie, Interview three). Many of the women described recurrent efforts to manage their weight. Faith reported that she made plans to take action to lose weight, ‘all the time, but I just don’t stick to it’ (Faith, Interview two). There was significant variation in the length of time the women described having been able to maintain their weight loss efforts from a few days to several months. Central to the issue of sticking with it was maintaining motivation to persist with their efforts and the women described fluctuations in their motivation that they attributed to a range of factors. Mary stated,

> I seem to get motivation in waves and then it sort of fizzles off and then a couple of months later I’ll start again. It’s hard to be consistently good with food choices and exercise. I do find that hard (Mary Interview three).

*Sticking with it had two properties, keeping going, and resisting temptation.*

### 5.5.1 Keeping Going

Keeping going pertained to the aspects of their weight loss efforts that involved additional activities in their daily or weekly routines, specifically exercise. Despite the fact that many of the women enjoyed their chosen exercise they described having difficulty getting out the door to do the exercise. Faith, who walked to the local ocean baths and swam for exercise, stated, ‘I think once I actually just get dressed and go and it’s getting up, getting dressed and going. Once I’m out the door I’m fine’ (Faith, Interview one). Karen, who also walked to a pool to swim for exercise stated,

> Like, it’s enjoyable. The last couple of times I did it, to get there I really had to push myself to get there. But once I’m there I’m fine. It’s just getting there, you make up all the excuses under the sun. (Karen, Interview one)

Nuela also remembered this from when she was attending the gym on a regular basis,

> I hated actually getting ready for the gym, and I didn’t like the fact that I had to pack a bag with towels and pay for it. But once I was actually at the aerobics setting and just a little bit beyond started I went for 45 minutes or something and then it’s like, whoa (Nuela, Interview three).

Abbie and Emily, who both walked for exercise and reported that they liked this activity, also described having the motivation to initiate going for a walk being
something of a challenge. Abbie stated, ‘it’s easy for me to say, oh, I don’t want to go for a walk today’ (Abbie, Interview two). Elizabeth also described, ‘always looking out for motivation to get myself going for the walks (Elizabeth, Interview one).

A less frequently described phenomenon was keeping going with the exercise once they were out the door. Most of the women suggested that this was less of an issue as they generally enjoyed what they were doing. Abbie, despite liking to walk, described using a mantra to keep herself going once she was walking, ‘Like, get that ass moving. It’s a quote from a movie. I sort of repeat that in my head and that motivates me to keep walking’ (Abbie, Interview one). Contrary to many of the other women, Nuela did not enjoy the exercise she did. She stated in the third interview that, ‘I actually hate walking’ (Nuela, interview three) which not only made it difficult for her to initiate going but also to continue once she was doing the activity. Similarly she described needing support at the gym to ‘get me through’, because, ‘I feel really bored when I’m there’ (Nuela, Interview three).

5.5.2 Resisting Temptation

The other aspect of sticking with it described by the women was resisting temptation to engage in previous behaviours that were counter-productive to their weight loss efforts. This particularly related to eating the foods that they identified as being unhealthy and were often the foods associated with binge eating or emotional eating. The women described temptation coming from three sources, exposure to particular foods in their environment, cravings and in response to emotional states.

The most commonly referred to source of temptation was the presence of foods that they had decided they should avoid being present in their environments. Isobel said,

> It’s hard to – like you see something there, like a piece of cake or a packet of chips and some biscuits, and it’s so easy to eat them. It’s like okay, you’ve eaten them and then you think oh, I shouldn’t have eaten them (Isobel, Interview one).

Their home was commonly an environment in which the women described experiencing temptation, but it was for many also the most manageable environment. They talked about not keeping foods that they were likely to over eat in their home,
which is discussed in chapter eight as one of the strategies in having a plan. It was an ongoing challenge for Nuela, who lived with her parents and had limited control over what food was kept in the house,

So my mum will say, okay, we'll do a less butter diet because she loves butter and cheese. So how about we don't buy butter and cheese for a month. Then the next week she's got butter and cheese in the fridge (Nuela, Interview three).

She also found other people eating in her presence a challenge, ‘Like my dad, he eats pizza all the time, like every day. That’s full of cheesy smells and then all you want is cheese’ (Nuela, Interview two). Nuela also described watching TV at home as a source of temptation, ‘If I see something on TV I want to eat it because they do food pornography...where burgers look really delicious’ (Nuela, Interview one). The supermarket was also an environment that was often described as a challenge to resisting temptation but for which many of the women had also developed strategies. Despite the use of a shopping list however Emily found that, ‘when I get into the supermarket I get a bit carried away sometimes and buy all the wrong things...chocolate ice-creams, chocolate, chips, nuts’ (Emily, Interview one). Like many, Abbie highlighted the challenge posed by, ‘the confectionary aisle and the ice-cream aisle’ (Abbie, interview one). She described the sort of internal battle that waged sometimes, ‘One part of me will say, oh, chocolate’s delicious, it’s so yummy, oh, it’s nice. Then the other part of me says oh yes, but it’s going to make you even fatter if you eat chocolate all the time’ (Abbie, Interview one).

Another source of temptation was what the women described as cravings, to which they attributed no clear trigger. Danika described how, ‘it probably comes along every week and a half or so where I just want to bust out of my diet and like eat like at 10.30 or one o’clock at night’ (Danika, Interview one). She described a specific incidence of this, which had occurred the previous evening, ‘I had like three squares of chocolate and I had some popcorn, then late at night, at a quarter past one I was thinking I want to go to the shop and buy some chocolate biscuits’ (Danika, interview one). Elizabeth also described regularly being tempted to go to a Chinese restaurant located near to her home, ‘I love Chinese food. I keep wanting to go down and have a pig out on
Chinese food, or takeaway’ (Elizabeth, Interview One). Nette also described being tempted by takeaway, ‘I feel like takeaway but, of course, I can’t really afford takeaway. So, that’s why lately I bought a frozen bag of chips, frozen chips’ (Nette, Interview one).

At other times however the eating occurred in response to the trigger of negative experiences or emotional states. For Nuela,

It’ll be my mood and some external event, but mostly my mood will – if I’m feeling really low it’s like it doesn’t matter in the future, it matters what I feel now and what I want to feel now is yummy food (Nuela, Interview three).

Teixeira et al. (2010) identified disinhibition, the tendency to overeat in response to a range of stimuli, as both a risk factor for obesity and a mediating factor in weight loss studies.

5.6 Summary

In this chapter I described in detail the core category doing as much as I can, which encapsulates the approach the women in this study took to managing the significant weight gain they experienced as a double-whammy with their diagnosis of SSDs.

Regardless of how much they were doing the women described three core activities they saw as the right things to do to lose weight, doing exercise, and modifying their diet by cutting down, both their overall consumption and their intake of unhealthy foods, and then trying to make sure they were eating more healthy. They described adjusting expectations both in terms of what they were capable of doing to manage their weight, and the goals they were likely to achieve in order to make them realistic.

Starting to do it occurred usually in response to reaching some sort of limit either of behaviour, weight or the consequences of behaviour. While starting often was initiated at the urging of others the women identified the importance of taking ownership of their weight loss goals for success. The women described starting on several occasions due to the challenges of sticking with it. These challenges were twofold, both in maintaining the motivation to continue with exercise and resisting the temptation to eat too much of the foods that contributed to weight gain.
The women’s ability to enact these strategies to manage their weight fluctuated in response to variations in three mediating factors, *knowing, mental health and wellbeing,* and *practical considerations.* I describe each of these *mediating factors* in the next chapter.
Chapter 6  Mediating Factors

6.1 Introduction

In the previous chapter I described the core category and basic social process, doing as much as I can, which encapsulated the women’s response to the weight gain they experienced as a double whammy with their SSD. The process of doing as much as I can comprised the four components, doing the right things, adjusting expectations, starting to do it, and sticking with it. The women’s ability to engage in the process of doing as much as I can to manage their weight fluctuated in response to three categories of mediating factors, which were: knowing, mental health and wellbeing and practical issues. As depicted in Figure 6.1 below, the mediating factors impacted on each other as well as the basic social process. In this chapter I describe in detail each of these categories of mediating factors and their relationship with doing as much as I can. I also discuss these concepts in the context of the existing literature.

Figure 6.1: Mediating Factors

6.2 Knowing

The first factor that the women described as mediating their ability to act to manage their weight was, knowing. The women talked about three different types of
knowledge, the presence of which mediated their abilities to manage their weight at any point in time. These types of knowledge, *knowing the issue, knowing what to do, and knowing how to do it*, comprise the three properties of the sub-category of *knowing*.

### 6.2.1 Knowing the Issue

The first type of knowledge that the women referred to was, *knowing the issue*, which refers to their awareness that they were facing a problem with weight gain. The importance of this knowledge is summed up in a statement that Abbie made, ‘because if you don’t know what’s going on how can you do anything about it?’ (Abbie, Interview three). The two dimensions of *knowing the issue* related first to being aware of the potential for weight gain, specifically, *knowing about medication side effects*, and secondly realising that they were gaining weight, *being aware of weight gain*.

#### Knowing About Medication Side Effects

The women believed that their weight gain was in large part due to the side effects of the medications they took to for their mental illness. Consequently they also believed that knowing about this weight gain side effect was an important factor in being able to manage it. There is perhaps some salience here with the concept of insight, which includes awareness that one has a mental illness that requires treatment, awareness that the illness is ongoing and awareness of the symptoms and their consequences (Baier, 2010). Impaired insight in schizophrenia is linked to poorer psychosocial functioning and prognosis, (American Psychiatric Association, 2000; Gharabawi et al., 2007) just as the women in my study suggested that lack of awareness of medication side effects is associated with poorer weight management. Most of the women in my study described being unaware of the weight gain side effects of their medication at that crucial time when they were first on medication and experienced the most dramatic and rapid weight gain. This resonates with the findings of an English study exploring the experience of taking anti-psychotic medication, in which participants reported that they were given insufficient information about side effects (Carrick, et al., 2004).

Nuela was certain that she had not been informed about the side effect of weight gain as she clearly recalled being informed of other side effects,
they would more advise me on what an overdose would feel like or what missing medication would feel like. They never really - especially the first few, they never really said that you’re going to get really hungry on this. I think they described the really serious sort of side effects like tremors and stuff (Nuela, Interview two).

More often however the women attributed their lack of awareness of the weight gain side effects of their medication to not remembering, rather than not being told. Karen said, ‘I don’t remember them saying that. They might have said it but I don’t remember them saying it’ (Karen, Interview one). Danika described how in the early period of her illness, ‘I didn’t understand anything about any of it’, and even when given information at this time she found it would go, ‘in one ear and out the other’ (Danika, Interview two). Despite remembering being told Mary stated that she, ‘didn’t really understand how much weight could be gained’ (Mary, Interview two). She went on to suggest that,

when you’re unwell it’s difficult even with all the information, I think, to follow it if you’re really extremely unwell. I think you can only really deal with the illness when you’re unwell and everything else goes out the window (Mary, Interview three).

Their lack of awareness about the weight gain side effect of their medication was seen by the women as a significant limiting factor in them being able to manage their weight, ‘I couldn’t help it. I just didn’t know about the side effects’ (Elizabeth, Interview two). Lack of knowledge, particularly of medication side effects was one of the themes arising in the study by Abed (2010) examining the factors impacting on lifestyle decisions in people with schizophrenia.

The women generally recalled realising, or being informed about the weight gain side effects of their medication after their weight had become a problem. Abbie could not remember anyone talking about this with her until, ‘after I got fat. Then it was said to me, you know, it’s possible that the medication has contributed to the weight gain, but not before, no’ (Abbie, Interview two). Timing of this awareness was significant as many of the women believed, as Elizabeth stated, that finding out after they gained weight was, ‘just too late’ (Elizabeth, Interview two).
Emily and Mary did remember being informed about the potential for weight gain but recalled this being presented as inevitable. Emily, who had not previously experienced weight gain despite taking antipsychotic medication for several years, was changed to one of the newer antipsychotic medications after a relapse two years prior to our first meeting. She recalled being told by her psychiatrist at the time she was commenced on the new medication that, ‘you’ve either got to be well and plump or sick and thin. I said I think I’ll pick well and plump’ (Emily, Interview one). Similarly, Mary recalled being told when she was commenced on her medication that, ‘a lot of people do put on weight from that medication but that I’d have to go on it anyway’ (Mary, Interview two).

**Being Aware of Weight Gain**

As with their awareness of the weight gain side effect of their medications many of the women described not being aware of their own weight gain, ‘I just wasn’t aware of how much weight I had put on’ (Abbie, Interview three). Often they did not become aware until they had gained quite considerable amounts of weight. Nuela described realising incrementally as she needed to buy new clothes,

> Well it took a long time to catch up because sometimes you go through stretchy clothes where you don’t realise that they’re stretching and stretching and stretching. It’s not until you try and buy a size 18 later on, that you’re like oh I’m a size 20 or 22 (Nuela, Interview one).

Abbie and Danika did not realise until they reached the ‘limit’, discussed in Chapter Five (5.2.3) at which time other people drew their attention to their weight. Danika described being confronted by her sister with whom she was staying at the time. Despite being at her heaviest weight of 128 kilograms, Danika reported that until her sister drew it to her attention, ‘I just didn’t see it’ (Danika, Interview two). Similarly Abbie described being unaware of her weight gain until it had reached a point where it was dangerous to her health and her doctors advised her that she needed to lose weight. She recalled that when her weight gain was drawn to her attention she felt,

> a bit embarrassed because I’d got to this stage where I was so huge. I didn’t think about it until it was said to me, you know, you really need to lose weight. Then I was like, oh gosh, I really am fat. Yeah so it was a bit embarrassing (Abbie, Interview Two).
Again, as with the knowledge about medication side effects, the lack of awareness of weight gain was attributed in large part to the women’s attention being drawn elsewhere when they were unwell or struggling to come to terms with their illness. Abbie stated, ‘I wasn’t thinking about my body at all. It was all going on in my head’ (Abbie, Interview two).

The women who reported that they became aware of the weight gain earlier identified that this was drawn to their attention by others as is described by Karen who said that in the early days, ‘everyone was telling me as I was putting the weight on’ (Karen, Interview three). Alternatively they reported that preoccupation with their weight or physical health was a feature of the presentation of their illness as described by Faith, ‘just obsessed with being thin: too overly obsessive with being thin. So yeah I noticed it pretty much straight away yeah’ (Faith, Interview three).

6.2.2 Knowing What to do

The second type of knowledge that the women talked about was, knowing what to do, which related to their knowledge of what actions were necessary to manage their weight. The two dimensions of knowing what to do were: guidelines, which relates to the women’s knowledge of public health guidance for diet and exercise, and practical knowledge which refers to understanding of how to implement the guidelines in their day to day lives.

Guidelines

The degree of awareness among the women of the detail of public health guidance around diet and physical activity varied. This variation occurred between different women, as well as in individuals at different times. When describing what they knew regarding guidance around healthy eating many of the women referred to Nutrition Australia’s healthy living pyramid which is one of the food selection guides used in Australia that reflects the national dietary guideline principles (Smith, Kellett, Schmerlaib, & Smith, 1999). Some, like Abbie and Elizabeth in their early interviews, recalled little other than the fact that such a pyramid existed, ‘there was a food pyramid but that’s all that I can remember from it’ (Abbie, Interview one). Others, like Karen, Mary and Nuela, were able to describe the pyramid in more detail,
So it’s either grains or fruit and veg at the bottom, poultry and meat about that with eggs and protein and stuff, dairy above that and little bits of fat and little bits of sugar. So I think I’ve got it – I’ve got an image of it in my head with pictures of the food on it (Nuela, Interview one).

Others talked in more general terms about guidance around the types of food that should be eaten more and those foods that should be eaten less. ‘Good lean meat and vegetables is the best thing and fish, I’d advise that. Stay away from the junk food and not eat too much carbohydrate and quite a bit of protein’ (Emily, Interview one).

Despite varying degrees of familiarity with the specific guidelines, the principles that the women described were generally consistent with the Australian Guidelines for healthy eating which recommend eating a wide variety of foods from the five food groups (vegetables; fruit; grain; lean meat, poultry, fish, eggs, tofu, nuts and seeds; and milk, yoghurt and cheese), and limiting foods containing saturated fat, added salt, added sugar and alcohol (National Health and Medical Research Council, 2013). While most of the women were familiar with these broad principles they were less confident in the detail such as portion sizes. Most of the participants with severe mental illness in the study exploring factors affecting food choices by Carson et al. (2013) also expressed a basic understanding of what is recommended for a healthy diet, but struggled with finer details such as portion sizes. This would appear to be consistent with nutrition knowledge in the general population. Hendrie, Coveney and Cox (2008) conducted a survey in South Australia which found similarly that basic knowledge such as the need to eat more fruit and vegetables and less fatty and salt foods were well understood but people were less aware of more detailed nutritional information.

Most of the women identified a target of at least 30 minutes of exercise on most days which was consistent with the minimum levels of physical activity required to gain health benefit identified in the Australian Guidelines for physical activity at the time (Department of Health and Aged Care, 2005). Karen stated, ‘you should walk at least 30 minutes a day, exercise at least 30 minutes a day’ (Karen, Interview one). Some of the women suggested that more exercise was necessary for weight loss. Nette recalled, ‘50-55 minutes a day they used to say to us’ (Nette, Interview one).
The finding in my study that the women generally had knowledge regarding what constituted a healthy diet and level of exercise is consistent with findings of other recent studies of people with schizophrenia (Abed, 2010; Xiao, et al., 2012). The women varied in their degree of confidence in their knowledge of relevant guidelines. Some, like Nette had little confidence in their knowledge while others like Emily were more confident, ‘I pretty well know what I should eat’ (Emily, Interview two).

The women described gaining their knowledge of guidelines from a range of sources such as school,

Through school, multiple places, which show me the food pyramid. You go places and they’ve got posters of it around. But yeah I think it’s from my generation, it’s been sort of thrown at you at school a few times (Nuela, Interview one).

or posters and brochures in waiting rooms, ‘Yes there were a few pamphlets that I’d get from Supported Recovery. I can’t remember the name of the pamphlets but they were roughly sort of like five serves of vegetables a day or something like that’ (Abbie, Interview two). Isobel described researching a lot on the internet to inform herself, ‘I Google how many calories are in certain things. I Googled how many calories are in a piece of Turkish delight’ (Isobel, Interview one). In the later interviews many of the women had accessed professional advice regarding managing their weight through referral to dieticians and exercise physiologists and this was associated with greater knowledge and understanding of guidelines. ‘I still have trouble with all of that but I know a lot more now since I’ve seen the dietician’ (Abbie, Interview two).

The women saw having knowledge about the guidelines as important to managing their weight. Abbie stated, ‘So educating myself is an important thing in learning what’s healthy and what’s not because if I hadn’t done that, I would have no idea (Abbie, Interview two). Irrespective of the degree of knowledge they had the women described working towards the guidelines that they were aware of in their efforts to manage their weight both in relation to diet and physical activity as illustrated in the statement from Elizabeth that, ‘I’m going to try to go for a half-hour walk each day. I think that’s the minimum you’re supposed to do to lose weight. So I’m going to try to work that into my routine’ (Elizabeth, Interview two). As such, the women identified
the level of knowledge and understanding they possessed of this guidance as a mediating factor in how able they were to effectively manage their weight. This perception is in line with the evidence that suggests that nutrition knowledge, while not sufficient in and of itself, is an influential factor for favourable diet related behaviour (Hendrie, et al., 2008). Nutrition knowledge was also found to be a mediator between socio-economic position and diet quality in a study of new mothers by McLeod et al. (2011).

**Practical Knowledge**

While the women identified that knowing the *guidelines* was important to them being able to manage their weight they found that these guidelines were not always easily interpreted. *Practical knowledge* refers to knowing how to apply the *guidelines* in their daily lives. While many of the women had a good idea for instance of the guidelines for dietary intake, they did not always understand how to put these into practice. This is highlighted by Abbies comment, ‘how do you translate the food pyramid into a meal plan? It’s very hard, especially when you’re not thinking about that as well. You’re just doing whatever you need to do to survive, just to keep going (Abbie, Interview three). Similarly Elizabeth, while she was confident she knew what were healthy things to eat, struggled with the concept of portion size, ‘I want to know how much meat I should have, how much veggies I should have, how much potatoes I should have’ (Elizabeth, Interview one).

The other aspect of practical knowledge was being able to make sense of the information that is available, such as the food information on packaging. Isobel identified this as a key source of information, ‘Basically the tin - whatever’s on the packaging. I read - everything I eat, I read what’s in it, calorie-wise and fat-wise and saturated fats and trans fats I try to avoid’ (Isobel, Interview one). Others however found this more difficult,

I look at the labels and I have some idea when it’s high in carbohydrates and things like that but I think a lot of it goes over my head as well. I’m not a hundred per cent if what I’m eating is all that healthy (Mary, Interview three).
Following her diagnosis of diabetes in the third interview Nuela described paying more attention to meeting specific requirements when selecting food items in order to manage her blood sugar levels. She gave detailed description of the factors she considered in choosing types and portion sizes of food using the information on the package,

Specifically I go in the 100 - per 100 grams or per 100 millilitres and look at fat. If it says 10 or less I can keep on looking at the food. Then I move onto the other per serving and then look down onto the carbohydrates and find out how much carbohydrates are in a serving. Then I look at how much a serving is and whether that will be enough for what I think I would want right now.

So I could use Weetbix as an example. Weetbix has much less than 10 grams of fat per 100 grams so I can keep looking at it. Then I look at the carbohydrates and it probably says 17 or 15, which is about - per two biscuits, which is about one exchange and that sounds pretty reasonable to me. I could eat two Weetbix and have a bit of skim milk on it and I could probably even put some fruit on it. That would be acceptable (Nuela, Interview three).

The concept of practical knowledge described by the women in this study has salience with the ‘technical knowledge’ described in a model of successful weight loss among African American women in the study by Adams (2008). ‘Acquiring knowledge’ was one of the strategies identified by the women in the third phase of Adams’ model with ‘technical knowledge’ described as ‘the practical knowledge one needs’ and an example being knowing how to translate food labels.

6.2.3 Knowing how to

The final type of knowledge was knowing how to, which pertained specifically to the activities associated with purchasing and preparing food. As was the case with the other kinds of knowledge, there was great variation among the women regarding their perceived levels of knowing how to. There was a general consensus however that knowing how to effectively shop for and prepare meals was a mediating factor in their ability to manage their weight. Some, like Abbie, had never developed this knowledge prior to becoming unwell,

Because I grew up in foster care and I never really got a sense of this is how you cook food. It was always sort of, ... like whatever the minimum is. I remember crumbling Weet-Bix up, putting butter on it and putting it in the microwave. That was the food that we had. So I never really learnt
any proper cooking skills or, you know, this is what you eat, this is what you don’t eat (Abbie, Interview two).

She described feeling overwhelmed by the choices in the supermarket,

It would be haphazard. I would just grab whatever I saw and I’d get confused because there's so many different types of yoghurt, for example. I'd be standing there in the cold food section going which yoghurt do I buy? They’re all confusing and distressing. Several times I just had to give up and leave (Abbie, Interview two).

Faith also described having never really learned how to cook, ‘very basic foods I can cook, but I’m not very confident’ (Faith, Interview Two).

Lack of knowledge of how to cook contributed to a reliance on convenience foods, ‘I eat a lot of ready-made meals’ (Faith, Interview two). Abbie described how she ate mostly take away or,

things that could be eaten straight away out of the tin because I couldn't really cook at all. So it would be things like corn kernels and tins of tuna and things like that that I could just open and eat straight away (Abbie, Interview one).

An analysis of food diaries of people with schizophrenia found a strong reliance on convenience foods and café bought snacks (Hardy & Gray, 2012). Studies comparing dietary habits of people with SSDs with the general population tend to find a greater reliance on convenience foods among the group with schizophrenia (Ratliff, et al., 2012; Roick, et al., 2007). This reliance on convenience foods was viewed by the women in my study as being less healthy and contributing to their issues with managing their weight. Abbie, for example, believed this contributed to her significant weight gain when she was first unwell, ‘I think that that may also have helped me gain so much weight because I was not eating properly. I’d buy a whole [BBQ] chicken and eat the whole chicken instead of having proper portions’ (Abbie, Interview One). This perception is consistent with the findings of a study of people in the general population in Germany which found that consumption of ready meals was associated both with poor cooking skills and with obesity (van der Horst, Brunner, & Siegrist, 2011).
Many of the women who participated in my study had developed their knowledge of how to shop for and prepare food prior to the onset of their illness and remained confident of their skills in this area. Mary, while only 21 when she became unwell, had been living away from home and shopping and cooking for herself since she was 18. She described herself as, ‘pretty good at life skills usually’ (Mary, Interview three). Emily and Gaye had both developed their illnesses later and had well established knowledge and skills in shopping for and preparing food although Gaye reported that her mental state meant that she often did not feel up to carrying out these tasks, ‘Yeah sometimes I find it hard to think so I just throw anything in my trolley and can’t wait to get home. But I’ve been doing it for years on my own so I get by’ (Gaye, Interview one). Others like Karen and Nuela who were confident with their knowing how to, ‘I know how to cook, I’m quite good at it’ (Nuela, Interview One) and enjoyed it, found that this could also be counter to their ability to manage their weight, ‘That’s the trouble, I love cooking. I just made a slice yesterday and I’ve eaten half of it. Because someone gave me some passionfruit and I made a passionfruit slice’ (Karen, Interview one).

6.3 Mental Health and Wellbeing

The second factor that the women described as mediating their ability to carry out the necessary activities to manage their weight was the state of their mental health and wellbeing. Schizophrenia has been described as one of the most debilitating of all mental illnesses. Bettazoni, Zipursky, Friedland and Devins (2008) found that illness intrusiveness, which is defined as illness induced lifestyle disruptions which interfere with participation in valued activities, in people with schizophrenia was amongst the highest compared with other populations of serious medical and psychiatric illnesses. Participants in the above study experienced considerable disruption, especially in the instrumental life domain (Bettazzoni, et al., 2008). The women who took part in my study talked about the impact of mental health and wellbeing in two different phases. The first of these phases was in the beginning, which was then followed by an ongoing pattern of ups and downs.
6.3.1 In the Beginning

The first phase of mental health and wellbeing that mediated the women’s ability to manage their weight was in the beginning, which pertains to the onset, diagnosis and initial period of treatment for their illness. For most of the women this was also the time when they experienced rapid and significant weight gain. The two dimensions of in the beginning are, all going on in my head, and doing what you need to survive.

All Going on in My Head

All going on in my head describes how, despite the period around the onset and commencement of treatment for their SSD being the time when they experienced the most significant weight gain, the women were largely unable to respond to this due to pre-occupation with and effects of their mental illness. The word ‘scary’ was used by most of the women when they were talking about the onset and early period of treatment for their SSD. They generally didn’t understand what was happening at first. Danika remembered, ‘I didn’t know what was wrong with me. I just know everyone was against me and they’re trying to feed me tablets that made me feel dizzy and eerie and stuff’ (Danika, Interview two). Similarly Elizabeth described not knowing, ‘what the hell was going on... I actually felt like I wasn’t with it. It’s like everything was happening at once. I wasn’t in touch with reality’ (Elizabeth, Interview one).

They described being fearful of symptoms,

I was having really bad hallucinations and voices and paranoid beliefs that people in the street are looking at me and there’s a big conspiracy and all that kind of stuff. Yeah, so it was pretty terrible when I first got sick (Abbie, Interview one).

And they generally experienced significant disruptions in their lives. Some like Abbie and Emily experienced breakdowns in relationships with their partners. Emily recalled, ‘I was very frail and my marriage did make up for about 18 months and then I just thought, oh I don’t want this anymore. It’s not fair on my husband, so I just took off’ (Emily, Interview two).

Many of the women also found they needed to withdraw from their work or study. Abbie, Mary and Nuela all withdrew from university study in the context of the onset
of their illness. Mary recalled, ‘I had just finished two years full-time at [Regional City] uni. I was going to uni out there at [University]. Then I became unwell in the holidays before my final year’ (Mary, Interview One). Karen had completed her study and just started working as a teacher when she became unwell,

I went to college and I did a teacher diploma in primary education. I completed that and I also completed a religious education diploma, which enabled me to teach in Catholic schools because I’m a Catholic. I got the qualification and not long after that I got sick (Karen, Interview one).

The characterisation of the time around the onset and diagnosis as a time of considerable upheaval and loss is consistent with findings of other qualitative studies of the experience of living with SSDs (Chernomas, Clarke, & Chisholm, 2000; Shepherd et al., 2012).

Their mental health difficulties and the challenges in overcoming these were all consuming at this time. In recalling this Abbie suggested that it may have contributed to her weight gain,

I found that when I first got sick I was existing inside my head and I completely ignored my body. I feel that kind of contributed to me gaining so much weight because I didn’t really care about my body at all (Abbie, Interview one).

To some extent there was a lack of awareness of the issue of weight gain due to the preoccupation with the mental health issues. Abbie puts this quite starkly, ‘I mean I didn’t even realise I wasn’t eating correctly because I was out of it. You know, hearing voices and hallucinating. The last thing you want to think about is whether or not you should be eating fruit’ (Abbie, Interview one).

