CONSUMER PERSPECTIVES ON THE SUNNYBROOK
PROGRAM OF ASSERTIVE COMMUNITY TREATMENT (SUNPACT). IMPLICATIONS
FOR PROGRAM DEVELOPMENT AND EVALUATION.

by

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Abstract

Consumer perspectives on the Sunnybrook Program of Assertive Community Treatment (SunPACT). Implications for Program Development and Evaluation.

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The present study examined the subjective experiences of individuals living in the community with a severe or persistent mental illness receiving services from the Sunnybrook Program of Assertive Community Treatment (SunPACT). The researcher employed McCracken’s (1998) Long Interview Method to interview a sample of 8 clients from SunPACT. The aim of this research was to explore client perspectives on their experiences of SunPACT and their perception of its impact on their quality of life. The findings from this study overlapped with the literature, as well providing new and vital information in the implementation and monitoring of quality of care of an ACT model. This research demonstrated that clients experience the effects of their treatment differently, and therefore, understanding client feedback is imperative to understanding how to maximize treatment benefits and provide effective services. All participants spoke highly of their team and services. Specific details about their experiences are outlined. Implications for social work practice are discussed.
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CHAPTER 1: INTRODUCTION

Scope of the Problem

The Assertive Community Treatment (ACT) model was developed in the late 1960s in Madison, Wisconsin. This model was developed to treat clients who were considered difficult to engage in treatment, and who had a recorded history of a so-called ‘revolving door’ cycle of admissions to hospital where the client would engage in a frequent admission-disengagement-readmission process (Allness & Knoedler, 2003). Treating clients in the community was seen as an alternative to recurrent hospital admissions, however, it seems the effect on one's daily living and improvement in the community setting is less clear and underreported (Marshall, Gray, Lockwood, & Green., 1997). Assertive Community Treatment (ACT) is a client-centered, recovery-oriented mental health service delivery model that provides treatment to individuals with severe or persistent mental illnesses1 in the community. There has been substantial empirical support for the positive effects of ACT models, and their role in helping individuals being facilitated successfully into community living (Bond, Drake, Mueser, & Latimer, 2001). After ample research in Madison and at other replication sites, the ACT model had proven to decrease the time persons with severe and persistent mental illnesses spent in hospital, as well it helped to facilitate the community living and psychosocial rehabilitation of these individuals (Jacobson & Curtis, 2000). However, whether or not one’s subjective experience of quality of life had changed since receiving services from an ACT model was not as well documented or researched.

Research has shown that since the “de-institutionalization era of mental health care” programs have been developed to treat clients in the community. The emerging empowerment

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1 The term “severe and persistent mental illness” is used throughout this document to reflect its common usage in the literature addressing assertive community treatment.
movement has also contributed to more community care in that the focus of receiving health care relates to the autonomy of clients (Chodoff, 1983). This change has been reported to occur from a paternalistic model of the therapeutic relationship where as it was considered that the ‘doctor knows best,’ to a more collaborative relationship where clients are seen as the expert in their own illness process (as cited in Watts & Priebe, 2002, pg.440). This new empowerment era can be considered ‘post-psychiatry’ in that there is a shift from the traditional psychiatry, which appeared to be more medically oriented and coercive, to now clients taking control, thus redefining the role of the professional (Bracken & Thomas, 2001). The Recovery Model emphasizes the importance of hope, autonomy, self-determination and consumer participation when developing evidence-based approaches to mental health care (Frese, et al, 2001). Often and traditionally individuals with a mental illness were given a diagnosis and a prognosis for a life lost. In the recovery model, clients are encouraged to hope for a future and optimally functional life. This entails incorporating their illness into their lives and not letting it run their life (O’Connor & Delaney, 2007). Essentially, this new ideology emphasizes that the voices of survivors and consumers should be the main focus in treatment of individuals with a severe and persistent mental illness (Bracken & Thomas, 2001).

When conducting research on outcomes of implementing an ACT model, researchers are inclined to report on treatment compliance, decrease in hospitalizations, and the economic gain to the government in treating clients with a severe and persistent mental illness in the community. For instance, it may be less costly for mental health systems to shift individuals to a less intensive service, such as assertive community treatment, than to maintain treatment in an inpatient hospital setting (Assertive Community Treatment Literature Review, 2000). The fact that clients are using hospitals and emergency rooms less, and are maintaining treatment
(whether medication or therapy) is a great outcome. These results can be measured quantifiably and they can give evidence to the fact the clinicians are doing their job. But the most important factor that can be overlooked and one that is hard to measure, is how happy are the clients? How do the clients view their treatment process? Do the clients think it has benefited their life and how? After all, at the end of the day is this not what matters most? By asking clients we can gain a look into how clients view their life in the context of their illness and treatment. We can understand the areas the clients’ gained most from and what areas they would like to see changed. This vital information can only be obtained through asking clients receiving the services. From the client’s lived experience we can get a more accurate and informed account on how well a treatment modality is working for a certain population group. Furthermore, asking the clients for their feedback empowers clients to feel that their opinions and feedback matters and thus implies they can be and are active members in their treatment process. From this analysis there is a hope to gain recommendations and suggestions for using an ACT model with other populations with mental health concerns as well as recommending the integration of clients by becoming active members in their treatment team. Previous research has shown that clients living with a severe and persistent mental illness feel their thoughts and feelings have been discounted and seen just as symptoms, rather than expressions of their subjective experiences of living in a world with a mental illness. Clients reported feeling they are not being listened to, and thus this causes their sense of separation and estrangement from society (Horowitz, 2002).

The majority of existing studies found that consumers and their families were more satisfied with assertive community treatment than with other types of intervention (Bond, Drake, Mueser, & Latimer, 2001; Burns, & Santos, 1995). Using outcome measures to evaluate and track consumer gains and program success is critical for effective implementation of an evidence-
based practice. Outcomes are identified that can be monitored as part of routine clinical practice. The tracking of outcome measures is used as a feedback mechanism for clinicians, supervisors, and administrators. Researchers propose that “given the variations among assertive community treatment programs in research studies and in actual practice. It would be helpful to program planners to know which core components are critical for effectiveness and which can be altered to fit local needs without affecting outcomes” (Phillips, Burns, Edgar, Mueser, Linkins, Rosenheck, et al., 2001, pg.773 ). The following study will address what are the critical components to effectiveness for individuals with a severe and persistent mental illness receiving treatment from the Sunnybrook Program of Assertive Community Treatment. The core components will be revealed through one on one client centred interviews, where participants will tell the researchers what are the core components to the care they receive by looking at several main areas of the ACT model: the client’s understanding of SunPACT, medication management, housing situation, hospital versus community experience, substance use management, the team dynamic and implications for the therapeutic alliance, family or social involvement, symptom or illness management, justice or legal involvement, social supports (employment, recreational, or volunteer work), financial management, negative experiences, future care (fears or desires) and, finally, overall quality of life. Essentially, the researcher aims at understanding whether these areas have been addressed in the treatment of clients from a program like SunPACT and whether these areas impact one’s subjective perception of quality of life.

Unfortunately, it seems to be that users’ perspectives on ACT have rarely been studied, and as a result it is unclear how clients experience an ACT model. This study will aim to seek consumers’ voices on what treatment means to them and whether or not an ACT model has
provided individuals with a severe and persistent mental illness, living in the community with a satisfactory quality of life. Researchers have found that the ACT model has the therapeutic goal of increasing personal autonomy; however, there is no specific evidence to support whether this has occurred based on the client’s perspective (Watts & Priebe, 2002). For a model that promotes autonomous practices, it seems the clients are not getting the personal autonomy to share how they think ACT has improved their lives and living situations. This will not be possible unless we have more information about the perspectives of clients receiving treatment from an ACT model. Furthermore, from this we can gain more information on what clients view as quality of care, and thus quality of life for individuals living with a severe and persistent mental illness in the community. The thesis will focus on the integration of the findings to the literature, and implications for practice and policy.

**Sunnybrook Program of Assertive Community Treatment (SunPACT)**

The SunPACT Program has been in operation for 10 years and serves a clientele list of 72 clients in total. The SunPACT program adheres to an ACT methodology in that it consists of a multidisciplinary team approach providing client-centered individualized support and rehabilitation to persons with severe and persistent mental illness (primarily schizophrenia and bi-polar disorder) living in the community. The members of the team work interchangeably providing services such as, health teaching (primarily in terms of medication and symptom management), crisis intervention, counselling (individual and family), assistance with activities of daily living, assistance accessing food, social support, help with legal issues, help with substance use, social skills development, vocational rehabilitation, developing leisure and recreational opportunities (excerpted from SunPACT Program Brochure). It provides services to clients in the greater Toronto area and the client-to-staff ratio is about 12:1. SunPACT claims a
mission to support their clients to live in the community and achieve their identified goals. They also claim to enhance their clients’ quality of life and to help their clients maintain independence; “We seek to improve the lives of people by helping to create more informed, effective and responsive communities and systems of care” (taken from SunPACT brochure). SunPACT is made up of a team of clinicians that includes, social workers (3) (including the program coordinator), psychiatrists (2), registered nurses (3), occupational therapists (2), a vocational counselor (1), and a peer support worker (1). The team also has a program assistant. They aim to provide continual care, resources and information to their clients. The team offers an intensive, outreach approach seven days a week.

The goal of SunPACT and ACT like modeled teams is to serve persons with a severe and persistent mental illness who have complex needs related to the client’s long term and serious mental health issues, in the community and in their homes. The clients from SunPACT have also experienced difficulties living in the community and require more one to one support. The pertinent goals of an ACT team like SunPACT involve reducing hospital admissions for psychiatric treatment, frequent use of emergency departments and/or crisis services, re-occurring substance use difficulties, inability to follow through with structured programs, extreme or long term isolation, inability to maintain stable housing and finally, involvement with the criminal justice system. Furthermore, the SunPACT team values the empowerment of individuals in meeting their personal goals through promoting autonomy and respecting self-determination of each client. The team aims to enhance the quality of life of each person through lessening or eliminating the debilitating symptoms of mental illness so that clients can function in the community. The service plans are created on an individualized basis in order to meet the unique needs of each client and every plan is developed and reviewed with each client.
Purpose of the Study

The objective of this study is to seek the neglected perspectives of individuals receiving services from an ACT model, and to convey those views to the existing literature and existing ACT teams, in particular to SunPACT (Sunnybrook Program of Assertive Community Treatment) by investigating the following questions:

• How do individuals living in the community with a severe and persistent mental illness define ACT and their needs from an ACT team?
• What are the experiences of clients receiving treatment in an ACT model?
• How do they feel about being involved with SunPACT?
• What do they believe is the impact it has on their life? How does it contribute or take away from what they would consider a good life?

The research will provide the Sunnybrook Program of Assertive Community Treatment essential information for the development of interventions that are more effective, and more empowering, for people living with a severe and persistent mental illness in the community. This research will shed light on the experiences of clients and whether or not an ACT model has provided them with the resources to live a satisfactory life in the community as it intended. The study will use a qualitative design, where semi-structured in-depth one-on-one interviews will take place with a group of clients from Sunnybrook’s Program of Assertive Community Treatment (SunPACT) in Toronto, Ontario.

The research proposes that ACT models like SunPACT do contribute to a client’s quality of life. In this research the clients will be expressing the exact areas in their life that are contributing to their perceived quality of life. For example, how does ACT contribute to your quality of life of living in the community? A qualitative design can help reveal new themes to inform health care practice. This is an opportunity to obtain the perspective of the client receiving the treatment. This type of knowledge can help enhance our existing ACT models and increase our understanding of how individuals with a severe and persistent mental illness live in the
community. The main benefit of this study lies in the gathering of information that can be applied to SunPACT and also for other existing ACT teams. It will also give clients a chance to speak up about their needs and make them the focus of the treatment and not the treatment the focus. Key terms used in this study are defined in Appendix E.
CHAPTER 2: REVIEW OF BACKGROUND LITERATURE

There is a body of evidence and literature in which researchers have shown the efficacy of Assertive Community Treatment (ACT) teams. The evidence for the effectiveness of ACT is quite consistent across numerous reviews that have appeared in the literature (e.g., Bedell, Cohen, & Sullivan, 2000; Bond, Drake, Mueser, & Latimer, 2001; Latimer, 1999; Marshall & Creed, 2000; Mueser, Bond, Drake, & Resnick, 1998; Ziguras & Stuart, 2000). In a study conducted by Bond et al. (2001), 25 randomized controlled trials of ACT were summarized and they concluded that, compared to usual community care, ACT is highly successful in substantially reducing psychiatric hospital use, engaging clients in treatment, increasing housing stability, and moderately improving symptoms and subjective quality of life. Research has shown that typically clients are satisfied with their treatment teams; however, the specific areas they are satisfied with have not been fully researched.

In Ontario it has been found that patients who repeatedly visit a general hospital emergency room (ER) are those seeking either a mental health intervention, or they are a client with a mental health diagnosis, but are seeking an intervention related to social stressors, like housing, finances, or legal issues (Coristine, Hartford, Vingilis, & White, 2007). Research shows that in 2006-07, 66% of individuals who received services from an ACT team had no days spent in hospital (Ontario ACT Data Outcome Monitoring Report, 2006-07). In addition, it costs the government $6000 to support a client in the community, whereas it costs $8-10 000 to support a client in the hospital (Health Canada: A 10-Year Plan to Strengthen Health Care, 2004).

Due to the lack of resources in the community addressing social stressors, ACT teams were developed to provide more frequent support to their clients who require such support. The current national concern about the cost of health care has increased efforts to decrease cost and
increase efficiency. This has greatly stimulated interest in moving consumers from costly, high intensity programs to less costly and less intensive treatment programs. The result of doing this has not been systematically studied (Drake & Burns, 1995; Burns & Santos, 1995). It could be concluded that ACT is one of the most extensively researched models of community care for people with severe mental illness; however, users’ views of their needs and the treatment team have rarely been studied. Furthermore, there could be very differing perceptions of ACT treatment as individuals present with various personalities, illness types and needs. Thus, it is imperative to understand individual client’s needs as it could lead to more effective services and outcomes. The following is a summary of the literature exploring clients with a severe and persistent mental illness receiving ACT and their experiences of ACT teams. This review will demonstrate the need for more research in this area as well as the need to increase our understanding and incorporation of clients in their treatment service provisions so that effective teams can be developed in the future.

This chapter is presented in 8 sections. The first section will discuss previous literature which describes the Assertive Community Treatment Model. The relevance of this section is to give the reader an understanding of how the ACT model was developed and the major areas it aims to focus on in the treatment of individuals with a severe and persistent mental illness living in the community. The second section reviews literature on clients’ experiences of being treated by an ACT model. This will demonstrate the lack of detailed research in this area using client perspectives. The third section speaks to the research that has been conducted on the quality of life of clients receiving treatment from an ACT model. This will demonstrate whether or not ACT models have an impact on quality of life. The fourth section speaks to the research on social functioning, and whether there is an impact on clients social functioning when being
treated by and ACT team. The fifth and sixth sections will describe the recovery, psychosocial rehabilitation and empowerment models. These models are the foundations of an ACT modality. They are also the guiding theoretical frameworks for the research methodology of the present study. These sections will give the reader background information on what these models entail and how they relate to the present study. The seventh section discusses the possible negative perceptions of ACT that have been addressed by some researchers. This section will review the negative responses to ACT models and demonstrate that there is no concrete evidence for these views. Finally, the eighth section will discuss the research questions that guide this study.

The Assertive Community Treatment Model (ACT)

The term Assertive Community Treatment (ACT) or the Program for Assertive Community Treatment (PACT), describes continuous treatment teams or intensive psychiatric community care teams that encompass a multidisciplinary team approach providing client-centred, individualized support and rehabilitation to persons with severe and persistent mental illness living in the community (Allness & Knoedler, 2003). The ACT model was developed from the work led by Arnold Marx, M.D., Leonard Stein, M.D., and Mary Ann Test, PhD. They worked on an inpatient research unit of Mendota State Hospital in Madison Wisconsin in the late 1960s. It was found that after clients were treated in the hospital, with 24 hour care and support, and discharged, clients did not do too well in the community and were often found back in hospital. It was hypothesized by the researchers that lessening clients’ symptoms of mental illness was just as important in the community as in the hospital. To prove this the researchers moved a hospital ward treatment staff into the community and called this the Program of Assertive Community Treatment (PACT). They would maintain a multidisciplinary team, 24 hours staffing, and provided intensive treatment, rehabilitation and support services to clients in
their homes, on the job or in social settings (Allness & Knoedler, 2003). Some of the services provided by assertive community treatment teams include, rehabilitation in relation to daily living, family involvement, employment opportunities, health promotion and education, medication support, housing support, financial management, and counselling, either individual or family (Allness & Knoedler, 2003). The team members collaborate to integrate various interventions and each intervention is carefully monitored to ensure it is meeting each client’s individual needs. The treatment is facilitated by a daily review of each consumer’s status and through joint planning by the team members.

To examine the longitudinal effects of ACT, researchers examined and compared the functioning of individuals with schizophrenia and other mental illnesses, using the global assessment of functioning (GAF) scale (Diagnostic and Statistical Manual of Mental Disorders, 4th ED, Text Revision (DSM-IV TR), pg. 34) following enrollment in an ACT model. The GAF scale is based on the clinician’s objective judgment of level of functioning. The scale measures social, occupational and psychological functioning of individuals with a mental illness. The scores were completed every 6 months over a three year period. Results showed that subjects functionally improved while attending ACT and continued to improve significantly at 4-6 months and 34-36 months into the program (Tibbo, Joffe, Chue, Metelitsa, & Wright, 2001). Overall, the results showed that the enrollment of clients into an ACT program helped to improve the functioning of individuals with a severe mental illness.

ACT models are often based on the principles of a psychosocial rehabilitation, and a recovery model for persons who need constant support in the community, and who aim to reduce the need for recurrent hospitalizations. As well, these models aim to provide holistic approaches to help clients achieve fulfilling lives in the presence of a mental illness. In Ontario, there are
approximately 72 teams (Ontario ACT Data Outcome Monitoring Report, 2006-07). Increasingly, clients are being referred to such services and many areas in Ontario are turning towards implementing such teams. The research on efficacy of ACT teams when working with clients with severe and persistent mental illness has shown positive trends in reducing hospital stays and improving the lives of such individuals; however, there is a paucity of research in the area of understanding client’s perspectives of their treatment and quality of life, when related to the type of services they receive in the community. George, Durbin, & Koegl (2008) argue that it is necessary to attend to issues of ongoing feedback on practice for all ACT teams in Ontario in order to provide better implementation of its services. Furthermore, consumer satisfaction has not been studied thoroughly and there has been a lack of research on actual practice which could be helpful to mental health professionals and program planners in order to know which core components are critical for effectiveness (Phillips, Burns, Edgar, Mueser, Linkins, Rosenheck, et al., 2001).

*Research on Clients’ Experiences with an Assertive Community Treatment Model*

It has been found that services provided in the home can be more appropriate and less expensive than acute hospital care. Greater use of home and community care services can reduce wait times for acute hospital beds by making beds available for those who are more acutely ill, can provide choices for end of life care, and be an effective option for some patients with chronic mental health concerns (Health Canada: A 10-Year Plan to Strengthen Health Care, 2004). A typical hospital stay in Canada costs about $7000 per patient (Canadian Institute for Health Information, 2008). Mental or behavioural disorders are among the top 10 most expensive conditions to treat and account for 6.6 percent of costs (Canadian Institute for Health Information, 2008). Research has shown that ACT is effective in reducing hospitalization, it is
no more expensive than traditional care, and it is more satisfactory to consumers and their families than standard care (Phillips, et al., 2001). There seems to be a lot of research on cost effectiveness and reduced hospitalizations, which in turn affects costs to the government; however, there is little evidence on the client perception. The following is a report on the various research studies conducted on the subjective perceptions of consumer’s from ACT teams.

A phenomenological qualitative research study was conducted in 2002 by Watts and Priebe. They interviewed 12 clients using a grounded theory approach. The study’s aim was to understand and demonstrate how an ACT model can provide social control while also providing therapeutic change. The results of this study were negative. They demonstrated that due to clients’ having a lack of insight, and a previous history of rejecting any early intervention they had disengaged from ACT services, and as a result had all been subject to coercive interventions (Watts & Priebe, 2002). It was found that these coercive interventions the clients had previously experienced with psychiatric services resulted in an attack on their identity. The client’s reluctance to agree and maintain services was due to previous encounters with psychiatric services that were negative and coercive, and not due to the ACT program itself. The findings from this study demonstrated that the clients had experiences that foregrounded the role of power in treatment and this power imbalance needed to be further explored and incorporated when examining the ethics of community psychiatry. Furthermore, this study presents an account that frames the dilemmas in providing community services to clients with a mental illness as being due to the nature of the clients and their “difficulty to engage.” This stance is highly disempowering and implies that the problems in community psychiatry are due entirely to the clients, when the organizations should be looking at their practices and provisions of services as possible problem areas as well. Finally, a major finding in this study was the feedback from
clients that suggested ACT was a vital component in establishing social interventions. These interventions were seen as helpful in reducing anxiety through coordinating a wider social environment, providing help with housing, and providing social contact (Watts & Priebe, 2002).

In a study by Prince and Gerber (2005), 92 interviews were conducted with clients from four ACT teams across Eastern Ontario. Three aspects of community integration were examined, physical, social and psychological integration in relation to one’s subjective perception of well being. The results demonstrated that social support and social integration were most important to clients. This was demonstrated in the acceptance attitudes from their neighbourhoods, housing and house mates. Also, facilitating opportunities that enhanced one’s feelings of self worth, minimizing psychiatric symptoms and providing regular financial support were considered to be related most to the overall subjective well being experienced by clients of assertive community treatment services (Prince, & Gerber, 2005).

