A study to explore patients’ perception of their quality of life over time while being supported by a Psychiatric Outreach Team

By

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I would like to dedicate this dissertation

TO MY FAMILY
DECLARATION

I, hereby declare that I have conducted this study and this dissertation is entirely my own work.

Ms. Paulann Spiteri
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ABSTRACT

Quality of Life (QoL) has been identified as one of the important indicators for care outcomes in community psychiatric care. The effect of health care services, such as Outreach Teams is nowadays commonly being assessed by rating improvement in the QoL of those who receive this type of care. Furthermore, academics such as Barker identified the importance of helping patients to actively participate in discussing and designing a tailored care plan so as to address their needs. The Tidal Model, which was formulated on this concept, has been used as the philosophical background of this research study.

This study was aimed at exploring the perceptions of psychiatric patients living in the community, who are being supported by a Psychiatric Outreach Team. An additional objective was that of exploring any changes that might occur in the QoL over time. A mixed-method design, which is mainly descriptive and exploratory qualitative in nature, was used to explore the perceptions of the sample under study, as regards areas related to their QoL. Data was collected by means of an interview format which was structured on questions from an established questionnaire, namely the ‘Carers’ and Users’ Expectations of Services’ (CUES-U) questionnaire. Twenty individuals from the list of the patients being supported by the Outreach Team were randomly chosen and asked to participate in the study. Each of the subjects was interviewed twice with a period of two months between each interview. Descriptive statistics were used to analyse the quantitative data obtained while the qualitative data was analysed by means of content analysis.
Overall, the participants perceived their QoL to be satisfactory. However, there are issues, such as *social life, family and friends* and *fear* that were of particular concern to the respondents. Perceptions were found to change minimally, with borderline or significant positive differences on the areas of *Family and friends, Money* and *How the day is spent*. One cannot exclude that these changes were brought in effect by Outreach support, although other factors might have been involved. Finally, the trends in the findings were consistent with other research in this field of study and could be associated with the philosophy of the Tidal Model.

Despite a wealth of research about QoL and individual constituents of this concept, limitations in current knowledge as regards patient perceptions were identified and suggestions for future research were provided. Other recommendations regarding both research and clinical practice were included in an attempt to address the current situation and ways of improving it.
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Chapter 1

Introduction
1.1 Background of the study

In an era where deinstitutionalization is emphasized, the issue of Quality of Life (QoL) has received increased attention due to its importance for patient rehabilitation (Mavreas, 2003). QoL is known to be indicative of the level of social functioning in mental health patients (Kuyken, Orley, & Power, 1995). Furthermore, in evaluating community care, QoL is identified as a key outcome for evaluating community mental health services such as the Outreach Team service featuring in the current study (Sharir, Tanasescu, Turbow & Maman, 2007).

This has led to the recent growth in interest in the concept and measurement of QoL in community mental health. MacGilp (1991) described how mental illness can have a severe effect on the QoL of an individual. Furthermore, apart from the disabling symptoms that accompany most mental disorders, other social factors play an important role in determining the QoL.

A review of the literature has shown that research about the QoL of community psychiatric patients is vast, multicultural and rich. The majority of the studies located tended to focus on individual problematic known areas and their perceived effect on the QoL of the individual. Whilst, a number of studies exploring the general QoL with the use of established tools were also located, they were not as numerous as expected. Locally, QoL research within community psychiatry is gaining interest – one study was completed by Xerri (2007), whilst it is also known that several other similar studies are currently being undertaken.
A large majority of the studies concluded that the main problems in the patients’ life are: Social relationships, budgeting and stigma (Borge, Martinsen, Ruude, Watne & Friis, 1999; Barbato, Monzani & Schiavi, 2004) The hypothesis that intensive community psychiatric services have a considerable beneficial effect on the QoL of the patient, has led to the introduction of teams such as the Outreach Team. In fact, a longitudinal study carried out by Nasierowski (1999), showed that introducing a specialized community service resulted in reducing the number of hospital readmissions and in shortening of the mean hospitalisation time. Moreover, the quality of the patients’ life increased considerably, a conclusion that was also supported by other researchers such as Mercier, Tempier & Renaud (1992) and Blenkiron, Hong, Kuzen & Hammill (2003). However, other studies provided contradictory results, where the effect of community services was shown to be minimal and certainly not as profound as expected (Taylor, Leese, Clarkson, Holloway & Thornicroft, 1998; Huxley & Thornicroft, 2003). Locally, Psychiatric Outreach Team services are still in their infancy phase and their effect on the QoL is starting to gain attention but has not yet been formally studied.

1.2 Purpose

The need for this study originated from the knowledge that the Maltese psychiatric system is following the same pattern as other countries and consequently focusing on the reintegration of psychiatric patients within the community. This change in care brought with it the introduction of local intensive community services, which have grown substantially since their recent introduction and hold the promise of further rapid blooming.
The aim of this study was to provide management and staff involved in community care with a picture of the QoL of patients who are currently living in a community setting. In addition, the researcher attempted to detect changes in the QoL between two periods of time, in patients who are being supported by an Outreach Team. As a result of the findings, recommendations for improvements to the QoL of these patients were outlined.

In accordance with modern psychiatric care, this research study has been guided by the Tidal Model (Barker, 2000) and the core philosophy of the importance of valuing the story of patients. On the assumption that each individual is the expert in his own life, the researcher attempted to give the patients a ‘voice’ in order to encourage the communication of their perception on their QoL in the community.

This study sought to gain insight through research objectives, rather than test a hypothesis. Thus, an exploratory descriptive design was adopted as it was considered to be appropriate for this study. A mixture of both qualitative and quantitative approaches was utilized in order to meet the set objectives. An interview format based on the established ‘Carers’ and Users’ Expectations of Services’ (CUES-U) questionnaire was used to collect data from 20 psychiatric patients living in the community and receiving Outreach support. These participants were randomly chosen from a list of individuals who satisfied a number of pre-determined criteria. After 2 months, each participant was subjected to the same interview in order to capture changes in perception. Descriptive statistics were used to analyse the quantitative data, while the qualitative data was analysed by content analysis. The two data sets were then used collectively as correlates for each other – the qualitative providing context for the quantitative. It is hoped that
1.3 Conceptual Framework: The Tidal Model

A literature search revealed that there are various theoretical models that can be used to guide research related to the QoL of psychiatric patients. Phil Barker’s Tidal Model theory, specifically developed for psychiatric nursing, was the preferred choice because it is considered to offer a practical yet simple approach to understanding human feelings and behaviour as well as action plans. Additionally, the design of the Tidal Model makes it applicable to both research and therapy. Hence, the integration of this theory in the current research is felt to help with the application of the findings to clinical practice.

The Tidal Model is a model for the promotion of mental health developed by Professor Phil Barker, Poppy Barker and their colleagues. It developed from action research into the role of the nurse (Barker, Jackson & Stevenson, 1999). This framework being both theoretical and philosophical in nature focuses on the continuous process of change inherent in all people. It seeks to reveal the meaning of people’s experiences and emphasizes the importance of their own voice when carrying out an assessment. It aims to empower people to reclaim control of their lives using the three domains, these being ‘the self’, ‘the world’ and ‘the others’ domains. The Tidal Model originated from Peplau’s original emphasis on the nurse-patient relationship (Peplau, 1952) as well as having its basis in Chaos Theory. However, this model additionally aims to develop an appreciation of the chaotic nature of change, which is the only true constant (Barker,
Chapter 1 - Introduction

2000). The Model introduces methods by which professionals might help people in their care to become aware of the small changes which are occurring to them as part of everyday reality. More importantly, the model emphasizes pragmatic ways that people might learn ‘what works’ for them and why. Such ‘personal wisdom’ represents the basis of the person’s recovery – the knowledge that should be used to navigate the metaphorical storms of the recovery voyage.

Unlike many psychiatric models, the Tidal Model holds few assumptions about the proper course of an individual’s life, preferring instead to focus on the kind of support people might need to rescue them from crisis or to help put them back on the life course. This framework is deeply rooted in metaphors, where individuals who experience life crisis are in *deep water and risk drowning*, or they feel as if they have been *thrown onto the rocks*. Furthermore, the experience of trauma and complex life problems often leads to one reporting a loss of the ‘sense of self’. This is similar to the trauma associated with nautical piracy. In these critical instances, people need a sophisticated form of life saving (psychiatric rescue) which may take the form of crisis intervention in the community or the ‘safe haven’ of inpatient settings. Once the rescue is complete, the emphasis switches to an exploration of what caused the storm in the first place and helping the individual ‘set sail again’ and return to a meaningful life in the community. In practice, the Tidal Model Theory is characterized by a range of holistic assessments, which aim to generate person-centered interventions based on the patient’s resources and capacity for solution-finding.