Others suggested that even if they had been given guidance around managing their weight at this time they would not have been able to follow it due to their preoccupation with managing their mental health. Faith said, ‘Probably not just with everything going on’ (Faith, Interview three). This prioritisation of addressing their mental health needs at this time was also in many cases reflected in the actions of those around them. Karen recalled that while there was a general recognition that she was gaining weight when she was first treated for schizophrenia, ‘That wasn’t a focus because I was pretty unwell at the time so anything to get me better was preferable to
the weight gain. People weren’t focusing so much on that’ (Karen, Interview three).

Mary described having been aware of the potential for weight gain as a side effect of the medications but had found herself unable to address this due to the symptoms of her illness, ‘I wasn’t really. I was too unwell, I think’ (Mary, Interview two). She recalled trying to exercise, ‘I started off walking twice a day and then when the paranoia got too much when I was walking and I had to stop doing that’ (Mary, Interview two).

Doing What you Need to Survive

The second dimension of in the beginning, was doing what you need to survive. This reflected that in the context of the overwhelming experience of the onset and commencement of treatment for their illness the women were often not able to effectively carry out the activities of daily living associated with managing their weight, specifically shopping for and preparing food. This was a time when they were more likely to rely on take-away or convenience food. It was also a time when comfort eating developed in response to the difficulties they were facing.

The women described this early period of illness as a time when their behaviour was often quite chaotic. For some of the women like Faith who were also dealing with drug addiction this was even more the case, ‘I was living here, there and everywhere for a while. Heavily using. I didn’t really manage it very well. I didn’t cope with any of it.’ (Faith, Interview two). Abbie described in detail the difficulties she experienced in the supermarket,

I was afraid of the supermarket because there are so many things to look at. Like so many different brands of baked beans and I would be standing there trying to make a decision and it would be too confusing. It was sort of almost like the sensory input from all the sights and sounds and stuff was too much for me. I’d end up having to go home (Abbie, Interview one).

Some of the women were able to rely on their parents at this time to provide for their needs. Mary recalled, ‘I was living at home and I just had everything done for me really at that time’ (Mary, Interview two). Others, who did not have this support, reported that they were more likely to rely on takeaway or convenience food at this
time, ‘I ended up just takeaway; chickens and McDonald’s. I’d eat when I was starving’ (Abbie, Interview two).

In the beginning was also a time when the women experienced disordered eating and ate more than they would usually do. In some cases this was due to the side effects of their newly prescribed medication. For others it was comfort eating as a coping strategy. Abbie described eating in response to the fear she felt from her symptoms.

   It helped me because I was so afraid of all these symptoms. If I ate lots of food, comfort food, it made me feel better about the scary things that were happening. If I was afraid, I’d eat. I was afraid a lot (Abbie, Interview two).

Faith also described comfort eating at this time although she viewed this as a coping strategy for coming off the illicit drugs she had been using as well as dealing with the distress of her illness,

   I think it’s a combination of coming off the drugs, having schizophrenia and not having my privacy. I think it’s contributed to my weight gain. I eat for comfort, whereas when I was using I wouldn’t eat, but it was just - yes, I have put on a lot of weight, I’ve put on about 40 kilos in recovery (Faith, Interview two).

6.3.2 Ups and Downs

Following the onset and diagnosis of their mental illness the women experienced, ups and downs during which they were more or less able to carry out the activities they saw as necessary to manage their weight. These ups and downs could be due to fluctuations in the severity of the symptoms of their SSD, low mood either as part of a diagnosis of schizo-affective disorder or a co-morbid diagnosis of depression, or in response to adverse life events. The women found themselves less able to manage their weight at these times either due to finding it more difficult to do activities such as exercise or because they were more likely to engage in comfort eating. The three dimensions of ups and downs are: symptoms, mood and life, everything’s an effort and wanting comfort food.

Symptoms, Mood and Life

There was significant variation in the course and severity of their SSD among the women in this study although all described some times when the symptoms of their illness were more intrusive and they were less able to carry out their daily activities,
including those involved in managing their weight. Abbie and Karen had both had hospital admissions at the time of their first episode of illness but then went on to live for extended periods without requiring hospitalisation and with minimal intrusion from psychotic symptoms. At the time of the first interview Abbie described her symptoms in terms of,

...ebbs and flows. Depends on how stressed I am. If I'm really stressed they're very severe and it's very frightening. But there's - I might go for like a month or two and not have any [hallucinations] or any things and sometimes they just happen even without stress (Abbie, Interview one).

By the third interview this had decreased to the extent that she had,

...not very many symptoms, no hallucinations, no voices, no paranoid thoughts. Every now and then I think I hear someone calling my name and I know there's nobody there, but I just ignore that because it's not really all that distressing. It's just something that happens every now and then (Abbie, Interview three).

Similarly, Karen reported that, ‘mostly I'm pretty well - when I'm well I'm quite well. I don't have any really paranoid thoughts or anything’ (Karen, Interview two). At the other end of the spectrum some of the women lived with frequent if not constant distressing symptoms. Elizabeth had numerous and frequent acute episodes of illness, ‘I have had a lot of periods of being unwell. But when it does happen it gets pretty bad because the schizophrenia is pretty severe’ (Elizabeth, Interview two). The severity of these episodes was such that she was usually admitted to hospital and she had two admissions during the period she was engaged in the study, despite the instigation of a comprehensive relapse prevention plan, ‘I’ve had too many. I’ now trying my best with my relapse prevention plan that’s done by Support Recovery, to try to keep it under control and to stay out of hospital because I’ve had too many admissions’ (Elizabeth, Interview one). Faith had not been in hospital for some years when we met, however she also lived with almost constant positive symptoms which fluctuated in intensity and which she referred to as ‘not having my privacy’. She reported in our first interview that she experienced more intense symptoms every few days or so but this was an improvement for her, ‘It comes and goes but it's not sort of there 24/7 anymore’ (Faith, Interview one).
In addition to the ups and downs of fluctuating levels of psychotic symptoms many of the women also lived with significant fluctuations in their mood. For some, like Nuela, this was part of a primary diagnosis of schizo-affective disorder which caused her to experience periods of hypomania as well as depression. Others such as Abbie, Elizabeth, Emily and Karen had comorbid diagnoses of depression. For some like Abbie this was well controlled with medication,

I think there was trouble when I first was on medication to find the right medication. But once they found the right combination, things have been pretty good for me emotionally. Yeah. I haven’t felt suicidal or depressed or anything like that for a long time (Abbie, Interview two).

Others like Emily experienced episodic low mood, ‘my thoughts get very sad and I think how am I going to cope with these’ (Emily, Interview one). And again at the other end of the spectrum was Gaye also had a diagnosis of depression and when we met she was going through an extended period of low mood that was not responding well to medication. She described herself as, ‘slow in the head and very, very sad’ (Gaye, Interview one).

_Everything’s an Effort_

The first way in which the ups and downs impacted on the women’s ability to manage their weight was in making it more difficult for them to engage in the activities and routines that were necessary to this goal. Mary expressed a belief that, ‘you can only really deal with the illness when you’re unwell and everything else goes out the window’ (Mary, Interview three). The women in the study by Chernomas et al. (2000) also described finding that the illness itself often took precedence over other significant issues in their lives. Similarly, in the study by El-Mallakh (2006) participants did not believe that they could care for their diabetes unless the symptoms of their schizophrenia were stable. During one episode Mary’s paranoia was so severe that there was a six month period during which, ‘I couldn’t leave the house or anything, so it was difficult to exercise and stuff like that’ (Mary, interview one). More commonly however the women found it difficult to do their usual activities during times of acute illness because of impaired concentration. Mary stated, ‘It’s just really distracting. It’s hard to do the day-to-day things’ (Mary, Interview One). Abbie also described having
difficulty concentrating on tasks when she was unwell and described this in relation to shopping,

Because your brain doesn’t always work properly. Trying to do something and then you get distracted because there’s so much going on and it can get confusing. You’re trying to concentrate on one thing and all this other stuff is happening around you and it’s hard. Especially like going to the supermarket; there’s all these other people, there’s all the produce to look that. It can get overwhelming. I suppose it can be underestimated how difficult that is (Abbie, Interview two).

And cooking,

It’s really hard to concentrate on things. Like, I might be sort of trying to organise an omelette. I’ll be saying well, okay, I need three eggs and my brain it’ll be confusing. I don’t know how to explain it. It’s sort of like, you should be doing this, you should be doing that. It’s like a voice in my head commenting on what’s going on distracting me from what I’m trying to do (Abbie, Interview two).

The other way in which ups and downs impacted on the women’s ability to do the activities associated with managing their weight was on their level of motivation and energy. Abbie stated this directly, ‘because if you’re having symptoms you can’t be motivated’ (Abbie, Interview one). Faith found that when her symptoms were more intrusive, which happened ‘every few days’ she found that she was, ‘not very motivated, that’s all; not being motivated to do exercise and not looking after myself properly. Not really caring’ (Faith, interview one). The women found it harder to get themselves to exercise at these times. ‘When, I’m a bit down or unwell I find it difficult to exercise’ (Karen, interview one). Similarly, Emily who structured her exercise around walking found that, ‘when you’re on a downer, sometimes you think, I just can’t make the effort to go to the letterbox today, so I’ll put it off ‘til tomorrow. That’s happened quite a lot’ (Emily, Interview two). Participants with schizophrenia in the study by Rastad et al. (2014) also identified symptoms of their illness, including depressed mood, anxiety and paranoia, as barriers that complicated or obstructed participation in physical activity by making it more difficult for them to initiate activity or causing them to feel tired. They were also less likely to cook healthy meals for themselves, ‘if you’re not well it’s a real effort to get a meal’ (Emily Interview two), and more likely to rely on takeaway. Mary recalled that she, ‘ate more McDonald’s, I guess, when I think about it, when I was leading up to being unwell. I don’t go there
anymore usually’ (Mary, Interview three). Gaye had been experiencing an extended period of low mood and described finding ‘it hard to be healthy ‘cause I’ve got depression’. She reported that in this state she found that ‘everything is an effort’ (Gaye, Interview one).

The finding that the women were less able to carry out the activities they saw as necessary to manage their weight when they were experiencing more symptoms of their illness is consistent with other studies of people with SSDs. Participants in the study by Soundy, Faulkner and Taylor (2007), described how their routines and lifestyles could change frequently and unpredictably due to their illness with manifestation of mental health problems causing deterioration in lifestyle. This is also reflected in the findings by Abed (2010) that psychotic symptoms were one of the categories of factors that affected lifestyle choices in people with schizophrenia, with examples such as being unable to leave the house or to concentrate on preparing meals. In their study of 81 inpatients with a diagnosis of schizophrenia Lipskaya, Jarus and Kotler (2011) found that the degree of positive and negative symptoms and general psychopathology was inversely related to the level of functioning in instrumental activities of daily living.

These low periods when they were less able were, for most of the women, balanced by ups which generally were the times when they were more well and felt more able to do tasks. Karen described this in terms of fluctuating energy levels,

…my energy levels are sometimes really good and all my housework’s in order and I’m all organised and everything’s on top - I’m on top of everything and then I go through lulls where I’m - everything’s a bit of a mess and - not too messy but I never let it get too much out of hand but definitely my energy levels go up and down (Karen, Interview three).

Others also described feeling more able to do activities when they were more well. Emily described how ‘if my thoughts are a bit happy, I’m on top of the world and I can do almost anything (Emily, Interview one).

Nuela differed somewhat from the other women in that sometimes the ups were also episodes of illness, hypo-mania, in the context of which she was in some respects more able to manage her weight than when she was well, ‘exercise is quite easy when I’m
feeling elevated and happy’ (Nuela, Interview three). She recalled one episode during which,

There was a bit of a routine for it and it went ongoing for a few months and I was thinner, I had more energy, things like that. I felt really good at that time but I don’t think I was on the correct medication. So I think – my brain was a little bit loopy at the same time so I think was going through mania but not severe mania where you get hospitalised (Nuela, Interview one).

While she recalled being more able to exercise at these times she also recalled however that, ‘food choices become more impulsive’ (Nuela, Interview three).

**Using Food to Cope**

The other way in which ups and downs affected the women’s ability to manage their weight was that in the down times they were more likely to engage in comfort eating to cope. ‘When you’re feeling really bad you want comfort food and invariably that’s something that’s not good for you; chocolate and fizzy drink and full fat ice cream or cheese’ (Abbie, Interview three).

Comfort eating occurred in response to downs from different sources. The women described comfort eating to cope with the symptoms of their illness both in the initial period as described above in doing what you need to survive, and during exacerbations when their symptoms became worse as described by Mary below,

I don’t know, just becoming unwell can do that but also just getting sicker – just – it happens gradually like you start eating a few bad things and before you know it you’re buying a block of chocolate a day or stuff like that (Mary, Interview three).

Others like Emily described comfort eating in response to depressed mood, ‘They’re [thoughts] really out of this world but they get me depressed because I believe they’re true so I eat (Emily, Interview one).

Several of the women also described comfort eating in response to adverse life events. Nuela recalled in our third interview, ‘I was getting emotional about something the other day, I don’t remember what is was, but every time I’d see the opportunity for chocolate I really wanted it’ (Nuela, Interview three). Karen described eating as a response to conflict with others, ‘When someone upsets you or something like that you
feel like giving it all away and just pigging out or something’ (Karen, Interview three). They also described comfort eating in relation to loneliness and isolation, which they saw as stemming from their illness. Mary described how, ‘When I’m unwell I withdraw from a lot of things and it just - yeah. You use food as something to help you get through the day’ (Mary, Interview three). Karen also described comfort eating in response to loneliness, ‘Living on my own too, I use food for comfort sometimes’ (Karen, Interview one).

6.4 Practical Issues

The third category of factors that mediated the women’s ability to engage in activities to manage their weight was practical issues. The women described two main considerations, watching your money and juggling.

6.4.1 Watching your Money

All of the women who took part in this study relied on the disability support pension (DSP) as their only or main source of income. This is consistent with the findings of the Australian survey of high impact psychosis (SHIP) in which 85% of the respondents relied on the DSP as their main source of income (Carr, Whiteford, Groves, McGorry, & Shepherd, 2012). Financial matters were the lead challenge identified by respondents in the SHIP study (Carr, et al., 2012). The women who took part in my study reported that their limited financial resources impacted on the choices available to them for managing their weight. There is considerable evidence that overweight and obesity are more prevalent among socioeconomically disadvantaged people and that in developed countries this association is stronger in women (McLaren, 2007). In an Australian study looking at socioeconomic differences in weight management, Siu, Giskes, and Turrell (2011) found significant differences in weight loss behaviours across socioeconomic groups and that people from low socio-economic groups were more likely to believe that losing weight was expensive. The three dimensions of watching your money were, just getting the basics, healthy is expensive, and depending on the weather.
Just Getting the Basics

The women described finding it a challenge to meet all of their expenses on their limited incomes, which in most cases consisted only of the disability support pension payment. Karen said, ‘financially it is a struggle sometimes’ (Interview One). They found that this limited their choices when it came to grocery shopping with many finding it a struggle just to, as Abbie said, ‘purchase as much food as I need with the little amount of money that I’ve got’ (Abbie, Interview Two). She, like many of the participants, described being anxious to avoid, ‘the situation where I get to the checkout and don’t have enough money’ (Abbie, Interview One), and described the challenge of making, ‘sure that I’ve got enough food and stuff to last me a fortnight’ (Abbie, Interview Two). Some, like Gaye, found that they were not always able to manage this, ‘sometimes if you get an electricity bill or a phone bill you might be a bit short’ (Gaye, Interview One). They commonly identified that they had to, ‘just buy the basics’ (Karen, Interview One). Similarly Elizabeth reported, ‘I just get the basic stuff that I need and leave the luxury stuff out of it’ (Elizabeth, Interview Two). Many of the women described as Danika did that they, ‘usually try to get the cheapest stuff I can’ (Danika, Interview Two). Limited finances have been identified as impacting on lifestyle decisions relevant to managing weight gain in other studies of people with SSDs (Abed, 2010; Vandyk & Baker, 2012; Xiao, et al., 2012). Participants in the study by Carson et al. (2013), exploring influences on food choices in people with SMI, also reported being concerned about not having enough money for groceries and making decisions based primarily on the cost of food.

Healthy is Expensive

Their need to buy more inexpensive items to ensure that they were able to get enough to last them the fortnight lead them often to make selections that they considered less healthy, because the healthy options were more expensive. In our third interview Nuela identified that, ‘the three star mince is always less that the five star mince…margarine, the regular one which is bad for you is as cheap as chips, the one that reduces your cholesterol, that’s really expensive’ (Nuela, Interview three). Karen described only buying, ‘healthy bread when I can afford it’ (Karen, Interview One).
Similarly Abbie described not always being able to afford to buy fresh fruit and vegetables,

    Especially with fruit because sometimes fruit’s so expensive that I can’t really afford it. Things like bananas when they’re $5 a kilo, I can’t afford that. So I end up buying tinned fruit and some tinned veggies as well; corn and that kind of thing. Yeah so it would be really nice if I could afford lots of fresh fruit and veg, but sometimes they’re just too expensive (Abbie, Interview one).

They also described finding that the more healthy takeaway food options were more expensive, and they were therefore less likely to buy these. Nuela said, ‘if you go to the food court or something and you want a salad sandwich, that is probably, I don’t know, $7 or something, whereas there’s a cheeseburger for $2.50 (Nuela, Interview Three). Similarly, Elizabeth identified that, ‘I like to go to Subway because their stuff is pretty healthy but I don’t do that very often either because their food is quite dear’ (Elizabeth, Interview One).

In a review, Darmon and Drewnowski (2008) found considerable evidence for a socioeconomic gradient in diet quality, with high quality diets associated with affluence and energy dense diets that are nutrient poor consumed by people of low socio-economic status. They identify the disparity in costs between energy dense and nutrient dense foods as a causal factor. In their (2009) study, Kettings, Sinclair, & Voevodin found that the cost of eating in line with the Australian guidelines for healthy eating would consume 40% of the income of welfare-dependent families, compared to 20% for families on an average income. The perception by the women who took part in my study that eating healthy food is more expensive is consistent with several studies of women with low socio-economic status both in Australia and internationally. Inglis, Ball and Crawford (2005) conducted a qualitative study in Melbourne to investigate factors that might contribute to socioeconomic inequalities in diet behaviour among women. Perceived cost of high quality food was identified as a predominant barrier. A number of studies with women living on low-incomes in America and the United Kingdom also report cost as a barrier to purchasing healthier food (Dammann & Smith, 2009; Lawrence et al., 2009; Weber Bucholz, Huffman, & McKenna, 2012; Wiig & Smith, 2009). Similar findings were also reported by Barre et al. (2011) in their study exploring barriers to healthy eating in persons with schizophrenia.
Participants in the study by Hardy and Gray (2012) suggested that a reason for their low consumption of fruit and vegetables was because these items were too expensive and they could not afford to buy them.

In some of the later interviews some of the women who participated in my study had modified their views on their ability to afford healthy items, usually following intervention by dietitians or other health professionals. Abbie, in our third interview, reported that while she still found the healthy items to be more expensive, she was able to afford these by cutting out some of the more unhealthy items that she had been purchasing, ‘I found that if I didn’t buy the other things that were bad like cheese and full fat ice-cream, I could afford to get the fruit and veg’ (Abbie, interview three). Similarly Karen, in our second interview reported that she had found that ‘you can eat really healthy and it doesn’t cost much but you just don’t eat as much meat’ (Karen, Interview two). She also reported ‘I’ve discovered tofu and tofu’s so cheap. You buy one block of it and that’s two meals and it’s so cheap with vegies and it’s healthy’ (Karen, Interview two). This strategy of finding inexpensive ways to access healthy food was identified as one of the categories of restorative health behaviours among the low income women in the study by Weber Buchholz et al. (2012).

**Depending on the Weather**

Their limited finances also impacted on the options the women were able to take up with regard to exercise. Abbie, like many of the women identified walking as her exercise option and stated that a key factor in this choice was that, ‘it’s free’. Another free option that some of the women took was swimming in the local ocean baths. For both of these ‘free’ exercise options the women found that they were dependent on the weather. Abbie stated, ‘If it’s raining, I don’t really want to go for a walk in the rain…if the weather is not nice it just doesn’t happen’ (Abbie, Interview two). Isobel who also walked for exercise said, ‘if there is a storm outside I won’t go’ (Isobel, Interview One). Nuela had been swimming when we first met but at our next interview stated, ‘I haven’t been since, it’s just too cold or it costs too much where it’s heated’ (Nuela, Interview Two). These findings reflect those in the study by Ussher, Stanbury, Cheeseman and Faulkner (2007) of the physical activity preferences and perceived
barriers among people with severe mental illness in the United Kingdom, in which the
most popular form of exercise was walking and the weather was the most frequently
reported barrier. Many of the women who took part in my study expressed a
preference for a different exercise option but found that they were not able to access
these, or accessed them less often, because of the cost. Like Nuela, Karen swam in the
ocean baths but expressed a preference for swimming in the indoor heated pool, ‘you
can see the bottom and like you can have a whole lane to yourself. It’s more the, the
conditions are just better’ (Karen, Interview two). She suggested that, ‘some kind of
concession for the indoor pool so I could go all year. Some deal where I could go all
year and it wouldn’t cost so much’ would be helpful in supporting her efforts to
manage her weight (Karen, Interview three). Other women expressed that they would
like to be able to access a gym to exercise but found the cost prohibitive, ‘Gym is a bit
expensive’ (Danika, Interview two). Some like Elizabeth had attended gyms in the past
but had not been able to afford to keep going, ‘I stopped going before because I don’t
have enough money’ (Elizabeth, Interview one). Again, when considering what would
enable her to better manage her weight in interview one Mary said, ‘if the gyms were a
bit cheaper’ (Mary, Interview one). At the time of our third interview Mary had been
linked in with the ‘Brighter Futures’ program for several months. Brighter Futures is a
NSW government funded early intervention program designed to achieve long-term
benefits for children identified as being at high risk of entering the child protection
system due to a range of vulnerabilities including parental mental health issues
(Brighter futures program, n.d.). The program provides a range of tailored services and
had been funding Mary’s access to a gym. During this time she had been attending the
gym several times a week and had been steadily losing weight. She expressed concern
in this interview however that, ‘I’m only linked in with the program till, for another six
months...I’m not sure what will happen with the gym’ (Mary, Interview three).
Participants with schizophrenia in the study by Rastad et al. (2014) also identified
finances as a barrier to physical activity participation.

Finances also limited the women’s ability to access commercial weight management
programs, which some of them had found helpful. Prior to her engagement in the
study Karen had done ‘Jenny Craig’, ‘for about a year, and I did lose about ten kilos’
but stopped going, ‘mainly [because of] the cost’ (Karen, Interview one). At the time of our first interview she had been attending ‘Weight Watchers’ for some months but found that the cost of the sessions was limiting her ability to attend,

It’s a bit expensive. It’s gone up to $17 a fortnight now. One of the ladies that works there, she seems a bit resentful because you’ve got to go once a week and I talked to the leader and I said, ‘look, I’m on the disability pension can I go once a fortnight?’ and she said ‘sure’ (Karen, Interview one). She reported that she would prefer to attend weekly if she could afford it as she found it difficult to maintain her motivation for the two-week period between meetings, ‘when I go I feel motivated and after I’ve been and I feel okay, I’ll do this and I’ll do that and it lasts for about three days and then I’ll have two potatoes instead of one again’ (Karen, Interview one). Despite having negotiated for the less frequent attendance, by the time of the second interview she was no longer going because, ‘it was costing too much’ (Karen, Interview two). In considering what would help her to be more able to manage her weight she suggested, ‘help with a weight management program like weight watchers but not so expensive’ (Karen, Interview one). Nuela had also tried Weight Watchers but although she had lost some weight she found it, ‘too expensive to follow through with for more than a few months’ (Nuela, Interview one).

Participants in an investigation of dieting, weight loss and physical exercise in obese individuals also identified cost as a limiting factor in maintaining participation in commercial weight loss programs (Thomas, Hyde, Karunaratne, Kausman, et al., 2008). The women living on low incomes in the study by Weber Bucholz et al. (2012) also described financial barriers to accessing exercise options and weight loss programs.

6.4.2 Juggling

The second type of practical consideration that the women described was juggling. This referred to the challenges around finding time and energy to prioritise activities to manage their weight in the context of other competing demands. Abbie used this term in our second interview,

So I’m just sort of juggling; trying to do my diploma and also trying to take care of myself by exercising more and having healthier food and that kind of stuff. So, yeah, I really try to focus on
looking after my body better. So I feel a little bit pulled in two different directions with that (Abbie, Interview two).

The two dimensions of juggling were, *fitting it in to a busy life*, and, *prioritising different issues*.

**Fitting it in to a Busy Life**

The women described the impact of other demands on their time on their ability to carry out the activities they saw as necessary to managing their weight. These demands included those related to being mothers of young children for Mary and Nuela. For others it was work or study, ‘my calendar is full with work, TAFE, appointments, blood tests’ (Danika, Interview two). And finally there were the various appointments and visits with medical and allied health professionals, support groups and non-government organisation support workers and activities. Elizabeth had found that she was not able to maintain work or study but nonetheless had, ‘a very busy lifestyle with activities and stuff like that’ (Elizabeth, Interview One). Emily, while she did not go out much was finding that she was having to cut back on her walks because she needed to be home for the various support services that came to her, ‘I’ve had Anglicare coming three times a week…A lady from New Horizons. I’ve just had to be in – medication being delivered. You’ve got to be inside for all of these things’ (Emily, Interview two). These various demands on their time meant that the women sometimes found it difficult to fit in their exercise. Elizabeth said, ‘But if I’ve got a flat out day I just don’t get the exercise in my day’ (Elizabeth, Interview one). They found that they were doing it less often or fitting it in around their other commitments, Nuela described,

The other thing I do is - as exercise, which is different, is walking my son to one of his carers in the morning and then walking him back in a pram in the afternoon. That’s twice a week and that’s - I guess it takes 45 minute walk twice a day for those two days. I would rather it spread out onto every day but it’s just not going to happen (Nuela, Interview three).

Busy schedules also made it more difficult for them to manage their diet. Abbie described how,

I get up in the morning and I get dressed and I rush out the door. Then if I’m out and about and I don’t have any - I didn’t pack food for lunch or anything like that. I’m tempted to go and indulge in takeaway or chocolate or whatever. Then when I get home in the afternoon, I’m starving because I
haven’t had much to eat for the whole day. Then I get stuck into whatever’s in the fridge (Abbie, Interview Two).

Weber Buchholz et al. (2012), in their study exploring the weight loss efforts of women living on low income who had overweight or obesity suggest that, “health care providers should be cognizant of their patients complex lives” (p. 182). Many of the women in their study were overwhelmed by the daily responsibilities of home and work life and had little energy left to eat healthier and exercise more (Weber Bucholz, et al., 2012). Similarly, the women in the study by Parker and Keim (2004) identified having a hectic lifestyle, or children, as limiting their ability to develop the routines they saw as necessary to effective weight loss.

**Prioritising Different Issues**

As well as the time demands associated with their occupational roles the women also juggled different priorities both in terms of the allocation of their own time and energy but also the support they received from their mental health service providers. In particular they tended to prioritise their mental health. While they identified that taking care of their physical health and their mental health were both important their mental health tended to take precedence due to the more immediate and distressing effects of becoming unwell. Karen stated, ‘That’s what it comes down to: getting unwell. Anything that - it’s so horrible to be unwell that I’ll do anything to make me keep well’ (Karen, Interview three).

As a result they found that they needed to manage how much they tried to fit in to their day, which sometimes meant that they were not able to engage in valued activities or activities that they perceived were necessary for managing their weight, ‘I’m just saying there’s not much you can do if that interferes with your illness and then you get really unwell, you can’t just keep letting that happen’ (Elizabeth, Interview two). They also talked about the need to prioritise what they used the limited time available with their mental health service providers for. Abbie in interview one stated that while she did discuss the issue of her weight management with her case manager, ‘it’s not sort of a priority at the moment because I’m concentrating on TAFE and that kind of stuff’ (Abbie, Interview One).
6.5 Summary

In this chapter I described the factors that mediated the women’s ability to enact strategies they saw as necessary to managing their weight as described in the core category of *doing as much as I can*. *Knowing* was the first of these mediating factors. The women’s capacity to manage their weight was influenced first by their awareness that they faced an issue with weight gain, knowing the potential for weight gain as a side effect of the medications they were prescribed and having commenced the medications, awareness of their own weight gain. Secondary to their *knowing the issue* was *knowing what to do* which encompassed their knowledge of public health guidance around diet and exercise as well as the more *practical knowledge* of how to implement this in their daily lives. The second mediating factor was the women’s *mental health and wellbeing*. The initial period following their diagnosis and commencement of treatment for their SSD was when the women experienced rapid and significant weight gain. It was also however a very frightening time characterised by significant disruption and a time during which the women found it difficult to carry out many routine activities and were more likely to rely on take away food and seek solace through comfort eating. Following this initial period the women described a pattern of *ups and downs* which occurred as a result of fluctuations in the severity of the symptoms of their SSD, low mood either as part of a diagnosis of schizo-affective disorder or a co-morbid diagnosis of depression, or in response to adverse life events. In the down times the women found themselves less able to manage their weight either due to finding it more difficult to do activities such as exercise or because they were more likely to engage in comfort eating. The final category of mediating factors was practical issues. The women relied on the disability pension as their sole or primary source of income and found that their limited finances impacted on the choices available to them for managing their weight. They found it difficult to cover their expenses on their limited income and found that they were only able to afford the basics when it came to food shopping. This meant often choosing less healthy options because the more healthy options were expensive. Their finances also limited their options for exercise with most relying on free options of walking or swimming in the ocean baths, which made their routines vulnerable to the weather. Finally, the women were juggling the demands of
other occupational roles, which made it difficult for them to find time to carry out the activities they saw as necessary to managing their weight. They also described needing to limit the amount of demands they were dealing with in order to maintain their mental health, which meant that sometimes exercise or other activities to manage their weight were sacrificed in favour of higher priorities.