In a study using a multisite, participatory research methodology that emphasized the active participation of the participants of the research project in all aspects of the research process (Rogers & Palmer-Erbs, 1994), the researchers conducted six focus groups with clients from four assertive community treatment teams in south-eastern Ontario (Krupa, Eastabrook, Hern, Lee, North, Percy, Von Briesen, & Wing, 2005). There were a total of 52 participants. The results indicated by and large that the participants commended the services they received. The results showed consistency in descriptions of the services they received, such as, the assertive approach, individualized services, the team approach, flexible, 24 hour support, clinical competence, managing daily life in the community and upholding their rights (Krupa et al, 2005). The participant’s descriptions of their experiences were consistent with the assumptions underlying the structure of ACT which is believed to produce positive change. Finally, clients
described ACT as “assertively encouraging them to actively learn about and manage their illnesses, to understand and maintain their stability in the community and to anticipate and solve problems that, if left unchecked, could rapidly escalate” (Krupa et al., 2005, pg. 23-24). These practices are closely associated with the process of a recovery oriented framework in that the focus is on the capacity of the individual to control the course of their illnesses (Jacobson & Greenley, 2001). These practices are also empowering because they “promote hope, invite possibilities, and finally facilitate the ability to get on with life” (Krupa, et al., 2005, pg. 24).

Finally, there has been evidence among clients of Assertive Community Treatment teams suggesting that the integration of persons with a psychiatric diagnosis living in the community has faced barriers in terms of stigma received from the community. This can be seen in the experiences of inadequate housing, poverty, and unemployment. These were all seen as common barriers to community integration in a study that examined 95 clients from four ACT teams located in Eastern Ontario. The researcher’s aim was to investigate the relationship between perceived stigma and community integration (Prince & Prince, 2002). Their findings demonstrated that ACT clients believed their community members would reject them; this was related to their responses around feeling a lack of “sense of belonging” in their communities, especially among those who had less social supports and who had greater psychosocial skill deficits (Prince & Prince, 2002). This study suggests stigma has implications for self esteem and life satisfaction.

*Research on Quality of Life*

The use of client-elicited domains suggests that this approach to measuring subjective quality of life may provide more information to resolving some of the conceptual and practical issues associated with understanding and measuring the impact of community based programs
like ACT on clients with serious mental illness (Prince & Prince, 2001). Prince and Prince (2001) state, “there exists a pressure to account for mental health services and with the limited resources to provide these services; there is a great need to assess the care provided to psychiatric clients in the community” (Prince & Prince, 2001, pg.1006). Baker and Instigliata, (1982) have suggested that there is a focus on client “quality of life” as the desired outcome offers the most reasonable approach to evaluating community based services for individuals with a mental illness. The assessment of quality of life has typically focused on areas such as living situation, family and social relations, financial situations, work, leisure activities and health (Prince, & Prince, 2001). The quality of life paradigm suggests multiple variables which may affect one’s life. The variables include psychological, economic, social, as well as health in relation to the overall wellbeing of the individual (Prince & Prince, 2001). Sartorius (1992) stated that measuring quality of life should be at the centre of rehabilitation aimed for individuals with severe and persistent mental illness. Furthermore, he argued that the subjective perspective of quality of life by clients would be a vital factor in evaluating the success of rehabilitation efforts (Sartorius, 1992).

Hansson (2006) conducted a review of scientific literature on the quality of life in individuals with severe and persistent mental illness. Hansson (2006) found that subjective quality of life in people with a severe mental illness is not highly related to external life conditions. The major areas that were related to the determinants of quality of life were psychopathology, most importantly symptoms of depression and anxiety, as well as aspects related to social networking. Personality related issues like self esteem were also rated high. Finally, when looking at literature on comparative studies, Hansson (2006) found that clients in community care settings had a better subjective quality of life than clients in hospital settings.
(Hansson, 2006). Furthermore, Hansson (2006) concludes that to improve the subjective quality of life in individuals with a severe mental illness efforts should be made to pay more attention to assessment and interventions against unmet needs.

In a research study by Test, Greenberg, Long, Brekke, and Burke (2005), the authors examined the construct validity of a brief self report Satisfaction With Life Scale (SWL) (Test, & Stein, 1978). This is a 21 item version of one of the earliest measures of subjective satisfaction with life used with individual with serious and persistent mental illness which was developed to measure client satisfaction with life since being with an assertive community treatment team. The scales measure four domains: living situation, social relationships, work, self and present life. The scale was administered during three studies, two in Los Angeles, and one in Dane County Wisconsin. In all three studies the SWL scale was administered in face to face interviews with participants at their time of entry and then at subsequent six month intervals. It was found that affective symptom in the Wisconsin sample were negatively correlated with all the SWL subscales and have the strongest negative relationship with the report on self and present life. All participants reported that living in independent situations, such as apartments in the community, had higher satisfaction with their living situations than those living in restricted settings like hospitals. The number of clients who had a symmetrical social relationship (giving and receiving emotional support) reported higher satisfaction with social relationships, as well in relation to satisfaction with self and present life. Finally, those involved in competitive jobs expressed higher levels of work satisfaction than those who were unemployed. This could be the result of having employment leads to having access to more resources and better financial stability, which could lead to higher levels of satisfaction with their living situation. Generalizability of the study results is limited since the participants in the Wisconsin study focused on young adults, relatively
early in their course of their illness, compared to the participants in the Los Angeles study, and there was little ethnic diversity in all three studies.

Research on social functioning. The most noted factor researchers aim to investigate when assessing the outcome of community treatment models is social functioning. Social functioning can be considered the extent to which an individual has social bonds and is satisfied with them (Angell, 2003). This can be difficult for individuals with a severe and persistent mental illness. This research aimed to understand how clients view their social networks. Angell (2003) looked at an analysis of quantitative data and qualitative data related to understanding the social relationship development among ACT clients. This project aimed at examining the relationship and level of changes in clinical symptomatology to changes in social relationship functioning. The qualitative component of this study used a grounded theory approach involving in-depth, semi-structured interviews with 20 subjects. The interviews were designed to understand clients’ perceptions of what factors facilitate or impede the development of social relationships, as well as their own role in that process. The results of the quantitative study provide strong support for the role of clinical symptomatology on social relationship outcomes; however, it did not provide any support for the role of environmental factors, like housing or neighbourhood they lived in which were reported as factors or barriers to the development of social relationships.

In a comparison of consumers who have achieved stability in ACT and Clubhouse Programs, they interviewed 51 clients from the two programs who reported that they were less lonely, achieved stability, and community integration. This was contrary to the professional’s perception of their clients (Stein, Barry, Van Dien, Hollingsworth, & Sweeney, 1999). It appears the participants were satisfied with having few social networks. There were more participants
with employment in the clubhouse model, which could be due to the fact ACT models serve clients with more severe illnesses and needs.

Finally, the last section of the literature review will be a synthesis of the theoretical literature which this research project has used for its purpose and analysis, reflecting their importance in the development of ACT treatment as well. The theories this research project used to execute and understand the perceptions of each client’s care from an Assertive Community Treatment model involve the Recovery, Psychosocial Rehabilitation and the Empowerment model. The recovery model was selected because ACT teams were devised from a centred, recovery based model, and therefore to understand ACT models one must understand the recovery model. The psychosocial and empowerment models were also used to conceptualize the rationale of using client-centred research. The review is organized to reflect the overlap between these perspectives. Client centred research encompasses the inclusion of its participants as the main element of the research endeavor and results (Prince & Prince, 2001). Through the use of the participant as the main informant in the interview process, the participant can control what they want to achieve from the research. Furthermore, the research itself was a way to give participants the opportunity to talk about their needs from their treatment team and not vice versa. Thus, it is of utmost importance to make them the centre of the research project. The following is a report on the theoretical basis of these models.

*The recovery and psychosocial rehabilitation model.* Dr. William Anthony can be considered the founder of the psychosocial rehabilitation movement. He emphasized that “recovery can occur without professional intervention and that the aim of professionals should be to facilitate this natural process” (Anthony, 1993, pg. 531). Anthony (2003) views rehabilitation as something that must be done “with” clients, not “to” them. He believes that people can make
meaningful choices. Anthony (2003) continues to claim that individuals understand people living with a mental illness as those who set unrealistic goals and cannot hold demanding jobs. This has resulted in professionals taking choices away from consumers. In his words, “if people are allowed to choose they may request something that demands we change our actions or programs” (Anthony, 2003, pg. 23).

The Psychosocial Rehabilitation model (PSR) originated in Boston University. This model has shaped the development of many community based programs and services (Jacobson & Curtis, 2000). The basis of the model is the view that people living with a mental illness can recover even though their illness is not cured. The PSR model focuses on enhancing functional ability and attempts to look at all areas of a person’s life. This includes their strengths, resources, and barriers. The model seeks to improve one’s life by focusing on four main life domains. These are the practical skills of personal self care, home management, relationships and use of community resources, and finally leisure, education, and employment. The goal of implementing this model is to help individuals regain social functioning despite their living with symptoms, limitations, and taking medications. Areas such as housing, employment, financial gains, and social gains are vital to the rehabilitation process. These are often the major components which when not put in place can have a negative effect on one’s functioning. The fundamental principles of the PSR model include emphasizing the need for individually tailored interventions, understanding the need to adapt the individual’s capacities to environmental realities or that the environment must be changed to suit the capacities of the individual, it builds on the individual’s strengths and aims to restore hope. It emphasizes the individual’s vocational potential and extends beyond work activities to encompass a full array of social and recreational activities, finally the PSR model suggest that clinicians and family actively involve the individual in their
own care which entails an ongoing process that must continue over time (Jacobson & Curtis, 2000).

In a research study conducted by Brekke and Long (2000), they investigated the degree to which intensity and longitudinality of services were related to improvements in one’s subjective experience and clinical outcome. Over 100 individuals with a diagnosis of schizophrenia were followed for 36 months and data was gathered every 6 months over a three year period. The results demonstrated that greater service intensity and long term services were associated with client self esteem. There was evidence for rehabilitative change related to clinical, functional, and subjective experience outcomes; and finally, there were no reports demonstrating the impact of the program on symptom deficits (Brekke & Long, 2000). The psychosocial rehabilitation model believes in the client’s personal capacity for growth, and the implementation of services built on focusing on individual needs and preferences. Clients require ongoing evaluation to make sure continuous progress occurs; however, there is a lack of research on tools or strategies used by service providers to evaluate whether the progress represents the needs of each client, and thus their satisfaction of it.

The empowerment – recovery model. An empowerment theoretical view encompasses the idea that knowledge primarily comes from clients and that, to be ethical clinicians, we should use this knowledge according to our clients’ wishes in order to empower them further (Payne, 2005). There are two main premises to an empowerment approach, one is that clinicians must empower individuals by responding to their knowledge and understanding about the world, and two, clients have the best knowledge about their circumstances and objectives, which should be followed (Beresford and Croft, 1993). The recovery and empowerment philosophy claim that to recover means that one can reclaim their life in terms of being validated as an autonomous and
The main facet to the model is that it emphasizes that people are responsible for their own lives, and thus should have the right to choice, including the right to make mistakes. Empowerment recovery does not suggest that professional services are unimportant or unnecessary; however, such services are not intended to “fix” the person, but rather they should support him or her as the individual moves towards a healthy life. Individuals living with mental illness are seen as the agents of change, and professionals are one of the resources to be drawn upon (Deegan, 2001). Part of the empowerment approach is the notion of shifting the focus of program evaluation from the program developers to the program consumers. Programs were primarily evaluated from the point of view of the funders or professionals involved, which would create programs based on their own point of view and not their consumers. It is proposed that in community settings, professionals should be evaluating their roles and services through the clients’ perspectives.

In this model, psychiatric treatment is viewed as part of self-managed care. Adopting such an approach implies a shift away from the goal of treatment being the stabilization of illness through symptom reduction. Instead, the goal becomes to assist people to gain greater independence and control over their own lives. Through client centred research, the opportunity for clients to engage in a discussion about their treatment and life goals can enhance the sense of empowerment. Consumers have the right to make suggestions and reflections on the care they are receiving. Professionals in the mental health field are there to understand their clients to better serve them, thus asking clients if their needs are being met and how they can achieve this is vital to the therapeutic alliance, and the experience for the client. This research study aims to achieve this and to demonstrate the importance of consumer feedback in establishing treatment programs.
Possible negative perceptions of ACT. Surveys conducted have suggested that clients are mostly satisfied with ACT services (McGrew, Wilson, & Bond, 1996) to a greater extent when compared to clients receiving usual services (Mueser, Bond, Drake, & Resnick, 1998). It is worth noting that some researchers and providers believe that ACT programs can be considered coercive or paternalistic and they are not based on client choice. This criticism has been primarily based on theoretical arguments rather than empirical studies (Diamond, 1996; Fisher, & Ahern, 2000). There needs to be an understanding of where clients are coming from and why they are unsatisfied or feel the services are coercive. There is no merit in concluding ACT services are coercive when there is no evidence to prove this and since no client has stated this overtly. There may be conflicts between the best interests of the client and their expressed preferences (Diamond & Wilder, 1985); however, this occurs in many health care settings and treatment modalities. Some consumer groups believe that ACT is a way of exerting social control over individuals with a mental illness, notably, through the use of medications, this can be thought as coercive, paternalistic and it may foster dependency (Fischer & Ahern, 2000). A recent study demonstrated that more coercive interventions, such as committing individuals to a hospital against their will were used with less than 10% of consumers. In fact, the more coercive interventions were used on consumers who had a substance use issue, a history of arrest, or an extensive history of hospitalizations or more severe symptoms (Neale & Rosenheck, 2000). Furthermore, an earlier study of consumers who were receiving assertive community treatment found that about one of every ten believed the treatment was too intrusive, confining or that it fostered dependency (McGrew, Wilson, & Bond, 1996). The assertion that ACT limits client choice is contrary to what ACT clients have actually experienced. In essence, consumer’s dissatisfaction with treatments offered by the mental health system has a basis in their own
individual experiences. Therefore there is a need to expand research on consumer’s perspectives of assertive community treatment beyond studies of consumer satisfaction.

Research objective. It is acknowledged that ACT models are premised on providing psychosocial supports to individuals with a severe and persistent mental illness so that they can functionally and optimally live in the community despite having a mental health concern. Such supports include housing, financial support, social support, employment opportunities, medication management, symptom management, integration into the community, team dynamic and the therapeutic alliance. The present study is interested in how these are viewed by the consumer; if there are areas that need to be further addressed or if there are areas that need to be recognized. The research is also interested in conceptualizing from the client’s perspective how these supports relate to their quality of life by reflecting on the years they have been with their ACT team and if they have noticed any changes in their psychosocial functioning, and if so what are these changes and why do they think these changes have occurred. This will be further explored through the client’s perceptions. Furthermore, this research aims to incorporate its findings to the existing literature as well, add new and vital information in the implementation and monitoring of quality of care of an ACT model.
CHAPTER 3: RESEARCH METHODOLOGY

**Research Questions:** What are the subjective experiences of clients with a severe and persistent mental illness receiving treatment from the Sunnybrook Program of Assertive Community Treatment (SunPACT)?

**Sub-questions:** How do individuals living in the community with a severe and persistent mental illness define SunPACT and their needs from an ACT team? How do they feel about being involved with SunPACT? What do they believe is the impact it has on their life? How does it contribute or take away from what they would consider a good life?

**Rationale for Qualitative Methodology**

The proposed research project aims to explore how individuals living in the community with a severe and persistent mental illness understand and evaluate the care they are receiving from their ACT team. The researcher chose a qualitative design to address the research questions because it allows for a deep contextual and exploratory understanding of one’s lived experience, which would otherwise be restricted by the parameters of a quantitative research methodology. Qualitative research yields thick descriptions that present a holistic experience from the participant’s point of view. Furthermore, the basis and relevance of the lived experience is used as the central component to generating theory and knowledge. The researcher was interested in using the qualitative approach to generate categories and in depth experiences based on the individual and their differences rather than on “seeking generalizability to a larger population, or gaining information about the distribution and/or frequency of the research question” (McCracken, 1998, p.17).

This research report will discuss the use of client interviews in research, the effect on quality of life, the effect on the quality of research data, and thus the effect of this new role on
the self esteem and empowerment in the client interview process. From the above literature review it appears subjective satisfaction with services and quality of life are best reported and understood through a qualitative design in which the researcher can explore further these areas. Clients can elicit information through this exploration that may not have been explored before when using a narrow quantitative quality of life or satisfaction with service scale. Scales may only capture a glimpse of the reality. For example, studies using scales cannot be entirely generalized to the greater community. Individual differences such as age, gender, ethnicity, type of illness, length of illness are all factors to take into account. Although these scales do suggest a relationship between social status, housing, and employment when asking about satisfaction with life, this may not be the totality of one’s perception of satisfaction with life. As well, these are scales devised by individuals who in their subjective view, value these as important factors to a satisfied life. This may not be the similar case with individuals living with a mental illness in the community. Therefore, the needs of clients living in the community receiving treatment such as an ACT model needs to be further explored.

According to Padgett (1998), qualitative methodology is used in the exploratory stages of research to generate information about a topic in which little is known. As indicated by the literature review, there is little research solely looking at the lived and perceived experiences of clients receiving treatment from an ACT model. Therefore, exploring the generation of such categories and themes, as well as, their interrelationships is an entry point for further qualitative or quantitative study.
Research Design: The Long Interview Method

The present study employed The Long Interview Method (McCracken, 1998) because it delineates a concise and structured guide to the discovery of cultural and analytic categories which emerge from an inductive research design. A qualitative, long interview design is premised on the principle that “less is more.” It is more important to work longer and with greater care, with a few people than more superficially with many of them, and thus eight respondents, is sufficient (McCracken, 1988). McCracken (1998) states that the use of an in depth literature review begins the process of the long interview method; however, he cautions that this may create a potential for the interviewer to develop preconceptions. Therefore, he stresses that the use of a literature review can also help the interviewer bring about detachment from the taken-for-granted categories that organize the researcher’s world (McCracken, 1998). A literature review offers a way to reflectively, deconstruct the academic discourse and to help make the interviewer aware of some of the ideologies that situate both the interviewer and the respondent (McCracken, 1998). This method includes four steps: 1) the review of analytic categories, 2) the review of cultural categories, 3) the discovery of cultural categories, and 4) the discovery of analytic categories (McCracken, 1998).

For this research project, the researcher conducted an extensive literature review to bring analytical categories about the research question to the forefront. As well, the literature review can be used to provide a framework for the construction of the interview guide, as it “specifies categories and relationships that may organize the data” (McCracken, 1998, p. 31). In the review of cultural categories, in this research area, it would be the cultural experience of living with a severe and persistent mental illness; the researcher must use him or herself as an ‘instrument of inquiry’ by situating himself/herself in the culture of investigation (McCracken, 1998).
McCracken (1998) states that the researcher must be cognizant of the assumptions, associations and incidents that surround the specific topic in his or her mind in order to name one’s cultural assumptions, distance themselves, as well as prepare him/her to match assumptions or cultural categories with the codes that emerge from the data analysis (McCracken, 1998). To document such constant self-reflection, the researcher has included in this report a cultural review, which is useful in organizing the existing cultural categories and to aid in the creation of the interview guide (McCracken, 1998).

Discovery of cultural categories encompasses the third stage of the Long Interview Method. This refers to the construction of the interview guide and the interview procedure (McCracken, 1998). This will be discussed further on in this chapter. Finally, the ‘discover of analytical categories’ entails the fourth and last stage of the Long Interview Method and this involves using a top-down and bottom-up step in analyzing the data (McCracken, 1998). This will be further explored in the section of this chapter called ‘Data Analysis’.

Cultural Review

To review cultural categories, the researcher continuously questioned and situated herself in the varying experiences reported within and outside the community of individuals living with a severe and persistent mental illness. This was achieved through ongoing and active self-reflection, peer debriefing (with other students, faculty supervisor, field instructor and program coordinator), and the write up of the cultural review which follows:

My social positioning as a student in the Master of Social Work program at the University of Toronto, specializing in the Health and Mental Health field allowed me to explore my interest in issues related to mental health much further. I have been exposed to this population through previous educational and vocational
experiences and became greatly involved in this community when I was an undergrad in university studying psychology, and volunteering for a mental health organization for many years. The researcher in this study was a past social work intern with the Sunnybrook Program of Assertive Community Treatment. The researcher did not have any prior knowledge or experience with an ACT model, but became very intrigued through her internship. The researcher had past internships in hospital inpatient settings, as well as a forensic mental health setting which guided her understanding of mental health services and the impetus for this research study. The researcher observed the team members interact with the clients, and a growing interest in understanding how effective was this treatment approach. The researcher wanted to gain a better understanding and felt the use of clients’ perspective was best.

I became interested in the various types of people I met and the stories I heard from individuals who relate to this community. At times, there were stories of resilience and stories of disappointment, sadness and failure. This was mostly understood when talking about the care/services clients were receiving, as well as, the treatment they received from the public and their families. I became angry and frustrated at the little power I had to make a difference, and then I thought to myself, “how do these individuals feel?” If I feel powerless, then what could they be feeling? It occurred to me I could not understand how they felt no matter how hard I tried. I used my power as a student and researcher to obtain employment positions that involved advocacy and reporting to the government about the core issues in our mental health system, but I still felt like there was something
missing. There was a power struggle between me being a healthy, young female student who was living in a world dominated by powerful individuals who did not know or understand what it felt like to live in this world with a mental health diagnosis wanting, but deserving the best care they could obtain. I could read journals and textbooks about what a diagnosis meant, or how to treat it, but there was no text book on stories about what life in the everyday was like. What challenges did these people face and why do we even have to refer to individuals with labels and negatively infused language.