It is believed that this model is revolutionary in that it focuses on actively listening to the patients, as opposed to traditional psychiatric care that often diminishes the person’s
voice, especially by over-reliance on diagnostic jargon (Kirk & Kutchins, 1997). Regrettably, many people talk about themselves using the technical terminology of psychiatry, as if their own story, spoken in laymen terms is not good enough.

Perhaps the main reason why this theoretical framework was deemed as the preferred one for the current study, centers around the fact that the Tidal Model is founded on the very same aim of the study – that of allowing the patients to discuss their requirements and opinions. It is believed that this will help management and staff involved in psychiatric community care to understand the life of these patients in order to be able to offer the best possible care.
2.1 Introduction

Traditional asylum psychiatry is often associated with dramatic scenes of institutionalisation and depersonalisation of the affected individual (Katschnig, 1999). Criticism of this morbid era has proved to be fruitful since nowadays, psychiatric care exhibits a more dignified and professional approach centered on the individual’s subjective experience of the illness. Furthermore, the current aims of mental health policy focus on de-institutionalisation and re-integration of the patient into the community. This is in line with one of the foundations of the Tidal Model (Barker, 2000), which focuses on the importance of returning people to the ocean of experience found in the community, so that they can continue their life journey, after the psychiatric crisis.

The downsizing of psychiatric wards that could be witnessed during the recent years raised several issues, one of most prominent being the query of whether community life really results in long term benefits for the psychiatric patient (Martin, 2007). As Rogers and Pilgrim (2001) (as cited in McAdam & Wright, 2005), amongst others, argued, community care has positively offered a humanitarian solution to oppressive hospital care. On the negative side, the community might also serve as a ‘dumping place’ whose only purpose would be to reduce institutional loads, irrespective of the potential effect on the mentally ill individual.

In view of these debates, Mavreas (2003) reported that the de-institutionalisation process brought with it a shift of attention to the functioning of the patient in everyday situations, life satisfaction and social roles. These domains constitute the ‘Quality of
Life' (QoL), a concept that is nowadays regarded as the main indicator of the global well-being of the psychiatric patient in the community.

In this literature study, the focus will be on the following issues, which were identified as having a major role in the QoL of the psychiatric patient living in the community and receiving Outreach support:

The QoL concept
QoL in Community Mental Health
Patients’ perception of their QoL in the community
The effect of Outreach support on the QoL

2.1.2 Method

PubMed and The British Journal Of Psychiatry database were searched for relevant articles using the terms Quality of Life and community psychiatry. These terms were combined with other terms: Outreach Team and community psychiatric patients. The references found were categorized based on their relevance to the issues mentioned above. Sources on the topic QoL could be found in abundance, though to a lesser degree when combined with Outreach Team. The literature sources originated mainly from the UK, followed by Sweden, Ireland, Scandinavia, Austria and Canada. No local studies could be found about the perception of QoL in patients who receive Outreach support. Moreover, using the terms Quality Of Life and community psychiatry, the national databases of Institute of Healthcare Library (Malta) and Medical School Library (Malta) were additionally included in the search for related literature on the topic.
2.2 The Quality of Life concept

2.2.1 Quality of Life meaning

From early on in the last century, governments started to regularly publish social reports. These reports contained statistics and analyses of social change data on areas such as income, education, consumption, housing and medical care. The method of data collection and presentation became more systematic from around the 1960s and this research area eventually became known as the social indicators movement. Social indicators research gained more popularity and importance in the 1970s (Daly, Greg, McDonough & Williams, 2002). However, there was little agreement on its methodology and objectives, which resulted in the development of several ways of measurement, rendering it a wide and diverse field. Eventually, the social indicators movement fragmented into areas that had little in common. One of the new areas emerging from this field was QoL research. QoL is generally described by a number of indicators such as life expectancy, quality of physical environment, crime rates, poverty rates, and economic statistics. However, after three decades of work in this area, there is no one generally accepted definition of QoL in the extensive literature. Terms such as social well-being, social welfare, and human development are often used as an analogy. Furthermore, a theoretical or methodological consensus on QoL measurement has not yet emerged. Owing to this situation, in 1991, a panel of researchers of the World Health Organization (WHO) started to develop a unifying and transcultural definition of QoL. The resulting definition was:

"...the individual’s perception of his or her position in life within the cultural context and value system he or she lives in, and in relation to his or her goals, expectations,
parameters and social relations. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment."

(Kuyke et al., 1995, p.1403)

Following this definition, WHO published a tool for assessing the generic QoL, known as WHO-QoL, a tool that has been since used in several QoL studies. Furthermore, in a literature review carried out by Berlim & Fleck (2003), 14 different QoL assessment tools were identified and found to be used commonly within different sectors. Hundreds of other tools exist, however they have not gained as much recognition. This shows that QoL is considered as vital and necessary in research. Although this concept has been widely researched in the medical field, it is not related exclusively to this area. In fact it has also gained importance in social services and education.

2.2.2 Quality of Life in health and mental health

The first medically documented use of the term 'Quality of Life' dates back to the 1940s. Over the following two decades, the term took on a deeper meaning and slowly evolved into a researchable concept. Notably, critics such as Elkinton (1966) started to question whether the medical profession was attributing enough importance to the maintenance of harmony between a man and his world.

The 1980s featured a less mystical exploration of the concept, in an area commonly described as 'Health Status Research'. This era experienced the birth of QoL assessment instruments, such as the Short Form-36 (Barge et al., 2006). The use of such
instruments led to a rise on the number of publications on QoL and since the 1990s a tremendous increase of research on the concept can be observed. In accordance with this fact, a Medline search presents more than 7000 published papers on QoL; a threefold increase over 1995.

The first medical specialty that gave prominence to the QoL concept was oncology, where, there were issues regarding the preference of a better QoL without treatment, as opposed to a longer life with unpleasant medication. In psychiatry, similar issues have been prevalent for a long time. The debate whether “the cure is worse than the disease” arose in the treatment of schizophrenia with conventional neuroleptic drugs as well as in asylum psychiatry (Gardos, Gole & LaBrie 1977). These psychiatric issues, being primarily clinical in nature, led to the narrowing of the meaning of the QoL concept, neglecting the ethical and the societal dimensions of this concept.

In a discussion focused on an exploration of the QoL in mental disorders, Katschnig (2006) analysed the gain in popularity of the QoL concept as a replacement of the ‘biopsychosocial model of disease’ proposed by Engel (1977). McLaren (1998) supported this observation by adding that nowadays, the QoL concept has gained a wider acceptance in the medical literature than the “reductionist" biomedical model. As a result, the scope of QoL research could be seen expanding from a clinical to a societal perspective.

The issue of QoL has received particular increased attention from the psychiatric sector due to its importance for patient rehabilitation (Lustig & Crowder, 2000). The concept was first introduced in mental care surveys in the early 1980s (Megens & Meijel, 2006).
2.3 Quality Of Life in Community Mental Health

2.3.1 Meaning of Quality of Life in community mental health

QoL and its assessment have many apparent merits in the measurement of outcome in chronic illness, such as psychiatric illness. Its effectiveness relies on the fact that it can be used to measure incremental improvements rather than complete cure, the latter being often unattainable in severe mental illness. Furthermore, this concept takes into account a wide range of aspects of daily living as well as being patient-oriented (Oliver, Huxley & Bridges, 1996). Sharir et al. (2007) contributed to the listed benefits of QoL measurement by pointing out that QoL is known to be indicative of the level of social functioning in mental health patients living in the community.

Though the relevance of the QoL issue had already been highlighted in inpatient settings, greater interest was stimulated by the plight of deinstitutionalised individuals with mental illness. The hypothesis that community psychiatric patients experience a better QoL, was closely scrutinized by many critics of deinstitutionalization who questioned whether this idealistic picture was in fact realized. Concerns about safety, stigma and marginalisation challenged an idealised view of life quality (Clark, 2004). In the Tidal Model, Barker (2000) analysed these factors in relation to the individual’s need for security. Consequently, it is acknowledged that these world experiences can result in a sense of ‘threat’, which can in turn diminish the QoL.
2.3.2 Research and measurement

Since the concept of QoL has been cited as a fundamental justification for the choice of living place for the psychiatric patient i.e. either at hospital or in the community (Mechanic, 1989, Grob, 1994 as cited in Korr, Encandela & Brieland, 2001), several measures were designed in order to directly assess the dimensions of daily life such as financial issues, relationships and accommodation. These assessments range from ‘objective’ measures, using checklists or rating scales, to those that assess QoL with no predetermined structure (Megens & Meijel, 2006).