The women also identified factors that had, or they thought would be helpful to them in their efforts to manage their weight, *someone to do it with, having a plan and talking about it*. I describe each of these supporting factors in more detail in the next chapter.
Chapter 7  Facilitating Factors

7.1 Overview of the Chapter

In the previous chapter I described the factors that mediated the ability of the women who took part in my study to do what they considered necessary to manage their weight. These mediating factors were: knowing about the potential for weight gain and what to do about it, mental health and wellbeing which included the impact of the initial onset of their illness as well as it’s episodic nature in many cases the co-occurrence of depression, and finally practical issues, which included living on a limited income and juggling, managing their weight with other concerns and life demands. In this final findings chapter I discuss the factors that the women had either found through experience, or thought would, facilitate their ability to more effectively manage their weight. The three categories of facilitating factors are, talking about it, someone to do it with, and having a plan. I describe each of these categories in detail and situate the findings in relation to existing research.

7.2 Talking About it

The first factor that the women described as facilitating their efforts to manage their weight was, talking about it. They described three different foci of talking about it, which helped in different ways. These different foci are the properties of talking about it, from the most basic of keeping it on the agenda, through providing encouragement and finally, education and advice.

7.2.1 Keeping it on the Agenda

The women described the importance of having some external support to keep the issue of their weight on their agenda and to help maintain their motivation. There were two ways in which this was seen to occur, through measuring and monitoring and regular ongoing discussion of their efforts to manage their weight.

Measuring and Monitoring

Having their weight, and sometimes their waist circumference measured by a third party on a regular basis was identified by the women in my study as helpful in keeping their attention on managing their weight and motivating their weight loss or weight
management efforts. They described this measuring and monitoring being done by a range of people. Most commonly it occurred at the community mental health service when they went for their, usually monthly, appointment with their psychiatrist as described by Danika, ‘I get weighed and my stomach measured every month before I go to see Dr [psychiatrist], which is good’ (Danika, Interview one). Elizabeth’s monitoring occurred at the pharmacy, ‘the pharmacies weigh me about once a month to make sure everything is OK and I am not gaining too much weight’ (Elizabeth, Interview two). Emily was weighed by her GP, ‘she weighs me every time I go to visit, takes my blood pressure and all of that’ (Emily, Interview One).

The women described being weighed regularly by a third party as helpful in maintaining their awareness of their weight and any changes that were occurring. Mary said, ‘I get weighed each week at [mental health service] and it’s monitored. So I can sort of keep track of whether that was a good week or that was a bad week’ (Mary, Interview two). This awareness of their weight and any changes that may be occurring was seen as helpful in motivating them to take action, ‘So you can keep track and know exactly how fat – how heavy you are’ (Nuela, Interview two). While she was weighed at her monthly visits for the psychiatrist Abbie thought it would support her motivation if she was more engaged in the monitoring,

I do see the psychiatrist once a month and get weighed and everything. But I’m sort of a bit vague about it. So maybe if I sort of kept a record of how much I lost each month that would help me be motivated and say, okay, well last month I lost half a kilo so I can do better than that this month (Abbie, Interview one).

The women’s perception that having their weight monitored regularly, and moreover being engaged in this monitoring, would be supportive of weight loss is borne out in general population studies of the strategies employed by people who successfully maintain weight loss. Participants in Hindle and Carpenter’s (2011) qualitative study identified regular weight checks as an important strategy, which allowed quick identification of any changes and added to the feeling of being in control. Similarly, a number of studies that compared successful weight loss maintainers with those who had regained weight identified that maintainers were more likely to carry out regular
weighing (Chambers & Swanson, 2012; Elfhag & Rossner, 2005; Kruger, et al., 2006; Reyes et al., 2012).

**Ongoing Discussion**

The other aspect of *keeping it on the agenda* was having at least one person with whom they discussed their weight and their efforts to manage it on a regular basis. Again this finding is reflected in the identification by weight loss maintainers of the importance of structured support from commercial weight loss organisations or health professionals to their success in the study by Hindle and Carpenter (2011). Similarly, the women in Adams’ (2008) study exploring the processes used by obese menopausal women to manage their weight, identified negotiation of formal support from professionals as a factor that helped with success.

The women in my study generally thought that their case manager would be a good person to discuss this with, ‘it’s something I should talk to my case manager about. If she’s talking about it, like once a month would be good’ (Faith, Interview two). However most did not discuss their weight with their case manager or if they did it was not consistent, ‘I do talk to my case manager about it. Yeah it’s not really – it’s not sort of a priority at the moment’ (Abbie, Interview one). This finding is reflected in studies with mental health case managers and nurses who, while recognising the impact of physical health issues for people with mental illness, generally see this as being of secondary importance to addressing their mental health needs and inconsistently addressed it in practice (Faulkner & Biddle, 2002; Hyland, Judd, Davidson, Jolley, & Hocking, 2003).

When the women did have someone they discussed their weight with on a regular basis they found that it helped with their motivation. At the time of our third interview Abbie had been seeing a dietitian monthly and said,

> Seeing the dietitian once a month is fantastic for me, because I’ve got someone I can talk to about it, about my food, and about my exercise, about my weight and all of that. It keeps me going and stuff (Abbie, Interview three).

They described feeling motivated after the discussion, ‘I feel motivated after I’ve been and I feel OK, I’ll do this and I’ll do that’ (Karen, Interview one). They also described
how knowing that they would meet with the person and discuss their weight motivated them to act in anticipation of the meeting, ‘I’m like, I see the dietitian in three weeks, I’d better lose a kilo before then’ (Abbie, Interview three). One of the challenges the women faced was accessing someone that they could see frequently enough and on an ongoing basis. In her third interview Abbie described having found a dietitian whom she was able to have a monthly appointment with, ‘I’ve got someone there helping to motivate me and it’s an ongoing thing now instead of just starting and then not having someone to talk to about it’ (Abbie, interview three). Prior to that she, like many of the women in my study, had accessed this kind of support via the Chronic Disease Management individual allied health services through Medicare, which provides a maximum of five services per patient each calendar year, with no additional services available under any circumstances. They found that this meant they were not able to have appointments frequently enough to be useful, or that if they did have them frequently the five visits were used up in a short period of time and they were unable then to afford to have any appointments for the remainder of the year. While Abbie was happy with monthly appointments the other women tended to express a preference for weekly or at least fortnightly appointments. Mary described how she had been seeing an exercise physiologist under the scheme, ‘I saw her weekly for the first three weeks, and then fortnightly and then monthly’ (Mary, Interview three). But after the allotted sessions under Medicare had been used up she found that, ‘I couldn’t afford to keep going’ (Mary, Interview three). She suggested that, ‘weekly was great but even fortnightly would be enough’ (Mary Interview three). Nuela also expressed that it was necessary to see someone at least fortnightly, ‘I think going more than two weeks without seeing anyone, you forget all of that stuff that you said’ (Nuela, Interview two). Karen, who at the time of our third interview had also began to see a dietitian through the scheme expressed a preference for fortnightly visits as she found, ‘I was just starting to go off the rails the day before I saw her once a fortnight’ (Karen, Interview One). However she found that, ‘I can’t afford to see her every two weeks so I have to make do with five times a year’ (Karen, Interview three).

The value of ongoing follow-up has also been identified in other qualitative studies exploring the experiences and perceptions of individuals engaging in efforts to lose
weight or maintain weight loss. In the study by Reyes et al. (2012) both weight loss maintainers and regainers identified the need for ongoing in person follow-up, particularly in the maintenance phase. Among the participants with obesity in the study by Bidgood and Buckroyd (2004) one of the themes was that the lifestyle changes required for successful weight loss maintenance can seldom be maintained without ongoing help.

7.2.2 Encouragement

The women described encouragement as being really important for their motivation, both in order to start making efforts to lose weight and to sustain their efforts once they had started. When contemplating what she thought would help her in her efforts to lose weight Elizabeth stated, ‘I think I just need some motivation and encouragement’ (Elizabeth, Interview one). The role of social support in the success of health behaviour change is well recognised and there is emerging evidence for its importance in supporting weight loss and maintenance in overweight women. In the study by Cho, Jai, Choo and Choo (2014) higher levels of interpersonal support were associated with higher levels of health promoting behaviour among women with abdominal obesity and conversely lower support was associated with lower levels of health promoting behaviour.

The women in my study described two types of encouragement, pushing and praising. Abbie described both of these types of encouragement when discussing why she preferred her new dietitian to the one she had been seeing previously,

...somehow she keeps me motivated more than the other dietitian did, because she praises me when I’ve lost one kilogram and it’s nice to get praised. She’s like, you’ve lost a kilo, well done, very good, keep it up. Whereas the other dietitian would say, you have to do this and that, focusing on the things that I need to do rather than what I have achieved (Abbie, Interview three).

Praising Encouragement

Praising encouragement as described by the women in my study was characterised by a focus on the steps they had taken and the things they had achieved, rather than what hadn’t or still needed to be done. Emily also differentiated between two of the people who offered encouragement in her life on this basis, her cousin who ‘gave me the
praise for doing things’, and her daughter who ‘feels that I’m not, still not, doing enough’ (Emily, Interview two). The women experienced praising encouragement as positive. They described feeling better about themselves and more motivated after receiving praise. Karen described experiencing this type of encouragement from her GP whom she described as being,

...so happy that I’ve given up smoking, that she kind of said, don’t be too hard on yourself with the weight. It will happen in time and you know, she kind of encourages me and she doesn’t kind of say, ‘oh you big fat thing (Karen, Interview One).

She described a boost to her mood when she saw her GP, ‘she just always praises me, like she’s always building me up which I find she – I always feel good when I go to the doctors surgery’ (Karen, Interview two). Abbie also described a positive response to the praising encouragement she received from her dietitian,

I’ll be like, oh no I’ve only lost a tiny little amount of weight and the dietitian will say, that’s fantastic, well done, brilliant. Then all of a sudden I feel good about myself that I’ve lost a tiny little bit of weight. So, getting praise really helps (Abbie, Interview three).

Nuela, who struggled to find support in her immediate networks, described receiving praising encouragement via Facebook,

I said, on Facebook, I’m really happy I’m fitting into old jeans. Then five or six people almost immediately have put likes on it. That felt really good...I thought, wow, they really like that I’m doing well...So they didn’t have to say words of encouragement, they just had to agree with my words of encouragement to myself (Nuela, Interview Three).

In addition to helping them to feel better about themselves the praising encouragement motivated the women to continue with their efforts to lose weight. Mary described how the praising encouragement she received from the people at her gym when she had her monthly weigh in made her, ‘want to try, and show them that you’re trying’. (Mary, Interview three). The motivating power of this praising encouragement is reflected in the theory of behavioural change in weight loss developed by Berry (2004) on the basis of interviews with women who had maintained weight loss for a year. In this theory the importance of validation, which involved people noticing and making positive comments, was identified as motivating for the women to maintain weight
loss and make more changes (Berry, 2004). Similarly, in a study by Aschbrenner, Bartels, Mueser, Carpenter-Song and Kinney (2012) of the perceptions of people with severe mental illness regarding the perceived benefits of involving family and friends in a healthy lifestyle program, different types of social support were identified with the most beneficial being emotional support which included praise and encouragement.

**Pushing Encouragement**

Pushing encouragement, which was characterised by a focus on what hadn’t been, or still needed to be done, also assisted with motivation to act. This type of encouragement was seen as helpful in assisting with the decision to start taking action to manage weight. Danika, whose sister ‘pushed’ her to eat a more healthy diet and go to the gym suggested that, ‘you start here with your weight and actually you need a bit of a push until you get down a bit and get a bit – I guess more energy or something’ (Danika, Interview One). Emily’s daughter was, ‘always telling me, get out and walk mum, don’t get stagnant and lazy’ which she found helpful as a prompt to act, ‘It makes me think, time to go for a walk’ (Emily, Interview One). Karen, who described her younger sister as, ‘boot camp material’ found that, ‘I just think of my sister’s nagging and that gets me going’ (Karen, Interview One).

While pushing could help in instigating action the women generally did not like this kind of encouragement. Karen said, ‘you know it’s good for you but you don’t like it’ (Karen, Interview Two). The women described pushing as having a negative impact on their mood or self-concept. Emily described how her daughter’s comments, ‘makes me feel terribly useless’ (Emily, Interview One). Karen also described how her sisters ‘nagging’ sometimes ‘makes me feel worse’ (Karen, Interview Two). Pushing could be experienced as discouraging such as the conversations that Karen described with her case manager as, ‘like a broken record. Even if I have been trying she still goes on about how I need to work on it and things like that’ (Karen, Interview three).

Participants in the study by Thomas et al. (2009) also described support from their family and friends which was more confrontational and demonstrated doubt or disapproval as unhelpful. Their preferred support was characterised by empathy, the use of reinforcement and avoiding criticism.
Karen also described how when her sisters were ‘pushing’ her to take action about her weight she felt ‘like she doesn’t understand sometimes too’ (Karen Interview three). The feeling of not being understood which was associated with pushing could also result in self-defeating behaviour. Nuela described, ‘feeling sadness and anger at the same time. That made it worse so I’d want to eat more’ (Nuela, Interview three). Participants in the study by Xiao et al. (2012) also found that negative responses to their weight by peers, family and support networks, reduced their motivation to lose weight as they felt that the difficulties they faced were not understood.

7.2.3 Education and Advice

The women described receiving education, and more frequently advice, from a range of sources and in a range of ways. There were three types of education and advice that were identified as being helpful: that which involved filling in the details of knowing what to do to manage their weight, practical suggestions and perhaps most importantly, that which occurred in an environment where the women felt like they were being listened to and understood.

Filling in the Details

As I discussed in the section about knowing which was one of the mediating factors, most of the women were familiar with the broad principles of healthy eating but were less confident when it came to details such as portion sizes. The first type of education and advice that they described as helpful was that which addressed this perceived gap in their knowledge. Elizabeth said, ‘I can ask things like, what I should have more of and less of and how much I should have of it’ (Elizabeth, Interview Two). This largely related to specific information about how much of different types of food they should eat. Abbie said, ‘The dietitian helped me with portion sizes and eating more protein and stuff like that so, yeah and less carbohydrates’ (Abbie, Interview one). Similarly Danika said of her experience of seeing a dietitian, ‘It was helpful too. Yeah, we just talked. She put me onto skim milk and told me to eat less sugar and stuff, my portions’ (Danika, Interview One). This kind of education correlates with the ‘technical information’, the acquisition of which was identified as supporting weight loss success in the women in Adams’ (2008) study.
Practical Suggestions

The other type of education and advice that was described as being helpful were practical suggestions. These largely addressed the aspects of knowing described in chapter six as practical knowledge and knowing how to do it. Again, when the women were talking about practical suggestions they largely focused on diet. In some cases the suggestions were about what to eat, such as from Karen’s dietitian, ‘She kind of had an eating plan for me and it was really kind of practical and helped me – guided me – just from basic things like what to have for breakfast, what to have for lunch’ (Karen, Interview Three). Mary described suggestions from her dietitian to modify things she was already eating to make them healthier, ‘I was eating some lasagne a bit and she suggested I change a few ingredients to make it a bit healthier’ (Mary, Interview three). As well as what to eat, practical suggestions often included strategies for managing planning and preparing food, for example to prevent over eating or eating things that they saw as unhealthy. Abbie described the suggestion by her case manager to take food with her when she was out during the day such as when she went to TAFE and avoid resorting to junk food or take-away, ‘the suggestion to make my sandwiches for the next day the night before. I did do that when I was at work experience a couple of weeks ago, that worked out really well’ (Abbie, Interview three).

Practical suggestions did not always come from professionals. Advice from family and other carers was helpful to the women in overcoming challenges as they arose such as Elizabeth mothers suggestions to manage her snacking when she was first medicated, ‘Mum sort of steered me in that direction and said you’ve had enough for now, have something a little bit later, …or have a piece of fruit or something’ (Elizabeth, Interview one). She also described practical suggestions from disability support staff,

you know what my carer was that used to take me shopping told me to do? When you are going through the soft drink aisle or you are going through a fat food aisle just look straight ahead and go – whoo [demonstrates speeding down the aisle] (Elizabeth, Interview two).

Practical suggestions also referred to the ease and accessibility of the information or strategies that were provided. Guidance that involved weighing and measuring foods, ‘The dietician suggested that I measure I think it was like 100 grams of protein per
meal and, you know, so much juice per thing. I was like; I don't like the measuring and that kind of thing’ (Abbie, Interview two), or keeping track of points such as in weight watchers were considered to be less practical and accessible.

    counting the points did not interest me because I don't want to be spending all day counting points and that. It just bored me to tears. It didn’t interest me. I don't want to be focused on food so much that I’m thinking every day oh, how many points is that? (Karen, Interview three).

Instead the women identified advice that had been given to them which was more practical such as visual images or associations to indicate portion size,

    So she’ll say, okay a portion of meat is about the size of the palm of your hand. When I'm in the shops that's easy, I can look at the palm of my hand and go okay, the meat's about that size, I'll get that instead of having to look at how many grams it is and saying I need 200 grams of this and 200 grams of that. It makes it difficult to figure things out and try and do some maths in your head about how many grams of meat there are in the packet (Abbie, Interview Three).

Also the relative values of familiar foods to assist in making choices, ‘Like, she just showed me. Instead of having like half a [slice of] pizza I could have three pieces of bread to half a slice of pizza and just put that up’ (Danika, Interview One).

**Being Listened to and Understood**

Crucial to how useful education and advice was perceived to be was the context in which it was delivered. There were numerous examples of the women differentiating between helpful and unhelpful education and advice that they had received and the differentiating factor was the context of the relationship in which the education or advice was given. It was crucial that the women felt listened to and that the person giving the advice understood their needs and preferences and was considering these in the advice they gave. Abbie spelled this out,

    Maybe sort of instead of trying to enforce something like a meal plan, try to sort of listen to how the woman’s feeling. Because that will affect how their going to stick to a diet or stick to an exercise regime. Because if the woman doesn’t feel like she wants to do it, or that it’s important or not, she’s not going to help (Abbie, Interview One).

In her third interview Abbie described finding her new dietitian so much more helpful because,
…she kind of tells me what to do in a way that I can understand and in a way that I can do something about it …. She understands that I don’t like the regimented thing of counting calories or counting grams of this and grams of that. She gives me guidelines to say a portion of meat is about this big (demonstrates with her hands), so you want a piece of meat about that big. She really understands me and how I am about food (Abbie, Interview three).

This was in contrast to the dietitian she had seen previously who,

wanted me to walk every day for a certain amount of time and to use a pedometer and walk so many steps… And also ‘suggested that I measure I think it was like, 100 grams of protein per meal and you know, so much juice per thing (Abbie, Interview two).

Wood et al. (2010), based on their qualitative study of mothers interpretations of dietary recommendations, emphasised the importance of reinforcing healthy eating messages with more personalised communication that takes account of how people live and think about their eating. This is further corroborated through the findings of Ferrari, Seiga-Riz, Evenson, Moos and Carrier (2013) who found that that the women in their study saw the provision of recommendations that were too general and not clearly applicable to them as individuals as reasons not to follow dietary advice.

Nuela also described the value of feeling listened to by the dietitian she saw such that she found that she gained as much from talking about what she did as she did from the information provided by the dietitian who ‘told me a lot of things I already knew’ (Nuela, Interview Two). She described how,

before she told me any of the healthy habits she asked exactly what I was doing. Just hearing myself say it, like I eat two bowls of cereal in the morning, felt like I was wrong for doing that. So the next day I tried to eat less’ (Nuela, Interview three).

Karen also compared experiences where she had found the advice and education to be helpful or unhelpful. Again that which was unhelpful was characterised by not reflecting an understanding of her needs or preferences. She described seeing a dietitian whom she ‘didn’t relate to’ and said, ‘I didn’t find him very helpful, yeah, he was just – he said you’ve got to get used to being hungry. That doesn’t sound very nice to me, being hungry all the time’ (Karen, Interview Two). In contrast the dietitian she was seeing at the time of our third interview she described as ‘really good and I like her as a person and she’s helpful and encouraging’ (Karen, Interview three). The
quality of the relationship and the sense that the person was attuned to their needs even made advice that was difficult to hear palatable, such as that from Karen’s sister about her comfort eating,

she makes me realise I’ve got to think about the consequences of when I - if I over eat the consequences will be that I’ll be uncomfortable of I’ll – just for an instant gratification, like it’s not worth it to put on more weight and to feel uncomfortable. She does have some empathy because she said you must feel so uncomfortable some times, and she – I know that she loves me and that and she wants the best for me (Karen, Interview two).

7.3 Having a Plan

The second factor that the women described as facilitating their efforts to manage their weight was, having a plan. They described three different contexts in which having a plan was helpful. These included the use of budgets, meal plans and shopping lists to support their ability to carry out activities associated with managing their diet, routines for eating and exercise, and strategies to manage challenges. These three contexts form the properties of having a plan.

7.3.1 Budgets, Meal Plans and Shopping Lists

The women talked about three planning tools that supported their efforts to carry out activities to manage their weight through managing their food choices, budgets, meal plans and shopping lists. Many of the women had received assistance in developing these tools and were provided with templates or checklists for ongoing support. At the most basic level these tools made the tasks, particularly shopping, more manageable for the women. Abbie recalled that, ‘when I first got sick, going to the supermarket was a very stressful ordeal. At the moment, now, I love it because I’ve got a strategy of what I need to do’ (Abbie, Interview one).

The difficulties that the women identified in carrying out these tasks may have been due at least in part to deficits in executive function which is a recognised area of cognitive impairment in people with schizophrenia and has been found to impact on their ability to carry out activities of daily living tasks such as grocery shopping, meal planning and cooking (Lipskaya, et al., 2011; Rempfer, Hamera, Brown, & Cromwell, 2003; Semkovska, Bedard, Godbout, Limoge, & Stip, 2004). Based on their finding that
knowledge of grocery shopping skills mediates the relationship between cognition and performance. Brown, Remfer, Hamera and Bothwell (2006) suggest the need for interventions which involve providing knowledge of these skills, such as occurs for social skills training. The use of environmental supports, such as checklists and forms, to support these skills is consistent with cognitive adaptation training which has been found to effectively compensate for cognitive deficits and facilitate functional performance in people with schizophrenia (Velligan et al., 2008; Velligan et al., 2006).

As well as reducing the stress associated with shopping, the budgets and lists helped the women to purchase what they needed within their means, ‘because when you’re budgeting you think that’s not on the list, if I don’t buy it I can do without it, and I won’t overspend’ (Emily, Interview two). Economic self sufficiency and managing transactions have been identified as a specific area of difficulty in independent living in people with schizophrenia (Tenorio-Martinez & Medina-Mora, 2009). Similarly in their qualitative study exploring what helped and hindered people with schizophrenia from doing what they wanted to do, Cook and Chambers (2009) found that difficulty managing finances and lack of money was identified as a limiting factor, and support with this as a facilitating factor. The support with budgeting was critical in helping the women in my study ensure that they had enough food to last them between their income payments and shopping trips, ‘plan what you are going to buy so that you’ve got it for the next two weeks. Now that you’re not overeating you – it will last two weeks’ (Karen, Interview three). This food security helped the women stick to the dietary intake they saw as helpful to managing their weight, ‘Because I know what I’m going to be eating and, yeah, I just – I don’t have times where I don’t have anything to eat. That’s when it’s tempting to get take away’ (Mary, Interview three).

The planning also helped in their perceptions of their ability to afford healthy food,

I’ve also discovered that buying healthy food is not as expensive as I thought it would be, because it means that I am not buying the things that are more expensive that are bad, like full fat ice-cream and things like that (Abbie, Interview three).

Having their shopping list also helped the women avoid the temptation to buy things that they may be tempted by in the supermarket but which were not helpful to their
efforts to manage their weight. Mary described managing not to buy the ‘unhealthy’ items at the supermarket by, ‘writ[ing] a list and I don’t get anything that is not on the list’ (Mary, Interview three). Abbie also described, ‘sticking to my list and using a bit of willpower to not buy the things that are bad’ (Abbie, Interview two). This description of the shopping list as a kind of ‘pre-commitment’ strategy is endorsed by the findings of the systematic review by Au, Marsden, Mortimer and Lorgelly (2013) that the pre-commitment strategy of shopping to a pre-determined list is a cost effective means of reducing obesity.

The women also identified that having some form of meal plan that helped them know what to eat was helpful, both in terms of managing their money and their food purchasing. Danika planned a few days at a time, ‘say I plan tonight I’m going to have like a steak and vegies, I’ll go out and buy the potatoes. I don’t have like bulk vegies in my house’ (Danika, Interview two). Isobel also planned and shopped every few days, ‘we get enough for about three days of vegetables’ (Isobel, Interview One). More commonly however the women planned and shopped for the fortnight, which was the frequency of their income payments. Some of the women had assistance from a dietitian in developing a meal plan that helped them know the types of things they should have for their meals.

It was really kind of practical and helped me – guided me – just from basic things like what to have for breakfast, what to have for lunch. A general thing, and a general thing for breakfast like what to have, Weetbix and toast, and things like that. It was really practical, gave me an outline of what to eat each day (Karen, Interview three).

She found this helpful in reducing how much she thought about food,

I implement it, and I do the grocery shopping that includes the different things and then that’s it. I don’t think about it anymore; I just do it. That’s it. Then it’s in perspective and I’m not focusing all day about my food and that which I don’t like doing really to be honest. I’d rather be thinking of other things (Karen, Interview three).

Abbie talked about the importance however of having some flexibility in the meal planning. In interview one she described having been given a meal plan by a dietitian which, ‘worked for a while and I did lose a little bit of weight. But I found it really hard
to stick to’ (Abbie, Interview one). She was having much more success with the meal
planning with a different dietitian by interview three which allowed a bit of flexibility,

I have Monday this and Tuesday that and whatever, but I find if I stick to my shopping list and
only have good food in the house, that’s what I will eat. So it doesn’t really matter if I have steak on
Tuesday or Wednesday or whatever, as long as I have it (Abbie, Interview three).

The importance of a meal plan being developed in consultation with the woman and
suiting them is illustrated by Elizabeth who talked of the value of having a meal plan
but then went on to say that she had one that had been given her by a dietitian that she
kept in a drawer and did not use.

Meal planning has been identified as a strategy distinguishing between those who are
successful and unsuccessful in weight loss attempts (Kruger, et al., 2006). Participants
in the study by Hindle and Carpenter (2011) identified that planning in advance was
necessary to ensure they had enjoyable healthy options available to avoid temptation
to have takeaway or less healthy options.

7.3.2 Routine

The women described having a routine as helpful in ensuring they carried out the
activities they saw as necessary in a manner consistent with their efforts to manage
their weight. The importance of developing a routine to incorporate new habits for
successful weight loss has been identified in studies of the perspectives of other groups
engaged in weight loss and weight loss maintenance efforts such as those at high risk
of cardiovascular disease (Gallagher, Kirkness, Armari, & Davidson, 2012), and
overweight and obese low income women (Parker & Keim, 2004). There were two
aspects of routine, eating regular meals and fitting exercise in.

Eating Regular Meals

The women in my study saw eating regular meals as important to them being able to
manage their food intake. Eating regular meals was seen as helpful in preventing binge
eating or unhealthy snacking as described by Abbie, ‘it keeps my energy levels up and
it stops me from having a food blowout’ (Abbie, Interview Three). In their review of
factors associated with weight loss and weight loss maintenance Elfhag and Rossner
(2005) found that making changes towards a more regular meal rhythm as helpful and regularly eating breakfast as more likely to be reported among weight loss maintainers. Similarly, in their study of women in menopause who had overweight or obesity, Kong et al (2012) found that skipping meals was associated with less weight loss at 12 months.

Breakfast was often identified as a meal that the women didn’t eat. Abbie said, ‘I hardly ever have breakfast. I know that’s really bad for weight loss’ (Abbie, Interview two). There was recognition however that eating breakfast would be helpful to their efforts to lose weight, through preventing them seeking snacks later. ‘I know I should be eating breakfast because that will help me lose weight because it will reduce the food cravings in the day’ (Abbie, Interview One). Danika had recently started eating breakfast on the recommendation of her dietitian,

I used to like get up in the morning and go till about three o’clock then have lunch and have dinner. The dietitian said that she wanted me to eat three meals a day. I mean I don’t do it every day but some days I’ll have breakfast, lunch and tea and feel a lot better with three meals (Danika, Interview One).