The media and social constructions of mental illness did not help either. There was constant media coverage on violence and mental illness, and fearmongering. The public portrayed mental illnesses as something to be afraid of and the solution would be to just separate the masses from society. There were never any reports on the good things about mental illness, the survivor stories that showed how some people were strong and able to live full lives in the presence of their illness. It was difficult to make these stories public, or to even try to convince someone that media does not portray accurate truths. It appeared to me that the conception of mental illness had been a long standing battle that originated many years ago. This also lead me to believe that maybe some of our services and service providers were also treating mental illness as a problem that could not be fixed and thus individuals were doomed for a life lost. If our own services were doing this, then what hope did these people have? How can one be hopeful if the one thing they trust in doesn’t believe in hope for a future for them either?
My professional interest and clinical experience working with individuals who have mental health diagnoses created the impetus for this research. In the role of a ‘social worker,’ and ‘student’ I have had many dialogues with individuals in the mental health community to learn about how this relates to the information that shapes the multiple constructions of identity and programs available to survivors. I also struggled with using such terms as ‘mental illness’, ‘severe and persistent’, ‘diagnosis,’ and ‘disorder.’ As well, some participants made comments about the language used in this research study as they felt it was not an accurate representation of who they were (i.e. severe and persistent mental illness, and disorder). Many of the individuals interviewed demonstrated a vast knowledge in their experiences with the mental health system, and I felt it was important to make these thoughts available to the wider public to gain deeper cultural insight, sensitivity and knowledge about people living with a mental illness.

The identification of cultural categories in the above cultural review was an important component in my use of self during the data collection and analysis process. My knowledge and range of positive and negative experiences with the mental health community was used to position myself through the interview process. They were also used to bring to this project any matching or incongruent themes during data analysis. Ongoing peer debriefing was a useful component in facilitating the application of this cultural review in the data collection and analysis.

*The interview guide.* The researcher used a semi-structured, in-depth, client focused interview process asking open ended questions related to clients’ experiences of their ACT model treatment. The categories were framed more broadly to allow for range in the responses.
These included the following sections: a) definitions of SunPACT, b) medication management, c) housing situation, d) hospital versus community experience, e) substance use management, f) team dynamic and implications for the therapeutic alliance, g) family or social involvement, h) symptom or illness management, i) justice or legal involvement, j) social supports (employment, recreational, or volunteer work), k) financial management, l) negative experiences, m) future care (fears or desires) and finally n) overall quality of life (See Appendix A).

The development of questions adhered to McCracken’s (1998) suggestion that the interview be as unobtrusive and nondirective as possible. Thus, many of the questions were open-ended to elicit broad responses and were followed by prompts if the respondent required more cues. Planned prompts were also used in situations where the cultural or analytic categories were not obvious enough to emerge spontaneously and earlier on in the interview. I consulted with peers and the thesis committee members to get further feedback.

During the interview the researcher proposes to the participant that the main focus of the research study is to talk about how they understand SunPACT and how it has been apart of their life since the first time they became a client and up until the present moment. The long interview adopts a more efficient and less obtrusive form of information gathering. It requires more focus and highly intensive interviews which seek to diminish the redundancy that exists in more unstructured research processes. It is conducted between the investigator and a single respondent, and it looks to explore shared meanings rather than individual affective states (McCracken, 1988). Without a qualitative understanding of how culture mediates human action, we can only know what the numbers tell us, the long interview can help us situate the numbers in their fuller social and cultural context (McCracken, 1988). In a qualitative design the researchers are not interested in generalizing their findings, rather they are interested in accessing one’s cultural
categories and assumptions according to which culture the individual is from, and exploring these further (McCracken, 1988). There is a caution to such methodology in research, one should be aware that in a single setting one can not give all their attention and time, thus not every aspect of the participants experience is divulged. One must also take into account that not all participants favour the idea of having an observer into their lives for an extended period of time. Therefore, it is imperative that researchers are aware of time constraints and breaching one’s privacy are important elements that may get in the way of a qualitative analysis.

**Procedures.** The sample for this project was not chosen to represent some part of the larger world, but offers a glimpse into the person, organization or culture. Potential participants were selected through purposeful sampling, which involves seeking respondents from different subgroups of a population to illustrate subgroup characteristics, and facilitate comparisons between groups (Strauss & Corbin, 1990). With the small sample size of this study, the sampling focused on seeking participants experienced with ACT, and variance in age, gender, and ethnicity to explore differences that may exist in these subgroups. Analysing these subgroup characteristics could provide evidence that individuals experience ACT differently. Participants were recruited using a flyer which was posted in the F wing (Mental Health Services) of the Sunnybrook Health Sciences Centre, as well as, distributed to potential participants by the team members of SunPACT (See Appendix B). Participants were selected if they satisfied the criteria of having a mental illness greater than or equal to 5 years. This was important because research investigating long-term outcomes of mental illness have shown that the five year point is the end of the “first episode” period (Johnstone, Macmillan, Firth, Benn, & Crow, 1990; Scottish Schizophrenia Research Group, 1992). As a result, for individuals diagnosed with a mental illness this may be considered an important milestone in one’s development. Research has shown
that a sample size of approximately 10-20 participants is required to achieve an in-depth analysis and theoretical saturation (Sandelowski, 1995). For this research project a sample of eight adults were found. This was due to time constraints, as well as, a low participation response rate and the recommendation from McCracken.

All participants’ were living within the city limits at the time of the study and were between the ages of 30-65 years old. In the sample interviewed, there were four males and four females, from various cultural backgrounds. Only one participant was in a relationship, one was widowed and the remaining identified themselves as single. Two participants reported being involved in volunteer work. The majority of the sample had college or university level of education. All participants, except for one, had an income below $19,999/year. Almost all were receiving Ontario Disability Supports Program (ODSP) as their primary income. All, but one were Canadian born, all were Canadian citizens. The length of living with self identified mental illness ranged from 10-31 years. The length of years the participants had been a client of SunPACT ranged from 5-10 years. The majority of the sample had not been hospitalized in the last year, and the last hospitalization ranged from 1 month to 10 years ago (See Table 1).

Respondents self reported their diagnoses and would self identify if they had schizophrenia, bipolar disorder or other. There were those who self reported as living with schizophrenia, schizo-affective disorder, obsessive compulsive disorder, bipolar and clinical depression; however, one respondent used the phrasing he had “anxiety problems” and he did not want to label himself as having a disorder. The researcher responded to enquiries and screened potential participants through a telephone screen guide for eligibility (See Appendix C). Interviews took place in a private room at Sunnybrook Hospital or at the participant’s residence (this included group homes, apartment suites, and boarding homes). The specific locations were
determined in consultation with the respondents to ensure comfort and confidentiality. Four males and four female participants were interviewed for this study. Five participants were interviewed at Sunnybrook Hospital in a private office, and three participants were interviewed in their place of residence (this ranged from a group home, private apartment and a boarding house).

**Instruments.** A demographic information gathering sheet was used to gather information related to age, gender, ethnicity, level of education, any current employment, income level, any current or history of hospitalizations; one’s self reported diagnosis, length of illness, current living situation and length of time receiving services from SunPACT. The interview guide was used to ask open ended questions as well to prompt new emerging ideas about the ACT experience. For example, in the interview protocol some of the questions included: if you were to describe SunPACT to a friend what would you tell them? What ways has SunPACT helped you manage your symptoms? In what ways does SunPACT help you manage your medication, finances, or housing issues? Can you talk about the experiences you had in the hospital versus being treated in the community? Can you talk about the team approach in your treatment? Can you talk about where you see yourself in the future and whether or not you feel your quality of life has changed since being with SunPACT? Finally, the researcher asked participants to comment in general on the most important factor the public needs to know and understand about SunPACT in the context of mental illness.

**Data collection.** Eight participants agreed to participate in the study. Interested participants were linked with the interviewer through staff providing their contact information. At the interview, participants were given a detailed consent form and were asked several questions in order to assess the participant’s capacity to consent (See Appendix D). This was to
ensure the participant was aware of the research process and their rights as a participant, as well, to ensure the safety of the participant and the researcher. The interviewer began the interview by completing a demographic information form with the respondent and then proceeded to interview the participant using the semi-structured interview guide. Participants were interviewed for one hour, and were given ten dollars honorarium and transportation reimbursement if other modes of transportation were used (TTC or taxi chits). All interviews were audiotaped and then transcribed. Tape recordings, transcripts, and demographic information sheets were stored in a locked cabinet in a locked office at the University of Toronto, Faculty of Social Work. Any computer based data was stored on a secure password protected database provided by the University of Toronto. All transcripts and recordings would be later destroyed after the transcription process was complete.

Data analysis. Coding and identification of categories took place manually throughout data analysis. The researcher and her supervisor examined the transcripts to assess inter-rater reliability of categories. The interview guide sought information about the respondent’s experiences of receiving treatment from SunPACT and how it has been apart of their life. The interviews were audiotaped to facilitate transcription and analysis. Participants were assured of the anonymity and confidentiality of the information they provided and were told if any names were mentioned they would be deleted from the transcript. After the interviews were transcribed verbatim, the last stage of the Long Interview Method is data analysis. McCracken (1998) states that the object of such analysis includes:

…. the determining of categories, relationships, and assumptions that inform the respondent’s view of the world in general and the topic in particular. The investigator comes to this undertaking with a sense of what the literature says ought to be there, a glancing sense of what took place in the interview itself (p. 42).
The researcher analyzed the data generated from the interview guide using the suggested five stages of analysis detailed in the Long Interview Method (McCracken, 1998). These include: 1) the utterance identification and making observations, 2) the expansion of observations, 3) the comparison of observations, 4) theme development, and lastly, 5) the comparison of different interview themes (McCracken, 1998).

The use of utterance identification and making observations involves the researcher conducting a literal, line-by-line reading of the transcript or of each ‘utterance’ to compile a set of observations which include “key terms, metaphors, interpretations, statements which suggest underlying assumptions and values, and immediate referents to the question or to analytic/cultural categories” (Crabtree & Miller, 1991, pg. 148). The researcher then expands on these initial observations through placing them in context and developing meta-observations (McCracken, 1998). The observations are compared to each other to develop key organizing concepts (McCracken, 1998). Theme development, analysis and reduction takes place in order to sort out general themes, and finally, the themes or cultural categories transform into abstractions, or broader analytic categories. Each response on the transcript was treated as a meaningful unit of information and was developed using codes to fit the data. Each category was reviewed individually to develop an understanding of the meaning of the data and to highlight any important aspects of ACT service delivery. The demographic data was entered into the Statistical Program for the Social Science (SPSS) for analysis of demographic frequencies and percentages.

The interviews were audiotaped and transcribed to create text documents for manual and electronic analysis. The tapes of the interviews were destroyed after transcription. A coding manual was developed based on review of the literature. The transcripts were first coded by hand, then coded electronically and analyzed using qualitative data management software.
(NVivo 8), to identify categories and themes. A series of analyses were conducted to explore categories/themes that emerge across groups and within groups. Furthermore, comparisons within cases, across cases, and with the existing literature and cultural review was used to develop emerging themes that gave rise to the analytic categories or hypotheses. The researcher developed codes, categories, and themes to be reviewed and presented these to the research committee to ensure trustworthiness and credibility of analysis.

**Trustworthiness & credibility.** Padgett (1998) defines a trustworthy study as “one that is carried out fairly and ethically and whose findings represent as closely as possible the experiences of respondents” (p. 92). Furthermore, credibility asks whether the research is believable, whether the meanings are placed in context, and whether the data accurately and holistically conveys the participant’s experiences (Padgett, 1998). Possible threats to trustworthiness and credibility are: reactivity, the researcher’s potential to distort natural context researcher bias, researcher’s potential to bias and filter data because of his/her subjective position and respondent bias, the respondent’s potential to withhold or streamline information because of the research context (Padgett, 1998). This research made attempts to increase trustworthiness and credibility of thought through the use of prolonging engagement, negative case analysis, theoretical and interdisciplinary triangulation, peer debriefing, member checking, and creating an audit trail.

Prolonged engagement is comprised of building of trust between the researcher and the respondent that is likely to increase with the duration of time (Drisko, 1997). In this research project, respondents were screened over the telephone prior to an initial meeting between the interviewer and respondent, to ensure there was greater respondent familiarity with the research process upon onset. Each interview was approximately one hour in length, allowing enough time
to build rapport, and decrease the distortions that may arise from the newness of the situation. Also, the experience of the researcher in the field of mental health contributed to the prolonged engagement with the subject matter.

Padgett (1998) defines negative case analysis as a “self imposed ‘devil’s advocate’ position assumed during data analysis” which can enhance the study’s credibility (pg. 101). This was achieved throughout data analysis by utilizing a constant comparison of contradictory categories and themes within the transcripts, between transcripts, between the literature review and the cultural review, as well as, highlighting contradictory findings as important components to the overall project results.

Theoretical and interdisciplinary triangulation was also used to build the credibility of this research. The categories from the literature review were based on a variety of theoretical and disciplinary perspectives to provide greater triangulation in the development of an interview guide, and throughout the data analysis. The researcher utilized peer debriefing, feedback or consultation from peers and supervision team, throughout the course of this research to guard against researcher bias arising from enmeshment in the research process. The peer debriefing process consisted of ongoing consultation in thesis supervision from the faculty supervisor, formal and informal conversations with students and researchers at the Faculty of Social Work. Member checking or the inclusion of the research stakeholders in the interpretation of the data was carried out informally by confirming and summarizing responses with the respondents throughout the course of and at the end of interviews. As well as, offering the contact information of the researcher to the respondent for future questions about the research, or copy of the transcripts to ensure they were satisfied with their responses. Creating an audit trail is a means to enhance trustworthiness, by providing openness in the documentation of data
throughout the final written product (Padgett, 1998). This thesis report includes many direct quotations in order for readers to verify that the development of categories was grounded in the data itself, and thus enhances the credibility of the findings.

**Ethical considerations.** The present research project was approved by the Health Sciences, Ethics Review Committee at the University of Toronto, as well as, the Ethics Review Committee from the Sunnybrook Health Sciences Centre in Toronto, Ontario. Thus, this research followed the ethical guidelines to ensure safety, privacy, confidentiality, and informed consent. The researcher obtained written and verbal informed consent from the respondents, after communicating any potential risks and benefits to participation. The researcher also provided contact information for the thesis supervisor so that respondents could ask any questions about the research process, review copies of the final research findings and/or request copies of their interview transcripts.

The respondents were also informed of the limits to confidentiality, prior to their participation in the study. The screening interview and information sheets both addressed the researcher’s professional obligation to report any disclosure of intention to harm oneself or another person. Respondents were informed that they could withdraw consent at any time and request the return or deletion of an audio recording and/or transcript, as well that they could stop the interview at any time without penalty should they require a break or wish to permanently withdraw from the study.

To protect the respondent’s rights to confidentiality, the anonymity of identities were safeguarded by removing all identifying information from the research documents and final thesis. Information such as names, agencies, and/or other personal identifiers were removed accordingly. During the data analysis, interview documents and audio recordings were identified
using numerical and string codes, and stored safely in a locked cabinet. Interview audio recordings were destroyed after transcription, and the transcripts were saved to allow respondents access, should they request a copy in and up to the period of five years.

Potential benefits to participation in this study involved an opportunity for participants to reflect on, and offer their own personal experiences in a way that contributed to the advancement of culturally sensitive, social work knowledge. Many of the participants in this study expressed interest in reading the final product of this thesis, and seemed enthusiastic to advance knowledge to the public based on their lived experiences. The interview process was an opportunity to embrace lived experiences of clients with a severe and persistent mental illness, living in the community, receiving assertive community treatment care as central to the research process and specifically to the findings. Thus, this may have been experienced as an empowering process. In addition, the participants may have viewed the interview process as educational and therapeutic, since it provided a forum for them to construct personal insights generated from their own critical reflections, while in a supportive environment.
CHAPTER 4: FINDINGS

The results of this study are presented through the themes and categories that emerged when analysing the transcripts through manual and electronic coding. The results will present the ways in which SunPACT was experienced as a contributing factor to community living and quality of life through looking at the major themes which emerged from the interviews. The categories include: i) participant definition and construction of SunPACT, ii) medication management, iii) symptom and illness management, iv) team dynamic – therapeutic alliance, v) family and social involvement, vi) social supports, vii) experiences of perceived stigma, viii) negative experiences, ix) housing, x) financial management, xi) hospital versus community care xii) future care – desires or fears, xiii) quality of life and finally xiv) recommendations to the service. The categories ‘substance use’ and ‘justice or legal involvement’ have been excluded from the results section due to the fact all eight participants did not report any events related to SunPACT’s involvement in these two areas. The categories ‘experiences of perceived stigma’ and ‘recommendations to the service’ were added since these categories were addressed for many of the participants. This section includes specific examples of SunPACT services that were experienced from the participants which were either beneficial or unpleasant, as well, any recommendations for future services. Direct quotations from supporting data are included.

Interpretation of the Data

According to McCracken (1998), the Long Interview Design, uses a 5-stage data analysis process, where the researcher partakes in an in-depth reading and re-reading of the eight transcripts, and their subsequent comparisons, this formed the foundation of the emerging themes. The interview guide reflected both the cultural and analytic categories from the literature review, as well as, it formed the basis for which participant responses were elicited (see
Appendix A). Many themes emerged from a holistic reading of the transcripts and the interrelationships between categories. The categories and themes, as mentioned above, will be presented in this chapter by each theme. Participant responses were edited for clarity, as well any location names were deleted from the responses to ensure protection of any identification of client or place. The following responses are grouped according to their relation to the themes and will be illustrated and quoted verbatim to emphasize the importance of client feedback and interpretation of services.

**Participant Characteristics**

Respondents in the Long Interview Method are not a ‘sample’ and ‘should not be governed by sampling rules’ in the traditional sense (McCracken, 1998, p. 37). The participants in this study were not treated nor conceptualized as a sample, but more as expert informers on an area of research the researchers did not have any knowledge about. In this study, the aim was to interview respondents who were clients of the SunPACT program. The researcher was interested in clients who had been involved with the program for more than a year, as well, participants who had been living with a mental health concern for more than 5 years. This was important because research investigating long-term outcomes of mental illness has shown that the five year point is the end of the “first episode” period (Johnstone, Macmillan, Firth, Benn, & Crow, 1990; Scottish Schizophrenia Research Group, 1992). The researcher also wanted to interview participants who had a vast experience within the mental health system, for example, frequent and extensive hospitalization experiences. This was to demonstrate the client’s more detailed perspective in terms of their treatment over the years and comparison of community treatment to hospital experiences. The sample included four male and four female participants representing a
variety of ethnic backgrounds. Table 1 provides a summary of the participants’ demographic characteristics.

**Participant Definition and Construction of SunPACT**

To elicit participants’ definitions of SunPACT I simply began the interview by asking, “How do you define SunPACT and what it means to you?” And “if you were to tell a friend about SunPACT how would you describe it?” Participants’ answers to these questions were immediate; they qualified and thickened their definitions as the interview proceeded. Each respondent defined SunPACT in highly positive terms and commonly used the word “friend” to describe SunPACT. All participants referred to SunPACT as a team who provided a service, which included medication delivery, assistance with grocery shopping, assistance with cooking skills, obtaining housing, or someone available to talk to.

Below are some examples of how respondents defined their understanding of SunPACT:

“SunPACT are my friends. They help me with my ideas and support my ideas sometimes, most of the time. They help me medically too” (Respondent 1).

“I get different people’s opinions too on how I’m doing and I get suggestions from each member of the team on how I can improve my life. So I enjoy it! It’s very helpful and I look forward to my SunPACT appointments. They’re…you know it’s like seeing a good friend, you know, instead of a worker” (Respondent 2).

“They’re open, they don’t force issues on you or no matter how bizarre you may seem, they work with you. They accept me” (Respondent 3).

“They’re accessible. They used to have a nightline too, but because of cutbacks, they’re unable to have the nightline” (Respondent 4).

“And they sort of work together. The nurses sometimes help me work with the same thing that my social workers are helping me work with, like housing, everyone sort of came together and threw ideas out of where I could live and that sort of thing. So I have to say that they work really well together. They’re a good team of health professionals” (Respondent 5).
“Well it’s a group of… it’s a group of people that are social workers, doctors and nurses and they come for daily visits and they give you your injections, they give me my injection once every two weeks and they bring over medication once a week and they talk to me to see how I’ve been doing and see who I’ve been seeing and if I’ve been continuing doing volunteering, just to chit chat, do groceries, go to the bank, take a walk, whatever. And they’re pretty good, they’re friendly” (Respondent 6).

“I’d say they have a great team and they have a great leader, _____, and every member of the team is wonderful and Dr. _____ and they’ve helped me immensely, although there have been hospitalizations while I’ve been a member of SunPACT for five years, the duration of the hospitalization has been short. Whereas when I wasn’t with SunPACT, I lived here the summer of 2003, I was admitted nine times and so I find SunPACT looked after me beautifully, they’re there as a support, an extreme support. I can’t emphasize how extreme, to what extreme measure they go to, to keep you safe and they’re just there for you; for me” (Respondent 7).

“They listen a great deal and have suggestions and also they don’t minimize the problem. I’m not going to use the word sympathise with you or patronize you, I think they support and understand the misery that you’re going through. They support me and they seem to make it a big deal, as big a deal as what I’m making it, you know, and they understand that. That’s what I’ve found with all issues, they didn’t minimize, they didn’t say “Oh ____, stop being such a baby.” They never said anything like that. They said “Oh no!” or “Oh, gosh!” you know, “how can we help” (Respondent 8)?