QoL measures have been considered as successful in comparing different populations of people with mental illness in different circumstances. (Lehman, Possidente & Hawker, 1986; Kaiser, Briebe & Barr, 1996; Ruggeri, Bisoffi, Fontecedro, 2001). However, since there is no generally agreed definition of QoL itself, it is felt that one must be cautious when interpreting and comparing the results of different QoL assessments. Studies generally focus on how QoL should be defined, and what factors have an influence on a person’s QoL. Another part of the focus in research is directed towards methods for measuring QoL (Thapa & Rowland 1989; Koivumaa-Honkanen et al., 1996; Leplege & Hunt, 1997).

According to Lauer (1999), most researchers believe that both subjective and objective data is necessary to provide a valid QoL profile of an individual. In objective terms, a person’s QoL can be measured by a number of objective criteria, such as the severity of symptoms, the level of income, living conditions, social status and financial situation. Subjective criteria defining the QoL concern the patient’s self-report as related to the
perception of his/her QoL, including the level of satisfaction with the living situation and general well-being (Mares, Young, McGuire, & Rosenheck, 2002).

However, research findings have shown that the subjective appraisal of life often fails to correlate with objective life circumstances amongst patients with an enduring mental illness (Barry & Crosby, 1996). Researchers consistently observed that these patients were more satisfied with their lives (subjectively) than might be expected in view of their (objective) living conditions (Thapa & Rowland, 1989). This observation is another reason for being cautious when comparing results of different assessments, as objective and subjective QoL are two different concepts with only a limited connection (Cohen et al., 2003). In the literature, the trend is towards accepting the subjective perception of a person’s QoL as the ‘gold standard’ and that objective criteria provide complementary data (Thapa & Rowland, 1989; Koivumaa-Honkanen et al., 1996; Leplege & Hunt, 1997; Cohen et al. 2003). This is the basis of the Tidal Model, which is the theoretical framework of the current research study. Barker (2000) suggested the use of the Tidal Model in order to encourage the appreciation of the patient’s life story, which is believed to hold the key to the individual’s recovery. However, several authors have arrived at the view that in the case of individuals whose mental illness is accompanied by severe intellectual disability, brain-damage or dementia, the subjective QoL rating should be considered invalid. (Trauer, Callally & Hantz, 1999; Voruganti, Heslegrave, Awad & Seeman, 1998).

In the same manner, the assessment of persons with psychiatric disorders has traditionally relied on the judgment of clinicians (Burlingame, Lambert and Reisinger, 1995). The Tidal Model was proactive in guiding professionals to find a balance between respecting patients’ wishes and fulfilling their professional role (Barker, 2000).
Gradually, the focus changed to subjective QoL. This change, linked with the reorganization of psychiatric services, called for more systematic and quantified assessments.

Because of this prevailing concern that QoL measurement should rely on the patient’s perspective, the past decade was the birthing era to several patient-rated instruments of measurement. The following is a summary of some of the instruments that have been used to measure the QoL of psychiatric patients in the community. The tools selected were the most common ones used to obtain data during the research studies cited in this literature review.

**Lehmans QoL Interview - QoLI (Lehman & Burns, 1990)**

Lehman’s QoL Interview (QoLI) can be used in inpatients or outpatients with serious mental illness. It is a self-report tool and uses a direct response by the patient for several issues, by means of an interview. The simple structure renders it appealing in the context of a multicenter clinical trial, however it consists of 143 QoL related items, which might render it time-consuming to complete. The reliability and validity of the scale are well established (Lehman & Burns, 1990). The main negative criticism is that it does not include activities of daily living (includes only social activities) and neglects the assessment of specific problems related to the symptoms of the mental illness.
**Wisconsin QoL Life-Client Questionnaire – W-QLI (Wisconsin QoL Associates, 1993)**

This assessment tool was developed at the University of Wisconsin in response to a need for information as part of the Wisconsin Medicaid Program for reauthorization of clozaril (a psychotropic medication). At the time of development, the QoL of psychiatric patients was being measured predominantly in terms of symptoms. Thus, this tool was amongst the first of its type that attempted to introduce a holistic assessment including clinical, personal and social issues. It includes 12 self-rated sections that have been consensually identified by professionals and patients as the main areas that affect the QoL. These include Background information (e.g. age, status, type of accommodation and income), Satisfaction Level, Activities and Occupation, Psychological Well-being, Symptoms/Outlook, Physical Health, Alcohol and other drugs, Social relations and support, Importance Level, Money, Activities of Daily living and Goal Attainment. The W-QLI was rigorously tested for content and face validity by both consumers and professionals considered to have expertise and extensive experience with persons suffering from mental illness. Whilst one can appreciate the depth of information that can be obtained by the use of this detailed questionnaire, its lengthy might be a major impediment in its implementation.

**Carers and Users Expectations of Services - CUES (Lelliott et al., 2003)**

CUES is a self-rating questionnaire that has been found to be a useful tool as a QoL indicator and for the evaluation of community mental health services. It was developed jointly by the National Schizophrenia Fellowship, the Royal College of Nursing
Institute and the Royal College of Psychiatrists. Since CUES is a new type of scale, it cannot be easily compared to any other. The results of the sub-studies comparing CUES with the ratings of other instruments suggests that CUES scores correspond to other tools used to assess QoL. The novelty and beneficial aspect of CUES arise from the fact that it was constructed after a large-scale study involving 500 psychiatric patients. These participants were asked to identify the main issues, which determine their QoL. The priority issues identified were used to construct CUES, which consists of 16 different topics related to the QoL of psychiatric patients in the community (Lelliott et al., 2001). The authors of CUES performed various validity tests including content validity, construct validity and criterion validity as well as stability testing and internal consistency checks. The tool collects both qualitative and quantitative data. The limitations of CUES lie in that it has not been tested by people from minor ethnic groups and that about one quarter of service users will need help in completing the questionnaire.

Measuring the community functioning and QoL of persons with mental illness is complex because of multiple domains, different stakeholders, limitations of self-report data, as well as the bias of carer-rated objective assessments. Given these issues, it is not surprising that most of the instruments used to measure QoL in the community contain various limitations. It is unlikely that any one instrument can meet the many demands across various settings. The potential utility of any instrument needs to be evaluated in terms of the specific population being studied as well as the type of information required.
2.4 Patients' Perception of their Quality Of Life in the Community

An initial search for research studies involving the term ‘Quality of Life of community psychiatric patients’ generated studies involving the perceptions of professionals working in psychiatry. Since the focus of this research is on the perceptions of the patients themselves, it was suspected that there was a dearth of literature in this area. However, on using broader terms like ‘patient satisfaction in the community’ and ‘community functioning’, a large amount of information was discovered.

Barry and Zissi (1997) reported that studies show the majority of patients living in the community as having high levels of satisfaction with their living situation. Comparing a life in the community to that within a psychiatric hospital, patients experience an increase in freedom and independence and despite having several problems, few desire to return to the hospital. However, lack of money, concern over health matters, poor social and family relations, and personal safety issues consistently emerge as factors that adversely affect patients’ QoL (Kelly & McKenna, 1997; Erdner, Nyström, Severinsson & Lützén, 2002). In a phenomenological study carried out by Johnson & Montgomery (1999), the researchers adopted a subjective approach in an attempt to explore the experiences of a group of chronic mentally ill individuals who were re-entering the community after hospitalization. As is typical in phenomenological investigation, the method of data collection consisted of two long interviews with each of the eight individuals participating in the study. This involved an interactive process utilizing open-ended comments and questions with the aim of encouraging the participants to tell their story. Data was analysed and the findings were restated.
conceptually as three main themes. The first theme reflected the notion that although a patient is living in the community, ties to the hospital often remain strong. The participants' idealistic expectations desire a community that is similar to the hospital environment in that it is a place where one is understood and accepted, a place that provides help with daily living and the provision of safety and security. These expectations often fall short in being met since the mental illness may affect the individual's capacity to be gainfully employed. This results in having to contend with meagre financial resources and thus marginalised living conditions as well as social exclusion due to stigma. These personal circumstances consequently affect the person's health and ability to cope with the symptoms of the illness, thus creating a vicious circle highlighted in the second theme of the study. The third theme reflected the participants' goals in the community and barriers to achieving these goals. Amongst these barriers featured lack of resources, lack of knowledge about how to pursue goals and pervasiveness of the illness. These findings suggest a somewhat negative view of the life of the psychiatric patient in the community. However, one must keep in mind the limited sample size of the study (n=8) and the fact that no questions were asked as regards the individuals' overall satisfaction of their life in the community.