In our second interview Danika reported that she had been, ‘eating breakfast mostly every day’ and found that if she did this, ‘you don’t feel sort of ‘mmm’ at 10 o’clock’ (Danika, Interview two). Having regular meals was one of the specific strategies that supported their successful weight loss maintenance identified by the women in the study by Hindle and Carpenter (2011).

**Fitting Exercise In**

Routine was also seen as helpful for the women to ensure they managed to fit their exercise in. Finding time in their week to make this happen was identified as a challenge. Abbie talked about returning to TAFE in our third interview, ‘with exercise I don’t know when that is going to happen, because I probably won’t have much time’ (Abbie, Interview three). One strategy the women talked about for fitting exercise into their routine was identifying opportunities for incidental exercise, ‘maybe trying to increase my incidental exercise while I am at TAFE, so up and down the stairs and walking from TAFE to [shopping centre] at lunch time’ (Abbie, Interview three).
They talked about wanting to do this. Abbie described her ideal of, ‘Go(ing) for a walk in the morning and come home and do all my chores’ (Abbie, Interview two).

People with schizophrenia, in the study by Rastad et al. (2014) identified that having a schedule was a facilitator of their participation in physical activity. Similarly, participants in the qualitative study by Xiao, Baker, and Oyewumi (2012) who had been newly prescribed antipsychotic medications also identified establishing routines around diet and exercise as something they thought would be helpful for successful weight control.

7.3.3 Strategies

Strategies were primarily talked about in relation to the women managing their dietary intake, and more specifically to limiting their consumption of the foods that they saw as unhealthy and on which they were likely to binge. There were two main foci of these strategies, avoiding temptation, and managing cravings.

Avoiding Temptation

The first focus of the women’s strategies was to avoid situations in which they would be tempted to eat unhealthy foods or those foods on which they were more likely to binge. Having clear strategies for coping with daily temptations was a characteristic that distinguished weight loss maintainers from regainers in the study by Chambers and Swanson (2012). The women in my study achieved this at home by not buying those unhealthy foods when they were grocery shopping so that the only food at home was the healthy options. Mary stated, ‘I just don’t buy that sort of stuff because if it’s in the cupboard I eat it’ (Mary, Interview three). In order to make sure they didn’t purchase the foods that they didn’t want to have in the house the women employed a range of strategies in the supermarket. Elizabeth who also reported that, ‘when I do my groceries, like on the food side of things, I only buy the healthy stuff, nothing else’ (Elizabeth, Interview One), described how, ‘if there’s an aisle I’ve got to go through and there’s lots of fattening food, one thing I’ve told myself to do is just look straight ahead, keep going, and pretend it’s not there’ (Elizabeth, Interview One).
Others, like Nuela, described avoiding certain aisles in the supermarket altogether, ‘I don’t even go in to the chocolate aisle’ (Nuela, Interview three). Making sure that they planned to eat before they went to the supermarket was also identified as helpful in avoiding temptation while grocery shopping. Mary identified as one of her strategies, ‘don’t go shopping while you are hungry’ (Mary, Interview three). Karen also reported, ‘I find that eating lunch before I go shopping. That’s helpful. They say that. I’ve always done that. Don’t go shopping with an empty stomach (Karen, Interview two). Planning ahead and packing their lunch, or snacks to take with them when they went out was also a strategy to avoid temptation. Abbie described what happened when she didn’t take food,

Then if I’m out and about and I don’t have any – I didn’t pack food or lunch or anything like that. I’m tempted to go and indulge in take away or chocolate or whatever. Then when I get home in the afternoon I’m starving because I haven’t had much to eat for the whole day. Then I get stuck in to whatever is in the fridge (Abbie, Interview two).

Karen also described packing lunch to avoid temptations when out and about,

There’s this food court in [town]. It’s all you can eat and sometimes I’m tempted to go there and have lunch there and it’s Chinese and that’s a real disaster when I do that. So, if I pack my lunch I’m not tempted to do that (Karen, Interview three).

Similarly, Nuela stated, ‘I try and carry food with me so I can eat something before I get really hungry and want like a hamburger or something’ (Nuela, Interview two). The stimulus control type strategies described by the women in my study reflect a similar approach described by the women in Adams’ (2008) study of the processes used by women in menopause who had obesity engaged in a weight control program.

**Managing Cravings**

The women also discussed a range of strategies for dealing with what they described as cravings, for unhealthy foods. They described using self-talk to avoid giving in to their cravings. For some this was as simple as telling themselves no, ‘late at night quarter past one thinking I want to go to the shop and buy some chocolate biscuits, but then I just said no, no, no, no. I didn’t end up getting the chocolate biscuits’ (Danika, Interview one).
More often the self-talk involved reminding themselves of the consequences. To avoid over eating Karen described reminding herself of, ‘the uncomfortableness, and thinking I’ll feel uncomfortable’ (Karen, Interview two). To stop herself from buying sweets Nuela stated, ‘I know that if I eat them I wont just stop at one lolly, I’ll eat lots and then I’ll get really tired because of the diabetes and that feels really bad. So I just have to remember that I’ll feel bad if I eat it’ (Nuela, Interview three). Emily described resisting cravings by telling herself that, ‘You won’t fit into that nice dress in the wardrobe if you eat those’ (Emily, Interview one). Positive self-talk including self-encouragement and action steps was identified as a strategy employed by weight loss maintainers in the study by Reyes et al. (2012).

The women who took part in my study also described using distraction to avoid giving in to cravings. Elizabeth reported that, ‘I just stay out of the kitchen and do other things to keep my mind off being hungry’ (Elizabeth, Interview two). Emily found that, ‘if I put on a relaxation tape it takes my mind off my tummy’ (Emily, Interview two). She also found that being in company helped and commented in our second interview that, ‘I haven’t been hungry talking to you’ (Emily, Interview two).

There was a sense that on some occasions it was necessary to give in a little to their cravings. Abbie said, ‘If I have a craving that I need to give into, I’ll try to make it as little as possible’ (Abbie, Interview One). She saw this as a strategy to avoid more significant lapses,

I try to reduce the amount of times I give in to things that I know are not good for me. But then I know if I don’t have a little treat, I might go binge eating and eat vast amounts of food to fill whatever craving it is (Abbie, Interview one).

Isobel also described fulfilling cravings by just having a small amount and found that, ‘that sort of satisfies me. I’ve had a taste. I don’t need to eat the whole thing’ (Isobel, Interview One). Nuela articulated in more detail her thinking around this strategy of having,

A little bit of what you fancy, and then putting it into your head that you actually had it and that was the craving. It’s over now. You got it. If you’re still hungry you don’t need that one, you can go and eat a salad sandwich or something (Nuela, Interview three).
She described having implemented this the week before when she was feeling emotional and bought herself a block of chocolate and, ‘I ate a little bit of it and then folded down the rest of the packet and forgot about it. So I got rid of it’ (Nuela, Interview three).

This more flexible approach to eating self-regulation which allows for small lapses or splurges has been found to be associated with more success in weight loss and weight loss maintenance than a more rigid approach (Chambers & Swanson, 2012; Hindle & Carpenter, 2011; Reyes, et al., 2012). Teixeira et al. (2010) in their study of mediators of weight loss and weight loss maintenance in overweight and obese women found that while total restraint could be effective in achieving short term weight loss, more flexible dietary restraint was associated with more long term outcomes. Blouin et al. (2008) in their study of people taking second-generation antipsychotics found that those recently commenced on the medications showed a higher level of dietary restraint than in their general population comparison group, but that duration of treatment with the medication was associated with less restraint and increased weight. They suggested that this was because complete restraint was unsustainable and people who adopt that approach tend to overeat or binge when restrictions are lifted. They suggest that this points to the importance of early intervention in addressing the issue of weight management with people commenced on such medications in order to develop a sustainable approach.

7.4 Someone to do it with

The final factor that the women described as facilitating their ability to manage their weight was someone to do it with. The women talked about the value of having someone to do it with in three ways, to get me going, it’s a confidence thing, and helping me out.

7.4.1 To Get me Going

The first way the women described the value of having someone to do it with, was to get me going, which related to motivation, and was mostly described in relation to exercise. Elizabeth stated in our first interview, ‘I need someone just to get me going with the walking’ (Elizabeth, Interview One). Faith, whose cousin came to wake her in the
morning and went swimming with her several days per week described how having someone to do it with, ‘motivates you more’ (Faith, Interview one). Other studies have also found that women engaging in weight loss efforts find it beneficial to have others to exercise with. Low income women in the study by Weber Bucholz, Huffman and McKenna (2012) who had exercise ‘partners’ for a period of time had more success in adhering to their weight loss program and establishing a fitness routine. Similarly, the women in the study by Thomas et al. (2009) expressed a preference for a program they could enrol in as a pair and go through the process together. The people with SSD who took part in the study by Rastad et al. (2014) also found that having someone to go with facilitated their engagement in physical activity. There were two ways in which the women believed that having someone to do it with would help with their motivation which form the dimensions of this concept, accountability, and companionship.

**Accountability**

The first way the women described having someone to do it with helping their motivation for exercise was through a sense of accountability to the other person. In some cases this accountability came from the other person. Mary, in our first interview described finding it hard to initiate exercise but stated, ‘my parents help. They motivate me’ (Mary, Interview One). She went on to describe that this motivation was as simple as them saying, ‘come on, we’re going for a walk now’ (Mary, Interview one). Danika, who had lost a great deal of weight, described how her sister used to ‘push’ her to exercise by taking her to the gym and exercising alongside her, ‘we started an hour on the walking machine, the bicycle, the steppers and stuff like that and we would just talk and we’ll do this for another ten minutes’ (Danika, Interview one). Karen in our first interview stated that she thought, ‘it would help me if I had a personal trainer or someone who would motivate me’ (Karen, Interview One). More often though the women described how just knowing they had the arrangement with the other person, or group of people, would create in them the internal motivation to attend, as they would feel a sense of responsibility to the other person. Abbie, who walked for exercise on her own thought it would be helpful to be in a walking group,
It’s easy for me to say, oh, I don’t want to go for a walk today. Whereas if there’s a group of people going for a walk, we I’d be letting someone down if I didn’t go for a walk with them (Abbie, Interview two).

Similarly Karen in our first interview stated that, ‘it would be good to have someone to go with me’. She believed that if she had an arrangement to exercise with someone she would be more motivated to go because,

I wouldn’t want to lose face. They’d say, okay I’ll meet you there at a certain time or say, if they picked me up or whatever, you know, like I’d have to commit myself and I’m a person that has had commitments in my life and I usually stick to them (Karen, Interview one).

By the time of the second interview Karen had people that she exercised with two days a week. One day she would go swimming with her sister, and on another day she would walk and sometimes swim with a volunteer from ‘Compeer’ which is a program through which volunteers become friends with a person who has become socially isolated through mental illness. She described this as being helpful in assisting her to maintain a more regular routine of exercise, ‘Just motivation mostly, yeah, and not having – like it’s good that I’ve got people to do it with for two days. Because they - like I don’t want to lose face, yeah so’ (Karen, Interview two).

At the time of our third interview Mary had been attending a gym for about six months. She went with a friend and described the benefits to motivation as reciprocal, ‘someone to motivate you or- and then you can motivate them’ (Mary, Interview three). Participants in the study by Aschbrenner et al. (2012) identified one of the benefits of involving their family and friends in a healthy lifestyle program was making themselves accountable for attending the exercise sessions.

**Companionship**

The other way in which having someone to do it with helped with motivation for exercise was through the sense of companionship this afforded. The women in my study described how having someone to go added an additional enjoyable aspect of socialising to the exercise. Karen suggested, ‘like make it a social thing’ (Karen, Interview one). Mary in her third interview described the social aspect of the gym she attended as one of the attractions, ‘it’s a women’s only gym and the ladies are really
lovely there. I’ve met a lot of people through going there’ (Mary, Interview three). In
their exploration of exercise behaviours and preferences of people with SSDs, Bassillos,
Judd and Pattison (2014) found that the potential for social interaction was an incentive
for exercise activity. The social aspect of having someone to go with addressed some of
the challenges the women faced in doing their exercise. For some like Emily it was
about helping divert her attention from her worrying thoughts so she could engage in
the exercise, ‘plenty of company to get me out of my thought world’ (Emily, Interview
one). For others it was distraction from the exercise itself, which they did not find
intrinsically enjoyable. Gaye described,

Yeah, if I’m with someone else I still don’t like it but it’s better. I did it with my grand-daughter and
It’s an effort, but once I got going, well I enjoyed it because I don’t see so much of her. So I did
enjoy talking to her and stuff (Gaye, Interview one).

Similarly, Nuela described liking to have someone to go to the gym with because, ‘well
I feel really bored when I’m there and unless somebody’s talking to me and making me
forget what I am doing’ (Nuela, Interview three). And finally it helped overcome
anxiety or embarrassment they may feel about going alone. Nuela said, ‘it’s a bit scary
going to places sometimes by yourself so it would be alright turning up with someone
else’ (Nuela, Interview two).

The final aspect of companionship that the women described emanating from having
someone to do it with was supportive in that they were not on their own in their
weight loss endeavours. Abbie, who thought it would be good to have a walking
group made up of people accessing the community mental health service, suggested
that this would provide the opportunity of, ‘other people that I could chat to and sort
of share, you know, I’ve lost this much weight this month and that kind of thing. You
know, instead of just being me, yeah’ (Abbie, Interview One). Karen had a similar
suggestion of,

A kind of program where you can go and exercise together as mentally ill women and do an
exercise program together. I don’t know if there’s one going already, I don’t know. I seem to feel
like I am doing it all on my own sometimes, you know I haven’t got any support (Karen, Interview
one).
She went on to suggest something, ‘like Weight watchers but not so expensive’ (Karen, Interview one). Participants with high cardiovascular risk in the study by Gallagher et al. (2012), identified the exercising in a group with people with similar circumstances and goals motivated and encouraged them to continue with their weight loss efforts.

Similarly, participants with schizophrenia who were able to engage in a physical activity program through their community mental health team found that being with others with a similar mental illness, and the support of fellow participants made it easier to participate in the study by Johnstone, Nicol, Donaghy and Lawrie (2009).

Nuela also suggested some sort of supportive group where she could talk about what she had done in her weight loss efforts would be helpful. She suggested a small group and talked about both weight watchers and alcoholics anonymous as models for such a group that would involve also a sense of accountability, ‘when you’ve got that club then you can go to them and you’ve got them to answer to as well as yourself’ (Nuela, Interview two). Participants in the study by Xiao et al. (2012) also identified that having a peer, or family member or a group helped boost their motivation to initiate or maintain a healthier lifestyle. Participants in Hindle and Carpenter’s (2011) study identified support from family and friends as a key factor in their successful weight loss maintenance, this involved others also making lifestyle changes and in some cases joining them on their weight loss journeys.

7.4.2 Helping Me Out

The second way the women talked about the benefit of doing it with someone, was helping me out which generally pertained to activities associated with purchasing and preparing food. There were two dimensions to helping me out, which represented apparent differences in goals. Doing for me, was more compensatory and teaching me how, was more about remediation and supporting the woman to take increased responsibility for the task.

Doing for Me

Doing for me involved another person or persons taking on all or part of an activity and was usually described by the women in my study in relation to domestic tasks. Some of the women described particular times when others took on all or the majority of
these tasks for them. Mary, for example talked about this occurring when she was first unwell, she left university and went back to live with her parents, ‘I was living at home and I just had everything done for me at that time’ (Mary, Interview One). Emily had lived with her mother for many years after the breakdown of her marriage and described an arrangement where, ‘She did all of the cooking and I did a lot of the housework’ (Emily, Interview Two). Elizabeth and Emily had assistance from Homecare to do their household cleaning during their involvement in the study. ‘I do most of the jobs, like the small jobs on the day they come, and they do all the bigger jobs for me’ (Elizabeth, Interview two). Gaye was in the process of having this put in place, ‘Cause I can’t organise anything or get clean’ (Gaye, Interview One).

More commonly others took on part of an activity to support the women to manage some level of independence. This generally involved assistance with the planning aspects of tasks such as budgeting and shopping and/or transport. Elizabeth’s parents provided her assistance with managing her money,

> The good thing is that my parents help out with my budget. Mum does. She’s brilliant like that. If I did not have my parents to help with my budgeting now, I tell you now I wouldn’t have much money left-over for anything. I’m not very good at budgeting at the moment, or working out a budget’ (Elizabeth, Interview one).

She also had assistance from her case manager who constructed a shopping list template based on her usual purchasing so that she just needed to circle the things she needed on each occasion.

> She has got a shopping list on the computer for me. All I have to do is circle if there is something I need. If I don’t need it, I like to cross out the stuff that I don’t need. So I understand what I have to get and what I don’t have to get (Elizabeth, Interview two).

Nette’s case manager also provided her with a shopping list template, ‘and I just got to circle them because that suits me. Some things aren’t on it but it’s not too bad, you can just add them’ (Nette, Interview one). Her case manager also accompanied her to the supermarket and, ‘She usually walks with the calculator and I just throw it in. Then she says, well how much was that? Where did that come from? That’s more or less my shopping’ (Nette, Interview One).
For others, the person accompanying them on their shopping trip was primarily there to provide transport. Emily had transport for grocery shopping provided by a support worker from an NGO but did the actual shopping independently, ‘I do the shopping alone and she looks around the shops and that and then we meet at the front door so that’s quite alright’ (Emily, Interview One). Similarly, Faith’s cousin took her to do her grocery shopping but his assistance centred largely on providing transport and helping, ‘me carrying up the stairs’ (Faith, Interview One). Faith’s cousin also helped out with other tasks such as cooking meals for Faith and her father and, ‘helps out generally like in doing the washing and stuff like that’ (Faith, Interview two). Nuela also described assistance with transport as a key factor in helping her to manage the task of grocery shopping as she would like. She relied on her parents to drive her for tasks such as shopping which they then did collaboratively. She expressed a preference however for,

being driven to the shops, being told to buy everything that you think you need for the next three or four days and then be driven home by someone who is not going to boss me around and say, you should buy this one because I want that (Nuela, Interview one).

**Teaching Me How**

*Teaching me how* in some cases involved people doing similar aspects of tasks as in *doing for me*, but in such a way as to increase the women’s independence in tasks such that they would ultimately not require this assistance. Again this largely centred on activities related to obtaining and preparing food and addressed primarily the organisational aspects of these tasks. Abbie described this assistance as particularly helpful and had received it from her case manager in relation to a range of tasks, ‘I’ll come to her with my problems and say, look I have trouble writing a grocery list or budgeting or that kind of thing’ (Abbie, Interview two). Her case manager would do aspects of these tasks with and for Abbie but in such a way that the assistance was tapered back and Abbie was able to manage the tasks independently. Similarly her case manager had been doing some cooking with Abbie to support her to develop a selection of meals that she could cook independently rather than relying on take away or convenience food as she had in the past. Abbie was pleased with this intervention and reported in Interview three, ‘I’m learning to cook. I can do a stir-fry, which is a
good skill to have because I eat a lot of that, an omelette, and things like that. I’m doing better.’ Mary also described intervention from her case manager that involved, ‘go[ing] shopping with me and do a meal plan and a shopping list and that sort of thing’ (Mary, Interview One). The goal of this intervention was to help Mary to establish a more healthy diet through, ‘some healthy snack options that I haven’t thought of or some new recipes.’ (Mary, Interview one). Danika, while she stated that, ‘I pretty much knew how to cook all the time’ (Danika, Interview One), had also received support in developing her knowledge and skills during an extended stay in a psychiatric rehabilitation unit and then supported accommodation prior to her engagement in the study,

Pretty much [in hospital] was like we had our own room and there was five of us and we had to cook one night each. [Supported accommodation] pretty much I had to do cleaning every week, but [support worker] would come in and have a look and see if I cleaned alright. Pretty much bills and just stuff like that, organising money for groceries and bills and car fuel, stuff like that (Danika, Interview one).

Both Faith and Nuela expressed that they thought assistance like this would benefit them.

7.5 Summary

In this chapter I described the three categories of factors that the women had found, or thought would, facilitate their ability to carry out the activities they saw as necessary to managing their weight as described in the basic social process of *doing as much as I can*.

*Talking about it* was the first of the facilitating factors. The women described the value of having regular monitoring of their weight and the opportunity to regularly discuss their weight loss efforts in keeping it on their agenda and maintaining their motivation. As well as having regular opportunities to discuss their weight loss efforts the women described the importance of encouragement to maintaining their motivation and distinguished between *pushing encouragement* which could be helpful in prompting them to take action, and *praising encouragement* which was experienced as more positive and more helpful in the longer term. The final aspect of talking about it was the *education and advice* the women received which helped them with understanding
the detail of what they needed to do to address their weight and *practical suggestions* of how to apply this knowledge in their own lives. Crucial to the effectiveness of this advice and education was that it occurred in a context where the women felt listened to and understood.

*Having a plan* encompassed the second category of facilitating factors. The women described the benefits of planning tools such as *budgets, meal plans and shopping lists* in overcoming some of their difficulties in managing the tasks associated with obtaining food, thereby supporting their access to a reliable supply of the foods they saw as appropriate to managing their weight. Developing *routines* were also seen as important to establishing and maintaining habits around diet and exercise that were supportive of their ability to manage their weight. Finally the women described *strategies* to address challenges to these more healthy habits, in particular the temptation to eat more unhealthy foods.

*Having someone to do it with* was the final category of facilitating factors. The women described the value of social support, particularly in motivating them to engage in and maintain exercise regimes. Having someone to exercise with provided motivation, through the women feeling a sense of *accountability* to that person, as well as through providing the opportunity for *companionship* and the sense of being in it together. Doing it with someone also sometimes involved the other person *helping me out*, either by doing part of a task for the women which then enabled them to do other aspects, or through helping them develop skills and ultimately independence in tasks.

The factors that the women in my study identified as facilitating their ability to do the tasks in the categories of talking about it, having a plan and someone to do it with were consistent with factors identified as helpful in studies with similar populations, and also frequently identified as effective in outcome studies of weight loss or weight loss maintenance. As such they provide clear direction for developing interventions that are likely to be successful in addressing the *double-whammy* of weight gain that comes with diagnosis and treatment for SSDs. These directions will be further explored in the discussion chapter.
Chapter 8  Discussion

8.1 Overview of the Chapter

In this chapter I discuss the basic social problem of the *double-whammy* and the associated process of *doing as much as I can*, as a whole. I first position these findings in the context of existing theory by comparing the components to the principles of recovery and some of the health behaviour change theories more commonly employed in weight management programs. I then suggest a reframing of the issue of weight gain and obesity in women with SSDs including discussion of the value of seeing the *double-whammy* as ‘dual diagnosis’ and treating obesity as a chronic disease, especially when it co-occurs with another chronic illness such as a SSD. Based on the findings of my study and the discussion outlined above I then suggest seven principles that should characterise interventions to address weight gain and obesity in women with SSDs. Finally I discuss the implications for mental health services, and more specifically for occupational therapy.

8.2 Positioning in Relation to Other Theory

In this section I discuss the findings of my study in relation to recovery which is seen as the overarching theory guiding mental health service provision in Australia and internationally. I then compare the theory generated in my study with prevailing theories of health behaviour change used in weight management programs.

8.2.1 Recovery

There are many aspects of the way the women who participated in my study described their experiences of managing their weight that align with core principles of recovery. This is perhaps unsurprising given the women’s experience that significant weight gain came as a second whammy along with their diagnosis and treatment for their SSD and that their efforts to manage their weight occurred in the context of living with a SSD. As I discussed in chapter one (1.2.4) there is no universally accepted definition or description of recovery. There are however, several key characteristics that are reflected in most of the published frameworks, which are consistent with the findings of my study. These include, the conceptualisation of recovery as a non-linear process...
rather than an end point, and the importance of self-determination, engagement in everyday and valued activities and life roles, and supportive relationships (Andresen, et al., 2003; Davidson, 2005; Drake & Whitley, 2014).

The characterisation of recovery as a non-linear process rather than an outcome is reflected in the central process described in my study of the women, doing as much as I can, to manage their weight. The process of doing as much as I can describes a pattern of engagement with the various activities that the women deem necessary to managing their weight that fluctuates over time in response to a range of mediating factors. This reflects the findings of other research that recovery is non-linear. Sutton, Hocking and Smythe (2012) found that patterns of occupational engagement also fluctuated in recovery. Perhaps the most commonly cited account of the journey like nature of recovery is that of Deegan (1988) who described recovery as, “not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again” (p.15). The women who participated in my study also described starting to do it as something that happened more than once due to the challenges of sticking with it. This is perhaps best illustrated by Mary’s statement:

I seem to get motivation in waves and then it sort of fizzles off and then a couple of months later I’ll start again. It’s hard to be consistently good with food choices and exercise (Mary, Interview three).

Self-determination and related concepts such as choice, autonomy and self-agency are identified as critical in recovery models and frameworks (Andresen, et al., 2003; Australian Health Ministers Advisory Council, 2013; Davidson, 2005; Onken, Craig, Ridgway, Ralph, & Cook, 2007). Onken et al. (2007) highlight that because it is the person with the illness who recovers, it is they who need to decide the goals and the actions to take in pursuit of these goals. Similarly, the women in this study identified that their efforts to engage, and sustain engagement, in activities to manage their weight was most effective when the decision about starting to do it was their own. In addition, the contributions of others in assisting these efforts, particularly in relation to education and advice were perceived as most helpful when offered in an environment where the women felt listened to and understood, and in a way that was consistent with their own values and preferences.
Davidson, Rakfeldt and Strauss (2010) identify engagement in everyday but meaningful activities and roles as foundational to recovery. This is reflected in the review of autobiographical accounts of recovery by Drake and Whitley (2014) who also highlighted the importance of everyday activities, routines and normative life processes. The core process of doing as much as I can characterises the engagement in everyday activities that the women who took part in my study saw as being ‘the right things’ to do to manage their weight, doing exercise and managing their diet by cutting down and eating more healthy. While the women identified that managing their weight was their primary reasons for engaging in these activities, they also described benefits to their mental health, particularly of exercise, which gave them an additional reason to engage. This is reflected in statements such as from Mary when talking about going to the gym, ‘I think it’s helped with my mental health as well because I always feel a lot better when I walk out of there’ (Mary, Interview three). In addition the women described increased engagement in activities such as shopping for, planning and preparing meals as underpinning their ability to manage their diet in eating more healthy, and assistance to develop the skills required to perform these activities as facilitating factors.

While recovery is a personal journey, the importance of supportive relationships is emphasised both in individual accounts and published frameworks (Australian Health Ministers Advisory Council, 2013; Drake & Whitley, 2014). The role of others and the support they provide is a significant element of what the women in my study thought had, or would facilitate their ability to engage in activities they saw as necessary to managing their weight. Someone to do it with was one of three categories of facilitating factors and described three ways in which having a support person alongside them helped the women’s efforts. Having someone to do it with increased their motivation in getting me going and enabled them to do activities that they may have otherwise not been able to do either through teaching me how or doing for me components of those activities. Relationships were also central to a second category of facilitating factors, talking about it, which included the importance of having someone with whom they regularly discussed their efforts to manage their weight to keep it on the agenda, and also
the nature of the relationship that was a context for providing education and advice and encouragement.

8.2.2 Behaviour Change Theories Used in Weight Management

In a review of published obesity interventions with general population cohorts Sharma (2007) identified that the majority of studies involved programs that were atheoretical and suggested that programs should be based on behavioural theories. Much of the published research about weight loss programs with people with SSD also lacks theoretical underpinnings (Galletly & Murray, 2009). This has been identified as a potential explanation for the lack of long term benefit for participants, as the factors that motivate individuals to initiate and maintain behaviours conducive to weight loss are not considered (Powers, Koestner, & Gorin, 2008). Behaviour change theories that have been identified as useful in weight loss research in general population cohorts include, Transtheoretical Model of Health Behaviour Change, Social Cognitive Theory, and Self-Determination Theory. In this section I compare the tenets of the theory generated in my study with those of the above identified behaviour change theories.