An important component that was elicited from one of the participants was that being on an ACT team involved the prevention of any crisis situations that would later require hospitalizations. It was stated that with their ACT team any issues were addressed quickly and effectively. This led to a more satisfied quality of life and a more qualified manner to cope with any symptoms related to their illness. There was also the implication that the client was very appreciative of his worker taking the time to spend with him around addressing such issues. Below is his response:

“Any little problems that come up are nipped in the bud before they become big ones. Also if I need extra help, I can always phone in and speak to someone if I’m having a really rough time. And on occasion I know _____ has come up once on a Friday; he knew I was having a rough time and sat with me out back at the picnic table for about half an hour to an hour and he
got me through that weekend. So having this additional support, to be able to talk about what’s troubling me and give me some positive feedback has helped me sort of rethink what I’m going through so I can see it’s not so bad after all, I have to do this, this and this as so and so has recommended and I’ll feel better. So I do that, that and that and I feel better so I no longer seem to be in crisis all the time” (Respondent 7).

One respondent felt that the team was very in tune to any changes in her behaviour or appearance and this has been a great benefit to her quality of life and functioning.

“For myself they’ve been good with the counselling, primarily with diagnosing my illness, with making sure that I’m receiving the right type of medication, that if something needs to be added or taken away from my dosage, the doctor gets involved and the team operates as a unit so that if they notice any changes in my behaviour or my demeanour they talk about it and they relay it to one another and their findings in reference to my illness” (Respondent 8).

Accessibility of services was also a common term applied to SunPACT. Many respondents referred to how accessible their team was and they were able to call and leave messages on the phone and a team member would call them back within the hour. To some participants having voicemail was beneficial because they felt secure knowing that they could get a thought off their mind and a team member would call them back to talk to them. This was important to participants who did not have many social networks or supports. Having ongoing interaction though phone or visits is viewed by the participants as beneficial to their well being. Two respondents commented on this feature of SunPACT:

“So having voicemail too is important. You say things that you may not have say to a person in real life, you know. So voicemail, sort of giving me ideas, facilitating them” (Respondent 1).

“Because I know they’re going to call me the next day and the next day and the next day until...and I also know that they’re watching out for my safety that they....you know _____ always says “_____ do you feel safe”; meaning am I going to do myself harm? So at times I’ve said “no I don’t feel safe” so I go into the hospital and other times I feel, no I’m safe, you know I’m okay” (Respondent 6).
When asked about the accessibility of seeing their doctor, participants responded in a positive manner. Respondents felt that their doctors were always there and they did not have to wait for service, which can be commonly seen with clients who are not connected to ACT programs.

“And if you ever want to see your doctor, it’s that easy for you or you don’t have to wait. No, it’s pretty easy, yeah” (Respondent 1).

The respondents explored the benefit of having someone on the team to talk to. Sometimes they would talk about their how their week was going or life in general. Their treatment was not primarily medication and psychosocial management, but just having informal conversations allowed participants to feel like a “normal person”. There was also the notion that any team member, whether it was a nurse, social worker, or occupational therapist (OT), they all took part in the informal conversations.

“Interviewer: So if you were to see a nurse on the team, what would you talk with them about? Respondent: Just everything that’s gone on in the week. Oh, so they all talk about your life. Yeah, and we sort of joke around” (Respondent 5).

“Well, when we meet, we meet like, there’s also a person who works at SunPACT who is a peer counsellor, __________. She’s a peer counsellor and they just talk to like you’re a normal person. And you know we talk about, we don’t just talk about my illness, we talk about the news, we talk about this and that, parties that they’ve had here, just a lot of talking” (Respondent 8).

One respondent referred to SunPACT as a mechanism which allows them to cope with life. Some respondents were very reliant on their SunPACT team and associated their success in life with their involvement with the team. One respondent reflected:

“Uhm, it’s a program that is useful in me to cope with life. It sure beats the alternative, which I would say that if I didn’t belong to a SunPACT team, I would probably be in a mental institution. However, because I do have SunPACT, I seem to be able to cope and sort of a half decent life. So, yeah, it helps me to cope” (Respondent 3).

One respondent noted that they are able to explore other interests in their life through SunPACT, where they were not always getting medical treatment, but they were able to explore
hobbies and other recreational tasks.

“They help me to develop interests, like writing or knitting or embroidery or housework, but they do a lot more” (Respondent 2).

One respondent valued the importance of being acknowledged through SunPACT. He was thankful for SunPACT being there for him and for providing someone to talk to or somewhere to go when he needed help. He also commented on how being connected with an ACT team helped him get time efficient services because the team knew him and his history of illness. Because of this he could be brought into hospital when he needed it, and the staff would advocate for him because they knew he needed treatment. He really felt that his care was more accurate and efficient when he was recognized as a client from SunPACT, when he was referred to the hospital:

“Because you know that at least you’ll be recognized. If you go to some other hospital they don’t recognize you. They don’t know what you’re about. They don’t know me here, I’m not some social person. I don’t have a party line, you know, I don’t go to parties and you know, hey, I’m part of the crowd, you know. I’m not a doctor. I’m not a lawyer So if I were to go to another hospital they would have a completely different viewpoint and they would probably only let you stay a night. And you would not be able to handle this one night. You’d want to stay longer until you get some help. And they give you some other medication that doesn’t work for you and you have to represent yourself where you’d be like ‘Well, I don’t want that medication. I want this one.’ And by the time you do that, you find yourself in a PICU somewhere and they don’t have your records and you have to get them signed over. That takes days, weeks and after if you disagree with them, then they say you have to go and you’re like totally zonked out, you know” (Respondent 3).

Finally, respondents referred to SunPACT as a service that is client-centred and where the clients are treated as people who need extra support in some areas of their life. They are supported no matter what the issue is, and most importantly the participants feel the team is honest with them. Respondents stated:
“I think it’s a good way to make you more at ease, to get out and to…it’s a good…you know sometimes there’s a problem like if they find out you’ve been drinking too much, they tell you if there’s a problem. They’re honest with you which is good because some social workers let everything go do what you want, you know, you can go to the mall, you can go out to eat, go drink beers all you want, they don’t care. But SunPACT take a genuine interest, they’re honest with you which is important” (Respondent 3).

“Oh no, these people don’t talk down to you, they talk with you. They discuss openly. They just don’t talk above your head, you know, they talk, they look you in the eye and they talk to you just like they’re experiencing the problems themselves” (Respondent 6).

Medication management. The SunPACT team provides a great deal of support around medication management. Many individuals who live with a serious mental health concern are required to take medication, often, for the rest of their lives. This can be very traumatic and disappointing for clients, as well, it can be confusing when you are required to take various medications for various illnesses. Access to information about medication is scarce, and often clinicians do not take the time to explain medication intake and use to their clients. The researcher discovered that medication was a great part of the participants’ lifestyle and postulated that this could have an effect on quality of life and service provision from SunPACT. Therefore, below are the following themes and connections made about medication management in the context of mental illness from the participants in the present study. It was found that participants were open to bring up any concerns they had related to their medication and their doctor would address this and consider it a valid concern. Below are statements made by many respondents related to experiences they had with medication and how it was addressed by SunPACT:

“Yes, I would trust them. I think they’re very concerned and they want the best for me, so I would trust them” (Respondent 6).

“Also, sometimes I have awful experiences where I used to have _____, it just started to come on ten years ago. So it was really terrible, I had really terrible experiences and stuff. So then I said ‘maybe it’s through the
medication’. Sometimes I would forget the medication and this might precipitate it, you know. So the medication does have an affect” (Respondent 2).

“If I don’t take it, I think one of the workers told me it’s sort of like a pathway, a mental pathway, so it comes from fighting the ‘____’ and this sort of opens up the pathway to the dark side and it just sort of, like the medication sort of, like all the arguments and discussions and fighting, sort of, so the medication does bring me through that” (Respondent 1).

“They deliver my medication to me. They explain the medication that I’m on. The most recent medication, which is _________ and that’s helped control my symptoms for a long time. It’s a very good drug. And that’s about it. I try to take this medication with water or without, full stomach or not, things like that” (Respondent 2).

“No, they just say if you have side effects, tell us about it or if you have any problems, tell us about it and we’ll see what we can do” (Respondent 5).

“My psychiatrist sort of oversees the medication, any complaints I may have or any concerns I may have I bring them to his attention and then when I run out of my medication, I give him a call and he calls my pharmacy, that kind of thing so he comes out and sees me in the community also” (Respondent 7).

Taking medication can be seen as a positive alternative when one is not feeling well. The above respondents have verbalized their understanding of needing medication and how it helps them feel better; however, for some individuals, like this one respondent, medication was not seen as a positive long term alternative. It is also suggested that the team is required to help explain the further complications medications can induce, and to address with their clients any current side effects or symptoms related to medication. One respondent discussed the implications of taking medication as difficult to ‘accept or realize’, and this respondent was concerned about the side effects and problems that certain medications can lead to:

“The hardest for medication is to accept when someone has to have their medication and the hardest thing for someone with a mental illness or anyone is to realize, yes, you have to take your medication. It also gets very complicated because some of the medications lead to problems. For instance, I originally just had bipolar, but then I ended up getting diabetes,
so it gets more and more and more complicated. So, it takes a lot of skill and I still don’t understand all of it” (Respondent 2).

Below are further comments by the respondents about the negative aspects of taking medication. The comments are grouped into themes of the importance of medication and taking it, side effects that can be unpleasant, and worrying about whether or not medications are working. These are common experiences the participants endure on a daily basis related to medication management:

“No, I mean you can go ahead, but my impression is that the drugs are pretty potent. And if you go around screwing around the medication, you’re just going to get yourself in trouble. Because if you don’t take the meds…” (Respondent 3)

“Well I have been complaining lately that one of my medications, the most recent one that was added, I may be on too high a dosage because I’m having difficulties in the morning getting out of bed. I’m having difficulties not sleeping, but just getting out of bed and feeling very lethargic in the morning so I’m having a lot of problems with lethargy. So overall it’s a complete….you know…I don’t know….I’m seeing Dr. _____ and hopefully we can come to some terms with the _______ that I’m on, that maybe he can reduce it by 25 mg or so to try to alleviate the lethargy and hopefully my symptoms won’t return, yeah” (Respondent 8).

“I worry about the medications working and they check that, you know, but you know it’s pretty easy when you think about it” (Respondent 2).

“A few of the side effects, I was on ______ and ______ and I hated those two drugs and that was Dr. ___ took me off those but I’m on one now that’s an anti-psychotic, it’s to boost the anti-depressant and that’s the one I asked Dr. ___ today “Dr. ____, remember your old first do no harm and I’m asking you a question that you don’t have to tell the truth; I love this anti-psychotic pill because it puts you to sleep just like that almost but is it making me fat because I’m not eating and I’m getting fat. I’m not eating, I’m only eating a bowl of soup a day, a bowl of cereal a day and I’m still 195 lbs.” And he told me the truth and he said “even if you weren’t eating anything, it would put the weight on you.” And we decided on a plan, get the apartment done, you know get finished, and then we’ll get off of ______. I’m not addicted to it but we’ll get off of ______ and we’ll get off the anti-psychotic. But right now the anti-psychotic pill, I love it, Dr.____loves it but I can’t go around at 195 lbs” (Respondent 6).
Symptom and illness management. When interviewing participants it appeared illness and symptom management were conceptualized as being connected, and thus will be reported in this manner. The participants reported their diagnoses and the sample included the following: three participants self identified as having a diagnosis of bipolar disorder, one person identified as having obsessive compulsive disorder and clinical depression, one person identified as having schizoaffective disorder, two respondents identified as having schizophrenia, and lastly, one identified as having “anxiety problems.” When asked about length of illness the majority of the sample had been living with their illness for 10-25 years. Two respondents reported having a mental illness for more than 25 years.

In this section, the researcher noticed during the interviews that the respondents had learned many ways to manage their illness while living in the community. This could be anything related to symptoms that emerged which indicated the need for more intense support or monitoring patterns in their illness, and how to deal with this. It could be proposed that many individuals end up in hospital more often because they are unaware of their symptoms and their illness. It appears from this data that the respondents, sometimes with the assistance from their team, were able to track their illness and deal with it as soon as it arisen. This could mean calling SunPACT, or admitting oneself to the hospital. The following responses will be grouped by the range in management from independent management, to management in partnership with the team, to finally complete dependence on the team.

Independent management. Below are comments about how the participants manage their symptoms and illness independently, where they articulate to their team when they need to be admitted or they need extra support because they feel their symptoms are becoming intolerable.
One respondent also expresses how his own participation in his illness management leads to changes in his symptom and illness presentation:

“For myself to notice it, it’s one thing, but someone else to catch on, it could take months, unless I have a place to vent my feelings on a regular basis and if I don’t get that chance to be able to do that, well there’s not much point in a lot of the things I say then, because I’m not really being myself. What I’m doing is acting and you have to act as someone you’re not and then you’re staying up till 3, 4, 5 in the morning and the medication, you’re still taking it, but you’ve already triggered yourself off. It’s hard to catch that” (Respondent 3).

“And when it comes to SunPACT unusually what I talk about is jumbled up at times and it’s hard for me to stand here and say you know, I need help. Yeah, when I came in here because of the fact that I was upset and paranoid, like last week I was still on medication, I missed a day or something and I was dreaming a bit, I was hearing voices and I came in here and I got the exit I needed to be able to go upstairs, right. And they didn’t want me to really at first, but when they hear you talking and saying you need help, you get a little bit better at getting accepted” (Respondent 3).

Interviewer: “I’m noticing that you said you got off the drugs and you have good housing and you’re now more aware of when you have changes in your mood.”
Interviewee: “Yeah, yeah.”
Interviewer: “I’m wondering if you think this is because SunPACT has been there.”
Interviewee: “Well, it’s part of my participation too, right” (Respondent 3).

“I just know that I’m aware of finding my needs; someone to talk to more than I was before. I don’t keep it to myself” (Respondent 4).

“At one point three weeks ago I was thinking I have to be in the hospital and then I just calmed myself down and said “No I want to go for an anniversary of the year”, not being in hospital, you know, so the team can appreciate the amount of work they’re doing to make me a healthy mental person” (Respondent 6).

“With me it comes on suddenly, but other than that, I don’t know what I would say to that because my symptoms come on suddenly and I don’t have much time to think about it. I guess that it’s good that I’m busy and they like to see me busy so that I don’t think about things too much” (Respondent 4).
Some respondents expressed the use of taking a sedative as a means to calm any anxious or agitated feelings. The action of taking a walk or doing something in their day was also expressed as a way one independently managed their symptoms.

“Well primarily I do take a sedative, I take _________ if I notice that I’m getting agitated or anxious or feeling a little bit out of sorts and I keep them with me all the time so in case I need one then I take one. I take 1 mg and you know sometimes I may, in the past when my symptoms were bad towards the end of last year and beginning of this year, I was taking two a day but I haven’t had to take one for awhile”(Respondent 8).

“They just ask me how I’m feeling and what are my symptoms and talk me through it until I feel a little bit better and you know sometimes I just take a sedative after or go for a walk or do something a little bit different and feel a little bit better, you know”(Respondent 8).

Management in partnership with the team. One respondent stated that calling SunPACT as soon as they felt different or in crisis was helpful and this was the way they primarily handled the situation. She stated:

“I call them immediately.”
Interviewer: “You call them and get them on the phone?”
Respondent: “Yeah, get them on the phone. I’m usually whining, you know, about the situation.”
Interviewer: “And what if no one was there to answer the phone?”
Respondent: “There always is. I mean they don’t answer the phone right when….they call you back in half an hour. I know that I put a call into SunPACT and within a half an hour to an hour, they call me back and I’m going to feel better” (Respondent 6).

When asked about emergency or crisis situations, one client responded that they have not had to be involved in an emergency in a while and that if they were in such a situation they would rather seek the help of SunPACT. While other respondents discussed how being an active participant in their crisis or symptom management was helpful.

“Well, fortunately it’s been so long, it’s not quite sure what they would do in an emergency any more. When you’re in emergency, especially when you’re a mental health client, it’s extremely stressful. Like in many ways, the emergency program in Emergency is entirely different from SunPACT”
Like I have to co-operate. But I would still like to be a lot better. I almost feel blind in a lot of ways. Like I feel blind because, I have my knowledge of how to get around, but I live a very different life now. I’m still having relapses. I have probably a couple of relapses a week and that’s really a hard shuffle. It’s not something you can easily deal with. You can’t go and get help all the time. At some point you have to stop yourself and discipline yourself and forget yourself and go with the flow. But that’s not the way it goes. It doesn’t go like that. You have to, I don’t know, it’s about you. It’s not about what limits you have” (Respondent 3).

“Well my nurse says if I ever go through that just take one of the pills that are in my pack and sit down and relax and listen to music, do something, go for a walk, have a coffee, do something enjoyable” (Respondent 1).

**Dependence on the team.** Finally, only one respondent stated that they would not know when their illness was acting up or things were going bad, they would rely on their nurse or doctor to tell them if they saw something different. This is commonly seen in clients visiting their physicians, not just people with a mental health issue, but people in general rely or trust their physicians to evaluate them and tell them if there is something wrong with their medical situation. It is interesting that only one respondent stated this.

Interviewer: “So how would you know that something is going wrong?”
Respondent: “Well I wouldn’t know, my nurse would know” (Respondent 5).

**Team dynamic and the therapeutic alliance.** An interesting feature to the ACT model is the use of a multidisciplinary team approach to providing client centred individualized care and support to its clients in the community. Typically individuals in the mental health system would see their doctor or psychiatrist on occasion, or have some involvement with a social worker; however, when clients are living in the community the intense services are no longer as frequent and accessible. Thus, the impetus for ACT teams to provide the intense hands on care as one would get in the hospital, but is now provided in the community. The researcher was interested in understanding how the clients from SunPACT felt about being treated by a team. There has
been research about diffusion of care, role diffusion, lack of consistent services, or even coercion into services (Stovall, 2001). There has also been speculation that it could be difficult for clients to adapt to the varying personalities and roles seen in having an allied health team involved in their care. Below is an account of what the respondents in this research study had to say about being treated by a team approach:

“Well, I like the team approach because they can always butt heads with each other and me and come to a conclusion that this is the best thing for me, so I think a team is a good idea. But I feel comfortable going to almost anyone on the team” (Respondent 6).

“And they sort of work together. The nurses sometimes help me work with the same thing that my social workers are helping me work with, like housing; everyone sort of came together and threw ideas out of where I could live and that sort of thing. So I have to say that they work really well together. They’re a good team of health professionals” (Respondent 4).

“I would never go back to private psychiatry. I would only stay with a team. A team, this team and any other team associated with a hospital, if this is the model of that team then a patient can be more successful in coping with their difficulties, their mental difficulties etc” (Respondent 6).

“I love it! I just love it. I love every one of them and they’ve changed over the years, over the last five years. I love that they take the interest and you know right up until yesterday they were calling me every day for two weeks just to make sure I was okay and would have come down or I could have come into the hospital” (Respondent 6).

A common theme noted by the participants was that even though they have varying members of the team treat them, they were aware of the fact people are individuals and have their own personalities. Participants were accepting of this fact and saw this as a positive factor. This was contrary to the suggestion in the literature which states ACT teams employ a disconnected or diffusion in their services due to the many and differing members on the team treating one individual (Stovall, 2001). The respondents stated:

“When I’ve been having my crises and having difficult times, they’ve been extremely supportive and it doesn’t matter which team member is seeing me
or having an appointment with me, they’ve always been extremely supportive and you know, they’re willing to see me more than once a week so I see them twice a week now because I’m just coming out of a crisis period. So you know, things are, I would say overall they’re a very good team of people and very caring and compassionate” (Respondent 8).

“Because the team is…each one of them is different and each one of them has a different skill and they bring to the table these different skills and they all work together with you so they have an impact on you” (Respondent 2).

“No, it’s different from each individual. Everybody is an individual and at first I didn’t like the approach because I was used to having one doctor and I saw him every two or three weeks. With this, each week I’m seen by different people and some people are very good with bringing things out of you and discussing things with you and bringing your feelings out and discussing the issues at hand but a lot of people also keep things very light and above board and just have conversations like you would with a friend and that’s good sometimes also. So it depends on the individual” (Respondent 6).

There was also a comment made in terms of the peer support worker that is on the team. It appears this is a huge benefit for some participants and this role has created great support to clients in terms of the relatedness of their life experiences:

“The peer support worker that works with the team, has been through a lot of the same symptoms that I had and has gone through a lot of the same difficulties that I had so I was able to you know, get a lot of support from her with everything that I was going through. And there are very good people on the team who are very, very supportive of everything that I’m going through and have gone through so it works out very well for me and I feel very comfortable with the way the team operates so I have no problems with it currently” (Respondent 8).

A common theme was found among respondents stating they did not mind being treated by a team, but they still had their “favourites” in terms of who they gravitated towards more than others. The following are comments made by the respondents about the team:

“What I found is that there are some workers who I might get along with or work with more than others. I also think it’s probably easier on the psychiatrist because they have more of a back-up. So they’re not expected to do all the work and yet, if there is something really important, they can step in. I noticed that the psychiatrists, I see one or the other of them every
couple of months, so yeah. And as far as the workers, I think my concern is that they tend to work a little bit too hard and my other concern is, and I’ve mentioned this to them over and over again, is it really wise for them to go driving all over Toronto when it’s hard to their car and all that sort of thing” (Respondent 2).

“No, everyone’s different right? So I have a different relationship with everyone on the team, so it’s sort of like a different slant on things. So I don’t mind, but I have some special friends in SunPACT, so I don’t mind seeing them” (Respondent 1).

“Some, I have a deeper relationship with one of the workers. So they know more of the story that I tell, so I would come to her for, if the ‘___’ defeated me, then she would help me out” (Respondent 1).

“I don’t think it’s whether or not I prefer certain people or what have you, I just think it works out that they’re able to find something more in common with certain people than others and it works out whereby you’re able to communicate with them and share your thoughts and it works out well with them in particular” (Respondent 7).

One respondent discussed the benefit of having his psychiatrist visit him for a session in his home. This respondent also provides evidence for the benefit of having a team constantly involved, which then results in needing to see their psychiatrist less, because most of their issues are resolved by the team.