Additionally, there are numerous indicators that former patients have a good QoL in the community despite the fact that adjusting to living outside the hospital is not easy (MacGilp, 1991; Pinkey, Gerber & Lafave, 1991; Leff, Dayson & Gooch, 1996). The Tidal Model offers an explanation for these paradoxical indications by Barker's analysis of the concept of crisis. He insisted that challenges that seem to make life difficult are actually inevitable and normal and often result in an opportunity to improve the QoL.
The review of the literature showed that studies exploring the general QoL with the use of established assessment tools were not as numerous as expected. This was a contradictory finding since during the literature search, it was noted that several QoL assessment tools have been developed, specifically for use to measure the general QoL in Community Mental Health. This finding might be explained by an observation of Gilbody, House & Sheldon (2002), who reported that QoL instruments that enable the production of a general QoL score, are mainly used in clinical settings as outcome measures and the results are not always published. Thus most of the research studies located were focused on individual problematic known areas that affect the patients’ QoL in the community. The main areas were stigma, employment and financial issues, social support and relationships, daily activities and support from services. Research studies related to each particular area will be reviewed as follows.

2.4.1 Stigma

Following the findings of a Swedish multicenter study, Ostman & Kjellin (2002) confirmed that stigma was one of the most important problems encountered by individuals with severe psychiatric disorders. It lowers self-esteem, contributes to disrupted social relationships, and adversely affects their ability to socialize, obtain housing, and become employed. These factors, in turn, have adverse effects on the QoL of the individual and were the real cause of rehospitalisation.

In a nationwide survey of 1,301 mental health consumers, interviews were used to explore the perceptions and experiences of stigma and discrimination. The interview was based on a questionnaire that was constructed by the researcher for the use of the
study. Wahl (1999) reported that the majority of participating patients tried to conceal their disorders and worried that others would find out about their psychiatric status and treat them unfavorably. Most of them had suffered from stigma particularly by families, churches, coworkers, and mental health caregivers. They reported discouragement, hurt, anger, and lowered self-esteem as results of their experiences, and they urged public education as a means for reducing stigma. Some reported that involvement in advocacy and speaking out when stigma and discrimination were encountered, helped them to cope with stigma. Although the participants were quite diverse, the self-selection process might have included only those psychiatric patients who are particularly susceptible to stigma. Furthermore, one must criticise the fact that schizophrenic patients were underrepresented and this may have led to inaccurate results given schizophrenia's reputation as the most highly stigmatized psychiatric disorder (Wahl, 1999). These limitations, however, do not negate the fact that almost all the participants had been adversely affected by stigma in their lives.

Sartorious (1998) (as cited in Hogbert, Magnusson & Lutzen, 2006) suggested that stigma is partially brought about because the general public often associates mental illness with dramatic behaviour such as hallucinations and incoherent speech. Additionally, a disorder like schizophrenia sometimes means losing the motivation and will power to live an active life, which may further contribute to the individual being stigmatised. According to Heginbotham (1998), mental illness frightens people, a fear partly rooted in lack of knowledge, resulting in intolerance of psychiatric patients.

In a study by Erdner, Magnusson, Nysrom & Lutzen (2005) it was found that psychiatric patients in the community look upon themselves as being ‘odd’, not as a
symptom of mental illness, but rather as a result of their own negative attitude towards mental illness. Similarly, Thesen (2001) explained that while the general public may view individuals with a mental illness as being ‘others’, these people accept and live the paradoxical identity of the ‘other’. Accepting and experiencing oneself as an ‘other’ is a characteristic dimension of stigmatisation and can render an individual prone to social isolation and harassment. This phenomenon of ‘the other’ is also clearly depicted in the Tidal Model where the individual is said to experience a loss of the ‘sense of self’, akin to the trauma associated with piracy. This can lead to a personal crisis.

The effects of stigma were particularly explored in an ongoing doctoral study into QoL for people with severe and enduring mental illness, where it was found that 60% of the respondents (n = 100) reported harassment/victimisation (Kelly & McKenna, 1997). A random sample of people who met the criteria for severe and enduring mental illness were interviewed, in their own homes, using a structured interview approach based on a QoL profile developed and tested for the study. The findings suggested that psychiatric patients living in a community setting are prone to harassment which ranges from the relatively minor, e.g. children knocking on the door and running away, to the more serious, where mentally ill people are physically abused. Harassment can be categorised into three broad themes: harassment while at home, harassment on the street, and financial exploitation. In the study report, it was not clear whether the participants lived in the same area and it is felt that this must be considered, since the environment surrounding the patient’s home might have a considerable effect on whether the patient experiences stigmatisation.
2.4.2 Employment and Financial situation

Another issue highlighted by psychiatric patients is that of money. Millward & Provan (1995) attempted to explain why the financial situation is attributed such importance by community psychiatric patients. The researcher noted that since poverty is one of the most hindering factors in attaining a good QoL level and can lead to social isolation and regression of the mental state, one can understand and interpret the perceived importance of money.

Another significant aspect, which is partially linked to the financial issue, is the patients' wish to be gainfully employed. The fact that most patients have this wish is a positive finding since it shows that the patients have 'personal wisdom' - an attribute which is given importance in the Tidal model, as it can help an individual to identify factors that lead to a higher QoL. Notably, several surveys of needs and QoL consistently found that employment was identified by the users as a priority in achieving a satisfactory QoL level (Hatfield, Huxley & Mohamad, 1992; Perkins & Repper, 1996; Patton, 2005). Surveys of the views of individuals with mental illness also emphasized the negative ramifications of not working, mainly, lack of money, inactivity and not perceiving themselves as 'mentally' well (Perkins & Repper, 1996).

In a study comparing working and non-working people with mental illness (n=92), it was concluded that those who worked had greater satisfaction with their QoL and significantly higher self-esteem than non-workers (Van-Dongen, 1996). QoL was measured by means of the Lehman's QoL Interview whilst Rosenberg's Self-Esteem Inventory was used to assess self-esteem. However, one must note that the participants
suffered from varying mental disorders and this can affect the self-esteem as well as the QoL. Interestingly, the study included a qualitative analysis of the findings, and it was found that non-workers had a lower QoL because of an inability to occupy their time as well as lack of money. More recently, a longitudinal analysis of unemployed people with serious mental problems in the United States found that those who were working at the time of follow-up had lower levels of symptoms, higher levels of global functioning and better self-esteem, as measured by a scale that was developed for the purpose of the study. A fact of great importance is that employment resulted in a higher income and greater financial satisfaction than those who were still unemployed (Mueser et al., 1997). Additionally, Rosenfield (1992) carried out a longitudinal study involving 157 patients, in an attempt to identify factors that affected the subjective QoL of the chronically mentally ill. In the report of the findings, the researcher discussed how the patients asserted that having an occupation was a means of empowerment both mentally (improved self-esteem) and physically (improved financial situation) and led to an increase in the sense of control experienced by these individuals. This in turn led to an improvement in the global QoL. Despite the usefulness of the findings, it is felt that the Rosenfield study entirely focused on the services provided by community mental health programs (such as employment) rather than global factors that affect the QoL, as suggested by the title of the study.

2.4.3 Social support and relationships

A well-functioning social network and a feeling of social participation are vital for the mental patient’s well-being as well as necessary to maintain a satisfactory life in the community (Perkins & Repper, 1996). The Tidal Model theory depicts the importance
of the ‘Others domain’ which centers round the various relationships that a person has and that are vital for recovery. To be an active participant in society leads to a sense of belonging and promotes solidarity. This in turn often leads to a positive outlook and faster recovery from mental health problems (Bengtsson-Tops & Hansson, 1999; Hardiman & Segal, 2003).

In his report related to the area of community psychiatry, Pirisi (2000) suggested that the social integration of individuals who suffer from mental health problems has not been as successful as anticipated, mainly due to the fact that forming a social network is one of the greatest barriers faced on returning to a community setting. Indeed, subjective studies involving psychiatric patients concluded that the presence of satisfactory social relationships improved the ability of the patient to function in the community and attain a higher QoL (Wahl, 1999).