Transtheoretical Model of Health Behaviour Change (TTM)

Perhaps the most widely used model of change for health behaviours is the Transtheoretical Model of Health Behaviour Change (TTM) (Prochaska, et al., 1992; Prochaska & Velicer, 1997). The TTM was first developed around intentional behaviour change in relation to addictive behaviours (Prochaska, et al., 1992). It is a stage based theory which comprises three core constructs: stages of change, processes of change and dependent outcomes (Bridle et al., 2005). The ‘stages of change’ construct suggests that change is not continual but occurs in a series of five stages; pre-contemplation, contemplation, preparation, action and maintenance, that are defined in terms of the attitudes, intentions and behaviours that are manifest (Prochaska, et al., 1992). The five stages and their definitions can be found in Table 8.1 below. The stages are seen to occur sequentially, although the model allows for the possibility of relapse and recycling (Prochaska, et al., 1992).
Table 8.1: Definitions of Stages of Change in the TTM (Prochaska, et al., 1992)

<table>
<thead>
<tr>
<th>Stage</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-contemplation</td>
<td>There is no intention to change in the foreseeable future. Individuals may be unaware or under-aware of the problem. May ‘wish’ to change but lack intent.</td>
</tr>
<tr>
<td>Contemplation</td>
<td>Aware that a problem exists and seriously thinking about addressing it but no commitment made to take action.</td>
</tr>
<tr>
<td>Preparation</td>
<td>Intending to take action in the next month, making some small changes and have unsuccessfully taken action in the previous year.</td>
</tr>
<tr>
<td>Action</td>
<td>Involves the most overt changes whereby individuals modify their behaviour, experiences or environment in order to overcome their problems and sustain this for between one day and six months.</td>
</tr>
<tr>
<td>Maintenance</td>
<td>Working to reduce relapse and consolidate the changes made during action.</td>
</tr>
</tbody>
</table>

Some elements of the various stages described in the stages of change construct are evident in the accounts of the women in my study of their experiences of managing their weight. For example in the pre-contemplation stage the individual may be unaware or under-aware of the problem. In my study the women talked about a lack of awareness of the potential for weight gain, or of how much weight they had gained in knowing the issue, which is a property of the mediating factor, knowing. Knowing the issue was largely described in relation to the early period of time following the women being diagnosed and treated for their illness and was described as a significant barrier to them taking action to manage their weight. There is some correlation between the stage of preparation in the stages of change construct and getting started, which is a sub-category of doing as much as I can and is characterised by the women deciding to act to address their weight. Similarly, sticking with it, also a sub-category of doing as much as I can, aligns well with the maintenance stage of change. The women in my study talked about the long term commitment required to manage their weight and the two broad elements of keeping going with the additional activities required such as doing exercise, and resisting temptation to engage in behaviours that are contrary to their goal such as eating comfort foods. The action stage of change can be seen in some of the accounts of the women in my study of doing the right things, a subcategory of doing as much as I can, in which the women described the actions they saw as necessary to managing their weight. In each of the properties of this category, doing exercise, cutting down, and eating more healthy, there were accounts by the women of times in which they were routinely engaging in these activities. While characteristics of many of the stages of change from the TTM are evident in the elements of doing as much as I can, the sequential pattern
suggested in the stages of change construct is less evident in the experiences described by the women in my study where change appeared to be much more of a fluid process.

A second construct in the TTM is that of processes of change, which describes actions or experiences that facilitate change, which may be undertaken by the individual spontaneously or foci of intervention for professionals. There are a total of ten processes, each of which include techniques that are drawn from a range of theoretical approaches (Prochaska, et al., 1992). Different processes are seen to be more relevant at different stages of change as illustrated in Figure 8.1 below. The TTM also suggests that the barriers to change are different at each stage and therefore that interventions should be targeted to a particular stage (Bridle, et al., 2005).

![Figure 8.1: Processes of Change from TTM (Prochaska, et al., 1992)](image)

Again there is some alignment between some of the processes of change outlined in the TTM and the mediating and facilitating factors that the women in my study identified in relation to managing their weight, see Table 8.2. However there were also some of the processes of change that did not align with concepts in my study, such as dramatic relief, environmental re-evaluation and social liberation. Similarly there were concepts in my study that were not accounted for by any of the change processes or which may superficially seem to be aligned but are qualitatively quite different. Someone to do it with, was one of the three categories of facilitating factors in my theory which is not accounted for in the change processes. While there is a process of ‘supporting relationships’ in the TTM this is more about having someone to discuss problems with.
rather than someone to engage in activities with. And finally, in line with the change process being more fluid rather than occurring in discreet stages for the women in my study, they did not tend to identify the various mediating and facilitating factors as being particularly relevant at specific stages.

Table 8.2: Alignment Between Processes of Change from TTM (Prochaska, et al., 1992) and Dealing with the Double-Whammy

<table>
<thead>
<tr>
<th>Processes of Change from Transtheoretical model</th>
<th>Corresponding concepts from ‘doing as much as I can’</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Consciousness raising</strong></td>
<td>Mediating factors</td>
</tr>
<tr>
<td>Increasing information about self and problem</td>
<td>Knowing</td>
</tr>
<tr>
<td></td>
<td>Knowing the issue</td>
</tr>
<tr>
<td><strong>Self-liberation</strong></td>
<td>Facilitating factors</td>
</tr>
<tr>
<td>Assessing how one feels and thinks about oneself with respect to the problem</td>
<td>Talking about it</td>
</tr>
<tr>
<td></td>
<td>Education and advice</td>
</tr>
<tr>
<td><strong>Counterconditioning</strong></td>
<td>Facilitating factors</td>
</tr>
<tr>
<td>Substituting alternatives to problem behaviours</td>
<td>Having a plan</td>
</tr>
<tr>
<td></td>
<td>Strategies (managing cravings)</td>
</tr>
<tr>
<td><strong>Stimulus control</strong></td>
<td>Facilitating factors</td>
</tr>
<tr>
<td>Avoiding or countering stimuli that lead to problem behaviours</td>
<td>Having a plan</td>
</tr>
<tr>
<td></td>
<td>Routine (eating regular meals)</td>
</tr>
<tr>
<td><strong>Reinforcement management</strong></td>
<td>Facilitating factors</td>
</tr>
<tr>
<td>Rewarding oneself or being rewarded by others for making changes</td>
<td>Talking about it</td>
</tr>
<tr>
<td></td>
<td>Encouragement (praising)</td>
</tr>
<tr>
<td><strong>Helping relationships</strong></td>
<td>Facilitating factors</td>
</tr>
<tr>
<td>Being open and trusting about problems with someone who cares</td>
<td>Talking about it</td>
</tr>
<tr>
<td></td>
<td>Education and advice (being listened to and understood)</td>
</tr>
<tr>
<td><strong>Dramatic relief</strong></td>
<td></td>
</tr>
<tr>
<td>Experiencing and expressing feelings about ones problems</td>
<td></td>
</tr>
<tr>
<td><strong>Environmental re-evaluation</strong></td>
<td></td>
</tr>
<tr>
<td>Assessing how ones problem affects the physical environment</td>
<td></td>
</tr>
<tr>
<td><strong>Social liberation</strong></td>
<td></td>
</tr>
<tr>
<td>Increasing available alternatives for non-problem behaviour in society</td>
<td></td>
</tr>
</tbody>
</table>
The third group of concepts in the TTM are labelled by Bridle et al. (2005) as intermediate and dependent outcomes and include pros and cons (or decisional balance), self-efficacy and temptations. Prochaska (2008) suggests that the decisional balance variables have clear and consistent relationships across the stages, where in pre-contemplation the cons outweigh the pros, in contemplation they are relatively even and from preparation on the pros outweigh the cons. This shift in decisional balance is seen as a critical factor in driving the behaviour change. This concept was not clearly recognisable in the accounts of the women in my study. They were quite clear about the potential benefits of addressing their weight and the factors that countered these ‘pros’ tended not to be ‘cons’ but more issues to do with lack of support, skills or resources. The concept of self–efficacy is adopted from the work of Bandura (1977), which is described in more depth below, and describes the level of confidence that the individual has that they can perform a behaviour (Spencer, Wharton, Moyle, & Adams, 2007). This concept is reflected in the mediating factors in my study. In each of knowing, mental health and wellbeing and practical issues the women describe the impact of these factors on their perceived ability to carry out the behaviours described in doing the right things. Finally, the concept of temptation describes the degree to which the person is tempted to lapse from their new healthy behaviour (Spencer, et al., 2007). This is accounted for in the properties of sticking with it. In much of the published work using the TTM the focus is largely on the pros and cons element of this part of the model with little attention given to self-efficacy.

While the TTM was originally developed to account for behaviour change around addictions it has since been applied to a range of health behaviours including diet and exercise (Bridle, et al., 2005) and to weight loss and obesity (Mastellos, Gunn, Felix, Car, & Majeed, 2014). There is some evidence for the effectiveness of TTM based interventions on weight loss (Johnson et al., 2008) and associated behaviours of diet and exercise (Mastellos, et al., 2014; Spencer, Adams, Malone, Roy, & Yost, 2006), although a number of systematic reviews have suggested that there is insufficient evidence to support stage based interventions for diet (Salmela, Poskiparta, Kasila, Vahasarja, & Vanhala, 2009; Spencer, et al., 2007). Bridle et al. (2005) suggest that this
lack of support may be due to fundamental differences between some health behaviours and the addictive behaviours for which the model was developed.

The TTM model has been used in studies with people with SSDs, both in relation to addiction and other health behaviours including those associated with weight management. Gorczynski, Faulkner, Greening, and Cohn (2010) and Bezyak, Bervan, and Chan (2011) both found correlations between TTM concepts and behaviour in relation to physical activity among people with schizophrenia and concluded that the model would be appropriate to structure interventions for this population. Bradshaw, Lovell, Bee, and Campbell (2010) found significant increases in reported physical activity and fruit and vegetable consumption following a trial of a health education program based on TTM for people living with schizophrenia. It is worth noting however that this study had significant limitations including possible recruitment bias, self-report of outcomes and not being a controlled trial.

**Social Cognitive Theory**

Social cognitive theory also includes a focus on decisional balance but introduces other elements that were important in my study, such as the role of knowledge and outcome expectations, in driving behaviour and a greater emphasis on the concept of self-efficacy. Social cognitive theory identifies a number of determinants of behaviour change including: knowledge, perceived self efficacy, outcome expectations, goals and the perceived facilitators and impediments to the desired behaviour changes (Bandura, 2004).

In social cognitive theory knowledge of the risks and benefits of different health behaviours is identified as a precondition for change (Bandura, 2004). Consistent with this, knowledge, or the lack thereof, is identified as one of the mediating factors affecting the ability of the women in my study to engage in the activities they saw as necessary to managing their weight. This included knowing the issue, which related to the women’s awareness of the potential for weight gain alongside their diagnosis and treatment for schizophrenia, and knowing what to do, which related to their knowledge of the guidelines for managing their diet and exercise. Knowledge itself however is not
sufficient and social cognitive theory identifies a range of self-influences that are necessary for the behaviour change to occur.

Self-efficacy is seen as central to the behaviour change process as it influences both the initiation of and persistence in maintaining new behaviours (Bandura, 1977). Self-efficacy is essentially the individual’s belief that they will be able to produce the desired behaviour change. Bandura (2004) argues that unless a person believes that they can produce the desired change by their action they are unlikely to act, or to persevere in the face of challenges. The central role of self-efficacy in mediating the relationship between knowledge and behaviour is evidenced by Rimal (2000) who examined both cross-sectional and longitudinal data from a study spanning five cities in America with several thousand participants. Rimal (2000) found that, in relation to diet, knowledge-behaviour correlations were higher in those with high self-efficacy, lower in those with lower self-efficacy and increases were found in the correlation over time for those who also increased their self-efficacy. This is reflected in the third subcategory of the mediating factor, knowing, in my study. Knowing how to do it reflects the women’s belief that their ability to effectively carry out tasks, particularly those related to obtaining and preparing food, mediated their ability to do the activities they saw as necessary to managing their weight. Self-efficacy is considered to be central not only because it affects health behaviour directly but also because of its impact on the other determinants such as the goals people set and the outcomes they expect to achieve (Bandura, 2004). The impact of self-efficacy beliefs on goals and expected outcomes, and the consequent influence of these factors on behaviour is evident in adjusting expectations which is a sub-category of doing as much as I can. Within this category the women describe adjusting their expectations both in terms of the goals they set, for example the weight they aim to reach, and in terms of the activities they will be able to undertake to achieve those goals. The women also discuss the importance of setting realistic goals to engaging and persisting with their efforts to manage their weight.

The final categories of determinants identified by social cognitive theory are the impediments individuals encounter to the changes they seek and the facilitators
available to overcome these impediments (Annesi, 2011; Bandura, 2004). The women in my study identified a range of potential barriers in the subcategories of doing as much as I can, and mediating factors. They also discussed three categories of facilitating factors they had found, or thought would enable them to overcome these barriers. While facilitating factors are accounted for in social cognitive theory it does not explicitly explore the factors that are identified as key by the women in this study. Social support is considered in social cognitive theory but only as a precursor to self-efficacy. A significant factor in the findings of my study that impacted on the women’s experience of trying to manage their weight and the support they received in relation to this was the degree to which they were in control and had choices that were respected. There is no clear correlation of this factor to any aspect of social cognitive theory.

Social cognitive theory and specifically self-efficacy theory have been found to explain why people may acquire and maintain health behaviours across a range of population groups. Of particular relevance to my study is its ability to explain changes in behaviour in relation to exercise (Allen, 2004; Dewar et al., 2013; Rogers et al., 2005) and diet (Anderson, Winett, & Wojcik, 2007; Anderson, Anderson, & Hurst, 2010; Lubans et al., 2012). Correlations have also been found between self-efficacy in relation to healthy eating, exercise and adiposity (Steele, Daratha, Bindler, & Power, 2011) and success in weight loss (Annesi & Whitaker, 2010). There is also some evidence for the effectiveness of weight loss programs based on social cognitive theory (Annesi, 2011).

Self efficacy has been identified as a limiting factor for people with schizophrenia in self management of their physical health (Schmutte et al., 2009), diabetes self management (Chen, Chien, Kang, Jeng, & Chang, 2014), and physical activity participation (Vancampfort et al., 2012). People with SSDs have also been found to have lower self-efficacy in relation to both maintaining a healthy diet and exercise than general population comparison groups (Leas & McCabe, 2007; Vancampfort, Probst, Sweers, et al., 2011). Leas (2007), found that self-efficacy was the single most important factor in determining intention to participate in physical activity among people with SSDs. There is also some evidence for the effectiveness of intervention programs for people with schizophrenia based on self-efficacy theory (Beebe et al., 2011; Beebe et al.,
2013). It is notable that many other theories of health behaviour change, including Self-Determination Theory, incorporate the concept of self-efficacy.

**Self Determination Theory**

The theory that most completely accounts for and is consistent with the findings of my study regarding the factors that impact on the motivation to carry out activities necessary for weight management is Self Determination Theory (SDT) (Deci & Ryan, 2000; Ryan & Deci, 2000). SDT is a meta-theory of motivation made up of sub theories, which together define intrinsic, various types of extrinsic motivation and the interplay between inherent needs and external forces that influence these. The first sub theory, Cognitive Evolution Theory (CET) defines intrinsic motivation as an inherent disposition to engage in activities to develop and use one’s capabilities to achieve internal and interpersonal integration and describes the conditions that support and diminish this tendency. Intrinsically motivated activities are those that are freely engaged in without the necessity of separable consequences (Deci & Ryan, 2000). It is recognised however that, as adults at least, much of what we do is externally rather than internally motivated. Another of the sub theories of SDT, Organismic Integration Theory (OIT), suggests a continuum of four levels of extrinsic motivation characterised by increasing degrees of internalisation resulting in more or less self-determination as illustrated in Figure 8.2, below.

<table>
<thead>
<tr>
<th>Amotivation</th>
<th>Extrinsic Motivation</th>
<th>Intrinsic Motivation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>External Regulation</td>
<td>Introjection</td>
</tr>
<tr>
<td>Behaviour controlled by external contingencies</td>
<td>Individuals maintain external regulation</td>
<td>Recognise and accept value of the behaviour</td>
</tr>
</tbody>
</table>

Internalisation Non Self-determination \(\rightarrow\) Self-determination

**Figure 8.2: Extrinsic Motivation Characterising Degrees of Self-determination (Deci & Ryan, 2000)**
Internalisation is described as the process by which the individuals assimilate formally external regulations. Greater degrees of internalisation are associated with more likelihood of the behaviour being maintained and with better performance. This is reflective of the concept deciding to act, which was one of two factors in the category of starting to do it in the process of doing as much as I can in my study. The women described starting to take action to address their weight on many occasions, often at the behest of others but believed that their efforts were more sustained and effective when they owned the decision themselves.

A further sub-theory, the Basic Psychological Needs Theory (BPNT) argues that there are three intrinsic psychological needs, for autonomy, competence and relatedness, which are essential for psychological growth and wellbeing. The degree to which individuals are able to internalise previously external regulations is seen as a function of how well these basic psychological needs are being met when they engage in the behaviour. Efforts to facilitate integration of extrinsic motivation also rest on addressing these three needs through autonomy support, structure and involvement respectively. The psychological needs of autonomy, competence and relatedness and the facilitation through autonomy support, structure and involvement account for all of the factors that the women in my study identified as mediating and facilitating their ability to engage in the process of doing as much as I can to manage their weight. See Table 8.3 for correlation of factors.

Autonomy refers to the need to be able to make decisions about how one is going to act and to act in a way that is coherent with one’s own values and sense of self. For integration to occur the individual needs to be able to freely process the regulation and modify it if necessary. Thus to support integration, autonomy support is required. This involves the promotion of choice, being responsive to the individual’s feelings and thoughts and positive feedback regarding progress. This is reflected in dimensions of two of the properties of talking about it, which was one of three categories of facilitating factors identified in my study. In education and advice the women discussed the importance of being listened to and understood and that the person giving the advice understood their preferences and offered advice in accordance with this – thereby
enabling them to act in a way that was consistent with their sense of self. This was illustrated by Abbie’s comparison between the unhelpful advice from a dietitian who did not recognise that she didn’t like ‘the regimented thing of counting calories or counting grams of this and that’ and ‘suggested that I measure 100 grams of protein per meal’ (Abbie, Interview one), and the more helpful dietitian who ‘understands me and how I am about food’ and ‘gives me guidelines to say a portion of meat is about this big (demonstrates with her hands)’ (Abbie, Interview three).

Table 8.3: Correlation of Factors in BPNT and Dealing with the Double Whammy

<table>
<thead>
<tr>
<th>Basic Psychological Needs and Facilitators From BPNT</th>
<th>Corresponding Concepts from Doing as Much as I Can</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category</strong></td>
<td><strong>Sub-category</strong></td>
</tr>
<tr>
<td><strong>Autonomy</strong></td>
<td>Doing as much as I can</td>
</tr>
<tr>
<td>Ability to make decisions and act in a way that aligns with sense of self</td>
<td></td>
</tr>
<tr>
<td><strong>Autonomy Support</strong></td>
<td>Facilitating factors</td>
</tr>
<tr>
<td>Includes promotion of choice, responsiveness to feelings and thoughts and positive feedback regarding progress</td>
<td>Encouragement</td>
</tr>
<tr>
<td><strong>Competence</strong></td>
<td>Mediating factors</td>
</tr>
<tr>
<td>Understanding the reasoning behind and perceptions regarding ability to enact regulations</td>
<td>Knowing what to do</td>
</tr>
<tr>
<td></td>
<td>Practical considerations</td>
</tr>
<tr>
<td></td>
<td>Mental health and Wellbeing</td>
</tr>
<tr>
<td><strong>Structure</strong></td>
<td>Facilitating factors</td>
</tr>
<tr>
<td>Provision of optimally challenging tasks and assistance to form realistic goals</td>
<td>Having a plan</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relatedness</strong></td>
<td>Facilitating factors</td>
</tr>
<tr>
<td>Feeling connected in supportive relationships</td>
<td></td>
</tr>
<tr>
<td><strong>Involvement</strong></td>
<td>Facilitating factors</td>
</tr>
<tr>
<td>Interest in day to day pursuits and physical time</td>
<td></td>
</tr>
</tbody>
</table>
In encouragement the women differentiated between pushing encouragement and praising encouragement. Pushing encouragement focused on what hadn’t been, or still needed to be done, which although it had some effect in initiating action, was less motivating in the long term. Praising encouragement however, focused on the steps they had already taken and what they had achieved and the women perceived this as more motivating. The two categories of encouragement described by the participants in my study, above, are broadly reflective of the distinction between autonomy support and directive support (Gorin, Powers, Koestner, Wing, & Raynor, 2014). Autonomy support involves acknowledging the individuals perspective, providing choice and informational positive feedback, and avoiding excessive control and pressure. The distinction between autonomy support and directive support has been validated in studies by Koestner, Powers, Carbonneau, Milyavskaya and Chua (2012) and Gorin et al. (2014).

Weight loss studies have demonstrated that autonomy support is much more effective in facilitating weight loss progress than directive support, both when the support is provided by health professionals, and by family and friends (Gorin, et al., 2014; Koestner, et al., 2012; Powers, et al., 2008). A number of studies have found that autonomy support from professionals and significant others is associated with greater need satisfaction and autonomous motivation which are in turn associated with more healthy eating and exercise behaviour (Edmunds, Ntoumanis, & Duda, 2006; Ng, Ntoumanis, & Thogersen-Ntoumani, 2014; Rouse, Ntoumanis, Duda, Jolly, & Williams, 2011).

Competence refers to the person’s ability to understand the reasons behind the behaviours and the ability to enact these. So, people are more likely to integrate behaviours if they understand and can therefore assimilate the reasoning behind them and they are confident in their abilities to carry out component tasks and achieve the desired outcome. Competence is facilitated via structure, which includes the provision of optimally challenging tasks, assistance to formulate realistic goals and positive feedback on performance. This is reflected in the various properties of the mediating category knowing, as well as in the facilitating factors, having a plan and someone to do it with. The women described how different types of knowing, which mediated their ability to manage their weight. Firstly in knowing the issue the women identified that
not being aware of their potential risk for weight gain meant that they were less likely
to take actions to prevent it. Their degree of knowing what to do, particularly the practical
knowledge of how to apply guidelines for healthy eating and exercise in their day-to-
day lives, was also a factor in their perceived ability to act. And finally the women
described varying degrees of perceived competence in knowing how to carry out
activities associated with purchasing and preparing food. In having a plan the women
described a range of ways the plans contributed to their perceived competence in tasks
associated with managing their weight such as the use of budgets, meal plans and
shopping lists to help in carrying out activities associated with obtaining and preparing
food, routines to aid their ability to eat and exercise regularly and strategies to increase
their perceived ability to overcome challenges. Finally, in helping me out, a property of
someone to do it with, the women described the benefits of being taught new skills and
strategies on increasing their perceived ability to carry out the activities associated with
managing their weight.

Relatedness refers to the desire to feel connected with others in supportive
relationships. This need is directly facilitated by involvement, which includes ‘display
of support resources’ such as physical time and an interest in the person’s day-to-day
pursuits. This is reflected in the emphasis regarding the relationship that needed to be
present for education and advice to be effective. In keeping it on the agenda the women
described how having someone who took an interest in their weight loss efforts and
discussed it regularly with them helped with their motivation. Finally, in someone to do
it with they talked about how having someone do go with them, particularly for
exercise, helped their motivation. In the property to get me going they described the
motivating factors both of being accountable to the other person, and also the
companionship.

With optimal need satisfaction the individual may achieve integration to the degree
that there is autonomous regulation, which is considered important for optimum
behaviour change.

There is a growing body of evidence supporting the assertion within SDT that optimal
need satisfaction is associated with more autonomous regulation, which in turn is
supportive of changing and maintaining change in exercise and diet behaviour. Springer, Lamborn and Pollard (2013) found that satisfaction of the needs for autonomy, competence and relatedness were core to the establishment of being active and fit as part of the sense of self among individuals who maintained engagement in physical activity at the recommended levels. These findings are borne out in a systematic review of 66 empirical studies, that found consistent support for a positive association between more autonomous motivation and competence satisfaction and exercise participation (Teixeira, Carraca, Markland, Silva, & Ryan, 2012). Similarly in a review of the literature related to diet, Teixeira, Patrick and Reid (2011) found that autonomous motivation was associated with healthier eating patterns. This finding was also supported in a national survey of women conducted by Leong, Madden, Gray and Horwath (2012). Further, Pelletier, Dion, Slovinec-D’Angelo, and Reid (2004) found sustained dietary changes over a 26 week period was predicted by self-determination in a population at risk of coronary artery disease.

There is a small but growing body of research suggesting that programs informed by self-determination theory are effective in supporting weight loss and weight loss maintenance, and associated behaviours such as exercise participation. Gourlan, Sarrazin and Trouilloud (2013) used motivational interviewing in a self-determination theory framework to address physical activity participation in obese adolescents over a six month period. Those who had the experimental intervention reported greater autonomy support, greater increase in integrated and identified regulation and achieved greater increases in physical activity and reduction in BMI than the control group. Silva et al. (2010) in their randomised controlled trial of a 12 month weight loss program for women, underpinned by self-determination theory found that the experimental group had higher weight loss and levels of physical activity at the 12 month point and that the larger effect sizes were associated with perceptions of a more autonomous supportive environment and higher levels of autonomous self-regulation. Follow-up showed significant treatment effects on autonomous regulation and physical activity at two years and weight change at three years (Silva, et al., 2011).
Research has emerged in recent years supporting the applicability of self-determination theory for people with schizophrenia. The focus has largely been on the potential to explain and provide a framework for addressing motivational deficits associated with schizophrenia (Gard et al., 2014; Medalia & Brekke, 2010). However Vancampfort et al. (2013) found significant positive correlations between physical activity participation and amotivation, external regulation and autonomous regulation in a study of 129 people with schizophrenia. They concluded that self-determination may play an important role in adoption and maintenance of health promoting behaviours in this population (Vancampfort, et al., 2013). This suggestion is supported by the findings of Sorensen (2006) who found that among their participants, who included both inpatients and outpatients with SSD, intrinsically related motives gave an odds ratio of 2.0 for being active rather than inactive. The potential value of SDT with this population is further supported by the findings of Choi and Medalia (2010) that a cognitive remediation program underpinned by SDT resulted in greater learning of material, higher levels of motivation to attempt demanding tasks, greater perceived self-competency to learn and increased levels of participation.

8.3 Reframing the Issue of Weight Gain and Obesity in People with SSDs

8.3.1 ‘Double Whammy’ as ‘Dual-Diagnosis’

The findings of my study, together with existing research in the field provide strong support for viewing weight gain and obesity and SSDs as ‘dual-diagnosis’. The term dual-diagnosis refers to the co-occurrence of two health conditions but is generally recognised as referring to individuals who have both mental health and substance misuse disorders (Guest & Holland, 2011). The women who took part in my study described the co-occurrence of SSDs and weight gain resulting in overweight and obesity. As described in the basic social problem, they see the weight gain as a second ‘whammy’ that came with their diagnosis and treatment for SSDs. There are striking similarities between the co-occurrence of mental health and substance misuse and the co-occurrence of SSDs and weight gain and obesity as described by the women in my study. These similarities suggest that the principles of providing intervention in dual-
diagnosis (mental health and substance use disorders), may well translate to providing intervention for co-occurring SSDs and weight gain and obesity.

The first similarity is that in both cases there are a large proportion of people with mental illness who also have the co-occurring disorder. Canaway and Merkes (2010) in their discussion of the conceptual and practical issues associated with comorbidity service provision suggest that co-occurrence of mental health and substance use disorders is now recognised as the expectation rather than the exception. High rates of co-occurring mental illness are found in those accessing drug and alcohol services (Cole & Sacks, 2008). Likewise high rates of drug and alcohol use are reported among those with mental illness. Approximately half of the respondents in the recent national survey of high impact psychosis reported lifetime history of abuse or dependence on alcohol and the same proportion for illicit drugs (Morgan, et al., 2012). Similarly high levels of co-occurrence are reported for SSDs and overweight and obesity. Again from the national survey of psychosis, 46.4% of respondents were obese according to their BMI and 82% had abdominal obesity (Galletly, et al., 2012).

Many of the aetiological perspectives that have been used to explain the relationship between mental illness and substance misuse would also appear to apply to SSDs and weight gain and obesity. In particular the ‘self medication hypothesis’ and ‘multiple risk factor model’ outlined by Guest and Holland (2011) appear to fit with the experiences of the women who took part in my study. The ‘self-medication hypothesis’ suggests that individuals select substances that produce a desired effect to medicate or relieve distress (Khantzian, 1985, 1997). The women in my study described using food, and in particular ‘comfort foods’ which were generally high in fat and sugar, to alleviate distress associated with their illness. They described comfort eating in particular in the early period following diagnosis, and also in response to ongoing fluctuations in mood or other symptoms. They saw this comfort eating as making a large contribution to their weight gain which is consistent with the identification of comfort eating, or emotional eating as the most significant lifestyle factor in weight gain and obesity in general population samples (Koenders & van Strien, 2011). The multiple risk factor model (Guest & Holland, 2011) also fits with the accounts of the
women in my study who reported a range of factors that affected their ability to manage their weight which are recognised risk factors for overweight and obesity. These factors included some that apply to members of the general population such as being on limited income and having limited awareness of the issue and how to address it. Others were specific to people with SSDs, such as the weight gain side effects of the medications used to treat their illness.

Regardless of the chronology and aetiology, the co-occurrence of disorders brings with it added complexity both in terms of the impact of each disorder and it’s treatment (Canaway & Merkes, 2010; Sterling, Chi, & Hinman, 2011). As well as potentially stemming from self-medication to address symptoms and distress associated with mental illness, substance misuse can also exacerbate mental health problems and lead to a range of other negative outcomes (Sterling, et al., 2011; Torrey et al., 2002). Similarly the women who took part in my study also believed that while it stemmed from their mental illness and its treatment, their weight gain and resulting overweight and obesity also had a negative impact on their mental health. In particular they identified a negative impact on their self-esteem and mood, which is reflected in the findings of studies of people with obesity in the general population linking overweight and obesity with poorer mental health outcomes (Kasen, et al., 2008; Thomas, Hyde, Karunaratne, Kausman, et al., 2008). In addition obesity is associated with poorer physical health and reduced functional capacity including reduced cognitive function which may serve to further exacerbate the disability experienced by people living with SSD (Capodaglio, et al., 2013; Galletly, et al., 2012; Strassnig & Harvey, 2013). Again this was reflected in the perceptions of the women in my study who believed that their weight gain had already, or would lead to them developing health problems such as diabetes, and experiencing difficulties completing activities due to fatigue, shortness of breath and physical discomfort.