“Yes, I do. Yes, it’s very helpful. I don’t have to see him every week or every second week. I can see him maybe every month or two months, because the team will refer back to him” (Respondent 7).

One respondent commented on his preference for a one-on-one approach to care, which indicates that not everyone prefers a team approach to care, individuals are different in the needs and care they receive:

“Well, I don’t mind a team. I prefer one-on-one myself. Like, if it’s any one of these workers, I’ll sit one-on-one with them. If I’m not even meeting, if I hadn’t met one before, I’ll sit down with them because the other one gave the okay. I’ll sit down and be just as open with you or with them as I am, you know. And I know there is a line that you cut across that you can’t cross, you know, like you can’t exactly adopt a worker to take home with you for full-time care” (Respondent 3).
The following comment is a respondent reflecting on the fact that no matter who they see on the team you get the same service and they are all there to help. Therefore, this provides evidence that this ACT team provides a consistent service, as well as, a cohesive service to its clients. He states:

“The most important thing to know is that just because they’re an occupational therapist or a nurse or social worker, psychiatrist, it doesn’t matter because they all work together and yeah of course you have your primary worker, but everybody else helps you out just the same, like just because they’re a nurse, it doesn’t make a difference. They help you out to try to find a place. They’ll help you out to get employment, go to a volunteer place, recreation as you said. Even school, if I wanted to go back to school, I have an occupational therapist telling me she can help me get back to school and sending off a letter to get my transcripts and they all work together and it’s really great” (Respondent 3).

Family and social involvement. In this section respondents discussed any family or social involvement in their current lives. The clients of SunPACT primarily live in the community and the researcher wanted to gain an understanding of the type of family and social relationships clients had. This was explored because individuals with a mental health concern are people who have family members and friends that love and support them. The researcher also wanted to highlight that SunPACT was not the primary source of social interaction for the clients. Even though it has been researched that individuals with a mental health concern have few or no social networks (Stein, Barry, Van Dien, Hollingsworth, & Sweeney, 1999) it is important to see that this is not a pathological concern and maybe a personal preference from the individuals themselves. One respondent was married, while the others were primarily single. The participant who was married talked about how her husband was a great help and support to her. She also talked about her relationship with her husband and commented on how he copes with a wife who has a mental health issue:
“Mind you, my husband helps a lot. My husband made a hook in the bathroom to put my medication; I mean I can put it there. But there is still a lot to understand” (Respondent 2).

“I think he sort of has mixed feelings about things. Not so much to do with SunPACT, but having a wife with mental health issues, but he’s the sort of person who in many ways is very easy going, so I can for some reason drive him up the wall and he still doesn’t get too worried. So, I mean, this past week I’m having trouble sleeping and we also have a problem with the cat defecating on the mattress, so there’s a certain amount of conflict, but he doesn’t hold this against me, so” (Respondent 2).

One participant talked about how her family is very involved in her care and is very in tune to any changes they notice in her behaviour and provide an intervention strategy so she can stay out of the hospital:

“Well my family usually contacts them if they notice any kind of, any of my symptoms are acting up and if they think that I may be slipping you know with my medication or whatever, they have contacted the team in terms of getting me hospitalized, in terms of getting just for an intervention where…mainly to get hospitalized and to make the team aware that I may be slipping with my meds or something like that. Well my family is very involved in my care and they’re very compassionate also and care a lot about me and want to see me just get back out there again, it’s been too long, you know” (Respondent 8).

Another key issue in the literature on mental illness and community living is the notion that individuals with a mental illness have few social support networks (Stein, Barry, Van Dien, Hollingsworth, & Sweeney, 1999). The researcher wanted to explore this with the participants and noticed that many participants did not have many social networks. This was not viewed as a negative or problematic aspect but rather, the researcher wanted to understand the participants’ point of view in regards to having social networks. It appeared individuals with a mental illness do not want to have many friends, they maintain few contacts, but they feel much more comfortable being alone. A respondent states her thoughts about having friends in the community:
“I have one friend in the building, an older lady. Her and her daughter and I’m very close with them and she’s been a friend of mine since I first moved into the building. I do have other friends outside that I do see. My mental illness has made me a little bit more reserved and you know and introverted and I don’t really maintain the friendships I once had. If I see a friend who I haven’t seen in a long time, I’m very happy to see them and it’s great but I don’t go out of my way to maintain a lot of friendships that I make. Some friendships through the last admission that I had at Sunnybrook, I still maintain the friendships with these two people, so we’ll get together and go for dinner and we’ll talk on the phone during the week and so it’s nice, you know. But my ex-boyfriend is also a very good friend of mine and he spends a lot of time with me” (Respondent 8).

Some other respondents reflected on the fact that SunPACT has access to their family members contact information if they wanted some advice on how to keep the person well. The family involvement and contact information was received with the client’s consent. Some participants prefer having their family contacted and involved while others do not. SunPACT acknowledges this.

“They have my mother’s number and they keep in contact with her as well and she’s integrated with the team and that’s good because she can tell me what they said and I can go back to them and say ‘Did you say this to my mother?’ and they’ll say ‘Yes’ and I’ll say ‘Okay, you can explain it to me now’ and they’ll explain it to me. They look to her for advice and she looks to them for advice in the best way to keep me healthy and whatnot” (Respondent 4).

“Well I tell them about my friends, okay, and about I only have…I’ve got lots of nieces and nephews and great nieces and nephews but I only have my brother. My two sisters died. But no, I want to keep this part of my life between me and my team” (Respondent 6).

Furthermore, some respondents commented on the social networks they have maintained. One respondent talked about the contact they have maintained with their family and some also commented on what their family or friends feel or think about SunPACT. One respondent stated how he spends time with his sister and brother:

“I never used to see my sister and brother that much but I’ve been seeing them. I see them once every couple of months, my sister and brother. We go
up to ____ and have a coffee or lunch and they ask me if I’m going to all these places and still seeing my friends, how I’m doing, things like that” (Respondent 5).

Respondents talked about having friends and the challenges, as well as, the positives of being involved with a social network:

“Well it could be hard for some people, like getting along with the other people and living with other people. But it’s also good you have somebody with you and you’re not so alone. You could get lonely or end up going to your friends all the time or imposing on them but other than that case, my friend always calls me up all the time to come over and I don’t go half the time. I go on the weekends when I’m not at _______ but it’s pretty good. It’s not that bad” (Respondent 5).

“I also have a couple of very good friends that live in my house, my roommate is one of them and we often talk, at bedtime we’ll sit on our respective beds and talk back and forth for awhile if one of us is having a problem. You know I’m very fortunate in my roommate, he’s like an older brother to me and we get along really well” (Respondent 7).

Respondents below commented on what their friends and family think about them being a client of SunPACT. Most of the feedback from friends and family was positive in terms of feeling their loved one was doing well since being with SunPACT:

“Well they say if I’m with SunPACT I must be doing well. They think it’s the right thing for me to stay with SunPACT. They think they’re a good group of people” (Respondent 6).

“Like when we go out for coffee, they ask me, do you see your social worker, or are you still seeing a social worker? But my brother seems to think it’s the best idea for me to stay. He thinks they’re a good group and everything like that. He thinks they’re the best idea for me” (Respondent 5).

Community integration. For this section, the researcher wanted to explore the social supports SunPACT provided its clients in the community. Part of the mandate of an ACT program is to support clients in the community with the obtainment of employment, volunteer or recreational opportunities. The researcher aimed at exploring if these were already in place for some participants and if this was something they felt was vital to their treatment program and
quality of life. In the following account, several respondents verbalized interest in joining programs, but could not due to financial constraints. Participants in this study did not obtain competitive or gainful employment due to mental health concerns, were supported primarily by disability income, and could not afford to pay for memberships to certain community programs and centres. Therefore, it is not so much the individual not accessing community supports, but that the system is set up to make it more difficult for individuals to obtain such privileges.

“I’ve been volunteering at _____ and I make sandwiches, I do cash, I do reception and we take a lot of breaks, we have coffee and go out for a cigarette. People just come to join the clubhouse. It’s on _____ and ______. It’s for mentally disabled and they have it in the past or still are. They help you get jobs and they do a variety of activities at ________. And I was introduced to that by my occupational therapist” (Respondent 5).

“That’s the one thing where I wished they did more, although I’m not surprised they don’t. I’ve got to teach myself to go swimming, but employment, I think that’s very hard for someone like me to get employment” (Respondent 2).

“They’ve recommended that I go to groups for people with disability and I attended those, but they stopped because there weren’t enough people there. And they recommended me to go for exercise, get a ____ membership. They brought me the brochure and said they’d go to the interview with me, but unfortunately I don’t have enough money for that, but they helped me with accessing community resources” (Respondent 4).

“I’ve tried a recreational drop-in centre and I found it very boring, the people there. One of my former psychiatrists noted if I associated with normal people I tended to rise. If I get in with people that are ill, and talked about their problems all the time, I tend to sink. So I prefer to socialize with the neighbours for example than to go to a drop-in centre where I have to deal with other psychiatric patients. I’d rather be with normal people because then I feel normal” (Respondent 7).

“I’ve also been job hunting for something part time or possibly full time and I’ve been helped by the occupational therapist with that also. If I need help with a cover letter, I had a standard cover letter that I was using and I wasn’t getting much of a response based on that and I’ve had help with the occupational therapists on the unit or with the ACT team that has helped me with cover letters and my trying to find a job” (Respondent 8).
“I want to start off with something part time as opposed to something full time because I don’t think that I could go back into a full time thing right now. It’s been too long and I need to just sort of ease myself back into it I think. I don’t know, I don’t know if I could do full time right now” (Respondent 8).

“Well I usually find them on my own and then I’ll bring them to the OT’s attention, whichever one, like it’s usually been ____ or sometimes ____ and so I discuss it with them and then they’ll help me you know, go to the job posting and then try to compile a letter together and that kind of thing” (Respondent 8).

Many respondents commented on the fact that gaining employment was hard for individuals living with a mental health concern. The participants in this sample were interested in part time work and felt that this is what they could handle. As well, some participants felt that they were not ready to work and when they were they would let their team know. It is important to know that the respondents did not feel gaining employment was a priority, it was often mentioned to them by their team, but it appears this was not something the participants were too concerned about. The respondents who are interested in work have been collaborating with their team and various agencies. Thus, it is important to note that the participants mainly determined when they want to work and what they could do.

“I still say that it’s rather hard to have a mental illness with regard to employment” (Respondent 2).

“They have what’s called transitional employment and you can go for eight months or however long. I did one for a year, not a year, I did one before I got ill and did it again, I went back to _______, after I left the hospital and I needed my own place. I just did a newspaper route for _______. They do that for _______. So just a little bit of cash that helps” (Respondent 4).

“Work; I’d like to get a part time job. SunPACT thinks that’s a good idea but what I mentioned I mentioned to the person in SunPACT when she came to talk to me about a week and a half ago, and we’re going to get me a course in computers so maybe I can get a job along that line. So that will make it easier for me to get a job and she’s going to call the employment
agency once I finish the course and tell them how I did so tell them that I have an upgraded skill” (Respondent 5).

“Yes and when I’m ready to…____ has told me, so has ____, that when I’m ready to participate in volunteer work, they will help and assist me in getting accepted” (Respondent 1).

Experiences of perceived stigma. Previous literature has reported that individuals with a mental health illness living in the community would experience stigma (Prince, & Prince, 2002). This was demonstrated in the type of housing options or employment options clients would be offered. The researcher wanted to explore further with the participants if they had experienced any stigma in the community and if living in the community made it harder for the respondents to achieve a fulfilled life. When asked about being treated in a community the researcher proposed there could be fewer stigmas because you are not entering a hospital, you are treated in the home or seen in the coffee shop, therefore you would feel like a “regular” person. The researcher asked the respondents to comment on this. Below are comments by respondents who stated stigma was not a concern for them:

“It doesn’t matter, I don’t feel that stigma” (Respondent 1).

“No, I don’t suffer from that stigma, just the opposite” (Respondent 2).

“If they want to be ignorant, let them be ignorant” (Respondent 6).

“Mental illness is the same as cancer; it’s the same as Lou Gehrig’s disease, it’s an illness” (Respondent 3).

Other respondents commented on the media and the way people with a mental illness are portrayed. This was a concern to one respondent and it was something he felt was attacking him as a person. He stated:

“When I see the news about people with mental illness doing crimes, I don’t commit crimes, you know. I’m not a bad man. But, you know, it hurts me to watch that on TV, like when they say bipolar or mental illness, all these
things I know are very true. Probably in the long scheme they’re looking into, you know, causing a bit of propaganda on the news right, but they don’t reflect what I see here” (Respondent 3).

He further explains:

“Like, you know, it wouldn’t matter if I said ‘Well I have this education and I have this’, the fact that you have a mental illness automatically puts you in one section, right. If you were to even respond to what do you want to do in your life, like if you want to get a job, if you want to work” (Respondent 3).

“You know, I’m more humble than I am anything because whatever you do in Toronto or pretty well any place, if you walk in there and they find out you’re on medication, it’s not like having arthritis, you know, which is taken pretty simple. They think you’re pill popping. They think you’re an addict, right away, you know. You know, it’s hard to handle” (Respondent 3).

A respondent below talks about SunPACT reducing the stigma if one were to have suicidal thoughts. It appears when one states they feel suicidal there is more of a negative reaction that just makes the situation worse. The respondent talked about what works for her when she feels this way:

“Once you start thinking suicidal, they don’t go berserk, they don’t send 911 and the police and the cops and the fire engines and everything like that. I’ve been through that, yes and it’s terrible, a terrible stigma to it. They talk it out and then if they can’t talk you into keeping yourself safe, they bring you into the hospital. They usually say we’ll come and get you or will you come up and we’ll put you in the hospital for a week or two weeks because you need a change” (Respondent 6).

Negative experiences. Below are some of the experiences respondents talked about in relation to the negative experiences encountered with the healthcare system. This includes some challenges the participants had experienced in relation to dealing with the challenges of having a mental illness. One respondent talks about the change in his abilities. He reflects on the past when he felt he was mentally stronger and how over the years he is challenged by not being able to do the things he once could. He states:

“But as time goes by, you almost wish you had a better stand and that’s
what I want. I’ve always wanted a higher point to stand on mentally, since I got ill. Not because I didn’t have the ability, but I had the ability. To know that you have the ability to do something and it’s a matter of your brain work and not be able to figure it out. Leaves you pretty dumbfounded, you know” (Respondent 3).

He also talks about the struggles with obtaining housing in the mental health care system. This statement demonstrates the effects of stigma within the housing network system when it comes to providing affordable and optimal living conditions for individuals who have a mental health issue. He states:

“Like, they’ll give you a dream, like even getting an apartment. You go there, they tell the workers here one thing and when you get there, after a week the whole place changes, you know. The place I have now is probably the best apartment I’ve ever had. Usually the fact that it’s not changing into something completely reckless where, you know, there is no honour system, there’s no respect and there’s no this or there’s not that, but it’s still hard to stay there. SunPACT does what they can to help you with that, you know” (Respondent 3).

One respondent commented on the challenges of the mental health system where you are dealing with different people who do not know you, so the way they perceive you or treat you is different then if you were to be known by your peers. He also commented on the fact that some people who do not get hooked up to community supports end up living in an institution for years. He would prefer using the hospital as a means when extremely necessary, and still be able to get out into the community feeling better. He also states that he fears one day he could end up in the hospital, it appears, this is something he has already endured, and is in fear of it happening again.

“So, yeah, if I can stay at a hospital for three weeks or two weeks or a month or two months, whatever it is and get out and come out feeling a little better or even feeling like ah, I don’t like the idea of leaving or something like that, well yeah, compared to being stuck for five years, that’s reality. You could be stuck in a mental institution for five years and nobody would be even be able to understand a word you said about what you want and you’d be gone. And that would happen and I’ve been in a position such as that, not being in a hospital for five years, but I know that could happen” (Respondent 3).
One participant reflected on the challenges of being a man in the community and exploring the possibility to date women. For him the challenge involves going to a bar and he can not have a drink because he is in recovery from substance use, and then the issue of telling his date he has a mental illness. He also talks about how the medication has an effect on your physical performance and libido. These are all valid concerns, and at times clinicians forget to address or remember that people with a mental illness are people who experience many challenges that are not just related to their illness, but also to their status as a person who want to live a functioning life in the community. He states:

“Take the girl on a date and you drink your coca cola or your 7UP and she’d have her rum and coke and you’re just like, you know, you’re telling her about mental illness and as soon as you do, because you want to be honest, instead of lying to her. Some people say don’t mention it right away, its better that way. I just told her. I tell the girl if I was on a date with her, I’d say ‘I have paranoid schizophrenia’ or something like. I was all off anyway, right. But, you know, they listen to you and you may have a girlfriend after a couple of dates, but usually you know when to stop. And it doesn’t mean you’re going to have physical sex. And a lot of times on the medication, you can’t anyway. So you’re stuck in the frustration of not being able to have sex because you’re limp, right. So you end up trying to, you end up sexually frustrated and then you don’t know what to dream about” (Respondent 3).

Below respondents comment on the challenges of taking medication so they can have relief from their symptoms, but on the other hand the medication can reduce the ability to be creative, or get up in the morning to go to a full time job which usually starts at 8am. Thus, making it more difficult for a full time employment placement. While others commented on how medication was commonly used to relieve any symptoms related to an issue they were experiencing, but it was not helping them deal with it.

“Yes, there is a big change. I think I’ve lost a lot of my creativity because I’m a singer and a songwriter. I think I’ve lost a lot of my creativity, I think I’ve lost a lot of my joy and my spontaneity of thought and feelings. I think
the medication has dulled my senses but I’m not acting out in the same way. I don’t have those symptoms anymore, thank God but it’s taken away my creativity, yeah. I have to work so much harder just to write a song or to think of a poem or think of thoughts that are uplifting, you know, so I have a faith in the creator, the almighty God and that’s what I do, I put my faith in that and brings me through. But I wish I had my creative juices flowing the way they used to before” (Respondent 8).

“I do need advice at times on how to cope with things because for years when I was in ______, the only answer to everything was take some more _____ whenever there was a problem and that didn’t solve any of these problems so I didn’t learn a lot of the coping mechanisms or how to deal with certain things in life that come up such as the aging process. You’ll notice I’m no spring chicken any more, I’m sixty-three but they come up at SunPACT and they’re discussed” (Respondent 7).

“I want to get back into the workplace again but it’s just been difficult, you know, I guess just getting up in the morning. If I had a job and I have to get up at 6:00 in the morning to have a coffee and breakfast and showered and changed and ready to go to be someplace at 8:00 or 8:30, you know it would be difficult for me. I’d have to take my medication probably at 7:00 at night and I’m not used to taking it until 10 or 10:30 and so you know I’d have to make a big adjustment” (Respondent 8).

**Housing.** Housing is a basic and essential need that every person should be entitled to. It appears that individuals who are living in the community with a mental illness are constantly struggling to find affordable and suitable housing. SunPACT aims to help its clients obtain such housing since it is widely known that having suitable housing accommodations can have positive implications for one’s mental status, psychosocial functioning, and quality of life. In this study the 5 out of the 8 participants reported living in a supported living situation with other people with a disability. The remaining sample either lived alone or lived with their spouse. Below are some comments the participants made in terms of their current housing situations and whether or not SunPACT was an integral part in their obtainment of housing. One person commented on the role of their social worker from SunPACT who provided support in terms of the decision making for possible future housing. She states:
“My social worker says for the long run he’s going to keep me here but he is thinking of getting me my own place with apartment size housing, like it’s housing with apartments of your own in a building and it’s low rental. It’s hardly any rent, it’s geared on your income and its low rental and you get your own place and it’s like a bachelor with a bedroom and TV room and they’re thinking of moving me there. And it’s close to...most of them are close to Progress Place so I don’t have to travel on the TTC. That’s what they said they’re looking for in the future but I don’t know if it will happen, it could be anything” (Respondent 5).

“I mean living in that apartment was like living in a cell and I lived in apartments all my adult life from university and beyond. And to get into a house where in the good weather I could take the newspaper and go out in the backyard at the picnic table and read the paper and have a smoke is heaven in the warmer weather. And so I hated apartment living, I was always afraid of cockroaches, so I was always doing a lot of compulsive cleaning to prevent a dead fear of them and of course the anxiety would rise with the cleaning rituals and everything so once you got away from that that was a big difference too” (Respondent 7).

One person commented on their current housing situation. SunPACT was involved in the obtainment of his housing establishment. He states:

“The housing is fantastic. I have a room, which also has an atrium on it. It’s a beautiful room. So fall, spring and summer I can go into the atrium. It’s attached to my room. So it’s a beautiful room. Best room in the house. So SunPACT filled out the housings forms for me and then they came with me to the interview. I was so lucky to get it. I’m really thankful. So it’s really important. Because I don’t think I could survive in that boarding house for mental patients and stuff. It was fantastic” (Respondent 1).

One respondent commented on the ways SunPACT has helped him cope with the tasks involved in maintaining the upkeep of their house.

“I think what SunPACT does is help me to cope in the household. So they help me do things like learn how to organize my home properly and things like that” (Respondent 4).

The comment below describes SunPACT’s role in searching for suitable housing with the respondent. The respondent also makes a great conclusion where he states that because the team is out in the community they can see the various places and recommend them to the clients. He reflects on his experience:
“They took me to various interviews. They took me from the hospital, they drove me and then after we’d go to the interviews, then they would discuss what my feelings were about the place and how they saw it and how I saw it and that was very helpful. And finally, it was one of the nurses who came up with the place where I moved to out of the hospital, because they go out into the community and they see these places where other people live and just because they’re not social workers doesn’t mean they don’t notice the quality of care and whatnot that places have. So, they referred that back to my primary social worker and my primary social worker relayed it back to me and then we went to see the place and I liked it and they liked it and it was only supposed to be temporary and it was temporary, but it was good for me at that time” (Respondent 4).