In an ethnographic study, Erdner et al. (2002) carried out an analysis of the daily life of community psychiatric patients. The focus was mainly on psychosocial aspects, such as living arrangements, support, services and daily activities. The participants (n=12) took part in three open-ended interviews and identified social support and relationships as the two areas which had the greatest contribution in QoL. The researcher reported that while all the informants were aware of the need of having relationships, most of them admitted that they lacked the initiative to form and maintain meaningful social contacts. As a result, they were dissatisfied with their private interpersonal relations and one particular participant commented that on comparison with community life, institutionalization was not so daunting since it provided an opportunity for meeting other people. One must note that apart from the sample size being small, the patients
included in this study were all schizophrenia sufferers; a disorder that has been associated with social isolation. Thus the generalisability of the results is limited. Despite these limitations, the findings obtained were supported by other studies, such as the explorative study conducted by Granerud and Severinsson (2006). The aim of the Granerud and Severinsson study was to gain more understanding about how people with mental health problems feel about their reintegration into the community. Data collected by means of focus group interviews clearly showed that the participants identified financial resources, lack of daily activities and social relationships as the main factors that affected their life in the community. Family and family ties were listed as crucial for the participants as they were considered less demanding. Furthermore, as the family relationship was a long-standing one, having probably been established before the onset of illness, a family member's understanding of a person with mental problems was usually different to that of friends. However, family ties could also be problematic and approximately half of the informants reported conflicts with their family members. Another significant aspect that the participants discussed was the need to feel important to someone; a companion, with whom they could share their life, preferably someone close to their own age. In the Tidal Model, Barker (2000) discusses the need to develop a security plan in order to address these emotional as well as other needs. This helps the person to feel safe and adds meaning to life.

Apart from illustrating the importance of social support and relationships, qualitative research studies depict the poverty in this area. Additionally, quantitative data, such as that obtained by Blenkiron et al. (2003) also indicated that the participants' ratings for their satisfaction with their social relationships scored low when compared to other issues that determined the QoL of the individual.
In this particular survey, data was obtained by inviting 120 psychiatric patients living in the community to complete the Carers’ and User’s Expectations of Services (CUES-U) questionnaire. The researcher included individuals suffering from various mental disorders in an attempt to reduce the bias from any individual disorder. CUES-U ratings were lowest for "Social life" (49% satisfied) and highest for "Relationships with physical health workers" (88% satisfied). In this study, the social problem was truly depicted because the social life aspect was rated as the lowest, despite the fact that these participants were being supported by a community psychiatric team.

However, Young (2006) argued that the correlation between social functioning and overall life satisfaction, was inconsistent in research studies. Some studies reported that overall life satisfaction was positively related to the ability of the individual to interact in society (Sullivan, Wells & Lecke, 1991; Baker, Jodrey, Intagliata, & Straus, 1993) while some studies did not confirm this result (Okin & Pearsall, 1993; Barry & Crosby, 1996). A research study carried out by Young (2006), using Lehman’s QOL Interview, added evidence to the finding that overall life satisfaction is positively related to social interactions.

2.4.4 Daily activities

People with mental illness living in their own home in the community not only face the challenge of daily physical and social needs, but also that of filling their day with meaningful activities (Erdner et al. 2002). A number of authors have indicated that the area of ‘daily activities’ has been identified as one of the main determinants of the QoL of the psychiatric patient living in the community. The importance of activities has
been emphasized by Leff et al. (1996) who reported that those who were engaged in structured activities were less likely to exhibit negative symptoms. In contrast, Curson, Pantelis, Ward & Barnes (1992) found a weaker relationship between structured activities and a reduction in negative symptoms. A more recent study by Kelly, McKenna & Parahoo (2001) provided evidence to support Leff’s original findings. However, one must exercise caution in accepting these findings since it is those individuals with a lower degree of negative symptoms that tend to become involved in structured activities in the first place. However, the involvement in daily activities not only possibly resulted in a reduction of negative symptoms, but also improved the overall QoL. Perhaps this phenomenon could be described within the ‘resourcefulness’ principle of the Tidal Model. Barker (2000) recognizes and emphasizes the need for professionals to encourage patients to explore different resources that can help them to add meaning to their life journey. Regular daily activities can be one powerful resource.

A correlational study carried out by Diaz, Mercier, Hachey, Caron & Boyer (1999) explored the relationship between the meaning of daily activities and the subjective QoL of a group of people suffering from mental illness. In this study, the Wisconsin QoL-Client Questionnaire provided a global score for the subjective QoL. A total of 45 people with severe and persistent mental illness, living in Montréal, participated in a semi-structured interview. The results suggested that perceived competence in daily tasks and rest, pleasure in work and rest activities were positively correlated with subjective QoL. Despite the perceived importance of involvement in daily activities, several researchers reported findings that show the poor participation of mentally ill individuals in activities. Notably, a large-scale survey of 498 individuals with a mental illness in the community produced interesting results (Steinholtz-Ekecrantz, 1997 as
cited in Erdner, Nyström, Severinsson & Lützen, 2002). The study showed that 31% of the respondents had planned daily activities, while the majority of the participants (69%) did not. Thus, under-involvement in social activities was clearly an aspect of life for this sample of people with severe and enduring mental illness in the community.

More recently, a quantitative study involving 92 Irish respondents provided similar findings. The study carried out by Kelly et al. (2001) involved a ‘Daily Activities’ tool developed by the same author. The tool consisted of a 14-item list of daily activities and the participants were asked to indicate which of the activities they had participated in during the previous month. In order to assess the participants in a thorough manner, they were also asked to rate their satisfaction in relation to four aspects of living (things done at home, outside home, support received and pleasure received from TV and radio) by means of a Likert scale. In addition, the clients were asked to rate their global QoL by the use of the Cantril’s Ladder assessment tool. It is felt that the study method used was appropriate to the research question and yielded useful results. The findings indicated that over half of the respondents (56.5%) had no structured activity in their everyday life and a corresponding low level of self-reported QoL.

Furthermore, other researchers found that the issue of ‘daily activities’ was amongst the list of areas that were the least satisfactory in the individuals’ life (Pinkney et al., 1991; MacGilp 1991). It was often classified on the same level as the stigma and social support issues, which were other areas reported to be problematic for individuals living with a mental illness in the community. Barker (2000) advised the use of the Tidal Model to holistically explore the ‘self domain’. This helps to detect challenges such as the lack of daily activities. If such a challenge remains undetected, Barker warned that
it can lead to self-neglect and social isolation. This will harm the self and limit the patient’s resourcefulness.

2.5 The effect of Outreach support on perceived Quality of Life

Oftentimes, individuals who are discharged from psychiatric inpatient facilities need continuous assistance in community settings. The continuing of medication, rehabilitation, vocational assistance, and social support are of critical importance in helping to ensure successful living in the community (Curtis, Millman, Struening & D’Ercole, 1998). Since the 1970s outreach services have been widely promoted as an effective means of providing care and support to deinstitutionalized psychiatric patients. Markstrom (2003) asserted that outreach support is ideal as it helps individuals with severe and enduring mental health problems in their own homes, with the main goals being normalisation and re-integration into the surrounding society. Barker (2000) described how such a service can be based on the Tidal Model in order to generate person-centered interventions based on the patient’s resources for finding solutions.

The Outreach Team presented in the current study operates on a biopsychosocial model of care and thus holds that all aspects of a person’s life need to be addressed in order for psychiatric care to reach its objectives. The focus is on developing a comprehensive system of care and coordinating needed services into an integrated package to help the individual with mental illness integrate and live an acceptable life in the community.

In implementing this system of care, a case management/ key worker strategy becomes the primary means for ensuring that the services are available to every person referred to
the Outreach Team. Case management was described by De Cangas (1996) as a way of tailoring help to meet individual needs through placing the responsibility for assessment and service coordination with one individual keyworker or team. The hypothesis that intensive community psychiatric services, such as the Outreach Team, have a considerable effect on the QoL of the individual, has led to the undertaking of several studies.