**8.3.2 Treating Obesity as a Chronic Disease**

Related to the conceptualisation of SSD and weight gain and obesity as ‘dual-diagnosis’, is an argument for treating obesity, at least in this population, as a chronic disease. Despite the fact that it is listed in the ICD-10 (World Health Organisation,
there is much debate as to whether obesity is, or should be, recognised as a disease. In a review commissioned by the Council of the Obesity Society in America, Allison et al. (2008) argue that it is not possible to make a scientific determination as to whether obesity is a disease due to the lack of a clear and universally recognised definition of what a disease is. Obesity has since been declared a disease in the United States of America (Wirestone, 2013) but is not, at the time of writing this thesis, recognised as such in Australia. The benefits of recognising obesity as a disease are identified as including, an imperative to develop more effective interventions and associated with this greater funding for research, greater access to interventions, and decreased stigma and discrimination (Allison, et al., 2008; Beal, 2013; Wirestone, 2013). Allison et al (2008) also suggest that the recognition of obesity as a disease may also lead to more health professionals regarding its treatment as worthy of “effort and respect” (p.1161), which may go some way to addressing the issue of allocation of time and resources which I discuss further in section 5.3 of this chapter.

In addition to the recognition of obesity as a disease, recognition of the chronic nature of obesity would be of benefit. Obesity was described as a chronic disease in the World Health Organisation Technical Report, Preventing and Managing the Global Epidemic (World Health Organisation, 2000). Mauro, Taylor, Wharton and Sharma (2008) argue that obesity is a chronic and progressive condition, citing the fact that few people with obesity succeed in maintaining a healthy weight in the long term, and that lack of recognition of this chronicity is one of the key barriers to effective intervention. While there is limited reporting of long term outcomes of weight loss programs, reviews of research where this is supported suggest that only 20% of people maintain weight loss at one year (Wing & Phelan, 2005). The women who took part in my study described a range of challenges to maintaining their weight loss efforts, which meant that they were often starting to do it, over again. The ups and downs in their mental health were a significant mediating factor to their ability to maintain these weight loss efforts. For many people diagnosed with SSD the prognosis is one of fluctuating levels of symptoms over their lifetime (American Psychiatric Association, 2013). Given the ‘dual-diagnosis’ nature of the relationship between weight gain and obesity and SSDs
described above, it would follow that, in this population there is even more reason for obesity to be treated as a long term condition, or chronic disease.

8.4 Essential Characteristics of Intervention Programs to Help Women with SSDs Manage their Weight

The findings of my study, reported in chapters four to seven, and the discussion above, suggest a number of factors that should characterise intervention designed to support women living with SSDs to manage their weight. In this section I discuss seven principles that should characterise interventions to address weight gain and obesity in women with SSDs. These include that they: be integrated with intervention for mental health, commence concurrently with treatment for SSDs, be long term, be flexible and individualised, support competence in associated activities, address environmental and contextual factors and happen in the context of supportive relationships.

8.4.1 Be Integrated with Intervention for Mental Health

The recognition of the double-whammy as ‘dual-diagnosis’ suggests that the integrated approach to service provision, which is the preferred contemporary treatment model for people with co-existing mental health and substance use problems should also be adopted for SSD and overweight and obesity. An integrated approach means that interventions are combined at the level of the clinical interaction and are co-ordinated or provided by a single individual or team of health care professionals to treat both disorders in the same setting (Drake et al., 2001; Manley, 2005). The rationale for integrated rather than separate services for dual-diagnosis addresses three key factors, all of which have salience for SSDs and weight gain and obesity.

The first of these factors is access. The historical separation of mental health and substance use services has been found to result in individuals being denied access to one service until they have had the other disorder treated in the appropriate service, or in the co-existing problem being ignored or left untreated (Sterling, et al., 2011). Similarly, people with mental illness tend not to seek general health care and when they do, general health care professionals may over attribute symptoms to mental illness or underestimate their ability to intervene with unhealthy behaviour such as lack of appropriate diet and exercise (Ronis, 2008). Conversely, recognition and
The treatment of physical health problems in those accessing mental health services is less than optimal (Ronis, 2008). When individuals are able to access services for both disorders the difficulties involved in navigating two systems and co-ordinating their own care can prove challenging, particularly for those with cognitive or functional impairment, which is often present in SSDs (Drake, et al., 2001; Sterling, et al., 2011).

The second factor is the impact of mental illness and associated disabilities on the individual’s ability to engage with and achieve optimum outcome from programs designed to address the co-existing disorder. Co-occurring mental illness has been found to be associated with difficulties engaging with and achieving outcomes from substance misuse services (Manley, 2005). Similar issues may impact the ability of people with SSD to engage in and achieve desired results from lifestyle based weight management programs. Strassnig and Harvey (2013) suggest for instance, that the cognitive limitations of many people with schizophrenia may impact on their ability to effectively engage in standard weight loss interventions. In integrated services interventions are not only combined but in many cases modified to meet the needs of the particular client group (Drake, et al., 2001).

The final factor is the impact of each disorder on the other, and the potential for intervention for one to impact positively on the other. Strassnig and Harvey (2013) argue for integration of the treatment of cognitive deficits related to schizophrenia and interventions aimed at poor physical health on the basis that the treatment for each of these conditions has been shown to impact on the other, i.e. improved diet and exercise can improve cognitive functioning and improved cognitive functioning can improve the individuals ability to self manage around diet and exercise (Strassnig & Harvey, 2013).

### 8.4.2 Commence Concurrently with Treatment for SSDs

The finding from my study that the most rapid and dramatic weight gain occurs in the first weeks and months following the commencement of medication to treat SSDs is supported by other studies measuring the weight gain associated with antipsychotic medications (Addington, et al., 2003; Tarricone, et al., 2008; Wetterling, 2001), and mood stabilisers (Torrent, et al., 2008). It is logical therefore that efforts to prevent this
weight gain should commence concurrently with starting pharmacological treatment for SSDs. The Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of schizophrenia and related disorders identifies patients and families being fully informed of the benefits and risks of drug therapy as good practice, (McGorry, 2004). There is however no indication in the guidelines of what it takes for people to be ‘fully informed’. While it is possible that the women in this study were told about the side effect of weight gain this was not done in a way that enabled them to retain and act on this information in a timely manner. As I described in Section 2.1 of Chapter 6 many of the women did not recall being given this information. While in a few cases they were adamant that they had not been told, mostly they stated that they were simply not in a position to take the information in as it was offered or to act on it at that time without support. In a meta-analysis of self-management education programs for schizophrenia Zou et al. (2013) found that participants receiving more than ten sessions gained more benefit than those receiving ten or less sessions in terms of relapse and rehospitalisation and suggest that relatively limited amount of education was insufficient. It would therefore follow, that for people to be fully informed about their medication, its side effects and the actions required to manage these would require a more intensive approach than simply telling them in the context of a consultation, and that ongoing intervention, including but not limited to providing information, should begin at this time.

8.4.3 Be Long Term

The recognition of obesity as a chronic condition suggests a need for intervention over the long term, as is the case with other chronic conditions (Mauro, et al., 2008). Ongoing and regular support was identified by the women who took part in my study as a factor that had, or they thought would, facilitate their ability to maintain their actions to manage their weight via the process of keeping it on the agenda. The perception of the importance of long-term support is reflected in the findings of other qualitative studies of the experiences of people trying to lose weight or maintain weight loss (Bidgood & Buckroyd, 2004; Reyes, et al., 2012; Thomas, Hyde, Karunaratne, Kausman, et al., 2008). It is also supported by the findings of systematic reviews of factors associated with success of weight loss programs. In their review of
factors associated with weight loss and maintenance, Elfhag and Rossner (2005) found that prolonged treatment interventions and continuous professional support improved outcomes. Powell, Calvin and Calvin (2007) found that interventions that were effective in achieving sustained weight loss over two or more years “never stopped” (p.243), keeping treatments going for the duration of the follow-up, albeit often at reduced intensity. The evidence also supports the suggestion by the women who took part in my study that the support needs to be provided regularly and reasonably frequently. In their systematic review and phenomenological observation Perry, Hickson and Thomas (2011) found that one of the factors that distinguished successful weight management programs was frequent (weekly) follow-up and their recommendations included the provision of continuous regular support. The findings from the randomised controlled trial of weight loss maintenance by Svetkey et al. (2008) endorse the importance of ongoing follow-up but also the importance of this follow-up being provided in person. In their sample of adults with overweight and obesity, who were monitored over 30 months following the completion of a weight loss program, it was found that those who had personal (phone) contact, regained significantly less weight than those assigned to self directed and interactive technology based options (Svetkey, et al., 2008). The need for ongoing support, as well as for this support to be frequent, is also upheld by the findings of Centorrino et al. (2006) in their trial of a weight loss program for people with chronic psychotic illnesses and obesity. The program involved 24 weeks of intensive, twice weekly, support, followed by a further 24 weeks of less intensive support. They found that the weight loss was much higher in the first 24 weeks with more intensive support. But also, in the second 24 weeks those people who attended weekly continued to lose weight while those who came less often did not (Centorrino, et al., 2006).

The adoption of a long-term approach to addressing the challenges associated with weight gain and obesity for women with SSDs would also fit well with the Recovery approach in mental health. As I discussed earlier in this chapter (Section 8.2.1) the experiences of the women who took part in my study indicated that managing their weight was very much a journey, with ups and downs, reflective of the process of recovery in mental health. As with recovery in mental health, the focus was not on
achieving a defined end point, marked for instance by achieving a particular weight, but by doing as much as I can, at any point in the journey to be engaging in the actions supportive of managing their weight.

8.4.4 Be Flexible and Individualised

Interventions also need to be flexible to adjust to the ups and downs on the women’s journey of managing their weight. As I described in Chapter six, the women’s ability to manage their weight and their perceived needs in terms of support to do this, varied in relation to the mediating factors of knowing, mental health and wellbeing, and practical considerations. Intervention then needs to be able to be flexible to respond to these changing needs.

As well as having flexibility to accommodate for the fluctuations in an individual’s circumstances and needs, they should also actively accommodate variations between individuals. As I described in Chapter five, the women who took part in my study described being more successful in their weight loss efforts when the decision to act was their own. While there are approaches designed to support people to move towards making the decision to take action, these need to be able to accommodate to individual goals and priorities. For the women who took part in my study, deciding to act followed them reaching the limit. The specific nature of this limit however was different for different women. Huisman, Macs, De Gucht, Chatrou, and Haak (2010) found in a clinical trial of a weight loss program for people who had type II diabetes and obesity, that the only significant predictor of participants dropping out was the degree of ‘goal ownership’.

The women also described being more likely to engage with support when they felt heard and understood, and more likely to persist with actions when these were consistent with their own values and preferences. As discussed in section 9.2.2 this is consistent with the autonomy supportive approach suggested in SDT, which has been found to correlate with more autonomous motivation and in turn with healthier eating and more exercise behaviour (Edmunds, et al., 2006; Ng, et al., 2014; Rouse, et al., 2011). It is also consistent with the recovery approach in mental health, which emphasises
choice and the persons ability to live in accordance with their own goals and preferences (Davidson & Roe, 2007).

8.4.5 Support Competence in Associated Activities
The women’s awareness and confidence in their understanding of information about what they needed to do to manage their weight, and their perceived competence in carrying out these tasks, were key factors in their perceptions regarding their ability to do what they saw as necessary to manage their weight. This reflects the psychological need for competence identified in SDT and suggests a need to make sure that people with SSDs have information that is tailored to their needs, and support in knowing how to translate this information into practice, such as through skills training in associated tasks like meal preparation.

8.4.6 Address Environmental and Contextual Factors
As well as their own sense of competence the women described their ability to carry out the tasks they saw as necessary to managing their weight being impacted by environmental factors such as limited incomes, the facilities and resources available in their local areas and the other demands on their time and personal resources. Interventions to support weight management in this population need to consider these environmental and contextual factors and accommodate for them. For example, interventions to increase competence in meal preparation should consider the cost and availability of ingredients to make sure that these are accessible to participants. These interventions may also include guidance around sourcing healthy options at reduced cost. Interventions to support physical activity participation also need to consider cost. There is, for example, little value in providing a structured exercise option in a gym as part of the intervention program if this program is time limited and participants will no longer be able to afford to access the gym after completing the program.

8.4.7 Happen in the Context of Supportive Relationships
While each woman’s journey with managing her weight was individual, they all identified the important role that other people played, or could play, in helping them along their journey. Interpersonal support has been found to be a key factor in
supporting weight loss (Cho, et al., 2014) and in recovery for people with mental illness (Drake & Whitley, 2014). The women who participated in my study talked about the importance of having someone who took an interest in their efforts to manage their weight and with whom they could discuss this on a regular basis in keeping it on the agenda. That person, or perhaps another played a role in providing education and advice. And finally there was the value of having someone to do things with, either to support their motivation, help them develop skills or confidence, or to do aspects of the activity that they couldn’t manage to enable their participation. At various times, or for different people, these support people might be health professionals such as their mental health case manager or their GP, support workers from non-government organisations, family or friends.

Whether the person was a professional, friend or family members the quality of the relationship, and the way in which the support was offered was important. The women in my study talked about the importance of being listened to and understood, and of encouragement that recognised their efforts rather than focusing on what was yet to be achieved. These characteristics are consistent with autonomy supportive relationships in SDT as described above. Social isolation and strained relationships are commonly associated with people living with SSDs. In the light of this there may be a need to facilitate the development of new relationships, or provide some guidance to existing family members or friends so that there are supportive relationships outside of those with mental health service professionals.

8.5 Implications for Mental Health Service Providers

Despite increasing recognition of the poor physical health of people with SSDs and other mental illnesses such as bipolar disorder, there is also evidence that this population group do not receive appropriate support to address their physical health needs. People with SSDs are less likely than members of the general population to access physical health services either for monitoring and check ups or for treatment of existing health conditions (Happell, Scott, & Platania-Phung, 2012). There is also evidence that physical health needs are often not addressed in mental health settings. A number of studies have found low levels of even basic screening. An audit of 48
mental health teams for screening of blood pressure, BMI (or equivalent), blood glucose and plasma lipids showed much lower than recommended levels for people with psychotic disorders on antipsychotic medications with all four measures documented in only 11% of cases (Barnes, Paton, Cavanagh, Hancock, & Taylor, 2007). Similarly, an Australian study audited files of all people with SSDs discharged from three mental health inpatient units and found that only 63% had their weight recorded, 61% had their height recorded, but none had BMI or waist measurement recorded. Other screening was also low such as 31% for BSL and 17.5% for cholesterol and triglycerides (Nguyen, Brakoulias, & Boyce, 2009). In their audit, which included intervention as well as screening, Howard and Gamble (2011) found that over 50% of the case notes examined showed no nursing record for 39 of 44 targeted physical health related activities. As the focus of that audit was on nursing interventions it is possible that other team members provided some of these interventions. The survey by Happell, Plantania-Phung and Scott (2013) also focused on mental health nurses but asked the broader question of whether the service they worked in had a lifestyle program for consumers, finding that only 44% did. This reflects the experience of the women in my study. While some had their weight measured when they saw their psychiatrist, most did not address issues of their weight with their case managers. An integrated and long-term approach to addressing weight gain and obesity and SSDs, as indicated by the findings of this study, has a number of implications for mental health services. These include a need to address the culture and attitude, and knowledge and skills of staff, and allocation of resources, which are all identified in existing research as barriers to addressing physical health issues of consumers in mental health services.

8.5.1 Changing Culture and Attitudes

One of the identified barriers to addressing physical health needs of mental health service consumers is the ambivalence among mental health clinicians as to whether this is a legitimate part of their role. Dunbar, Brandt, Wheeler and Harrison (2010) in their qualitative study involving staff of nine mental health services in Australia, found that managing physical health was not perceived as part of the ‘culture’ of mental health services or as ‘core-business’. Similarly in surveys in the United Kingdom (Barnes, et al., 2007), and Australia (Organ, Nicholson, & Castle, 2010), uncertainty as to whether it
was their responsibility was identified as a barrier to mental health clinicians carrying out physical health screening. Hence if interventions to address weight gain and obesity are to be integrated into mental health services for people with SSDs there is a need for a change in culture for the clinical staff to recognise this as a core part of their role.

In addition, the attitudes of staff regarding the nature of the issue of weight gain and obesity and the people who live with that challenge would also need to be addressed. Studies have found stigmatising attitudes to overweight and obesity among health professionals (Forhan & Law, 2009; Merrill & Grassley, 2008). Such attitudes in health professionals can have a negative impact on the health behaviours of people with obesity including reduced willingness to engage in health promoting activities or to access health service settings (Brewis, 2014; Drury & Lewis, 2002; Lewis, et al., 2011; Merrill & Grassley, 2008). In their meta-ethnography of qualitative studies exploring the experiences and attitudes about obesity in health care settings Malterud and Ulrikson (2011) identified that perceptions regarding responsibility mediated stigmatising interactions, which were initiated by the provider and internalised by the ‘patient’. They suggest the assumption that lack of success in goal attainment is due to lack of motivation, and an associated dismissal of the patient’s experience and efforts, means that even apparently appropriate advice can be experienced as negative by the patient. These findings reflect the experiences of encouragement described by the women in my study. The recognition of obesity as a chronic disease may go some way to addressing this issue and increasing the perception that it’s treatment is worthy of more ‘respect’ (Allison, et al., 2008).

8.5.2 Developing Knowledge and Skills

One strategy to address the issues of attitude and culture identified above is education. Education of staff, in order to increase their understanding of the issue and how to integrate associated tasks into their routine work, was identified as one of the facilitators of mental health services implementing metabolic risk assessment in the qualitative study by Dunbar et al. (2010). Education of staff might include increasing understanding of the ‘dual-diagnosis’ nature of the double-whammy and the factors that
contribute to weight gain and obesity in this population, as well as the mediating and facilitating factors to consumer’s ability to carry out the necessary activities to address their weight.

As well as helping mental health clinicians to recognise the importance of addressing weight gain and obesity as a routine part of practice, education and training would also be of benefit in assisting them to do so in the most effective manner. The quality of relationships, as characterised by the communication and style of encouragement, was identified in my study as a crucial factor in the perceived effectiveness of support the women received in their efforts to manage their weight. Given that the experiences with mental health clinicians were often not ideal, education regarding the importance of ‘autonomy supportive’ relationships, and training in strategies to ensure that clinicians interact with consumers in an autonomy supportive manner is indicated. In addition, education and training regarding the more technical procedures that may be required is also indicated. The separation of mental health and substance use services is seen as a barrier to optimal service provision partly because of the lack of knowledge in both sectors about co-occurring disorders (Canaway & Merkes, 2010). This can also be seen as a limitation on effective intervention for weight and associated physical health issues in people with SSD, with the separation of the medical and mental health services. Lack of knowledge regarding how to interpret findings from screening and how to address issues with clients, were identified as factors limiting the implementation of physical health screening in the survey by Barnes et al. (2007). Other studies exploring factors impacting on the implementation of such programs also identified training in specialist skills and associated knowledge as facilitators (Dunbar, et al., 2010; Organ, et al., 2010). Similarly, although respondents to the survey regarding addressing physical activity participation among people with SMI by Happell et al. (2013) indicated that they were largely supportive, most thought they needed additional training to carry out this role.

8.5.3 Allocating Resources – Facilities and Manpower

Integrating interventions to address weight gain and obesity into mental health services would require additional resources in terms of space and equipment, which
may not be available in settings where the focus is currently purely on addressing consumers’ mental health needs. Again, studies exploring factors affecting the implementation of routine physical health screening in these settings have identified lack of access even to basic equipment such as tape measures, weighing scales and sphygmometers as an issue (Barnes, et al., 2007; Organ, et al., 2010). In addition to these and other items required for monitoring there may also be a need to acquire both the equipment and physical space to carry out physical activity or exercise programs and skills training in activities such as meal preparation. This may, in some cases, involve negotiating arrangements for consumers and staff of the mental health service to access such facilities in other settings such as commercial gyms, and community centres.

In addition to the need for infrastructure, there are also manpower implications. The integration of interventions to address weight gain and obesity will necessarily occupy more clinician time and therefore it will likely be necessary to increase staffing complement. Even among participants in the studies identified above who did see it as part of their role, the perceived extra workload was identified as a barrier to providing physical health screening (Dunbar, et al., 2010; Organ, et al., 2010). As well as simply increasing the number of staff there is a need to consider the makeup of the staff team in order that the necessary knowledge and skills are included in the professions represented. This may mean increasing the employment of professionals such as dietitians, and physiotherapists or exercise physiologists who are often poorly represented in the make-up of multi-disciplinary teams in mental health settings (Williams, et al., in press). In addition to including these professions in mental health clinical teams there may also need to be changes made to how these teams allocate work to enable best use of discipline specific knowledge and skills.

8.6 Implications for Occupational Therapy

8.6.1 Validating Occupation Centred Practice

Maintaining occupation centred practice has been identified as one of the contemporary challenges for occupational therapists working in mental health settings. Occupation centred practice occurs when the therapist practises in a manner consistent with the core paradigm of the profession, where occupation is at the centre of their
reasoning and resulting actions (Fisher, 2014). The difficulty many occupational therapists in mental health have in maintaining occupation centred practice is traced to deinstitutionalisation and the evolution of community based mental health care (Fox, 2013; Lloyd, King, & Ryan, 2007; Pettican & Bryant, 2007). Occupational therapists in mental health practice are most likely to be employed in multidisciplinary teams, in generic mental health worker, case manager or care-co-ordinator positions (Fox, 2013; Lloyd, et al., 2007; Michetti & Dieleman, 2014). As a result of the requirement to provide a range of generic interventions many occupational therapists in these positions find they have limited opportunities to provide occupational therapy interventions (Culverhouse & Bibby, 2008). In addition to reduced time available, the lack of understanding of occupation centred reasoning by other members of the multidisciplinary team and valuing of more dominant discourses such as the medical model or psychological theories also impact on the ability of occupational therapists to practice in this manner (Ashby, Gray, Ryan, & James, 2015; Fossey, 2001; Fox, 2013). As well as the potential for service users to have their occupational needs left unmet (Fox, 2013), recurrent surveys have also identified that challenges to maintaining occupation-centred practice and using occupational therapy skills are associated with reduced job satisfaction and retention of occupational therapists in mental health (Cerimidas, 2010; Hayes, Bull, Hargreaves, & Shakespeare, 2008; Scanlan, Still, Stewart, & Croaker, 2010).

One strategy for combatting this issue is for occupational therapists to be able to advocate for occupation centred practice and the ability to do this is strengthened by having evidence for the occupational challenges faced by the client population and the unique contribution of occupational therapy in addressing these (Ashby, Ryan, Gray, & James, 2013; Michetti & Dieleman, 2014).

The process of dealing with the double whammy reported in the findings of my study centres on the women’s ability to engage in a number of occupations that they viewed as necessary for managing their weight. These occupations, described in doing as much as I can, centred on developing, maintaining and managing routines for nutrition and physical activity for health and wellness promotion, which are recognised as a category of Instrumental Activities of Daily Living (IADL). IADL is one of the areas of occupation in the domain of occupational therapy as defined by the American practice
framework, described in chapter one (section 1.2.5). Many of the factors that the women described as mediating their ability to engage in these occupations related to their ability to carry out other IADL, such as financial management, meal preparation, shopping and community mobility. The challenges to their ability to perform these IADL reflected the other categories within the domain of occupational therapy, performance skills, performance patterns, including activity demands, client factors and context and environment. These findings therefore provide clear evidence of the occupational challenges faced by the women in relation to managing their weight.

There is a clear role for occupational therapists in developing competence in associated activities, which I identify as one of the core elements of interventions to address weight gain and obesity in women with SSDs in section four of this chapter. The use of selected purposeful activity to enable people to develop skills that enhance occupational engagement is a component of therapeutic use of occupations and activities, which is one of the five types of interventions identified in the Occupational Therapy Practice Framework (American Occupational Therapy Association, 2008). The role of occupational therapists in providing skills training in instrumental activities of daily living for people with severe mental illness is well established (Fossey, 2012; Krupa, et al., 2009) and has a moderate level of evidence for efficacy (Gibson, D’Amico, Jaffe, & Arbesman, 2011). In addition to skills training occupational therapists skills in activity analysis and assessing occupational performance would inform modifications to the activities and/or the environments in which they are carried out, to facilitate competence. These principles underpin cognitive adaptation training, which is a manual-driven range of compensatory strategies that has been found to be effective in facilitating functional performance in people with schizophrenia (Velligan, et al., 2008; Velligan, et al., 2006). And finally, the occupational therapist will be able to help in the development and maintenance of habits and routines supportive of weight loss and maintenance.

Taking an occupation centred approach to addressing the issue of weight gain and obesity for women with SSDs would also prompt evaluation of a broader range of outcomes. There is a strong emphasis on anthropometric measures and other physical
health indicators such as blood glucose levels as outcome measures in the existing research in this field (Alvarez-Jimenez, et al., 2008; Bonfioli, et al., 2012; Caemmerer, et al., 2012; Lowe & Lubos, 2008). The women who took part in my study also identified other benefits of their engagement in activities to manage their weight, which are consistent with the types of outcomes identified in the Occupational Therapy Practice Framework, such as participation and quality of life, and improvements in other aspects of their health such as their mental health. These kinds of outcomes are consistent with indicators of recovery and therefore align well with the integration of interventions to address weight gain and obesity in mental health services.

8.7 Summary

The explanatory theory developed as a result of my study correlates well with aspects of behaviour change theories that are more commonly used in interventions targeting weight loss and associated behaviours. The health behaviour change theory with which there is greatest correlation is Self Determination Theory (SDT), which has been effectively used in programs to support weight loss, and associated behaviours of exercise and diet. In addition to weight loss, SDT also shows promise in achieving maintenance of both weight, and the behaviours that support this. It has also been used with some success with people with SSDs. The elements of the theory of dealing with the double-whammy also align well with recovery in mental health. While correlating well with these theories dealing with the double-whammy is specific to the issue of weight management and the population of women with SSDs and therefore provides a targeted theoretical approach to developing interventions. The alignment between dealing with the double-whammy and recovery supports my suggestion, based on the dual-diagnosis nature of the double-whammy, that intervention for weight gain and obesity for women with SSDs should be integrated into mental health services. The nature of the double-whammy also supports the reconceptualization of obesity, at least in this population, as a chronic disease. The findings of my study and the reconceptualisation of the issue of weight gain and obesity in women with SSDs indicate that interventions developed to address this issue should; be integrated with intervention for mental health, commence concurrently with treatment for SSDs, be long term, flexible and individualised, support competence in associated activities,
address environmental and contextual factors, and happen in the context of supportive relationships. These criteria have implications for mental health services in terms of changing culture and attitudes, and development of knowledge and skills among clinical staff, and resource allocation. The findings of my study indicate a key role for occupational therapists in supporting the competence of women with SSDs in carrying out occupations associated with effectively managing their weight and developing and maintaining routines supportive of maintenance. This also addresses a contemporary practice issue for occupational therapists in mental health by validating occupation centred practice.
Chapter 9  Conclusion

9.1 Overview of the Chapter

In this chapter I provide an overview of the study as a whole and examine the findings in relation to the initial aims and research questions. I then discuss the significance of the study in terms of the new knowledge it adds to the field and the implications of this. I then provide an analysis of the strengths and limitations of the study before making recommendations for further research, some reflection on the process of carrying out this research and concluding remarks.

9.2 Overview of the Study and Key Findings

This study grew from my experiences as an occupational therapist working in mental health settings, and my observations regarding the impact of weight gain and obesity on the lives of the people with SSDs with whom I was working. In searching the research literature at the time I found there was little evidence for effective interventions, and even less regarding what the occupational therapy role might be, for addressing this issue. I also found that there was almost no research that explored the issue from the point of view of people with SSDs and it seemed to me that this was an essential ingredient in determining effective interventions. So my aim in conducting the study was to gain an understanding of the experiences of people living with SSDs of managing their weight and what they had found, or thought would support them to do this more effectively. Because of the recognised gender variation in the presentation, impact of medication for, and outcomes of SSDs and the fact that most of the participants in the existing research were male, I chose to focus on the experiences and perceptions of women.

I carried out the study following the principles of constructivist grounded theory methodology. There were 11 study participants, all of whom were women, over the age of 18, with a diagnosis of SSD, not acutely unwell, able to give informed consent and able to speak English. I recruited participants from three community mental health rehabilitation services in the Hunter region. Over the course of two years I carried out between one and three in-depth semi-structured interviews with each of the
participants. The early interviews were loosely structured around an interview guide that I had developed based on my early forays into the literature. Follow-up interviews involved filling in gaps and checking my interpretations of the data using summaries of the participant’s own data organised according to the categories that were emerging through my analysis. I carried out data analysis concurrently with data gathering, with each process informing the other. Analysis involved a process of initial open coding, followed by focused coding and the use of techniques and tools such as analytical memos, constant comparison, theoretical sorting and storyline. I eventually arrived at a theoretical framework, which included identification of a basic social problem, the double-whammy, and a basic social process of dealing with the double-whammy, which centred around the core-category of doing as much as I can.