Financial management. Financial management is another area that SunPACT addressed in their holistic team approach. For the participants in this sample, 6 participants were receiving financial support from the Ontario Disability Supports Program (ODSP). The remaining sample, were receiving income from a government pension. Furthermore, 7 participants out of the 8 identified as having an income below $19,999 per year. SunPACT provides financial management services to its clients, as well, some clients reported in this research project, that they handle their own finances or a family member also helps them with their financial management. One respondent commented on the negative experience he endured where his family did not support him financially, and when this occurred SunPACT tried to advocate on his behalf but they were not successful:

“My mother died and my brother sort, he was the executor of the will so he did not, he denied me everything. So this sort of, ____ tried to talk to my brother, he tried to talk to a lawyer, but didn’t get anywhere so” (Respondent 1).

One respondent discussed his hobby and love for book collecting, but he requires more support around managing his money so he can buy food which is important to his health.

“I sacrifice my money for buying books. So that was sort of a quest. So _____ said ‘You shouldn’t really do this. You have to eat.’ So I thought maybe I would go to a food bank, something like that. So, SunPACT gives me $60 a week. When they come, they have the money” (Respondent 1).
Another respondent comments on the way SunPACT supports him in managing his money:

“They handle that. And they handle, you know, they hold my money. They give me a hand because they know I’m clumsy sometimes. Sometimes I forget things and stuff like that. I’m on a low budget. I don’t have a lot of money. And all I have money for usually is cigarettes and coffee and I wish I could save money” (Respondent 3).

Some respondents commented on the way they manage their own money without the assistance of SunPACT:

“Well, I get my cheque once a month, right, my disability cheque and I cash it, come here drop off my deposit for the month and then I go pay my rent in cash. I get my receipt. The superintendent puts my receipt in the file at the house, the building and that’s it. And if I need money I come here usually once a week to pick up a couple of bucks for my week of whatever I’m doing, buying coffee, making coffee or for my coffee machine…” (Respondent 1)

Another respondent talks about how they receive a trust fund, where they go to the bank and take out the money they need for month. This participant is actively involved in her finances and is also working towards monitoring her spending:

“Well I used to get more from my trust fund $___ more. But at the beginning I did well, like managing my money; I even had money left over sometimes. It’s been lowered. It used to be $___ now it’s $___ plus my brother wants me to try and quit smoking and so does my doctor but SunPACT says for me smoking, just don’t smoke too much; that’s the main thing because they understand socially you need a cigarette, you know what I mean? But sometimes it’s a little hard for me to manage money, I spend it foolishly, you know, like when I go out with my friends and we go buy beers and sometimes we buy too much, you know what I mean”(Respondent 5)?

**Hospital versus community treatment.** ACT models are based on providing care in the community. The care is required to be similar to that of a hospital, just in a different setting. The researcher wanted to know how the participants perceived being treated in the community versus the hospital. This would further imply the benefits or disadvantages of the treatment setting, as
well, implications for further program developments. Below are some responses from participants in this study when asked about the difference between being in treated in the hospital versus the community:

“Well, in some ways it’s not exactly either all at the home or all at the hospital. The nice thing about SunPACT, I can still come to the hospital, have my therapy, whatever, and still go home. So, SunPACT doesn’t exclude the hospitalization, it just makes it easier” (Respondent 2).

“The hospital is not a good experience. You’re life is sort of, there’s not much to do in there, sort of stifled, a little bit stifled. So I never stayed in the hospital very long” (Respondent 6).

“Well the treatment team comes here, whoever is assigned to come and see me, comes and we walk up to _____ at _____ and _____, we have a coffee or a tea or a latte and we chat about how things are going on the way up and the way back and then it usually ends up being a bit of a social visit because things are going fairly well for me and have been for a long time now” (Respondent 7).

“Well in the hospital they seem to be more concerned about how are you feeling right now, do you need a PRN. There wasn’t the intellectual conversation that there was with the SunPACT members. So I find that we can….for example if you and I were….if me and you were a SunPACT worker and I was the patient and if something was bothering me today let’s say….and this happened and this is the way I feel about it, now I may be taking it very negatively and you would…we would discuss it and find out that I’m thinking about it the wrong way and I should approach it, what happened from a different point of view and then it wouldn’t seem so bad” (Respondent 7).

“I hate hospitals! It’s so confining, it’s so difficult, the food is terrible, conditions aren’t very good, you know and I wasn’t always at Sunnybrook Hospital, I was at the ______ through ______ or at ______ at ______ and ______ so both hospitals operate very differently than Sunnybrook did” (Respondent 6).

When asked about the community treatment model one respondent commented:

“It’s good, I get to do my own thing. I can watch TV a little bit and chant and pray. I have my own books. It’s much better living in the community” (Respondent 1).

For some respondents it did not matter to them where they were treated:
“I prefer community but like I don’t mind being in a hospital. It’s just I’m a smoker; you’re not allowed to smoke too much when you’re in the hospital. You know they take you out for one every couple, two, three hours and that’s it. So that’s the only problem I have but I don’t mind being in the hospital” (Respondent 4).

“Well either way is good. I’m not very good at finding my way around hospitals. So I guess if they changed the thing around that I had to come there for my injections and for the visit and they would meet me somewhere and take me both ways, like to the hospital and back, I would go. But with hospitals, some places I can’t find my directions at all” (Respondent 5).

Some respondents commented on the time they were often ‘in and out’ of a mental health hospital based in Toronto. It appeared the situation did not amend or make the matter any better.

Being treated in the community has made things much better for this individual:

“ At the time, I had been in the ______ off and on for about a year or two and I kept on going back and forth, back and forth and the doctor there, Dr._____ really didn’t know what to do with me and the psychiatrist I had before, he was having problems too. So, this is probably the best thing that happened to me. So, but yeah, it’s hard to get used to it” (Respondent 6).

Another respondent commented on the hospital experience for him:

“Living in the community and living in a hospital? Well, for one, you’re dealing with people who have the same problems and you’re not living with them. You’re not having to abide by their rules. You have nurses on the floor. You have doctors on the floor. Usually, the only thing that bothers me is when there is a time lapse when you have to go because they have a relapse of patients, right. So that does bother me. I would like to stay longer, but I can’t” (Respondent 3).

However, other respondents talked the hospital as a negative experience for them:

“He will come see me in my environment. It’s different than seeing me in the hospital because there are certain rules and things that you have to do in a hospital. You’re not as free. When I was in the hospital and they came to visit me, I would be in my room shared with three other people and it’s hard to talk to them. But when you’re in the community in your own room and they come in, you can talk to them and tell them how you feel, how you’re doing” (Respondent 7).

“Hospitalization is usually brief and if there was just someone you met in
the hospital for a brief period of time you wouldn’t get to know them, you wouldn’t get to be familiar with all that they do, all the resources they have to access for you. I think that being in the community means you’re more of a regular person, more of a regular person, not just a patient and that’s the way they treat you” (Respondent 2).

“Well the doctors in the hospital, they were…they came across kind of mean, you know abrupt, asking questions that didn’t make sense and stuff like that but some of them in past experience, some of them were good. Some of them were okay, like once I had a Chinese doctor, once I was in the _______ in 1989 when they diagnosed me with schizophrenia. And there was a doctor there and he was pretty understanding after awhile when he got to know me. Sometimes the doctors, some doctors you just…it’s hard to relate to, you know what I mean” (Respondent 3).

“Well you can go out, you can go grocery shopping; you can go out for coffee, you know, you can see a friend. In the hospital it’s pretty hard to do some things, you know what I mean” (Respondent 5).

Another respondent comments on the community experience. He states:

“Well, I like the fact that I have coffee shops in the area. I like the fact that I’m by _______. I worry about, well, I don’t meet anybody anymore. __________, the people that I could meet probably we’d just end up sitting in a bar somewhere” (Respondent 4).

This respondent talks about how she can go about her daily activities in the community, see her treatment team, and she can still get the support she needs. She states:

“Well I’m being in the community, they still follow me and when I go to ________, sometimes they come and meet me after ________ once I’m there, downtown. And they’ll ask me how I’m doing and I’ll tell them how it went, how the day went, what I did there. And I know it’s a lot better to have your meds dropped off than to have to come and stay at the hospital. And, it’s just frees up my time and I know it’s their job to help me in the community. They come to the place where I live and they’ll ask if everything is okay when they drop off the medications. And they’ll come and see me just to see me, just for the sake of my, they see how I’m doing in the community” (Respondent 5).

Some respondents reflected on living in the community and being exposed to other people:

“Well it could be hard for some people, like getting along with the other people and living with other people. But it’s also good you have somebody with you and you’re not so alone. You could get lonely or end up going to
your friends all the time or imposing on them but other than that case, my friend always calls me up all the time to come over and I don’t go half the time. I go on the weekends when I’m not at _________ but it’s pretty good. It’s not that bad” (Respondent 5).

In essence, it appears whether one benefit from a hospital or a community treatment modality is essentially based on the person. Individual differences and preferences were seen to show greatly in this section. For some, being in the hospital was safe and comfortable, while for others it was unpleasant. There is no conclusive answer to the situation, but it is important that we have obtained the viewpoint from the client. It is important to understand how they interpret the treatment they receive. It is also fascinating how one treatment is not the best choice for everyone, further enhancing the fact that individual differences are vital in program development and management.

*Future fears/ desires.* During the interviews the participants would talk about their view of their ACT team. There were many stories of positive encounters and reflections about the past when they were constantly being admitted to hospital. Many respondents were very grateful for no longer being in hospital. The researcher was interested in the participant’s view of the future. ACT teams are there to provide a service to their clients, but the question of how long or if it will be indefinite came across the researchers mind. The researcher wanted to explore if the participants ever thought about their future in terms of the care and support they would still require to live in the community. The researcher hypothesized that clients may develop the skills to function in the community and would no longer need their ACT team; however, below is a representation of contrary findings.

“I would want to be on maintenance because there are things that come up that, you know, they have to, I don’t know what the word is, they have to help me connect with the government offices and things like that that I’m not too good at and important papers and documents and all sorts of things. I had to go through with the trusteeship changing. I wouldn’t know how to
do that on my own” (Respondent 4).

“That even if they change workers that they will be here and that I can trust someone when I do feel completely threatened or completely even suicidal thoughts or racing thoughts. Someone I can go to that, because when you phone a help line, they don’t have the same reaction as people who are here in the hospital, right. So I do recognize that this is a very nice place” (Respondent 3).

“My friendship with SunPACT is solid, but if, I don’t think I would end up with another ACT team. They know all my ideas, sort of have a history, sort of built up over the years. So I think if I went to another ACT team, it wouldn’t have the same or have come to a similar conclusion” (Respondent 1).

“Well, forever is a long time. The situation works now, but I’m getting on in years, so, it might be that eventually I have to go into a group home, I have to go to a nursing home. I prefer not to think about that” (Respondent 7).

“Well, yeah, yeah, I hope I can stay with them as long as I’m alive. I just want help. I hope they stay. I hope they stay as good as they are and I’m more than happy with them” (Respondent 6).

Some participants commented on where they see themselves in the future. Many respondents commented on having a job or their own apartment as their future goal or desire.

“I see myself in my own apartment with a job, a part-time job and I think I’ll stick with SunPACT. I don’t think I want them to leave. So I’ll that’s the near future, an apartment, a job, getting on with SunPACT” (Respondent 4).

“I’d like to get a part time job. SunPACT thinks that’s a good idea but what I mentioned I mentioned to the person in SunPACT when she came to talk to me about a week and a half ago, and we’re going to get me a course in computers so maybe I can get a job along that line. So that will make it easier for me to get a job and she’s going to call the employment agency once I finish the course and tell them how I did so tell them that I have an upgraded skill” (Respondent 8).

“Well I don’t know, housing and get a new job and maybe I don’t know, that’s about it” (Respondent 5).

“To be a volunteer at this hospital, this part of the women’s auxiliary and also I’d like to work for the distress centre and like one night a week or one day a week or maybe two days a week. I want to get to that point. I want to also reconnect with my church, I’m Catholic and I say my prayers and the
rosary and watch the mass on television and sometimes I go but I want that
to be a habitual thing that I do every week or twice a week that I go to mass”
(Respondent 6).

Some respondents commented on how they see their needs changing in the future. Some
associated their needs as decreasing while others associated their needs as increasing. This was
due to the stage the individual was at in their life.

“I expect that maybe when I get my own apartment I’ll be needing some
more assistance as well, like some of the basic life skills and I think they’ll
help me with that” (Respondent 4).

Respondent: “My needs, I won’t be as needy”.
Interviewer: “Yeah, so you see yourself being more independent.”
Respondent: “Yes, yes.”(Respondent 6)

“I have no idea of where I’m going, like in ten years. I don’t have a ten-year
plan. I don’t have a five-year plan. I don’t have any faith that my ten-year
plan from ten years ago is feeling as good as it should and usually it’s the
medication too, right, it slows you down. So you’re not gratified with what
you have” (Respondent 3).

“Yeah because as you age, sometimes you can become depressed when you
reach sixty, sixty five and I have those issues to deal with also so I see
SunPACT being in my life forever and if the Premier of Ontario ever
dismantles it, it would be a terrible, terrible, terrible thing” (Respondent 7).

“I would not like to see my level of support decrease. I’d feel let down, I’d
feel really depressed because it’s meant so much to me and it’s raised me to
a level where I feel great” (Respondent 6).

“The only thing I’m afraid of is that SunPACT is going to get too big, you
know. That you won’t be able to see me as often, although apparently
they’re not going to do that, I’ve been reassured.
Yep, so I’m hoping that I can find something to do part time or full time
where I could earn more money and then you know, be able to stay in my
apartment, yeah” (Respondent 7).

“Well I think I’ll still be receiving care from SunPACT until the time comes
when I gain I think a little more independence via a job or perhaps a little bit
more success with my musical career, whatever, you know as long as there’s
a need, I think I’ll probably be associated and affiliated with them. I don’t
really know what will divide that unless I just didn’t have the time or my
schedule was too busy or something like” (Respondent 8).
Quality of life factors. There has been a myriad of research studies reporting on quality of life with individuals living with a severe and persistent mental illness in the community (Hansson, 2006; Test, Greenberg, Long, Brekke, & Burke, 2005; Test & Stein, 1978; Sartorius, 1992; Baker & Instigliata, 1982; Prince & Prince, 2001). Many of these researchers utilized a scale to assess quality of life factors, but these scales have been constructed by individuals who think they know what quality of life means to this population. In this part of the interview, the researcher wanted to understand what made life fulfilling for these participants. Below are responses from the participants, when asked about how they view their life in terms of satisfaction.

“I think the medication they have me on and then the kind of lifestyle, you know getting out, they like me getting out and going volunteering and seeing people which I’ve been doing is a healthy lifestyle” (Respondent 4).

Interviewer: “So why do you think that you’ve become so well?”
Respondent: “Someone to talk to and to relate to and, this helps greatly.” (Respondent 1)

“I guess you think it depends on each person, like some people may need more time. I think it’s good. I think it’s good” (Respondent 2).

“I used to have to go into Sunnybrook two or three times a year for respite care for two weeks at a time. I couldn’t cope with anxiety and depression; the stresses of normal life. Now since SunPACT has come on the scene, I see them twice a week” (Respondent 7).

“Well I’m happier. I’m getting on with projects that I’ve been putting off and I’m thinking of the future as opposed to not thinking about any future” (Respondent 6).

“Yeah they spend an hour with me Monday and an hour with me Wednesday and that’s usually enough as I say and if it isn’t enough, I can always phone in and speak to someone on a Friday or in one case when I was really bad, ____ came up on a Friday and just sat and talked to me for about half an hour. I mean this was after his work, he was on his way home but he dropped in. It is nice to know I have that support. It gives me the feeling of self confidence knowing that they’re there for me” (Respondent 7).
“I think it’s just the fact that this medication that Dr. ____ has put me on has calmed down the anxiety level so greatly that I just…I just go out! So if I feel stiff and sore and a little weak, I just say “okay it’s the arthritis, you’re just getting older, left foot in front of the right foot and let’s go to Starbuck’s, you know?” (Respondent 7)

“I saw one of the social workers and I was telling her that you know, it’s just too much. I think I’m on too much medication so without my asking, the doctor called me today and I’m seeing him next Friday so they do relay the messages and they are very concerned and they want to see that I have some quality of life, that it’s meaningful as opposed to just being over medicated or something like that” (Respondent 8).

An interesting finding when asking participants to comment on their life and if they have noticed any changes, it appeared some participants did not conceptualize their life that way before. This was something to explore further, it could be a characteristic of having a mental illness impacting one’s cognitive ability to conceptualize life in such abstract terms, or it could be the fact that individuals highly stigmatized in the community and mental health system were never asked how they felt about their life and the services they were receiving. The participants in this sample have been in and out of health care services all their life. So when finally asked to reflect on their life and any changes in their quality of life, participants could not give a response.

Interviewer: “Did you ever think about yourself and how you’ve changed?”
Respondent: “I can’t say I’ve given that a lot of thought. I don’t know what to say.” (Respondent 2)

Recommendations. The final section of the research results will be an account of recommendations made by the participants in this study about SunPACT. The researcher asked the participants if they had any recommendations to say to their treatment provider or to the Ontario government and Ministry of Health about the services they have been receiving. Essentially, the scope of the recommendation was to address if the participants would
recommend the implementation of future ACT teams in that more services are available in the community for individuals living with a severe and persistent mental illness.

Interviewee: “Would you recommend other hospitals to have ACT teams?”

Respondent: “Yes. I’d support it, so I support the ACT team to help me transcend my mental illness” (Respondent 1).

“I think tell them that it works and that’s the basic thing, it works” (Respondent 2).

“I would advise for more ACT teams” (Respondent 6).

“I would think it would depend on the circumstance, but I think the person would have to want to join. In any thing if you’re going to go into a program like SunPACT and you’re not going to try and try things and you’re very negative and stuff, in some ways you’re wasting things and perhaps you should another program. I don’t think SunPACT is for everybody” (Respondent 3).

“I think they’re all professionals. I suspect they’re underpaid, but that goes with the territory, I think. But yeah, they’re professionals. I’m hoping that they get the recognition that they do. It would probably be nice if they got a raise. And of course, I notice that the staff, not everyone that gets on SunPACT, a lot of them don’t stay and some just don’t work” (Respondent 2).

“My suggestion is there’s no suggestion I have with regard to this team because they just do perfection. I think this would be very good for a hospital to follow the approach of Sunnybrook because I just have nothing negative to say about it” (Respondent 6).

“Probably one of the best things that Mike Harris did to reduce the number of people kept in psychiatric beds in hospitals because I’ve found that this going into hospital, being medicated, go in a bed, didn’t help me. I could do that at home but getting a team of professionals to come up and see you twice a week and when you run into a problem, help you work through that problem. Now sometimes some of those problems come back but I could work through them now because I’ve learned from SunPACT so they’re not problems anymore they’re challenges. And working with an ACT team like this, it’s a more normal life and I feel better for it and it’s costing the taxpayer less for an ACT team rather than have me lying in a psychiatric bed feeling rotten and I just feel that” (Respondent 7).

“They’re really, really good in providing the care that I require and I prefer this method as opposed to just the one on one. I’ve become accustomed to it
so I don’t know, I just think it’s a much better way and they’re able to monitor my progress and if I need the hospitalization, I’m sure they would say you know “we think you need to be in the hospital” but the last time they said “we want to try to keep you out of the hospital so we’ll work with the medication and just the care. So that’s what they did” (Respondent 6).

“I would say that they’re a supportive group of people who are able to provide you with the best possible care that the health care system has to offer for people suffering with mental illness. I think it’s a challenge that they face everyday with working with people with a mental illness, being able to assess, being able to offer the right amount of care, being able to determine whether or not a person is going to be harmful to themselves or try to harm somebody else or you know, requires hospitalization. They’re just a really good group of people and they’re able to, at least they helped me with my care in the community and helped keep me out of the hospital which is very important to me because I don’t like hospitalizations” (Respondent 8).

“I would say do your best to get in with a team, there’s nothing like it” (Respondent 6).
CHAPTER 5: DISCUSSION AND CONCLUDING STATEMENT

This chapter will present a review of findings, situate these findings in the context of the literature and cultural review, identify the limitations of the research, and discuss implications for social work practice.

Review of Findings

The primary purpose of this study was to report the lived experiences related to service satisfaction and quality of life from participants who are clients receiving treatment from the Sunnybrook Program of Assertive Community Treatment Team (SunPACT) in Toronto, Ontario. The results indicated that being apart of an ACT team had great implications for community integration, social functioning, illness management and quality of life. There were many overlaps between the findings in the thesis, and the current literature related to quality of life and service satisfaction among clients treated by ACT teams. There was also the development of analytical themes not addressed in the literature at all. Most importantly the findings answered the questions that were specific to the experiences of individuals living in the community with a severe and persistent mental illness receiving care from an ACT model, a perspective that is most often absent from the current literature. There was also overlap found between the categories present in the interviews, as well as, themes that evolved from the respondent’s narratives which contributed to the overall theme of service satisfaction and quality of life. The categories were also determined by the respondents based on the relevance to them. The respondents feedback will be addressed in the following sections: 1) participants definition and understanding of SunPACT, 2) illness and medication management in the community, 3) impact of the team dynamic on quality of care, 4) family and social involvement in the journey to recovery, 5) negative experiences related to mental health care in the community, 6) the setting of care
delivery, and finally, 7) future considerations. The results of the study indicated that participants predominantly commended the services they received. Their descriptions of their experiences were consistent with the assumptions underlying the structure of ACT and the processes by which ACT is believed to produce positive change in their clients (see Stein & Santos, 1998).