One of the studies that attempted to explore the effect of Assertive Outreach on the QoL of psychiatric patients was carried out by Lafave, De Souza and Gerber (1996). The study assessed one-year outcomes for 110 clients with serious mental illness who were randomly assigned to an assertive community program and hospital-based program. Key elements of the community program included a multidisciplinary team on call 24 hours a day, home-based treatment, and instruction and assistance in basic living skills. Data from patient interviews after one year of service was used to assess clients' QoL, satisfaction with services, and psychopathology. Clients in the assertive community program reported better QoL than clients in the hospital-based programs. In addition, they were the group that were more likely to be maintained in community settings as opposed to rehospitalisation. It would have been interesting to add another participants group consisting of patients who were living in the community without being supported by an Outreach Team, in order to enable further comparison of results. Similar findings were presented by McGrew, Bond, Dietzen and Saylers (1994), in a study that examined outcomes of clients admitted to assertive community treatment programs in northeastern Indiana in the USA. The 212 participants were assessed at baseline and at six-month intervals for 18 months after admission to assertive community treatment programs. Data on rehospitalization, QoL, and level of functioning were obtained by
means of a tool developed for the study and compared using t tests. Progressive improvement was also examined by linear trend analysis. The results showed that the frequency of psychiatric hospitalization was reduced by one-third and the number of inpatient days by 50 percent while being supported by the Outreach Team. Improvements were progressive throughout the 18-month period. Progressive improvements also occurred in QoL as measured by both client and staff ratings. Clinical staff rated clients as having improved family and social support, increased self-reliance and independence, and improved daily living skills.

However, it is important to note that two well-designed controlled studies from UK provided contradictory findings. In the PriSM Psychosis Study, individuals with psychosis living in London received either standard psychiatric care (Time 1) or a support program involving assertive outreach (Time 2) (Thornicroft, Wykes, Holloway, Johnson & Szmukler, 1998). QoL was measured before and after the intervention in both the groups using a standardized measure that had a self-reported objective and subjective assessment of 8 life domains (family, finances, social relationships, work, leisure, living situations, safety and health), along with a global rating of the individual’s well-being. The findings showed that at Time 2, there were no improvements in the QoL of any of the two groups with respect to that at Time 1, and there was no inter-group differences either. Thus, from the perspective of the service users, the quality of care was apparently not related to any QoL improvement. The possible reasons discussed by the researchers included the small size of the sample (resulting in low power to detect true differences), insensitivity of the instrument to detect changes, or a true lack of effect of the interventions on improving the individuals’ QoL. In the second, randomized study named the UK700 trial (UK700 Group, 2002),
708 individuals with severe mental illness were randomly assigned to intensive (assertive community treatment) or standard case management systems in four British sites. QoL was assessed using the same instrument as in the PRiSM study. After 2 years, the patients' outcome was examined. In contrast to the previous study, the QoL of both groups showed significant improvement over the 2 years. However, even in this study, there was no significant difference in QoL outcome between the two groups. Interestingly, a depressive illness was associated with a better outcome than psychotic illness. Thus, it is debatable whether intensive care, such as Outreach Team support will necessarily lead on to an improvement in the QoL and further research was recommended in this area.

2.6 Conclusion

The literature suggests that there are several domains that affect the QoL of psychiatric patients in the community. Although it is important for health carers to rate the QoL of the patients under their care, it is probably of greater importance to give a voice to the patients and explore their perceptions as regards their life in the community. This was greatly emphasized in the Tidal Model, where the 'value of the voice' was proposed as fundamental when carrying out interventions and assessments. Recently, the introduction of community mental health services such as the Outreach Team, has been proposed to promote a life of higher quality. Locally, the late 1990s were the birthing years of community services in psychiatry. Although the literature located within this review is applicable to Malta, this can only be to a limited extent, since local community services had been shaped by the Maltese culture as well as by the available resources. Thus, they may differ substantially from foreign services. This highlighted
the need for local research studies in order to explore the QoL of psychiatric patients in the community and the effect of community psychiatric services on this concept.
Chapter 3

Methodology
3.1 Introduction

This chapter explores the method used to attain the goals of the study. The following is a navigation through the research techniques used, as well as a description of the population under study, sampling method and analytic techniques used.

3.2 Aims and objectives

The main aim of this study was to explore patients’ perception of their Quality Of Life (QoL) between two periods of time while being supported by a psychiatric Outreach Team. In order to address this aim, the following objectives were proposed to:

- Explore the QoL of patients while being supported by a psychiatric Outreach Team

- Explore patients’ perception of their QoL in the community

- Identify aspects in the life of the patients which have the greatest impact on the life quality

- Use a tool to capture patient perception data regarding potential changes in the QoL between two periods of time.
3.3 The Study Design

This study sought to gain insight through research objectives, rather than test a hypothesis. Thus, an exploratory descriptive design was adopted as it was considered to be the most appropriate approach for this study. The exploratory nature of the study was founded on the knowledge that this area has not been investigated locally. Such a design entails a thorough exploration of the topic under investigation and conclusions drawn from the data would include educated guesses or hypotheses for further research.

The descriptive design was the main foundation of the study, since a survey of the literature revealed significant research in the area, albeit a dearth of local research. This enabled the researcher to build on, and identify with, the work of others. However, this could only be carried out to a limited extent due to cultural barriers and due to the fact that only a minority of QoL research was targeted to explore the effect of community psychiatric interventions on the QoL. In accordance to Bowling (2002), the aim of this design was to demarcate the population by perceiving research parameters and compiling a record of that which had been perceived. Revision can then occur so that the perceptions derived can be thoroughly investigated.

Burns and Grove (2003) described how exploratory, descriptive studies are ideal to generate information about poorly understood concepts. Furthermore, Bowling (2002) discussed how data obtained through this design can be used to assess current situations and often uncovers specific ways that can lead to improvement.
3.4 The Research Setting

The study was based in a psychiatric setting involving patients who were leading a life in the community. Most of these patients had been formerly rehabilitated at a local psychiatric hospital. Once these patients reached the desired level of recovery, they were discharged from hospital and reintegrated into the community, keeping contact with psychiatric services by attending psychiatric outpatients appointments and/or making use of a community service such as the Outreach Team. Although a number of patients lived at home with their family, most of the individuals referred to the Outreach Team in the study tended to share an apartment (usually leased by the government, Non-Governmental foundations or by private owners) with other service-users instead of rejoining the family home. The interviews took place at a preferred location by the participants, as long as it was a suitable place for data collection. Since different participants preferred different places, it was hoped that by allowing the participant to choose the place, s/he would feel more at ease to divulge necessary information.

3.5 Target Population and Sampling Technique

The sample of patients was selected from the target population - a term defined by Polit, Beck and Hungler (2001) as the entire group in which the researcher is interested and to which the results of research are to apply. The target population for this study consisted of psychiatric patients living in the community who satisfied the following inclusion and exclusion criteria. These criteria were chosen after a review of the literature of QoL studies involving psychiatric patients.
3.5.1 Inclusion criteria

Patients were eligible to participate if they satisfied the following criteria:

- Had been discharged from the psychiatric hospital for a minimum period of 3 months (as this allows time to start settling in the community).

- Had been visited by the Outreach Team at least twice (as this provided time to start establishing a relationship and a care plan).

- Had been visited at least twice by the Outreach Team between the first and second interviews related to the current research study.

3.5.2 Exclusion criteria

- Patients could not participate if they had the following characteristics. Had:

  - Diagnosis of psychopathology or borderline personality disorder (as the nature of these diseases increases the chance of patients not giving answers that reflect reality).

  - Severe intellectual impairment (as this could bias the quality of the responses)

  - Residency in a community hostel (as this offered constant support by professional staff, which could bias the results)
A list of community psychiatric patients being supported by the Outreach Team was obtained from the Outreach Team database, after seeking permission from the relevant hospital authorities (Appendices B-G). The sample size of the study consisted of 20 patients. They were selected by means of Microsoft®Excel computer programme, utilising a probability random sampling technique. A larger sample size would have contributed to the extent of generalisibility of the research findings, especially the quantitative results. Time restraints did not permit this, especially due to the fact that each patient was interviewed twice (T₁, T₂), thus having a total of 40 interviews. However, it has been argued that in research, one should not judge the adequacy of the sample size solely by considering the number of participants (Leech & Onwuegubuzie, 2005). It is more beneficial to analyse the context of the research since, at times, even as small a sample as ten participants may be adequate (Sandelowski, 1995). Additionally, the sample chosen in the current study formed one-third of the total population and thus it was thought that the results have an element of generalisibility.

3.6 Research Method

Both quantitative and qualitative approaches were used to pursue the research objectives. Creswell (2003) identified one of the most prominent characteristics of a qualitative approach which is the strive to be holistic and subjective, so as to understand the phenomenon being studied as a whole. Consequently, such an approach is enriched by flexibility and in-depth analysis of the respondents’ attitudes and beliefs (Bowling, 2002). However, amidst the various criticisms of qualitative research, feature the complexity of data analysis and the small sample size that usually characterize such studies. Comparatively, quantitative research maximizes generalisability by requiring a
large sample size for data collection. Furthermore, this approach is rooted in cause-effect relationships and has the ability to effectively translate data into easily quantifiable charts and graphs. This makes data more understandable at a first glance – a useful characteristic when presenting the results to the relevant shareholders.