The findings of my study have four sections. The first of these is the basic social problem, the issue that was shared by all of the women. Labelled using the words of one of the participants, the double-whammy, describes the women’s experience that significant weight gain, often resulting in obesity, was a second ‘whammy’ that came with their diagnosis and treatment for their SSD. The women who generally did not have issues with their weight prior to their diagnosis expressed concern about their weight gain and associated issues such as physical health problems, reduced functional capacity and additional mental health problems. The remaining three sections are the components of the basic social process, the response of the women to the double-whammy.

This response centres on the core category of doing as much as I can, in which the women describe their engagement in what they saw as doing the right things, which included doing exercise, cutting down (on their over all consumption, but also more specifically on foods that they saw as unhealthy) and eating more healthy. Their engagement in these activities followed a somewhat cyclical process of starting to do it, which involved making the decision to take action, after reaching the limit in some parameter associated with their weight. They described the necessity of adjusting expectations, both in relation to their weight loss goals, and regarding their engagement
in the activities identified in *doing as much as I can*. Most had experienced several cycles of *starting to do it*, due to the challenges of *sticking with it*.

The women’s ability to do what they saw as necessary to manage their weight fluctuated in response to three subcategories of *mediating factors*, which comprised the third section of the findings. The first of these subcategories, *knowing*, involved firstly being aware of the potential for weight gain, and recognising this in themselves, following which, *knowing what to do* in terms of the guidelines for healthy eating and exercise became important, as did knowing how to translate the guidance into their daily lives, and *knowing how to do* related tasks such as shopping and meal preparation. Their ability to carry out activities to manage their weight also fluctuated with their *mental health and wellbeing*. They were generally unable to attend to this *in the beginning*, during the onset, diagnosis and commencing treatment for their SSD. Following this initial period the women described experiencing *ups and downs*, during which they were more or less able to manage their weight, which were sometimes associated with fluctuations in the severity of symptoms of their illness, low mood or adverse life events. The final subcategory of *mediating factors* was the *practical issues* that impacted on the women’s ability to manage their weight which were the challenges of living on low income and the perception that eating healthily and exercising were expensive described in *watching your money*, and challenges around prioritising these activities in the context of competing demands in *juggling*.

The final part of the findings contains three subcategories of *facilitating factors*, that the women had found, or thought would, support them to be able to do what they saw as necessary to manage their weight. *Talking about it*, involved having at least one person with whom they discussed their efforts to manage their weight in order to *keep it on the agenda*, as well as *education and advice* to fill in the gaps in their understanding of healthy eating and exercise guidelines and provide *practical suggestions* for how they might implement these in their lives. *Having a plan*, included making use of simple tools such as *budgets, meal plans and shopping lists*, as well as *routines* around eating and exercising and *strategies* for overcoming challenges such as temptation to eat things not consistent with their plan. Finally *someone to do it with* included the value of having
someone to exercise with, to get me going, and others helping me out, either by teaching them how to do associated tasks such as cooking, or carrying out components of tasks that the women could not manage to enable them to still participate.

9.3 Significance of the Study

This study adds important new perspectives to the small body of research exploring the experience of weight gain and weight management efforts of people living with SSD.

9.3.1 Redressing the Gender Imbalance in SSD Research

The focus of this study on the perspectives of women makes it unique. Not only are there no other studies that specifically focus on the experiences of women, almost all of the existing research exploring experiences of weight gain, and efforts of weight management, in people with SSDs has been carried out with participant groups that are dominated by men (Bassillos, et al., 2014; Loh, et al., 2008; McDevitt, et al., 2006; Rastad, et al., 2014; Tham, et al., 2007; Vandyk & Baker, 2012; Xiao, et al., 2012). This is of particular significance considering the documented differences for women and men with SSDs regarding the course of illness, response to and side effects from medication, and outcomes (Grossman, et al., 2006; Hakko, et al., 2006; Kelly, 2006; Kulkarni, 1997; Morgan, et al., 2008; Seeman, 2009). These differences mean that it is not safe to assume that conclusions drawn from research based on the experiences of men will be applicable for women living with SSDs (Longenecker, et al., 2010).

9.3.2 Providing a Longitudinal and Holistic Perspective

This study also provides a longitudinal and holistic exploration of the experience of weight gain that is not evident in existing research. Data generation for this study occurred over a more than two-year timeframe, with approximately half (5/11) of the participants engaging in three interviews and most (8/11) in at least two during that period. Existing qualitative research in this field has relied on a single interview with each participant (Bassillos, et al., 2014; McDevitt, et al., 2006; Rastad, et al., 2014; Vandyk & Baker, 2012; Xiao, et al., 2012). Conducting multiple interviews with most of the participants, over an extended timeframe facilitated a longitudinal exploration of
the phenomenon of interest, not only through the participants describing in a single interview their memories of how their experiences of living with and managing their weight changed over time, but also in comparing their experiences and perspectives in subsequent interviews throughout the duration of the study. The multiple interviews also allowed for development of the relationship between myself and the participants and as a result potentially more detailed data and the opportunity to fill any gaps in the data and gain a more detailed account of the participants’ experiences (Charmaz, 2003, 2006). In addition to being the only study that has used multiple interviews with each participant to gain a longitudinal perspective, my study is one of only two that consider the interrelated issues of weight gain, obesity and efforts at weight management in people with SSDs. Others tend to focus on a single aspect such as participation in physical activity (Bassillos, et al., 2014; McDevitt, et al., 2006; Rastad, et al., 2014), or the impact of the weight gain (Tham, et al., 2007; Usher, et al., 2013; Vandyk & Baker, 2012). The more holistic exploration of the issue in my study facilitated a reconceptualization of weight gain and obesity and SSDs and how it might be more effectively addressed.

9.3.3 Reframing the Issue of Weight Gain and Obesity in SSDs

The findings of this study also suggest a reframing of the issue of weight gain and obesity in people with SSDs, which has not been clearly evident in the literature to date.

The double-whammy as ‘dual-diagnosis’

There were significant similarities between the experience of the double-whammy as described by the women in my study, and the dual-diagnosis of mental illness and substance use disorders. These similarities suggest that an integrated approach to intervention, such as is the preferred model for dual-diagnosis (Drake, et al., 2001; Manley, 2005), is also indicated for addressing the co-occurrence of weight gain and obesity and SSDs. Despite increasing awareness of the high prevalence among people with mental illnesses such as SSDs, studies indicate low levels of screening and intervention for obesity and related health conditions in mental health settings (Barnes, et al., 2007; Happell, et al., 2013; Howard & Gamble, 2011). The reframing of the issue
of weight gain and obesity in SSDs as one of dual-diagnosis, and development of an integrated service approach, may help in more clearly identifying these interventions as ‘core business’ and worthy of staff time (Barnes, et al., 2007; Dunbar, et al., 2010; Organ, et al., 2010).

**Obesity as a Chronic Condition**

The women in this study described significant weight gain, as a second challenge that came with their diagnosis and treatment for their SSD, and an ongoing pattern where their journey of managing their weight was impacted by, and impacted on, their journey of recovery with their mental illness. Like many people diagnosed with SSDs, these women described a pattern of ongoing fluctuations in their mental health over a period of years (American Psychiatric Association, 2013). Related to this, their ability to take action to manage their weight also fluctuated but remained an issue over the same time period. While there is ongoing debate over whether obesity can be considered a chronic disease, in this particular population, where it is inextricably linked to another chronic disease and its treatment, there is a good argument that it should be. This has significance in terms of how interventions are structured and addresses one of the key limitations of the existing intervention research, which largely does not address the issue of weight loss maintenance.

**9.3.4 Defining a Role for Occupational Therapy**

The process of dealing with the double whammy centred on the women’s ability to develop, manage and maintain routines for nutrition and physical activity for health and wellness promotion. Their ability to do this was impacted by their abilities in other IADL such as financial management and meal preparation, which in turn were impacted by personal factors, activity demands and context and environment. There is a clear role for occupational therapy in supporting individuals with SSDs to overcome these occupational challenges, through interventions such as skills training in IADL, and supporting performance through adapting the activities and/or the environment in which they are performed and helping them to develop and maintain habits and routines supportive of weight loss and maintenance. The occupation centred nature of the role for occupational therapy in addressing this issue goes some way to validating
occupation centred practice which is a contemporary challenge in mental health occupational therapy.

9.4 Study Limitations

While this study makes a significant contribution to the knowledge base supporting practice in addressing the issue of weight gain and obesity in people with SSDs, there are also a number of limitations of my study that should be taken into account in considering transferability of the findings.

9.4.1 A Focus on Women

As I discussed above in section 2.3.1, this study goes some way to addressing the gender imbalance in research about SSDs by introducing the experiences and perspectives of women into a body of research that is largely dominated by male participants. This is however also a limitation of the study. For the same reasons that the findings of studies with primarily male participants do not necessarily apply to women living with SSDs, the findings of this study may not be directly applicable to men living with these disorders.

9.4.2 Recruitment Strategy

Recruitment from a Single Geographic Location

The choice to recruit participants from one geographical location was made on the basis of pragmatic reasons relating to my ability to arrange to meet with participants face to face to carry out interviews. I conducted this study while working as a lecturer in Occupational Therapy, and also became a mother early in the process of conducting the study. Both of these factors limited my ability to travel to engage with participants in other geographical locations. While many of the experiences described by the participants in this study resonated with findings from other studies with people with SSDs or women who were dealing with weight gain and obesity they will also of course have been shaped by the context from which the participants were drawn. For example, the women talked about making use of the free exercise options available locally including safe and accessible walking paths and ocean baths for swimming, which may not be available to people with SSDs living in other areas. In addition their
experiences in terms of the support they had received through the mental health service will have been shaped by the pattern and provision of services locally. The way in which mental health services are provided vary greatly across Australia, not only from state to state but also between different health districts in a single state. The geographical area from which the participants were recruited also impacts on demographics. In particular the Hunter Region has a relatively low proportion of residents who were born outside of Australia or for whom English is not the primary language spoken at home which is likely to be significantly different to other geographical areas, such as in some parts of Sydney.

Recruitment from Community Mental Health Rehabilitation Services

The choice to recruit from community mental health rehabilitation services was also on some levels pragmatic. I considered that it would be likely, due to the criteria for referral to these services, that their consumers would be most likely to meet the inclusion criteria of being not acutely unwell. The operation of the care co-ordination approach in these services also provided a means of determining if other criteria, such as the ability to give informed consent, were met. Again, while I made effort to recruit women with a range of experiences in terms of their duration and course of illness, it must be noted that not all people with SSDs access such services, and their experiences may have been shaped by their involvement with these services, which may also limit transferability.

9.5 Recommendations for Further Research

9.5.1 Determining Broader Applicability of the Theory

One direction for further research would be in response to the limitations of this study with regard the participants being all women and drawn from a single geographical location with limited cultural diversity. I would suggest further research to determine applicability of the tenets of the theory with other population groups, such as men or people from culturally diverse backgrounds. This could be achieved through further qualitative studies perhaps using focus groups.
9.5.2 Developing and Trialling Interventions

The second direction for future research would be developing and trialling interventions based on the principles of this theory. This would involve the development of an intervention framework that incorporates the seven characteristics identified in the discussion chapter: being integrated with intervention for mental health, commence concurrently with treatment for SSD, be long term, be flexible and individualised, support competence in associated activities, address environmental and contextual factors and occur in the context of a supportive relationship.

Related to this is the need for further research to develop the evidence base for some of the individual elements of such an intervention. For example, while there is some evidence for the effectiveness of skills training in developing IADL abilities in people with SSDs this evidence is not strong and there is a need for larger and more rigorous trials.

A further avenue for research would be developing and trialling interventions to help create an environment conducive to interventions to address weight gain and obesity such as the suggested programs to address the culture and attitude of mental health clinicians.

9.6 Summary

In carrying out this study I sought to gain an understanding of the experiences of women living with SSDs of managing their weight and what they thought had been, or would be useful in supporting this. Through an iterative process involving 24 in-depth semi-structured interviews with 11 women living with SSD over a two year period, and concurrent data analysis a theory was generated. This theory accounts for the women’s experience of significant weight gain as a double-whammy that came with their diagnosis and treatment for SSDs. It also accounts for their response to the double-whammy through a somewhat cyclical process of doing as much as I can, factors that mediated the women’s ability to engage in the activities they identified as necessary to managing their weight, and factors they had found, or thought would, facilitate their efforts. The significance of the study lies in the new perspectives it adds to the research
about the experience of weight gain and weight management in people with SSDs including: redressing the gender imbalance through providing women’s perspectives, providing a longitudinal and holistic perspective, a reframing of the issue of weight gain and obesity in SSDs as ‘dual-diagnosis’ and a chronic condition. In addition, the study provides some clear direction for occupational therapy intervention to address this issue. The transferability of the findings of this study may be limited by the focus on women, the recruitment from a single geographical location and participants who were engaged with community mental health rehabilitation services. Recommendations for further research include, determining broader applicability of the theory, and developing and trialling interventions.
References


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Appendix I: Participant Information Statement
Information Statement for the Research Project:

How do women living with schizophrenia manage their health and their weight?

Document Version 3; dated 21 April 2010

If you are a woman, over the age of 18, living with a diagnosis of schizophrenia or schizo-affective disorder you are invited to participate in the research project identified above. Kirsti Haracz is conducting this research for her PhD in Occupational Therapy under the supervision of Professor Susan Ryan from the School of Health Sciences, and Michael Hazelton, from the School of Nursing and Midwifery, Faculty of Health at the University of Newcastle.

Why is the research being done?
Previous research has shown that people who live with schizophrenia are more likely to be overweight, and have poorer health, than people who don’t have schizophrenia. But there is very little research that explores views and experiences of people with schizophrenia about this, and no research that specifically explores the experience of women.

I am interested in your experiences and thoughts about;

• Health and your health needs
• What you do to manage your health and your weight,
• What affects your ability to manage your health and your weight, and
• What you think would help you to be able to manage your health and weight.

The findings of this research may support the development of services to better meet the needs of women living with schizophrenia to manage their health and their weight.

Who can participate in the research?
You can participate in the research if you are a woman, over the age of 18, and have a diagnosis of schizophrenia or schizo-affective disorder.

What choice do you have?
Whether or not you participate in this research is entirely your choice. Only those people who fill in and return a consent form will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you in any way and will not affect your care or access to services.
If you do decide to participate, you may withdraw from the project at any time without giving a reason. If you withdraw from the project, you will have the option of withdrawing your data from the project also.

**What would you be asked to do?**

If you agree to take part, Kirsti Haracz will contact you to arrange an interview at Supported Recovery at a time that suits you. During the interview you will be asked questions about:

- your thoughts about health and your health needs,
- what you do to manage your health and your weight,
- what affects your ability to manage your health and your weight, and
- What you think would be helpful to you in managing your health and your weight.

Kirsti will put together a summary of the first interview and then contact you to arrange a second interview. This interview will involve a discussion of the summary. You will be able to clarify things and make corrections, and Kirsti may ask further questions to help make sure the summary provides a good reflection of your views and experiences.

Kirsti will make corrections to the summary based on the second interview and contact you for a final meeting where you will have the opportunity to check the revised summary and any final clarification and corrections will be made.

The interviews will be recorded using a digital voice recorder. You can ask for the recording to be stopped, edited, and sections erased at any time during the interview.

**How much time will it take?**

The length of each interview will be up to you. For each interview Kirsti will contact you to see if you agree to the interview and arrange a time that is convenient to you.

**What are the possible risks of participating?**

The risk of you experiencing any distress or harm as a result of this research is very low. You may refuse to answer any questions. If you do feel distress during the interview the interview will be stopped. You will be assisted to gain support from your usual support networks.

**What are the possible benefits of participating?**

Studies have suggested that people participating in interviews like the ones involved in this study, experience some benefit from participating in the interview.

**How will your privacy be protected?**

All of the information you provide will be kept confidential at all times.

The recordings and transcripts of interviews will be securely stored and only accessed by the researchers. Electronic data will be stored on a password protected computer and paper copies in a locked cabinet.
Your comments may be reported in the writing up of the research but your name will not be mentioned and you will not be able to be identified by what is said.

**How will the information collected be used?**
The findings from the study will be reported in a thesis to be submitted for Kirsti Haracz’s Doctoral Degree. They may also be published in scientific journals and conference presentations. You will not be identified in any report or publication. Participants will be able to get a copy of a summary of the findings of the research by contacting the researcher.

**What do you need to do to participate?**
Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, please contact the researcher.

If you would like to participate, please complete the attached Consent Form and return this in the reply paid envelope.

When the form is received Kirsti Haracz will contact you to arrange a time and place convenient for your interview.

**Further information**
If you would like further information please contact Kirsti Haracz at the University of Newcastle via email: kirst.haracz@newcastle.edu.au or phone: 02 49216338.

Thank you for considering this invitation.

Kirsti Haracz
Researcher
Lecturer, Occupational Therapy
T +61 2 49216338
F +61 2 49217053

**Complaints about this research**
This project has been approved by Hunter New England Health’s Human Research Ethics Committee, Reference Number – 09/02/18/5.11. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to:

Dr Nicole Gerrand
Professional Officer (Research Ethics and Governance)
Hunter New England Research Ethics Unit
Locked Bag 1
NEW LAMBTON NSW 2305
Ph: (02) 4921 4950
Fax: (02) 4921 4818
300erran.gerrand@hnehealth.nsw.gov.au
Appendix II: Consent Form

Consent Form for the Research Project:

How do women living with schizophrenia manage their weight and their health?

Document Version 1; dated 8 January 2009

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand that my participation is voluntary and I can withdraw from the project at any time and do not have to give a reason for withdrawing. If I choose to withdraw I can also withdraw all of the information about me that has been collected by the researcher.

I agree to participating in interviews with Kirsti Haracz.

I agree to these interviews being audio recorded, and transcribed.

I understand that my personal information will remain confidential to the researchers.

I agree to have my words quoted in reporting of the research. I understand that these words will not be attributed to me and I will not be able to be identified from the research report.

I have the opportunity to have questions answered to my satisfaction.

Print Name: 

Signature: Date: 

Contact Details

Address:

Telephone:
Appendix III: Participant Portraits

Abbie

Abbie was 32 years old and had been living with schizophrenia for 12 years. She had only required admission to hospital once, when she was diagnosed and commenced treatment. She continued to experience auditory and visual hallucinations although these were gradually diminishing in both frequency and intensity. She also took medication for depression. Abbie had limited social support, which consisted of one friend with whom she spoke on the telephone and her mother, who she saw monthly.

Abbie lived alone in a Department of Housing flat and was in receipt of the Disability Support Pension. She had discontinued her university studies and part time work following the onset of her illness. In the few years prior to and during her participation in this study however she had gained a range of TAFE qualifications in fashion and fine arts and planned eventually to return to university. In her spare time Abbie enjoyed window shopping and looking in antique stores as well as making things such as jewellery and fabric bags and hats.

Danika

Danika was 28 and had been living with schizophrenia for ten years. She estimated that she had been admitted to eight or nine hospitals as a result of her schizophrenia, including an extended period in a rehabilitation setting. At the time of the first interview she had been well for two and a half years, which was the longest period since her diagnosis. Her family did not live locally and she identified the community rehabilitation team as her primary source of support.

Danika lived alone in a housing association unit. She left school after completing year ten and had held a variety of short-term jobs since that time. At the time of the study she was doing a literacy course one day a week at TAFE. She was also working three shifts a week in hospitality in a supported employment setting. Throughout the time she was involved in the study she played team sports, softball in the summer and
baseball in the winter. In her spare time Danika also liked to go shopping in second hand stores.

**Elizabeth**

Elizabeth, who was 29 years old, was diagnosed with psychosis at the age of 16. She described having been ‘very unwell with schizophrenia and depression for a very long time’. Although her illness had improved over the years Elizabeth still experienced frequent relapses requiring admission to hospital. Her parents and sisters lived nearby and provided emotional support and her parents also provided practical support such as helping Elizabeth to manage her finances. Elizabeth had regular contact with her case manager and psychiatrist and a psychologist. She received support at home from a care worker from an NGO and home care for cleaning.

Elizabeth lived alone in a Department of Housing flat. She left school at 17 years of age having completed year ten. After finishing school she had made two attempts to study at TAFE but had been unable to complete these due to the effects of her illness. She had also attempted supported employment but found she was not able to manage this. Her primary source of income at the time of the study was the Disability Support Pension. Elizabeth maintained what she described as a busy lifestyle with weekly activities including attendance at a support group and a drop in centre for people with mental illness, a church service followed by coffee and chat group and dinner with a friend as well as appointments with her case manager and psychiatrist and outings with her support worker.

**Emily**

Emily was 61. She had become unwell with schizophrenia when she was 29 and had approximately six admissions to hospital over the next ten years. Following that she had not required admission to hospital until her mother, with whom she had been living, died nearly 20 years later. Since her mother’s death Emily had been admitted to hospital 10 times. She had a daughter who lived nearby and whom she saw weekly. Her daughter had been providing significant practical assistance but was less able to do this following the birth of her second baby. Emily had support from home care with
her house cleaning and a care worker from an NGO who took her grocery shopping. She had monthly contact with her psychiatrist and case manager and attended a day therapy clinic attached to a private hospital one day a week.

Emily lived alone in a retirement village. She had completed high school and had worked in business until she was unable to do so because of her illness. She had also commenced a teaching diploma but discontinued this when she had children. At the time we met Emily was receiving the disability pension. She enjoyed listening to music, reading, watching TV, walking and ‘mixing with people’.

Faith

Faith was 37 and had been diagnosed with schizophrenia at the age of 26. She attributed the onset of her mental illness to drug use. Faith had been hospitalised 19 times as a result of her schizophrenia but had had no admissions since she had stopped using drugs nearly five years prior to our meeting. She continued to experience positive symptoms of her illness, which caused her significant distress and interfered with her ability to engage in occupations and interact with others. Her primary source of support was a cousin whom she also described as her best friend. As well as emotional support he assisted her with practical tasks such as laundry, cooking and grocery shopping. Faith also went swimming or walking with her cousin several times a week.

Faith lived with her father in a department of housing flat. She left school half way through year 11 and went on to complete secretarial and bookkeeping qualifications through TAFE. Prior to the onset of her illness she had done a variety of jobs including book keeping, bar work and cleaning. She had not worked for 15 years however. Her source of income was the disability support pension. Her main daytime occupations were watching the television and surfing the internet, as well as sleeping.

Gaye

Gaye was not sure how long she had been living with schizophrenia. She attributed the onset of her illness to her previous amphetamine addiction related to a history of attention deficit disorder. She reported having not taken amphetamines for over ten
years but was still greatly distressed by the symptoms of her schizophrenia and ongoing depression. Gaye had ‘been to hospital on numerous occasions’ as a result of her illness. She had just commenced home care when we met.

Gaye lived alone. She described having little social support stating that, ‘my family don’t come and have nothing to do with me’, although she did spend weekends with her mother. Gaye spent her days watching television at home. She loved music and had previously played instruments although was not doing so at the time of the study.

Isobel
Isobel was 31 when we first met. She had been diagnosed with SSD when she was 21. She was unsure of the exact number of times she had been hospitalised but thought that she had been admitted a few times in the first few years of her illness. She had not been in hospital in the few years prior to our meeting. She had regular contact with her GP and case manager but no other services.

Isobel lived with her mother in private rental accommodation. She reported having left school at the end of year ten. She went on to TAFE but only completed six months of a clerical course. She had not engaged in any other education or employment since that time although she reported sometimes helping out in her mothers business. Her primary source of income was the disability support pension. She described spending most of her time at home where she assisted her mother with the domestic tasks. Isobel described her only social contact being with her mother, and occasional visits with her sisters.

Karen
Karen was 49 when we first met. She had been diagnosed with schizophrenia at the age of 30 although she believed that she had been unwell for about five years before that. Karen had only been hospitalised twice as a result of her illness, for three months at the time of her diagnosis and nearly 20 years later following a series of bereavements. She experienced few positive symptoms of her illness in between major episodes. Karen had long-term problems with alcoholism but had not had a drink for six years at the time of the study. She had also experienced episodes of depression.
Karen had eight living siblings with whom she maintained contact and whom she described as supportive. She saw many of them infrequently other than a brother who lived nearby and a sister who moved to the local area during the time of the study. Karen had regular contact with her GP and case manager. She also attended Alcoholics Anonymous, and had a sponsor from this organisation with whom she maintained telephone contact. During the period of engagement with the study she also started having regular outings with a volunteer mentor.

Karen lived alone in a Department of Housing flat. She had qualified as a primary school teacher in her 20’s but only taught for a short time before the onset of her illness. She had held a variety of other jobs since developing schizophrenia including seven years as a library technician and several years as a clerical assistant in the public service as well as telemarketing, cleaning and working in nursing homes. Her primary source of income during the time of the study was the Disability Support Pension. She supplemented this at different times with cleaning and childcare for her siblings and teaching scripture at a local primary school. During the time she was engaged in the study Karen completed a Business Studies course at TAFE. She also described a range of leisure interests including cooking, reading and going to the movies and out for coffee.

Mary

Mary, who was 26 when we first met, was diagnosed with schizophrenia at the age of 21, having just completed her second year of university. She had been admitted to hospital on several occasions as a result of her mental illness. Mary had one admission to hospital during the time of the study, between our first and second interviews. She described feeling well supported by her parents, extended family members and friends who all lived nearby. She had a case manager and psychiatrist, both of whom she saw on a regular basis.

When we first met Mary was studying part time at university and living in private rental accommodation with two other students. She also hosted her own community radio program. Not long after the first interview Mary found out she was 5 months pregnant and at the time of the second interview her son was 7 months old. She was
still living in the same accommodation but her flatmates were moving out and her boyfriend, the father of her baby, planned to move in. Her son was spending the days with her but overnight with her parents as Mary’s medication made it difficult for her to wake at night to care for him. Her primary activities were attending appointments and looking after her son but she planned to return to university the following year. By the time of the third interview Mary’s had separated from her son’s father. She was still living in the same house, and her son was living there with her. She rented the third room out to a family friend. Mary had returned to university at the beginning of the year but had subsequently decided to take a leave of absence and had enrolled in a Certificate IV in disability studies at TAFE with the aim of working part time as a disability support worker. Marys’ income was the disability support pension, which was augmented by additional benefits for her son.

**Nette**

Nette was 45 at the time of our meeting. She described having been diagnosed with schizophrenia in her mid teens and then later with schizo-affective disorder. Nette had been hospitalised several times as a result of her mental illness. She did not have any family support but was visited regularly by a mental health nurse and received support with activities of daily living such as shopping and cleaning.

When we met Nette was newly settled into a housing association property following a lengthy admission to a mental health rehabilitation unit. She had married during her time in that unit but was living alone as her husband was still in hospital. Nette reported having left school in year nine and not having completed any further education. She did not identify having ever worked and her primary source of income was the disability support pension. Nette described spending most of her time at home, going out only to appointments, to complete grocery shopping and once a week to attend a women’s group.

**Nuela**

Nuela was 24 at the time of our first meeting and had given birth to her first child just a few weeks before. She was diagnosed with schizo-affective disorder two years earlier
but had been seeing therapists and taking various medications since she was 15. Nuela had been hospitalised as a result of her mental illness on two occasions, the first around the time of her diagnosis with schizo-affective disorder and the second in the context of her pregnancy. She described herself as being a lot more well than she used to be and no longer had positive symptoms of her illness.

Nuela was living with her parents and sister. Her partner, and father of her baby, lived nearby. Nuela had been studying at university at the time of her diagnosis with schizo-affective disorder but had found herself unable to complete her degree. Prior to having her baby she had been working part time and studying at TAFE. Her primary source of income was the Disability support pension and she was in the process of arranging additional benefits for her child. Nuela’s preferred leisure time activities included ‘checking out the internet and drinking coffee in a café’. At the time of the second interview she had enrolled to study interior design at TAFE.
Appendix IV: Initial Interview Guide

Introduction
Can you begin by telling me a little about yourself?

- Age
- Living situation; who with; nature of residence
- What do you do during the day?
- Interests?
- How long have you been living with schizophrenia?
- How would you describe your health currently?
- How would you describe your weight? Are you of healthy weight, overweight, or very overweight?

Is there anything you would like to ask me?

Views on Health
Firstly I am interested in your views on health.

Can you tell me what you think being healthy means?

- Clarify aspects of being in good health, and engaging in health promoting activities.

What aspects of health are most important to you?

How important do you think bodyweight is?

- To your health?

How do you think having schizophrenia has affected your health?

- Can you tell me how you think it has affected your physical health?

Activities and routines to manage health
Now I am interested in your experiences of managing your own health.