The respondents asserted the value of autonomously constructing their identities related to their illness management. All respondents expressed varying responses about SunPACT and the influence this community treatment approach had on their quality of life. The responses ranged from praises of how happy they were with the service they were receiving, to issues raised about living in the community with a mental illness and experiencing stigma, challenges to gaining employment or recreational opportunities, or even barriers in obtaining substantial housing accommodations. There were also responses related to the differing experiences and preferences when it relates to the type of treatment, for example, some preferred one on one support while the majority preferred being treated by the team. In essence, there was ample positive feedback that was reflected in the respondent’s narratives of how they conceptualized the care they were receiving. The researcher wanted to emphasize that clients should be entitled to having an opinion on the care they are receiving, especially when they are going to be involved in the health system for many years. One can only assume that this would have an impact on one’s life, and thus the impetus for this project was to explore this further, as well, to incorporate this into the existing literature and to make the findings available to SunPACT and other ACT teams for future program development and evaluation. The respondents were able to articulate their experience which in itself is a form of empowerment for individuals whose lives are predominantly managed by the other people involved in their care plan.
1) Participant Definition and Understanding of SunPACT

The narratives in this research reflected the assertions in both the theoretical and empirical sources that Assertive Community Treatment (ACT) was effective in reducing hospitalization and increasing stability of housing and patient satisfaction. The findings on other outcomes, such as reducing symptoms, improving vocational and social functioning, and improving quality of life, are more mixed, but generally indicate that ACT is equivalent to or better than alternatives in these areas (Drake, 1998). ACT is considered to be the only psychosocial intervention for severe mental illness with a strong empirical base (Drake, 1998).

The respondents defined and conceptualized the SunPACT team as a “friend” and support which provides constant and cohesive support to their clients. Most importantly participants commented on how their interactions with the team made them feel like a “regular person.” The team was able to normalize their life by not always addressing their medication or health needs, but also being able to have informal conversations; however, important issues like health were addressed when needed. The respondents seemed to think that this was more of a benefit to their quality of life. They enjoyed having walks to the coffee shop and talking about their week. But they were also grateful to have SunPACT there when a crisis situation was occurring. Respondents felt their issues related to mental health would be addressed early on in order to prevent any further crisis from occurring, thus the reduction in hospitalization. The respondents also reiterated that having constant support and enhanced time in addressing issues related to mental health or life in general was very beneficial. The respondents often referred to SunPACT being a very “accessible” service, as well as, an efficient service. This was illustrated in the comments about having the voice mail to leave messages, and getting a call back within the hour. Most importantly, the respondents demonstrated how SunPACT allowed the clients to be viewed as a
person and not a client, therefore, the care they would receive would reflect this. This was associated to the fast, efficient and accurate services they received from their team. Finally, the respondents felt their team was honest with them and this made them feel accepted.

2) Illness and Medication Management in the Community

Research has shown that clients receiving treatment from an ACT team in the community provides a delivery of services which dramatically reduces the issues related to clients not receiving the needed services such as medications (Drake, 1998). ACT utilizes a smaller caseload which can provide intensive outreach. As a result, immediate crisis intervention and individual tailoring of supports can be given in a timely manner to help with an emergency in their community living situation. When discussing medication management with participants it was found that participants were open to bring up any concerns they had related to their medication. Their concerns with medication or their illness was understood as a valid concern. The respondents often used the word “trust” when describing their relationship with their psychiatrist and the medications their doctor was prescribing. There was also this sense of control and ownership, where clients could discuss openly with their physician about any side effects and the option of exploring other medications. Respondents also talked about how they were able to notice when they were in crisis they would call SunPACT right away if they needed to be admitted to hospital.

Medication is a great part of one’s life when one is not well. For clients with a mental illness, medication is apart of their life for a very long time, hence it was seen as having an impact on their identity and integration into the community. For example, when some respondents talked about community integration they referred to the sedative effects medication had on one obtaining full time employment (ability to get up in the morning to be at work by
8am), the long term side effects of taking medication (such as diabetes or tremors), and the difficulty of being intimate with a potential partner due to side effects of medication on physiological performance. This was also illustrated in the comment by one respondent who stated it was difficult to “accept and realize” when required to take medication for the rest of one’s life. This was further explored in relation to the long term effects medication had on physical appearance and physical functioning. From this research it was apparent that respondents had varying levels of independence (independent management, management in partnership with the team, and complete dependence on the team) in being able to track their illness and deal with symptoms as soon as they would arise. When asked about emergency or crisis situations, one participant responded that they had not had been involved in an emergency situation in a while, and if they were in such a situation they would rather seek the help of SunPACT. As a result, all respondents reported having a better understanding of their symptoms and illness and being able to manage them on a daily basis with the assistance of their team.

3) The impact of the team dynamic on quality of care. Research has demonstrated that being treated by a team approach can result in role diffusion or duplication by having several team members responsible for conducting similar services with their clients. There has been research stating ACT teams are coercive and disabling rather than assertive and client centred (Diamond, 1996; Fisher, & Ahern, 2000). The results of this study provide evidence where the participants perceived their SunPACT team as being developed with staff and resources that provide a remarkable service to its clients. The idea of “role diffusion” has also been postulated in the literature where staff members serve multiple roles which can be blurred at times; this necessary flexibility produces a role diffusion that can lead to dangerous boundary diffusion (Stovall, 2001). As well, there has been speculation that when clients are working with a team
they may engage in “splitting” where the client uses contradictory ideas and feelings and applies them to different people or situations with inconsistent results (Payne, 2005). This can lead to the team becoming incohesive and in conflict with one another. On the contrary, the therapeutic alliance experienced in this research sample demonstrated flexibility of the staff and the participants articulated several comments related to the benefits of being treated by the team; however, the participants did express having their favourite team member or the one they gravitated towards more comfortably. The respondents were cognizant of this fact and still verbalized a willingness to work with the other team members and felt they were receiving adequate services. The participants were aware of the fact people are individuals and have their own personalities, and this was seen as a positive factor in their treatment team. Finally, findings from a study conducted by Stanhope (2008) demonstrated that, for consumers, quality of service is associated with positive consumer-provider relationships and not feeling coerced. Therefore, clinicians working with clients need to have the clinical skills to understand the consumer perspective and prioritize the relationship within service provision. Stanhope (2008) states, the “more evidence related to the process of service provision will facilitate translation of research to practice and promote recovery oriented services” (Stanhope, 2008, pg. 3152).

4) Family and social involvement in the journey to recovery. There has been research stating that individuals with a mental health diagnosis are less likely to form social relationships or networks, and thus become highly isolated or lonely (Stein, Barry, Van Dien, Hollingsworth, & Sweeney, 1999). When discussing with participants about family and social involvement in their journey to recovery and care, several respondents described their friends or family who were supportive and satisfied with the way SunPACT had been involved in their loved one’s life. Family was often involved in noticing changes in behaviour and would address this with their
loved one or with the team, if given permission by the client. As well, some respondents articulated the experience of having difficulty making friends due to being more introverted as a result of their illness, or due to the fact that being alone was a more comfortable option for them and they did not want to make too many friends. When asked about social activities in the community, several respondents verbalized the interest in joining programs, but could not due to financial constraints. Research has indicated that lower functioning clients are joined with ACT teams for the extra intensive support they require, therefore, obtaining competitive or gainful employment is not a primary goal for clients (Stein, Barry, Van Dien, Hollingsworth, & Sweeney, 1999). Respondents articulated that obtaining competitive or gainful employment was not a goal because this was something they viewed as difficult to handle. The reason for this was due to taking their medication and the side effect of feeling tired, therefore, having to get up at 8am for a full time job would be difficult. Respondents were more interested in looking for volunteer work or part time employment options. Therefore, they were consistent with other ACT participants living with a serious and persistent mental illness who were unlikely to prioritize seeking competitive employment (Sartorius, 1992).

5) The negative experiences related to mental health care in the community. Research has demonstrated that individuals with a mental illness living in the community would experience stigma (Prince, & Prince, 2002). When asking respondents about stigma and their experiences most participants commented on the housing situations being uncomfortable and the challenges in obtaining substantial living arrangements. It was found that being connected to a team in the community allows for the workers to have extensive knowledge in the community resources, such as suitable housing options and therefore can refer their clients accordingly. There were also comments regarding the way the media portrayed people with a mental illness. When asking
participants about any stigma experienced related to being apart of an ACT program, all respondents reported they did not feel any stigma. This could be due to the type of personality of these respondents where they do not get affected by other people’s comments or reactions to them, or to having other ways of describing experiences that others might attribute to stigma. Some respondents discussed the negative experiences of being mentally ill and not physically or mentally strong as they were before, thus impacting on their abilities to play sports or be more active. Some discussed medication side effects and how it was limiting their abilities, such as being creative. One respondent was a singer and she felt that her medication dulled her creativity and as a result, it was more difficult for her to compose a song. One respondent commented on the mental health system in general and being a patient in a large hospital where no one knows you, how this affects the services you receive and the treatment by the staff. In comparison to being linked with an ACT team, the respondent commented how the team knows you as a person and knows your medical history; therefore the services are more efficient and accurate.

6) The setting of care delivery. The objective of deinstitutionalization was to provide better treatment and quality of life to many patients who were regressing in their illness and requiring constant re-hospitalizations (Guy, 1997). Assertive Community Treatment was developed to treat clients in the community in that they would no longer require constant re-hospitalization. Research has shown that ACT is highly successful in substantially reducing psychiatric hospital use, engaging clients in treatment, increasing housing stability, and moderately improves symptoms and subjective quality of life (Bond, Drake, Mueser, & Latimer, 2001). When asked about being treated in the community setting versus a hospital setting, the majority of the responses were positive about being treated in the community setting. The noted benefits were the comfort of being in their own home and surroundings, as well respondents felt
there was more to do in the community (going for coffee, grocery shopping, watching TV, meeting up with friends), being able to live freely with no rules, and feeling more like a “regular person” (one participant’s words) when treated in the community. It was also proposed that the service was more comforting in the community; whereas in the hospital staff can be distant to clients they did not know. When referring to the hospital experience one respondent commented on it being “so confining.” This was not contributing to the quality of life of this participant. In essence, there was a majority agreement that the community was a much better place to be treated. Another added benefit to community treatment was the fact that clients can maintain their volunteer work or part time work and still be seen by their worker on their lunch hour or break, whereas being in hospital it is more difficult for clients to leave and maintain their daily commitments in the community. Clients could maintain an active lifestyle while in the community, whereas in the hospital clients activities are limited; however, it is important to note that some respondents still addressed that they required hospitalization on occasion, and they prefer having the option to be admitted for a few days and come out feeling much better. Therefore, treatment is not primarily commenced in the community, but for the majority of time issues can be addressed in the community, and are often successful. As a result, hospitalizations are brief and less frequent.

7) Future considerations. The topic of the future and conceptualizing where respondents felt their needs and services would be in the future was addressed. It appeared the respondents were focused more on the present and would express that they had not thought much about the future. This could be a result of the question being too abstract for some individuals with a mental health concern to conceptualize, and thus the researcher should have asked the question in a different manner. Or it could be postulated that in therapy or treatment the focus is more
related to the here and now and the clients are taking their recovery process in a day by day process. Or perhaps some participants did not want to think about the future because they may feel it could be unpleasant. The theme of ‘future care’ was discussed by all 8 respondents. They had articulated wanting to be a part of SunPACT for a long time and they did not want to think about services ever being discontinued. This raises the question of what will happen when more clients are entering the service and no one is leaving. This is an issue for resourcing that should be addressed by the government when evaluating ACT programs across the province. There is limited research on the future of ACT and it does not appear to be clearly understood (Drake, 1998). All of the respondents articulated having ideas of the future in terms of obtaining employment, housing, or volunteer work. Some respondents addressed their needs changing over the years, but in essence the consensus was that the respondents did not want their treatment and relationship with SunPACT to end. There were differing views from respondents where some felt their needs would decrease over the years, while others felt their needs would increase. This was associated with requiring relocation to new housing in the future and assistance with basic life skills. Some viewed their needs changing in relation to their age. These respondents felt that as they age they will require more support around the difficulties of aging. Some respondents feared SunPACT would be saturated with so many clients that the constant care provided will decrease. In essence, there was an overarching fear of SunPACT discontinuing or changing the degree of services to its clients.

*Quality of life.* Finally, the research aimed at addressing whether or not an ACT model has an extensive positive impact on one’s psychosocial functioning and quality of life, and this was further explored through the client’s perceptions. There is ample research stating individuals receiving treatment from an ACT model have greater quality of life (Baker, & Instigliata, 1982;
Hansson, 2006; Prince, & Gerber, 2005; Prince, & Prince, 2001). This was typically based on using subjective scales developed where individuals would rate their quality of life. In this research, the researcher asked participants to speak about their life and how satisfied they were with their ACT team. The major findings suggested that participants were overall satisfied with their ACT team. The major impact SunPACT had on participants well being and functioning in the community was the fact the participants were no longer being hospitalized as often, and the duration in hospital was decreased, medications were helping relieve symptoms and allowing the participants to go out and become active in the community, like volunteering, and socializing with other people, and having a “normal life” (one participant’s words). Respondents stated they were able to get on with projects they had put aside because they were too ill to finish. Furthermore, the frequency of the contact with the team, and the constant support was greatly valued as a contributing factor to one’s quality of life. Essentially, the participants felt their team was consistent and dedicated to support their clients through what the respondents referred to as “challenges” and not problems. Lastly, respondents reported their self confidence increased knowing their team was there for them.

Implication of findings. The researcher was interested in obtaining a sample that would provide positive and/or negative feedback about ACT services. The researcher was interested in obtaining as much information about ACT teams and quality of services through clients’ perspectives, however the present study results indicated that the participants were those who were greatly satisfied with their services, and thus this was seen in the final product. The differences in attitude and illness awareness that emerged from this research has significant implications for clinicians and agencies working to help individuals with a severe and persistent mental illness obtain a substantial quality of life in the community. The feedback from the
participants supported the notion that when people have adequate information regarding their options and are supported in their decision-making, they are likely to make healthier and more positive choices (Waller, 2001). From this research it was discovered through participant feedback that it is essential for ACT teams to provide non-coercive services that are based on informed choice. Research has suggested that major developments in the field appear to be driven more by “ideology, self-promotion, available financing, and cost-shifting than by findings from research” (Drake, 1998, pg. 174). Including consumer perspectives in future research may also be helpful in making the message about ACT more concise for advocates and policy makers. The researcher aimed at clarifying the organizational issues related to ACT such as the clients for whom ACT is, the essential components of ACT that contribute to quality of life, quality of implementation, and quality of care. This was understood through the subjective lived experiences of a sample of participants from an ACT team in Toronto, Ontario.

Current research, such as that reported in this research study has provided support for client satisfaction and efficacy of ACT models with individuals living in the community with a severe and persistent mental illness. It is essential that we understand how to implement and maintain a high-quality ACT service. This requires knowledge related to implementation by incorporating the feedback and suggestions from clients and families involved in their loved one’s journey to recovery. We need to understand from the clients which service components and which disciplines are essential to the model and how do we engage clients and families so they can effectively share in decision making about the effective use of ACT. Respondents talked about family and friends who were involved in their life and how they felt about SunPACT being a positive influence on their journey to recovery. This could be a topic further explored, where researchers can interview family members and caregivers perception of ACT
teams. Furthermore, this study provides support that one on one in-depth interviews can be conducted successfully with people living with a severe and persistent mental illness. This creates awareness that mental health staff and agency personnel can talk to their clients about these issues and obtain substantial and vital feedback.

The current research provides evidence that the need for more suitable and adequate housing options and the need for more volunteer and part time employment options for clients are essential to contributing to quality of life. Furthermore, the current research provides a vital finding in which the participants cannot envision a future without their ACT team. This is a negative finding in that this raises concerns about clients becoming too dependent on the system; however, this is the feedback from the 8 respondents in this particular ACT team who have been with the team between 5-10 years, which indicates these participants may have more intense needs.

Allowing clients to be an active part in their treatment provides a sense of empowerment and control over one’s life and illness. A recovery oriented program, like ACT, should adhere to what is recovery to the clients and understand that this is a process. The respondents demonstrated an increased knowledge about their illness and symptoms and how to manage this in the community in order to live a fulfilled life. As well, the participants articulated a sense of control in their life related to being an active member in their illness management process. This was seen through respondents expressing how they would call up their team member when they noticed a symptom or a change in their disposition, when they felt they needed more support, and when they were unsatisfied with their medication, they were able to openly discuss other options with their physician. Furthermore, their feedback was considered vital by the team, and it was understood that the team worked with their clients.
The researcher’s experience. The researcher is aware that a possible limitation could have developed due to the fact the researcher was a social work student who previously conducted her internship with the SunPACT team, and some of the participants may have recognized her and associated the researcher with the program; however, when the researcher conducted the study it had been 7 months since her placement experience concluded. Furthermore, the SunPACT program frequently engages students to conduct their internships and the clients are accustomed to having students around, therefore I did not feel there was any role confusion in student/researcher-participant role. Finally, the researcher did not interview any of the clients she had formed a therapeutic relationship with as an intern previously, and she also reinforced to participants that they would remain anonymous throughout the entire process of the study. It could be postulated that respondents were reluctant to say anything negative because they were not sure if what they said would be linked back to them, and thus the fear of losing services. As well, conducting some of the interviews in participant’s residences seemed to provide more authentic feedback, whereas the participants in the interviews in the hospital setting were more guarded, due to the impact of being in the same setting and environment of their team. Therefore, future research should focus on conducting interviews with participants in the comfort of their own space.

Another interesting issue that arose through the research process was the use of incorporating the phrase “participants had to identify as having a severe and persistent mental illness” when the researcher read the objective of the study to participants. Some respondents did not favour using the term “severe” or “persistent,” as well as, using diagnoses or labels to identify themselves. The respondents did not think their mental health was “severe” and by calling someone’s illness severe or persistent did not promote a recovery oriented framework.
The researcher was thankful this was brought to her attention, as this can inform future research endeavours which aim to provide an empowering and recovery focused lens in their work with the mental health population. Therefore, the researcher changed the title of the project as she also agreed the phrase “severe/serious and persistent mental illness” was not at all relevant to what the participants conceptualized as their illness.

*Limitations of research.* A limitation in this research was demonstrated in the fact that working with service providers who are apart of the recruitment process can lead to selection bias in the sample. It could be that service providers would recruit the clients they felt would give a more positive report about the team; however, it was essentially up to the participant to agree to be interviewed and at times not all participants agreed. Therefore, the sample obtained is considered the best representation of the program, given the constraints of time and the mandate of the research project. Recruitment was difficult in that there was a low participant response. This could be due to the fact SunPACT team members were handing out the flyers and the clients associated the study with the team. There could be the perceived fear by participants that their identities would be revealed and they would lose services if they did not say anything positive about the team, therefore the researcher feels some of the comments were mostly positive due to this. The major limitation of the study was sample size. Although the sample represented consumers in the ACT program, larger numbers could potentially provide statistical information about variables like medication management, symptom and illness management, team dynamic, experiences of stigma, quality of life etc.; however, this project was designed to examine in-depth some of the salient issues for consumers living in the community with a mental illness and receiving treatment from an intensive program of care. The study demonstrated similarities across consumers, and therefore, the potential for using such data-gathering for future
program development. The sample also contributes to knowledge of the value of consulting with clients about programs they are involved in which can inform the work we are doing with them.

The sample population that was incorporated in this study demonstrated a more informed and diverse perspective on their experiences. This was due to the fact the sample recruited were individuals who had been living for over 10 years with their mental illness, some even over 20 years. Therefore, they had endured vast experiences where they could reflect on this and report this to the researcher. As well, the sample obtained were individuals who had been with the ACT program since its inception in the year 2000. Thus, they had been dedicated to the service and this could have been their motivation to be involved in the study. Furthermore, the sample is made up of individuals who were overall happy with the services given that they had stayed with the program for so long. They had invested their time to report for an hour about their experiences, which demonstrated their dedication to share their experiences; however, it is important to note that the study design limits the ability to determine if these individuals are representative of the larger population, or the other ACT teams situated in Ontario. However, the views discussed in the interviews support the assumption that the study captures many of the most important elements of the ACT experience. Furthermore, the sample is representative of the population for which ACT teams were developed for (Allness & Knoedler, 2003).

It is also important to note, that the majority of the responses were based in the here and now perspective and the researcher may have gotten the respondents on a good day. If there was an issue with a worker or a dispute of some sort, the researcher feels the feedback would be much different, therefore situational factors need to be considered. As well as, personality factors, which indicated each person is unique and therefore their responses represented this. Some participants may prefer being institutionalized, while others enjoy being treated in the
community and never want to step inside a hospital again. This is also due to the past experience the client had endured when being involved in the mental health system. The participants in this study had been with SunPACT since its inception, and therefore were accustomed to the organization’s function and mandate. A different range in responses may arise from individuals who were experiencing a first episode of their illness or who had just entered the program due to their uncertainty of the program and/or instability in their illness and symptoms. Thus, the sample obtained had ample experience with SunPACT, which was relevant to the outcome of the study. There was an equal split in gender and the researcher did not use this as a variable in the analysis of responses; however, future research could conduct a more in-depth analysis of how gender and culture impacted one’s perception of services and quality of life, which could provide valid information for implementation of gender and culture into program development for ACT teams.

The researcher proposes future investigation into whether or not ACT programs are designed on a “forever use basis.” Are the clients given the tools to transition to the community on their own, where they can become assertive individuals who can access their daily social living needs, no longer requiring the support of their ACT team? It appears that clients are verbalizing their fear and reluctance to leave SunPACT. Therefore, a future research and valuable question to the government of Ontario is ‘How is SunPACT and the Ministry of Health and Long Term Care going to address this issue without impacting the clients and the care they are receiving?’