Thus, it was decided to heed the advice of Mays and Pope (1995) and include a mixture of both qualitative and quantitative approaches to meet the set objectives. This is aimed to provide an element of width to the depth of the qualitative results obtained (Cormack, 2000). During the study, data was gathered by utilizing a survey approach, which entailed the collection of self-reports from the participants, with the purpose of describing the population under investigation. The choice of this method was based on the knowledge that one of the chief virtues of a survey is its ability to provide meaningful information on populations, with the use of relatively small samples (Nieswiadomy, 1998). Surveys may be conducted by phone, mail or through personal contact, as well as by means of a questionnaire, interview and observation (Polit et al., 2001). In view of the sensitivity of the population being researched, it seemed more appropriate to gain acquaintance with the participants and then collect data through personal contact. Since observation could not be effectively used to study the QoL concept, the researcher was presented with the choice of an interview or a questionnaire.

By conformity to the theoretical framework of the current research study, the interview technique was identified as the most suitable. This lies in its ability to allow the researcher to actively listen to the patient’s story and appreciate it, which is considered as being of vital importance by Barker (2000). Additionally, face-to-face interviews are beneficial in that they entail one-to-one interactions, which helps in unearthing hidden
ideas and perceptions (Cormack, 2000). Conversely, interviews are associated with lack of anonymity and privacy, which may affect the quality of the data collected (Burns & Grove, 2003). The researcher sought to minimise the effect of this setback by reassuring the patients that any information divulged would be kept strictly confidential at all times, would not hold any clue to the identity of each participant and would only be used for research purposes. Another limitation of interviews is that they are time-consuming and there is potential for interviewer-bias (Bowling, 2002). In this study, the researcher attempted to reduce influence on the interviewee by avoiding giving personal opinion or by using leading questions during any discussions that arose. Each participant was interviewed two times with a 2-month period difference between each of the interviews. This was done in order to capture patient perception data regarding changes between the two periods of time, using T₁ as the baseline comparator for T₂.

3.7 The Tool

The interview was structured on questions from an established questionnaire, namely the ‘Carers’ and Users’ Expectations of Services’ (CUES) (Appendix C). Although CUES was originally developed to be used as a questionnaire, it was noted that the use of the tool in an interview format would be more appropriate for the study. The primary reason for this is the fact that the population under study is characterised by illiteracy as well as cognitive impairments resulting from chronic mental illness. Thus the participants are unable to complete a tool that involves reading or writing. Additionally, it was thought that using the tool as an interview would enhance the relationship between the patient and the community worker by encouraging informative discussions. Furthermore, information from the original development activities of the tool indicates
that CUES can be used as an interview schedule when an individual has a difficulty in completing the questionnaire (Lelliott et al., 2001).

Several QoL research tools were reviewed and CUES was chosen for various reasons. Primarily, it is one of the few tools, which is related directly to psychiatric patients, unlike most of the other general QoL tools that were cited. Additionally, it is a tool that involves a self-report method rather than a carer-rated technique, thus focusing more on the opinion of the patient rather than that of the carer. Furthermore, the tool consists of both close-ended and open-ended questions plus free text responses.

3.8 The Interview

Since CUES was used as an interview format, the researcher asked the close-ended questions so as to obtain statistical and quantitative data. However, the main focus was on the qualitative questions, where the use of the tool as an interview format, enabled the researcher to probe and discuss with the patient.

Another advantage of CUES is that it was constructed after gathering information from several sources (literature review of surveys and other instruments, patient focus groups, interviews and consultation). This enabled the identification of the main issues that determine the QoL of psychiatric patients. These issues were then grouped into the smallest possible number of items and used to form CUES, which consists of 16 different topics related to the QoL of psychiatric patients (Lelliott et al., 2001). After its development, the tool was field-tested four times with consequent re-drafting, including a total number of 521 psychiatric patients living in the community. Each of the 16 items
in CUES is introduced with a normative statement, describing what a service-user would expect to be the case for the issue if it does not cause the individual any problems. The individual is then asked whether or not s/he agrees with the statement. The open-ended question which follows allows the subject to elaborate further on his/her response. Since no Maltese patients were interviewed during the development phase of CUES, it is acknowledged that the tool might have been affected by cultural differences. Thus, the researcher of the current study showed the questionnaire to a number of experts in the field. A consensus was reached that the tool is applicable to Malta, due to the fact that the topics found in CUES are indeed topics that are known to affect the QoL of Maltese psychiatric patients (Mifsud, 2003). Furthermore, CUES includes a final open-ended question that asks about the general QoL, with the aim of allowing an easy, open discussion, where the patient can mention issues not included in previously asked questions.

Permission for using the questions found in the tool and to translate the tool to Maltese was obtained from the Royal College of Psychiatrists (London) who hold the copyright of the tool (Appendix D). In order to have a faithful translation as possible, back translation was used where the questionnaire was first translated into Maltese, then back into English by a second person. By comparing the original English version with the second one, the researcher was able to verify that the translation was accurate.

3.9 The pilot study

Since the CUES questionnaire used for the formulation of the interview schedule originated abroad, and has never been used as an interview schedule, the researcher
carried out a pilot study, a process accurately described by Tulman and Fawcett (1996) as 'primary prevention'. This is further explained by Burns and Grove (2003) who discussed how pre-testing is important as it often serves to detect unforeseen problems and enables the researcher to improve the research tool. Primarily, piloting the study was deemed as necessary in order to ensure that the language was clear to the Maltese patients and that no confounding variable related to structure, language and understanding would affect the study.

A further purpose of pre-testing was to determine the feasibility of the study, test the questionnaire for use as an interview schedule, gain experience with the methodology and the instrument and identify potential problems in the data collection. Additionally, the researcher wished to record the average time for carrying out the interview, in order to manage time effectively when planning the actual data collection process. The pilot study involved four subjects, 2 male and 2 female, who were interviewed by the researcher. The individuals were selected by typical purposive sampling in an attempt to pilot the study with those participants who were similar in characteristics to the sample that was later used for the actual study. After having completed the interview, the sample respondents were asked for their comments and recommendations about the interview. No major changes were deemed as necessary, except planning to allocate more time for each interview.
3.10 Reliability and Validity

Nachmias and Nachmias (1996) described how reliability and validity are two concepts that measure the quality of a research study by defining and measuring bias and distortion.

Reliability refers to the extent to which a measurement procedure produces similar results on repeated trials (Cormack, 2000). Since CUES is an established tool, reliability testing was already carried out by its authors, namely stability (test-retest), internal consistency and the test for equivalence (by comparing the tool with Health of the Nation Outcome Scale (HoNOS) questionnaire). In order to enhance the reliability of the analysis of the data, an independent assessment of transcripts by an additional researcher was organised, followed by a discussion as regards comparing agreement between the raters. This process contributed towards inter-rater reliability during the analysis of the data.

Bowling (2002) defined validity as an assessment of whether an instrument/ study measures what it is intended to measure. The authors of CUES performed various validity tests, including content validity, construct validity and criterion validity. Nevertheless, since the questionnaire was going to be used as an interview schedule and in a different country other than its place of origin, the researcher felt the need to submit the questionnaire accompanied by the research proposal to a number of experts in the field. Overall, the majority of the topics in the tool were considered to be relevant to the Maltese culture, however it was strongly recommended to translate the tool to Maltese. Neither the field experts nor the original authors of CUES found any objection to the
tool being used as an interview format. Later, the study was piloted in order to further check its validity. An addition validation strategy that was employed in the data collection phase of the study, was the ‘feeding back’ of the findings to the participants to check whether they regarded the findings as a reasonable account of their experience. This is termed as respondent validation and is aimed to improve the credibility of the study (Polit et al., 2001).

3.11 Ethical Issues

3.11.1 Ethical approval

Prior to data collection, a research proposal, including the tool, was submitted for reviewing and approval by the Ethics Committee of the Institute of Health Care (Appendix B). Permission to conduct interviews was sought from the relevant hospital authorities, namely:

The Chief Executive Officer of the Hospital
The Director of Psychiatry
The Manager of Community Services
The Psychiatric Consultants of the community patients
The Data Protection Officer

Since the researcher planned to use an established tool as the interview schedule, permission was obtained from the original authors of the tool, in order to be able to translate the tool to Maltese and use it in an interview format (Appendix B).
3.11.2 Informed consent

Each potential participant was provided with an information letter (Appendix E). In the letter, the researcher introduced herself, invited the patient to take part in the study and provided a description of the research study. The letter informed the participant that s/he may withdraw from the interview at any time without giving any reason and that information divulged during the interview would remain strictly confidential. The participant was required to sign the letter and the attached consent form, in order to provide the researcher with written verification that the patient has been informed about the study and what it entails (Appendix E). Subjects were also asked to give permission for recording the interview and for field notes to be taken during the interview.