Can you tell me about any things you do to manage or improve your health?
For each activity identified:

• Can you describe for me how you do this?
• What health benefits do you expect from doing this?
• How often do you do this?
• How long have you been doing it?
• Have there been any changes in how you do this activity over time? Since you have had schizophrenia?
• Can you tell me about any aspects of doing it that are difficult for you?
• Can you tell me about any times when you are more likely to do it? Do it more frequently? Or it is easier for you to do?
• What helps you to be able to do it?
• Can you tell me about times when you are less likely to do it, or don’t do it?
• Can you tell me about any changes you would like to happen in how you do this activity?
• Can you suggest anything that would help you to be able to do this in the way you would like?
• Can you tell me about any recommendations regarding doing this activity that you are aware of?

Activities and routines to manage bodyweight (if not already covered above)

Can we move on now to your experiences in managing your body weight.

Can you tell me about things you do to manage your bodyweight?

For each activity identified:

• Can you describe for me how you do this?
• What health benefits do you expect from doing this?
• How often do you do this?
• How long have you been doing it?
• Have there been any changes in how you do this activity over time? Since you have had schizophrenia?
• Can you tell me about any aspects of doing it that are difficult for you?
• Can you tell me about any times when you are more likely to do it? Do it more frequently? Or is it easier for you to do?
• What helps you to be able to do it?
• Can you tell me about times when you are less likely to do it, or don’t do it?
• Can you tell me about any changes you would like to happen in how you do this activity?
• Can you suggest anything that would help you to be able to do this in the way you would like?
• Can you tell me about any recommendations regarding doing this activity that you are aware of?

**Identified Needs**

Can you tell me about anything that you would like to do, or you think is important to do to manage your health or your weight that you are not currently doing?

For each activity identified:

• What health benefits would you anticipate from doing this activity?
• Can you tell me about when you may have done this in the past?
• What prevents you or makes it difficult for you to do this now?
• What do you think would need to happen for you to be able to do it?
• Have you asked anyone to help you with this? Can you tell me about what happened?
• Can you tell me about any recommendations regarding doing this activity that you are aware of?

**Exercise (If not already addressed in question 5-7)**

Do you do any exercise to help manage your health or your weight?

If so:

• Can you tell me about any changes in what exercise you do? Since you have had schizophrenia?
• Can you describe for me what it is that you do?
• For each exercise:
• For how long and how frequently?
• How long have you been doing this exercise?
• Can you tell me about any aspects of doing this exercise that are difficult for you?
• Can you tell me about any times when you are more likely to do it? Do it more frequently? Or is it easier for you to do?
• What helps you to be able to do it?
• Can you tell me about times when you are less likely to do it, or don’t do it?
• Can you tell me about any changes you would like to happen in how you do this activity?
• Is there anything you could suggest that would help you to be able to exercise in the way you would like?
• Can you tell me about any recommendations regarding exercise or physical activity that you are aware of?

If not,

• Have you ever done exercise in the past? Can you tell me about this? What, how often etc.
• Would you like to be doing exercise to help manage your health or weight?
• What would you like to be doing?
• What makes it difficult for you to do this now?
• What do you think would help you to be able to do this?
• Have you tried to do this? Can you tell me what happened?
• Are you aware of any recommendations regarding exercise or physical health?

**Diet**

Can you tell me about how you manage what you eat?

• Can you tell me about anyone else who is involved in planning or deciding what you will eat?
• Do you think about your weight or your health when you make choices about what to eat?
• Does anything else influence your decisions about what to eat?
• Are you happy with how you manage your diet?
• What do you think would be a healthy diet?
• Can you tell me about times when your diet is more healthy?
• Can you tell me about times when your diet is less healthy?
• How far ahead do you plan what you will eat?
• How often do you eat take-away, or eat out?
• What usually influences this decision?
• What do you usually have?
• Do you think about your weight or health when choosing what to have?
• Can you tell me about how you manage grocery shopping?
• How often do you by groceries (or are involved in this task)?
• Do you plan what you are going to buy? Write a list?
• What influences your decisions about what you are going to buy?
• Can you tell be about anyone else involved in your grocery shopping?
• Can you tell me about any aspects of grocery shopping that are challenging for you?
• Can you tell me about anything that helps you to manage this task?
• Can you tell me about times when it is more/less challenging?
• Are you happy with how you manage your grocery shopping?
• Can you tell me about anything you would like to do differently?
• What do you think would help you to be able to manage this task in the way you would like?
• Can you tell me about when you cook or prepare meals at home?
• How often do you do/ are you involved in this task?
• Do you plan what you are going to cook/eat? How far ahead?
• What influences your decisions about what you cook/prepare?
• Can you tell me about anyone else involved in your meal preparations?
• Can you tell me about any aspects of preparing meals at home that are challenging for you?
• Can you tell me about anything that helps you to manage this task?
• Can you tell me about times when it is more/less challenging?
• Are you happy with how you manage preparing meals at home?
• Can you tell me about anything you would like to do differently?
• What do you think would help you to be able to manage this task in the way you would like?
• Has the way you manage what you eat changed? Since you have had schizophrenia?
• Are there things that you would like to do differently?
• Can you tell me about any guidelines for healthy eating that you are aware of?

Closing questions

What advice would you give to a woman newly diagnosed with schizophrenia about managing her health or her weight?

What advice would you give to health professionals about providing services to support women living with schizophrenia to manage their health or their weight?

Is there anything that you think I should understand better?

Is there anything you would like to ask me?

Can I can you again if I need to, to clarify or add to this interview?
Appendix V: Early Interview Summary and Prompt Questions for Follow-up: Abbie Interview Two

Abbie is a 32 year old woman who has lived with schizophrenia for 12 years. She is interested in fashion and has been studying at TAFE since 2003, completing a number of certificate courses in millinery and fashion design. She is now working towards a diploma in fashion design. Abbie likes to make things such as fabric bags, hats and jewellery to give to friends and hopes to develop a business selling these items on Ebay. She also likes shopping and looking around antique stores. She lives with her cat in a housing commission unit.

How far did you progress with education prior to illness?

Any other support apart from supported recovery?

Abbie had her first psychotic episode when she was 20 years of age. This was her first episode of mental illness. She remembers this as a really scary time when she was experiencing voices and visual hallucinations as well as paranoid thoughts, and she didn’t really know what was happening to her. At the time when she was first unwell Abbie describes existing within her head and not really caring what was happening to her body and she believes that this contributed to her weight gain. She said, ‘hearing voices and hallucinating, the last thing you want to think about is whether you should be eating fruit.’ She described being a size 12 and a healthy weight before she became unwell but putting on a significant amount of weight after her hospitalisation, reaching 128 kilograms at her heaviest.

Who were you living with when first unwell?

Support at this time?

Coping?

Abbie spent several weeks in hospital following her first psychotic episode but has had no admissions in the 12 years since. She does have periods of being unwell and
experiences episodes of positive symptoms approximately every 1-2 months but these have not been severe enough to require admission to hospital. The severity of her symptoms is usually reflective of her stress levels although sometimes she experiences symptoms when she is not feeling stressed at all. Abbie is also on medication for depression. She described how as she has become more well in her mind she has been focusing more on her physical health and described a shift in the last six months where she has decided that she needs to look after her body better.

More unwell? Since?

Abbie reported that both her psychiatrist and GP had suggested to her in the last few years that she needed to lose weight. She considers herself to be obese. She describes this as a big concern for her and said she needs to lose weight in order to be well and to prevent the onset of diabetes. Abbie did not think that her weight impeded her physical ability to do things but said it did impact on her self esteem and was emotionally hard. Abbie has a weight loss goal. She is currently wearing size 22 clothing and would like to get down to size 16. She reported that she was ‘doing as much as I can at the moment’, to achieve this, watching what she eats and increasing her exercise and had lost some weight over the preceding few years, dropping from 128 to 115 kg.

How did you feel when told you needed to lose weight?

How did you decide on weight loss goal?

How did you know what you needed to do to lose weight?

Any expansion on effects of weight?

Abbie has received professional support with her goal of losing weight from her case manager and a dietician. She reported that she had been talking with her case manager about her weight periodically for some time, although depending on what else was going on with her life this was not always a priority for her. Her case manager had provided assistance in helping her to develop daily living skills in grocery shopping and cooking which have supported her efforts to manage her diet. Her case manager
had also referred her to a dietician. Abbie had seen the dietician over a period of several months and reported that this had been helpful in developing her awareness both of her own dietary habits, and of healthy alternatives. She had adopted some but not all of the dietitians suggestions as she found some to be too regimented and prescriptive. Abbie commented that she doesn’t want to count kilojoules or steps on a pedometer as this feels forced and doesn’t make her feel good. Instead she has decided to ‘focus on healthy things that are yummy and nice rather than only having a certain number of kilojoules’.

**Any other assistance or guidance received?**

**Anything else you think you need or would like?**

Abbie reported that even prior to being unwell she didn’t know much about healthy eating or how to cook. She moved out of home at 17 and survived mainly on chips and soft drink and things she could eat straight fro the tin. She feels that this was then exacerbated when she became unwell. Recently she has been watching what she eats and trying to be more healthy. She had tried a regimented meal plan as suggested by the dietician but found that this did not work for her. Instead she focuses on only buying healthy things from the supermarket. Abbie described debating with herself when tempted to buy unhealthy food in the supermarket. She believed however that it was necessary to give in sometimes to cravings, with a small treat, to prevent bigger blowouts. Abbie tries to cook a meal at home at least every second day. Her ability to do this is affected by low confidence and difficulty concentrating. Abbie reported that her cooking sessions with her case manager had been helpful and she has more confidence in cooking meals after these sessions. She still prefers to eat things that don’t require a lot of preparation and on the days in between when she cooks she reverts to eating from tins. Abbie eats out 1-2 times per month, usually when she catches up with a particular good friend. She doesn’t think about eating healthily when eating out as she says it is miserable and depressing to be thinking about it all of the time. She described an ongoing process of getting more healthy and is currently focusing on trying to increase her fruit and vegetable intake.
Any further changes you would like to make?

Assistance that would help you to do this?

Abbie reported that she used to be afraid of grocery shopping when she was first unwell as she found it too confusing and was often overwhelmed by all of the sensory input and would have to go home before completing her shopping. She reports that, with the assistance of her case manager she has developed strategies for managing her grocery shopping and she actually enjoys it now. The strategies she employs include; having a budget with a designated amount allocated to grocery shopping, making a detailed shopping list that she marks of as she goes, and adding up how much she has spent as she goes along so as not to go over her budget. She also makes sure she allows plenty of time to complete her shopping as she finds if she rushes she gets stressed and has to leave. Abbie said cost was a significant factor in the choices she made when grocery shopping. She would like to eat more fresh fruit and vegetables but finds that these are often too expensive and she must have frozen or packaged items instead.

Abbie reported that she has increased her exercise by walking more recently, trying to go for walks to the shops as often as she can. She usually walks alone although neighbours have invited her to go walking with them. She described having a mantra, which is a quote from a movie, that she repeats to herself to motivate her to keep going on her walks. It had been suggested to her that she try swimming or going to the gym but Abbie reported that she was too self conscious of her body to wear a bathing suit and didn’t like gyms and so concluded that walking was the best exercise for her at this time. She reported that she would like to do more exercise and suggested that it would help her if there was a walking group she could attend at the supported recovery service.
Appendix VI: Summary for Later Interview: Mary Interview Three

Meet Mary

Mary, who was 26 when we first met, was diagnosed with schizophrenia at the age of 21, having just completed her second year of university. She had been admitted to hospital on several occasions as a result of her mental illness in the few years since she had been diagnosed. In the time between our first and second meetings Mary spent three months in hospital during which time her medication was changed to Clozapine. Mary described feeling well supported by her parents, extended family members and friends who all lived nearby. She had a case manager and psychiatrist, both of whom she saw on a regular basis.

When we first met Mary was studying part time at university and living in private rental accommodation with two other students. She also hosted her own community radio program. Not long after the first interview Mary found out she was 5 months pregnant and at the time of the second interview her son was 7 months old. She was still living in the same accommodation but her flatmates were moving out and her boyfriend, the father of her baby, planned to move in. Her son was spending the days with her but overnight with her parents as Mary’s medication made it difficult for her to wake at night to care for him. Her primary activities were attending appointments and looking after her son but she planned to return to university the following year. Marys’ income was the disability support pension augmented by additional benefits for her son.

Managing weight gain as part of schizophrenia

Mary had gained a lot of weight following the onset of her illness. Unaware that she was pregnant, she considered herself to be very overweight at the time of the first interview. Mary also thought she was overweight at the time of the second interview. She attributed her weight gain to her medications. Mary described ‘always feeling hungry’ and habitually eating much more since the onset of her illness than she had
done previously. She found that the medications that caused less weight gain did not control her illness as well.

Mary was concerned about the physical health consequences of being overweight, such as the potential for developing heart disease and diabetes. She had developed gestational diabetes when she was pregnant and identified that this could predispose her to developing type II diabetes. She was therefore anxious to lose weight to prevent this.

Mary found that her weight made it difficult for her to walk for a long time. While she described the physical limitations she experienced as a result of her weight as ‘not too bad’ she feared that if she continued to gain weight she would not be able to do many of the things she liked to do. She also found that the weight affected her self-esteem and described avoiding mirrors and cameras because she didn’t like the way she looked. Mary believed that being overweight contributed to mental health problems.

Mary had made several efforts to lose weight during the time she had been living with schizophrenia and felt frustrated at her lack of success.

**Doing as much as I can**

Mary had made frequent efforts to lose weight since the onset of her illness by engaging in a variety of exercise regimes. In the past these had included walking, swimming, attending a gym and on one occasion a six month program with a personal trainer. At the time of the first interview Mary was going for walks five times a week with her father or flatmates and going to water aerobics with her mother and aunt. At the time of the second interview she was walking each afternoon with her son. While she felt she was doing the exercise that she could manage on both occasions Mary expressed that she would like to do more, specifically to walk further and more often.

On both occasions that we met Mary also described efforts to modify her eating to assist with her goal of losing weight. At the time of the first interview Mary identified that she would like to eat less and for what she ate to be more healthy. She had been trying to watch what she ate, ‘like a bit of a diet’ but found this difficult due to always feeling hungry. At the time of the second interview she described cutting down on
junk food and not going through the drive through so often. She also described some of the more healthy meal options that she had been preparing for herself at home.

**Doing what I know**

Mary remembered her psychiatrist telling her when she was first prescribed medication that it could cause weight gain but that she would have to take it anyway. He advised her to watch what she ate. Mary did not however understand just how much weight could be gained.

Mary described trying to comply with what she understood to be public health recommendations for exercise, doing 30 minutes on most days. She was also aware of healthy eating guidelines in the form of the healthy diet pyramid and considered this when making food choices.

At the time of the first interview Mary prepared her evening meals in collaboration with one of her flatmates and they ate at home most nights. Mary reported that she generally did not have any difficulty with this task.

**Doing it when I can**

Mary’s illness often interfered with her exercise plans. She found that it was distracting and made it difficult for her to concentrate and perform activities. She also occasionally experienced paranoia and had once been unable to leave the house for six months which meant that she could not walk for exercise. She also found that she was less able to manage tasks such as grocery shopping and meal preparation when she was unwell, due to difficulty concentrating.

**Doing what I can manage**

Mary had a weight loss goal which was, ‘not as light as I was’, and would require her to lose 10-15 kg. She had decided on this goal based on what she thought was realistic and achievable.

Walking was the exercise that Mary most consistently engaged in and of course was free of financial cost. It was however vulnerable to disruption by the weather as she didn’t go if it was raining. Her preferred option for exercise was
to attend a gym but she found this was too expensive. She also thought it would be helpful to work with a personal trainer in order to push herself more but also found that she was unable to afford this. Cost also affected Mary’s food choices. She described this as being one of the criterion on which her flatmate and she chose the meals for their fortnightly plan. She found also that she was restricted to buying Home brand or the cheaper brands.

**Keeping on doing it**

Mary described ‘not losing any weight’ as one factor contributing to her not continuing with an exercise program.

She described having some difficulty motivating herself to go for her walks the first time we spoke. However she found this was less of a problem when she had her son because she found, ‘It’s really good to get out of the house’.

Mary described using self-talk and avoiding temptation to manage her eating.

**Talking about it**

When we met for the second time Mary was being weighed each week when she went to see her psychiatrist and found this helpful in keeping her aware of her weight and its fluctuations in response to her actions during the week.

Mary described receiving a lot of encouragement from the hospital staff to exercise each day during her last admission when she was commenced on clozapine. Prior to this she identified that her parents were also helpful in encouraging her to exercise. She had experience of working with a personal trainer and believed that having someone like this to push her would be helpful.

**Having a plan**

When we first met Mary reported that she and her flatmate made a meal plan and shopping list each fortnight. She described writing the shopping list as helpful in making sure they didn’t buy things they didn’t need.

On each of the first two interviews Mary described having a routine for her exercise.
Doing it with someone

Mary found having someone to exercise with helpful for her motivation. At our first meeting she reported that her father or flatmates usually came walking with her. She found that she was less likely to go if nobody came with her. At the time of the second interview Mary was walking each afternoon with her baby. She reported feeling more confident and able to motivate herself at this time and was happy to go just with her baby if nobody else was available to come with her.

At the time of the first interview there were plans for her case manager to take her shopping and work with her on developing meal plans and shopping lists. Mary was unsure what benefits she might gain from this but thought it was possible she would be able to identify some healthy snack options she hadn't previously thought of or new recipes.
Appendix VII: Excerpt of Open Codes from Elizabeth Interview One

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### Appendix VIII: Early Categories

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### Appendix IX: Early Focused Coding

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<th>Doing as much as I can</th>
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<td>Doing what I can afford</td>
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<td>I just piled on the weight</td>
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<td>It’s a confidence thing</td>
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<td>Someone to get me going</td>
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<td>Having a plan</td>
<td>Budgets and shopping lists</td>
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<td>Keeping on doing it</td>
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During Elizabeths interview it was sometimes difficult to discern whether she was talking about what she did, or what she thought she should or would like to do. There were occasions however where it was clear that she was identifying things that she would like to do in response to the questions and these were sometimes expressed with increasing intent, formulating a clear plan.

The example of this with the most references and development was in relation to using a meal plan. This arose initially in response to a question re whether anyone else was involved in planning or deciding what she would eat during the week. She responded:

‘if I wanted to get help with like an eating plan or whatever, I could maybe talk to Lucy or Maiwell and help do up on a computer like a menu plan thing how you’ve got the days up the top and then morning tea, lunch, afternoon tea, dinner and that. And it’s worked out in a chart thing like that.’

So in this response she has identified what a meal plan would look like and who could help her if she wanted to have one of these. She then commented on how this would be helpful to her.

‘I think that would help me a bit. That way I know when I go shopping that I know I’ve got enough food for each meal.’

She came back to it again when asked later how far ahead she plans what she eats.

‘Well, if I want to do up a meal plan, it could be on the day that I do the shopping.’

So here identifying more detail re when it would be done. She again at this point suggested that she would like some assistance with this and that it would be helpful to her.

‘I would like some help with it.’

‘But if I had help with the meal plan it would be a lot easier.’

And finally later again when asked what she finds helpful in managing the task of grocery shopping she expressed this with intent.

‘I’m going to get someone from either Supported Recovery or Maiwell to help me to do up a computer meal plan, and get them to draw it up all on a computer for me.’

Other examples, although less protracted are;

In relation to making choices when eating out at a regular venue, when asked if she thinks about her weight or health when making decisions re what to eat when she is out for dinner.
'And I do think, because of this place, on the Monday they serve soup and the main meal, which is quite healthy. But on the Wednesday they have the main meal and the dessert so what I’m going to do when I do go there is just have the dinner and notify them that I don’t want the dessert. You get free bread and cakes. When it comes to bringing the cakes out, I’m just not going to get any. I might get a bit of bread if I’ve run out of bread on that particular day. That’s it. I think that’s a good strategy for me.'

While at the beginning she frames it as if she is describing what she already does, it becomes clear throughout that she is thinking about what she could do and by the end of the paragraph she is confirming that she is happy with her plan.

This was unforeseen and unplanned. As a researcher I am trying hard to supress the therapist side of me and my goal in asking the questions is simply to glean the participants’ thoughts and experiences, not to impact on their behaviour. But is this an indicator of what might be helpful in terms of intervention? Consider, recovery model, strengths based approaches such as solution focused therapy.

14/03/2010 5:28 PM

This phenomenon came up again in Faith’s interview.

At one point she commented that it had been helpful talking to me about her efforts to lose weight and manage her health, that while she had been taking these efforts seriously talking about it made her think she would be more focused on it from now on.

Faith: It’s good actually sitting here talking to you about it, just the whole lot of it. It’s like, okay, well, I’m going to take all this on board.

Kirsti: But you’re already doing it because you’re just telling me what you’re doing, really.

Faith: Yeah, I mean take it more - just I’ve started it - probably taking it more seriously. I’m taking it seriously but I could take it more seriously.

Later, when asked about whether she thinks about her weight when deciding on what to eat she reported that she hadn’t up til now but would in the future;

Kirsti: Okay, and when you make choices about what to eat, do you think about your weight when you make those choices?

Faith: Not really, but I’d like to from now on because it’s about thinking well how well do you want to be, isn’t it?

At another point in the interview she goes through a process of identifying something that she could do, but deciding not to and giving a rationale for this decision.

Kirsti: You’re happy with the changes that you’ve made to your diet or is there anything else that you’d like to do differently with your eating?

Faith: I can eat - yeah, I can cut down even more I think.

Kirsti: Is that something that you’re...

Faith: Maybe not, because I do enjoy my food. It’s just about eating healthy.
11/06/2010

Elizabeth, Interview two. Again during this interview there was evidence of Elizabeth having an idea of something she could do, which as the interview progressed turned into a plan of what she would do. This was in relation to accessing a gym.

So, initially she refers to an idea she has had ...

*Because I have also thought of going to the gym. I probably wouldn’t go that often because depends how dear it is, like a casual visit. Every now and then I might do that because they have got a gym near here.*

Then a bit later she identifies a course of action she might take in regard to this...

*I might compare the prices of a few of the gyms.*

And finally a plan for when she leaves the interview.

*I will see how much - when I leave here I might check out the one next door see how much their casual visit is. I wouldn’t have a clue.*

Again this is all without any active encouragement on my part.

It is worth noting also however that I asked her about the plan she had made in our last interview to get some help with meal planning and she had not followed up on this.
Appendix XI: Memo: Talking About It

*Memo - Talking about it*

6/7/2011

Some participants did talk to their case managers about managing their weight,

*Abbie: I do talk to my case manager about it. Yeah it's not really - it's not sort of a priority at the moment because I'm concentrating on TAFE and that kind of stuff.*

*Abbie: I think I spoke to my case manager and we, together, decided that it would be a good idea for me to see a dietician.*

*Donika: So it was something that you talked about with [case manager]? Yes, we talked about a lot of things.*

Others however did not,

*Faith: (Is it something that you ever talk about with your case manager?) No. No. It's something I should a bit to my case manager about.*

Some participants emphasised that what was particularly helpful was them being given the opportunity to do the ‘talking’ and the health professional listening rather than feeling that they had to impart information.

*Abbie: Maybe sort of instead of trying to enforce something like a meal plan, try to sort of listen to how the woman’s feeling. Because that will affect how they're going to stick to a diet or stick to an exercise regime. Because if the woman doesn’t feel like she wants to do it, or that it's important or not, she's not going to help. Yeah, listen, that's all.*

*Donika: (So [case manager] suggested that you go to the dietician?) Yeah. It was helpful too. Yeah, we just talked.*

*Nuela: and then talking about my dietary habits, before she told me any of the healthy habits, she asked exactly what I was doing. Just hearing myself say it, like I eat two bowls of cereal in the morning, felt like I was wrong for doing that. So the next day I tried to eat less. Then the next day I tried to eat less as well.*

*Nuela: It was a lot of me talking and realising before she said anything, oh I'd rather not admit to this but I do this and this and this...Yeah, someone sort of listening to me say what I eat was probably good. So they’re sort of checking up on - and they didn’t say anything while I was talking, they let me talk. Only sometimes saying something like, do you eat meat, and things like that. (So they're listening to you is important there?) Yeah. Instead of saying - I'll go, I eat two bowls of cereal, I keep on using that because I still do it. Then they'll say, you shouldn’t do that. Then I say, then I have full cream milk on my cereal, then they'll say, no, no, have skim milk. I hate skim milk.*
Participants identified that through being given the opportunity to talk about it they were able to identify themselves what they needed to do rather than have the health professional tell them (see memo on 'generating ideas').

*Faith:* Just talking about it makes me realise I've really got to start looking after myself properly. Definitely, I think it's time.

*Nuela:* and then talking about my dietary habits, before she told me any of the healthy habits, she asked exactly what I was doing. Just hearing myself say it, like I eat two bowls of cereal in the morning, felt like I was wrong for doing that. So the next day I tried to eat less. Then the next day I tried to eat less as well.

*Nuela:* Yeah, after having them listen to what I was saying and put in the appropriate questions, to make sure I was putting all my diet down, and then ask me how much I drink of water and coffee and juice and stuff, and alcohol if I was an alcohol drinker. Then that sort of made me realise that I was eating wrong and if I wanted to change it then I'd have to - change my weight I'd have to change the diet.

They suggested that it should be something that they have the opportunity to talk about regularly and frequently in order to maintain their motivation and attention to addressing the issue;

*Faith:* It's something I should a bit to my case manager about. If she's talking about it every - like once a month would be good - just solely on my looking after myself and exercising. It would be a good idea because it will just keep me - talking about it every month, well then that would be better than every few months. It would keep you motivated. So that is a good idea.

*Nuela:* But I think going more than two weeks without seeing anyone, you forget all of that stuff that you said. Because by the time it got to the next appointment I realised that I'd gone back to the bad habits of two bowls of cereal in the morning or lots of cheese and sugars and bad things.
Appendix XII: First Version of the Storyline

24/05/2010

Story from analysis so far

Below is a summary of the picture that is emerging from the analysis so far highlighting key categories.

The women described the **onset of their illness** as a distressing time when they had a sense of not really knowing what was going on and were getting used to (or not) the idea of having a mental illness. Their focus was on their mental health and dealing with or coping with that. It was at this time that they were usually started on antipsychotic medication and without exception they described feeling really hungry all of the time. They didn’t often connect this with their medications at the time although all did in retrospect. Many didn’t remember being informed that this was a side effect of their medication. All of them gained a significant amount of weight, becoming overweight or obese at this time.

They described a range of **effects of being overweight**. Most commonly discussed were the health problems that could, and for many of the women were beginning to result from being overweight. The women were aware that overweight was associated with diabetes and heart disease in particular. They also described experiencing difficulty doing physical activities because of their increased weight, such as walking long distances or climbing stairs. A number also described impacts on their self-esteem and talked about hating to see themselves in the mirror. Associated with this was their disappointment with not being able to shop in regular women’s clothing stores and having difficulty buying clothes that they like and that fitted them. One participant also described feeling that she was discriminated against in the context of gaining employment and spoke of the dual stigma of being overweight and having a mental illness.

The women described reaching a **critical point**, or in some cases points, in their lives where they decided that they needed to do something about their weight and or their lifestyle. In some cases this was prompted by another person, their doctor, case
manager, or relative while for others it was a realisation that occurred to themselves without any external prompting. They all had at least a basic awareness of what they would need to do to lose weight, i.e. eat less, eat more healthy and exercise more and many had, at least for a period of time, taken such actions.

Participants identified a range of healthy living practices that they had, were at the time of the study, or planned to, implement to improve their dietary intake. Most commonly discussed were efforts to reduce the amount they ate, with participants talking of reducing their overall intake, having smaller portion sizes and trying to cut down on the amount of unhealthy foods they ate. The timing of meals was an issue for many and they variously identified a need to begin eating breakfast, eat at regular times and not eat too late at night. Participants also discussed the importance of including more fruit and vegetables in their diets.

They also had plans to or were exercising, or had done so in the past. For most their exercise consisted of walking. While for some this was incidental many also walked for the purpose of exercise. Other common activities were swimming and going to the gym. One participant played team sports.

They identified a number of supports that enabled them to, or they thought would enable them to, carry out these healthy living practices. Most often these supports were the actions of others including, going with them (particularly for exercise), encouragement and practical assistance such as providing transport.

The primary expected benefit from engaging in these healthy living practices was weight loss. Most had achieved some weight loss, and some had achieved significant amounts. They also identified other benefits that they either had, or anticipated they would, experience including feeling better and improved mental health.

Participants also identified many challenges that interfere with their ability both to engage in healthy living activities in the way they would choose, and also to sustain any changes that they do make to their lifestyle. Some of these challenges were a direct result of their illness such as, ongoing symptoms, acute episodes and medication side
effects. Other intrapersonal challenges identified included motivation and issues around confidence and self esteem. There were also external issues however, in particular financial barriers such as the cost of gym membership or involvement in weight loss programs, or even just the cost of healthy food at the supermarket.

As well as the supports identified above participants also talked about a number of strategies they employed to overcome specific challenges. A number of strategies were identified to address the financial challenges experienced including the use of a budget, meal planning and the use of a shopping list to manage grocery costs and in many aspects of their lives choosing less expensive options. Participants also described using a range of cognitive strategies to manage challenges, from avoiding satisfying cravings for unhealthy foods to boosting confidence.

Their ability to manage activities of daily living such as grocery shopping and cooking impacted on their ability to follow through with intentions for healthy eating.