Implications for social work practice. Barker (2001) asserts that joining individuals in the process of their treatment will aid clients in regaining a sense of meaning in their life. The identification of analytic categories to better understand the lived experience and inner world of
individuals with a severe and persistent mental illness living in the community holds a significant importance for social work clinical practice, administration, and research. More specifically this research has provided the Sunnybrook Program of Assertive Community Treatment essential information for the development of interventions that are more effective, and more empowering, for people living with a severe and persistent mental illness in the community. This research has shed some light on the experiences of clients and how this ACT model has provided them with the skills to live a satisfactory life in the community as it intended; however, it is important to note that the parameters of this research design and sample size do not allow for such generalizations from sample to the world. The participants in this study do not represent the whole world and the aim of this research was not to address this. The final results demonstrated that the participants were those who ACT works well, this was seen in the sample of participants who were committed to the program, and their subjective evaluation which suggests ACT has made a positive contribution to their life. This is a valuable perspective to have, as we want to know what works well for what clients and how we can build on this. For these participants, it was found that the treatment team and the treatment they received from their ACT team greatly contributed to one’s quality of life.

George, Durbin, & Koegl (2008) argue that it is necessary to attend to issues of ongoing feedback on practice for all ACT teams in Ontario in order to provide better implementation of its services. Furthermore, consumer satisfaction has not been studied thoroughly and there has been a lack of research on actual practice which could be helpful to program planners in order to know which core components are critical for effectiveness and which can be altered to fit local needs without effecting outcomes (Phillips, Burns, Edgar, Mueser, Linkins, Rosenheck, et al., 2001). The main focus of this project was to explore the lived experiences of individuals with a
severe and persistent mental illness living in the community receiving community treatment through an ACT model. Social workers are a major part of an ACT team and understanding the client’s point of view will only enhance one’s performance as a clinician. The research wanted to demonstrate what clients perceive as important contributors to quality of life. This was to inform social work practice as well as to inform the agencies who are developing ACT programs. As well, integrating client feedback into the construction and development of community programs is also vital to providing an effective and satisfactory service to clients.

Critical consciousness: the influence of power. This research brought to the attention of social work practice the importance of raising critical consciousness where one must reflect on how power influences who we are, how we think, and what we do. As social work practitioners we should be aware of how at times our position of power can be a disbenefit and in actuality can oppress the population you are working with. It is evident that when working with the mental health population regarding decision making, the power should be within the clients. Social workers should promote the involvement of people in the mental health population in organizational decision making in the agency from which they receive services. This involvement is consistent with the ethical principles of the National Association of Social Workers, Code of Ethics which states that social workers are to challenge social injustice, respect the inherent dignity and worth of people, promote self determination, and ensure access to decision making (National Association of Social Workers, 2000).

The participant feedback obtained in this study provides evidence for the importance of social workers and clinicians to understand their clients. It is also important for social workers and clinicians to help clients develop decision-making and social skills necessary to meaningfully participate in decision making and to be active participants in decisions made
about their care and quality of life. It is also important that as a social work practitioner who aims to work with the mental health population uses their expertise in a way that is culturally sensitive and competent, which can be addressed by asking clients how they interpret their services so that practitioners can provide the utmost effective and accurate support based on clients’ needs. Constant reflection on how needs can be met and how one can influence the lived experience of individuals needs to be taken into consideration. A therapist working with individuals within their life story requires the ability to work hard to collaboratively deconstruct and critically reflect within themself and with the individuals they are working with who require support in order to function optimally in the community. It is important one connects the discourse with the identity of the individual. In essence, clinical work in the mental health population could be enhanced by a clinician’s understanding of the complex and multiple ways one’s life is affected by the treatment they are receiving through listening to their narrative.

Lastly, the findings of this research provide the rationale to incorporate into social service interventions clients’ feedback and subjective experiences. This will provide social service programs that will empower and educate its clients. This will hold enormous potential for a variety of interventions that wish to address issues related to mental health and treatment engagement, treatment fidelity, quality of life, quality of care, satisfaction of service, improved social functioning, and becoming active participants in managing their health and well being in the community. Participation in organizational decision making is a basic human right where client participation in decision making can aid in the process of recovery from mental illness (Pratt, Gill, Barrett, & Roberts, 1999). Research has shown where clients meaningfully participated in the decision-making process they achieved favourable policy changes. This was found in implementing a consumer council, involving clients in the formal policy review process.
and including clients in the hospital’s performance improvement system (Linhorst, Eckert, & Hamilton, 2005). Therefore, the inclusion of client participation and feedback can improve agency effectiveness by incorporating the viewpoints of clients as key stakeholders.

**Concluding statement.** The ACT model was intended to be a community-based alternative to the hospital in that it could deliver equal and comprehensive services directly to the client in the community. The goal was to ensure that the client received the services they needed in order to remain in the community, functioning optimally while also maintaining quality of life. ACT was shown to reduce hospitalization and increase stability in the community and client satisfaction. Other research has demonstrated through feedback from clients that ACT is a vital component in establishing social interventions. This was seen in reducing anxiety through coordinating a wider social environment, providing help with housing and providing social contact (Watts & Priebe, 2002). Assertive Community Treatment provides the facilitation of opportunities that will enhance one’s feelings of self worth, minimize psychiatric symptoms and provide regular financial support (Prince, & Gerber, 2005). These were considered to be related most to the overall subjective well being experienced by clients of assertive community treatment services (Prince, & Gerber, 2005). Finally, in a previous study participants described ACT as “assertively encouraging them to actively learn about and manage their illnesses, to understand and maintain their stability in the community and to anticipate and solve problems that, if left unchecked, could rapidly escalate” (Krupa et al., 2005, pg. 23-24). The present study demonstrated that areas such as reducing symptoms, improving vocational and social functioning, and quality of life are mixed in findings, but conclude in general that ACT provides a service that is successful at addressing these areas.
The present research explored client perspectives on how and why ACT can work well. The delivery of services in the community, small caseloads, intensive outreach provide immediate crisis intervention, individual client-centred support, timely support in one’s own community, integration of team services rather than differing agencies all contributed to a positive experience by the recipients of SunPACT. It appears the future of ACT is not clearly understood. Future research can also help in sending the message to policy makers that ACT teams work, and clients are satisfied with the service. It is essential that we understand how to implement and maintain a high functioning ACT service. This requires knowledge and ongoing research. The present study aimed at trying to illustrate the effectiveness by asking the clients of an ACT model in Toronto, Ontario. This research shows that there are differences in experiences and outcomes related to illness management, social functioning, as well as, quality of life. Consulting with clients involved in their treatment services is vital and this study demonstrates how important it is to understand the impact of services on the consumer. As a research student I felt honoured to have the participants accept an unknown student into their homes and lives. They were truly understanding and forthcoming to my research.
References


Appendix A

The Interview Guide

Introduction. SunPACT is a multidisciplinary team approach providing client-centered individualized support and rehabilitation to persons with severe and persistent mental illness in the community. This type of community treatment program has many clinicians who work in a team to serve people with a mental illness in the community. Some of the areas the team works is in providing services such as: health teaching, primarily in terms of medication and symptom management, crisis intervention, counselling, either one-on-one or with families, assistance with activities of daily living, like laundry and grocery shopping, assistance accessing food, social support, help with legal issues, if any, help with substance abuse, social skills development, vocational rehabilitation, and also by developing leisure and recreational opportunities for clients. In this interview I will be asking you to talk about how you understand SunPACT and how it has been apart of your life since you began receiving services up until now.

The open ended questions asked will be focused around these central topics and questions:

- How do individuals living in the community with a severe and persistent mental illness define SunPACT and their needs from an ACT team?
- What are the experiences of clients receiving treatment in an ACT model?
- How do they feel about being involved with SunPACT? What do they believe is the impact it has on their life (based on the subtopics below)?
- How does it contribute or take away from what they would consider a good life?

Clients understanding of SunPACT: how do clients define SunPACT and what it means to them? If you were to tell a friend about SunPACT how would you describe it?

Medication: Can you talk about how your medication is managed with SunPACT? Can you talk about what happens if you do not understand something about your medication or how to take it? Are you satisfied with the medication you are taking now? If not, have you raised this with SunPACT?

Housing: Has SunPACT been involved in your obtainment of housing? How has that been for you? What happens if you require housing? Are you satisfied with your current living arrangements?

Negative Experiences/Stigma/Hospital vs Community Setting: when were you last in the hospital? What was that like for you? Can you talk about your doctor and how it is like for you to have him or her visit you in your home or community? Can you talk about living in the community and receiving SunPACT (when they come to your home vs. you going to see them at the hospital)? Can you talk about how you feel when you come to hospital?

Substance use: Can you talk about how SunPACT addressed your substance use, if you have had experience with this in the past or currently? (Counselling, referral to resources, psycho-
education, harm reduction frameworks) Do you think SunPACT had an impact on getting you help and if so, was the successful outcome of substance use decrease or abstinence?

**Team Dynamic/Therapeutic Relationship:** SunPACT is a model where clients receive care from a team as opposed to one physician (psychiatrist). When you need something what do you do and where do you go? Can you talk about the team approach to ACT where you are treated by many team clinicians? Can you talk about the positive and negative aspects of this? What are your suggestions?

**Family involvement/Social Contact:** How has your family been involved in your life and your treatment of SunPACT? Do you think your relationships with families and friends have changed since being a client of SunPACT? (Isolated vs. reconnecting with family and friends)

**Symptom management:** Can you describe how you understand your illness and how you control your symptoms and how to manage them in the community? Was this something you learned from SunPACT? Do you see improvements in your illness management?

**Justice System Legal Involvement:** have you been involved with the law since being with an ACT team? How has SunPACT helped you reduce your interactions with the law?

**Social Supports:** Can you talk about the social supports SunPACT has provided you. For example social opportunities, like employment opportunities, and recreational options or groups. Have you obtained employment since being with SunPACT? Are you getting enough support and how and why? Do you see too much of the team or too little?

**Financial Situation:** the management of money and obtaining financial supports. Can you talk about how SunPACT helps you get money, or how you manage your money?

**Future/fears/desires:** Where do you see yourself in the future? Do you see yourself still needing or using the services of SunPACT in the future? Will you still be with SunPACT? Do you think you will be able to acquire your daily needs on your own, by accessing them yourself?

**Summary:** What do you think are the most important things we need to understand about SunPACT in the context of mental illness? What is the most important thing we need to know about individuals, professionals, and most importantly community living? What is the most important thing we need to know about SunPACT?
Appendix B
Recruitment Flyer

**Sunnybrook’s Program of Assertive Community Treatment (SunPACT) Study**

Are you a client receiving services from SunPACT?

Would you be willing to talk about how your life has changed since being a client of SunPACT?

If you are a person who has been diagnosed with schizophrenia, schizoaffective disorder, bipolar, borderline personality disorder, or depression and are currently a client of SunPACT, you may be eligible to participate in a study about quality of care.

We are seeking individuals to take part in a 1 hour interview exploring how SunPACT has been a part of your life. We hope to speak with men and women, people who have been diagnosed recently and who were diagnosed a long time ago, and people who come from a variety of ethnic backgrounds.

The information from this study will be used to develop a model of quality of care through community treatments like SunPACT, by using the perspectives of people who have been diagnosed with a mental illness and who have been a client of SunPACT. You will receive a $10 compensation for your participation.

**If you are interested...**

**Contact:** Massina Micoli at **416.480.4611**

If no one is available to take your call, please leave a message including your first name, a telephone number, and a time when you can be reached.

**Principal Investigator:**
Joel Roth, MSW, Coordinator of SunPACT, 416-480-6100 Ext. 7079

**Research Student:**
Massina A. Micoli, MSW Student, University of Toronto, Faculty of Social Work.
416-480-4611

**Faculty Supervisor:**
Charmaine C. Williams, PhD, Faculty of Social Work, University of Toronto,
416-946-8225
Appendix C

Telephone Screen Guide

1. Introduction – review of study – may have seen info in flyer or from SunPACT team
2. There is a lot of research looking at the quality of life of clients who have a mental illness and live in the community receiving services from an ACT team, but this has mostly been done with satisfaction questionnaires or surveys. **There has not been a lot of research where clients are interviewed directly and asked what they are satisfied with and what they want to see more of from an ACT team? This study is a way to explore the clients’ stories and experiences from being treated by the SunPACT team.**
3. **Questions:**
   • What aspects of SunPACT are important?
   • What kind of services do people want from their ACT team? Not want?
   • Do you feel your quality of life or life in general has changed since being with SunPACT? If so how? And if not, how and why?
   • Most importantly: what advice do you have for SunPACT or other agencies that treat individuals with a mental illness in the community through an ACT model?
4. **You will be asked to:**
   • Participate in a tape-recorded interview that lasts 1 hour to 1 ½ hours
   • The interview is open ended questions so people can discuss the aspects of the topic that are most important to them. (more of a story telling than a direct/question answer period)
   • All participants will remain anonymous
   • Each participant will be paid $10 and reimbursed for TTC travel
5. **Very important aspect of this study is to get a range of experiences from a range of people who have been a client of SunPACT.** To determine your eligibility
   • Age? Must be over 18
   • Identify your ethnic origin? (to determine whether culture plays a role in perceived QOL)
   • What is your self reported diagnosis? (have to have an self identified mental illness)
   • Who provided the diagnosis: by a doctor, psychiatrist, psychologist, nurse, social worker?
   • How long have you had a mental illness? (must be more than 5 years)
   • How long have you been a client with SunPACT? (must be more than 2 years)
6. **We need to make sure that people understand the study and what they will be asked to do:** I will ask you a few more questions:
   - Could you tell me who is conducting the study?
   - Could you tell me what the study is about?
   - Could you tell me how you would participate in the study?

7. Based on this discussion are you interested in participating in the study?

Arrange date/time of interview. Interviews will be done at Sunnybrook Health Sciences Centre, F wing, 1st floor in a private office, or in the community (group homes, boarding homes or private apartments). This will be decided by the potential participant due to comfort and confidentiality.
Appendix D

Information Sheet/Informed Consent

**Full Study Title:** The subjective experiences of clients with a Severe and Persistent Mental Illness (SPMI) receiving treatment from the Sunnybrook Program of Assertive Community Treatment (SunPACT).

**Principal Investigator:** Joel Roth, MSW, Coordinator of SunPACT, 416-480-6100 Ext. 7079

**Research Student:** Massina A. Micoli, MSW Student, University of Toronto, Faculty of Social Work, 416-480-4611

**Faculty Supervisor:** Charmaine C. Williams, PhD, Faculty of Social Work, University of Toronto, 416-946-8225

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**Informed Consent**

You are being asked to consider participating in a research study that will help researchers learn about the experiences that people diagnosed with a severe and persistent mental illness have while receiving services from Sunnybrook Program of Assertive Community Treatment (SunPACT). A research study is a way of gathering information on a treatment, procedure or medical device or to answer a question about something that is not well understood.

Your experiences will help to outline implications for service delivery and provide an in-depth experience of the quality of care a program like SunPACT offers. Your experience will shed light on changes that need to be made or areas that need to remain. It will offer an in-depth program evaluation of SunPACT by none other than the receivers of care.

This form explains the purpose of this research study, provides information about the study, the procedures involved, responsibilities of the participants, possible risks and benefits, compensation, confidentiality, rights of the participants, and a set of questions asked to make sure you understand your role as a participant in this study.

Please read this form carefully and ask any questions you may have. You may take as much time as you wish to decide whether or not to participate. Feel free to discuss it with your friends and family, or your family doctor. Please ask the study staff or one of the investigator(s) to clarify anything you do not understand or would like to know more about. Make sure all your questions are answered to your satisfaction before deciding whether to participate in this research study.

**Procedures**

If you volunteer to participate we would ask you to do the following:

You will be asked to participate in a one time 1.5 hour interview. The focus of the interview will be your experiences as a person who is receiving services from SunPACT.

To ensure your confidentiality, you will be asked not to mention your last name in this interview.
The interview will be audio taped and the tape will be professionally transcribed. Any mention of your last name that may unintentionally be included on tape will be deleted from the interview and replaced with a false name. As a participant, you are able to view the transcript and tape at any time. It is most important for this study to involve member checking as it allows the researcher to obtain your full experience.

**How many people will take part in the study?**
It is anticipated that about 12 people will participate in this study. All Sunnybrook Program of Assertive Community Treatment participants will participate in this study at Sunnybrook or at the participant’s home. The length of this study for participants is 1.5 hours. The entire study is expected to take about 7 months to complete.

**What are the responsibilities of study participants?**
If you decide to participate in this study you will be asked to do the following: you will be given a consent form, which the researcher will explain to you and make sure you understand what your role is in the interview. The interviewer will explain to the participants that it is necessary to ask them some questions to ensure that they understand the study procedure and the consent procedure. The interviewer will assess whether a potential participant has understood information about the study and the consent. After you have read the consent form and understand the interview process, the researcher will ask you some information about yourself, like your age, if you have a job, if you go to school. After that the researcher will begin the interview process by asking general questions, but mostly asking the participant to explain to the researcher how their experience has been since being a client of SunPACT. This can include some of the good things you want to share and some of the things you would like to see changed. The interview will be audiotaped. If there are parts of the research study which you do not want to participate in you can choose not to participate. The interview will take place only one time and for 1.5 hours. After the interview the researcher will award the participant with $10.00 for their participation and will provide them with any transportation money if it was used. The participant can contact the researcher any time after the interview for a copy of the study results and to read the transcript of their interview. A copy of the consent form with all contact and study information will be given to the participant if they need to contact the researcher at any time for further questions or concerns.

**What are the risks or harms of participating in this study?**

**Potential Risks and Discomforts**
 Talking about your experiences with SunPACT may make you feel uncomfortable. You may skip questions that you do not wish to answer and still participate in the study; or you may end your participation in the study at any time without any undesirable consequences.

If you experience high levels of distress or discomfort during the interview, the interviewer is required to get involved and get you help. Some potential safety procedures may include: escorting you to an emergency room, escorting you to your home or to a relevant community setting, contacting your doctor or primary professional caregiver (with your permission and in your presence), or ending the interview.
Potential Benefits to Participants and/or To Society
You will not directly benefit from your participation in this study. The findings from this research may provide information to researchers and mental health professionals that will help them to work more effectively with individuals and families affected by severe and persistent mental illness receiving care in the community through programs like SunPACT. This investigation will bring about important and much-needed information to the ACT literature, service providers, clients and their families. By investigating and producing this type of knowledge you are aiding in the essential development of interventions that are more effective, and more empowering, for people living with a severe and persistent mental illness in the community.

Compensation for Participation
There are no costs to you in participating in this study. You will receive TTC if you had to travel to meet with the researcher and $10 for participation in this one-time interview.

Confidentiality
Confidentiality will be maintained during the interview in that your last name is never revealed and you are referred to only by your first name. Any personal identifying information that may be revealed in the interview will be deleted from the interview transcript. All identifying information that you provide will be stored separately from the interview tape and transcript.

You also have the right to review, edit or erase the research tapes of your participation in whole or in part. The researcher will review tapes and transcripts with participants upon request and delete data from audiotapes/transcripts as requested by the participant. Participants in individual interviews can also receive the entire audiotape/transcript if that is their preference.

There are two conditions under which we could not honour this promise of confidentiality; if you disclose that you may harm yourself or if you disclose that you may harm someone else. Under these circumstances, we are required to seek assistance from appropriate authorities and/or initiate one of the safety procedures described above. In the event that you provide information pertaining to your declared plan to harm yourself or someone else, this will be disclosed to other persons involved.

Participation and Withdrawal
You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so. Your participation in the study will not have any effect on your current or future access to services.

Publication of Research Findings
Research findings from this study may be published in professional journals or presented at professional conferences or community forums; only overall results across respondents will be presented; nothing that might identify you.
**Dissemination of Findings**
You will be given a copy of this consent form with the available contact numbers and personnel to contact if you have further questions regarding the study later on. As well as a research participant, you may request a copy of the final research report.

**Rights of Participants**
You waive no legal rights by participating in this research study and your participation or decision to not participate will not affect your access to any services.

If you have any further questions or would like follow-up information about the study, you can contact the researcher, Massina A. Micoli, or the principal investigator, Joel Roth, using the information on the first page.

**Capacity to Consent**
*Questions to Evaluate Capacity to Consent (Able to Provide a Yes/No Answer)*
1. Could you repeat back to me what will happen when we meet to do the interview?
2. Could you explain to me what it means when you sign the consent form?
3. Can you tell me what will happen if you decide you do not want to participate in the study?
4. Can you tell me what will happen if you tell me that you plan to hurt yourself or someone else?
5. Do you choose to participate in this study as it has been described to you?

**Signature of Participant**
I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

___________________________________                       _________________________
Signature of Participant     Date

**Signature of Investigator**
In my judgment the participant is voluntarily and knowingly giving informed consent and possesses the capacity to give informed consent to participate in this research study.

__________________________________
Name of Investigator

___________________________________                       _________________________
Signature of Investigator      Date
Appendix E

Key Terms

Subjective Perspective/Experience
• Refers to one’s self report based on one’s lived experience. It is information that is elicited from the individual’s viewpoint of their internal or external world.

Mental Health Diagnoses
• Refers to clients’ self report or self identification. As well to any diagnoses that fall under the DSM IV TR criteria, including clinical disorders, personality disorders, substance use disorders, etc.

Quality of Life
• Refers to the self expression, report and subjective experience of clients in relation to their psychosocial functioning in the community through the services they are receiving.

Recovery
• Recovery is the notion where one can live a fulfilling life in the presence of symptoms. This is understood as a personal experience (Anthony, 1993).

Client Centered Approach
• The incorporation of the client in their treatment care plan, as well as the expert informants in the research process and outcome (Prince & Prince, 2001).

Empowerment
• Clinicians empower individuals by responding to their understanding and knowledge about the world. Individuals are agents of change and we are there to guide them (Deegan, 2001).
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