3.11.3 Anonymity and Confidentiality

Anonymity occurs when the data collected during a research study cannot be linked to the participant. Confidentiality involves protection of the subjects’ identities by the researcher (Polit et al., 2001). Complete anonymity could not be achieved since the researcher herself carried out the interviews. However, fictitious names were used in the study report so as to limit the chance of the participants’ identity of being revealed. The information disclosed by the participants during the interview was kept confidential. In this way, the individual’s privacy and dignity were ensured at all times. The field notes and interview transcriptions were placed at a secure place and were destroyed upon completion of the study.
3.11.4 Protection from discomfort and harm

The participants were provided with the researcher’s contact number, to whom they could refer in case the interview evoked harmful feelings.

3.12 Data Collection

A list of all the patients referred to the Outreach Team was obtained from the Outreach Team’s database. After selecting 20 patients to form the sample population, they were contacted by telephone and given a brief résumé of the study. The potential subjects were asked to set a date to meet the researcher so that they could be provided with further information. The information letter and the consent form (Appendix E) were then personally delivered by the researcher, at a place selected by the patient. This was done with the aim of gaining acquaintance with the patients, which would possibly enhance the chance of participation in the study (Oppenheim, 1992).

Moreover, the patients were given ample time to read the information letter and clarify any difficulties or ambiguities as regards participation in the study. On recruiting the required number of subjects who had agreed to participate in the study, an interview date was planned with each of them. A semi-structured interview schedule was used as the researcher desired to have the flexibility to explore certain areas in a deeper manner, should the need arise during the interview process. Each interview was recorded and the information provided by the participant was re-checked for verification. Although this process resulted in a longer interview, it increased the likelihood of obtaining genuine information and of correcting any misinterpretations of the patient’s story. At the end
of each interview, the subject was reminded about the second interview, which would take place in 2 months time. As this time approached, the subjects were once again contacted by telephone and a second interview was scheduled.

3.13 Data Analysis

3.13.1 Quantitative data

Data analysis was performed with the use of the Statistical Package for the Social Sciences (SPSS). This was done to generate tables, graphs and carry out the relevant statistical tests, namely the Wilcoxon signed-ranks test which identifies and compares any difference between repeated measurements on a single sample. In the current study, the test was used to examine how the respondents’ ratings of different QoL areas varies with time.

3.13.2 Qualitative data

The qualitative data gathered during the interview was transcribed verbatim. Since the interviews were carried out in Maltese, the transcripts were first translated into English then back translated into Maltese by a second person. By comparing the original Maltese copy and the back-translated transcript, the researcher was able to diminish the possibility of having an inaccurate translation of the interview script. Following this process, content analysis was performed on the data obtained. This procedure involved the assembly and understanding of data, coding by theme or category and finally analysis and presentation of data (Bowling, 2002). The author is aware that this process is associated with the possibility of subjective interpretations, which can lead to biased
results (Polit et al., 2001). In an attempt to control this limitation, concurrent analysis of
the data was carried out by an independent practitioner, so as to confirm the themes
identified. This was followed by a discussion as regards comparing agreement between
the raters. This contributed towards inter-rater reliability of the data collected. The
results were finally classified and presented by means of a descriptive narrative account.

3.14 Conclusion

Following this description of the research process, the following chapter presents the
findings collected through the interviews.
Chapter 4

Research Findings
4.1 Introduction

This chapter presents the analysis and presentation of the data that was obtained during the two data collection sessions. In order to compile and process the data, Microsoft Excel and SPSS were used in collaboration with Microsoft Word.

The data analysis chapter is made up of two main divisions, namely, that of the quantitative data part and the qualitative findings section. Whilst the quantitative data plots change over time, as well as allowing for the generation of statistics, it lacks depth and meaning, which can only be put into context by referring to the qualitative data obtained.

The first section of the chapter (Section 4.2) begins with the demographic data of the 20 participants. The aim of including this information is to introduce the participants, who form the basis of this research. Demographic data was obtained by questioning the participants as well as by accessing Outreach and hospital records. The next part of the section was constructed in tabulated format, and depicts the quantitative responses given by the participants in exploring the 16 life issues identified in the Carers’ and Users’ Expectations of Services (CUES-U) questionnaire. The data obtained during the two periods of data collection was included in the same table in an attempt to simplify and clarify comparison of the findings. Statistical tests are also incorporated within this section.

The qualitative data obtained during the study is illustrated in Section 4.4. in the same pattern as the previous section. Thus, the data obtained during the two different periods
is combined in one table. The last part of this section presents the additional issues identified by the respondents as affecting their Quality of Life (QoL).

4.2 Demographic Data of Respondents

Respondents’ Gender

Figure 4.1 shows that the sample consisted of an equal number of males and females.

![Figure 4.1: Gender](image)

Respondents’ Age

The participants’ age was distributed throughout different age groups, the commonest being the “51-60” group. The mean age of the participants is 44.5 (Figure 4.2).
**Respondents’ Locality**

The participants were dispersed over 12 different localities, the most common area being the central part of the island (Figure 4.3).
Chapter 4 – Research Findings

Duration of Outreach Support

Figure 4.4 depicts the duration of Outreach support for each participant. This is measured as the time between the initial Outreach contact date and the date of data collection. It can be noted that slightly more than half of the participants have been in contact with the Outreach Team for 1-2 years. The mean duration of Outreach support is 1 year 6 months.

Figure 4.4: Duration of Outreach Support

Number of Hospital Admissions before Outreach Support

Figure 4.5 illustrates the number of hospital admissions prior to Outreach support. Most of the participants had 1-10 admissions (n=15).
**Figure 4.5: Hospital Admissions prior to Outreach Support**

![Bar Chart](chart.png)

**Number of Hospital Admissions during Outreach Support**

Figure 4.6 shows the number of the participants' hospital admissions during Outreach support. Most of the participants had no admissions (n=11).

**Figure 4.6 Hospital Admissions during Outreach support**

![Bar Chart](chart2.png)
4.3 Quantitative data

4.3.1 Participants’ satisfaction and comparison

The following two tables summarize the respondents’ perceptions regarding their QoL associated with sixteen major life issues. These issues, which were the themes used in the coding of the qualitative data analysis, were pre-determined by the tool. Lelliott et al. (2001) explained how these themes were identified by an extensive literature search in parallel with focus groups and interviews of mental health service users. In the current study, each issue was individually explored by asking the participant to rate his/her situation when compared to a descriptor of the ideal situation. The ratings obtained during the two points in time are depicted in Table 4.1. Furthermore, each respondent was requested to give a direct answer by stating whether s/he is satisfied with the situation. The responses issued by the patients when replying to this question are illustrated in Table 4.2.

Descriptor comparisons

The data yielded during the first interview highlights 16-20 participants who rated their QoL as good as the descriptor in 11 of the 16 life issues. The same pattern is consistently followed during the second interview. During the first data collection period, the respondents perceived ‘Social Life’ and ‘Family and Friends’ as being the main problematic areas, and consequently, half of the individuals rated these areas as being worse or worst than the descriptor. During the second period of data collection, ‘Social Life’ was placed at the lead of unsatisfactory life issues, with ‘Stigma and discrimination’ featuring close behind. The results obtained were consistent between
the two data collection periods, the two exceptions being ‘Family and Friends’-characterized by a positive change during the second interviews and ‘Medication’ which was rated as being more problematic during Time 2 (Table 4.1).

<table>
<thead>
<tr>
<th>Category</th>
<th>Time 1</th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Good</td>
<td>Worse</td>
</tr>
<tr>
<td>Living place</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>Money</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>Help with finances</td>
<td>16</td>
<td>4</td>
</tr>
<tr>
<td>How the day is spent</td>
<td>16</td>
<td>3</td>
</tr>
<tr>
<td>Family and friends</td>
<td>11</td>
<td>5</td>
</tr>
<tr>
<td>Social life</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Information and advice</td>
<td>20</td>
<td>0</td>
</tr>
<tr>
<td>Access to Mental Health Services</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>Choice of mental health services</td>
<td>20</td>
<td>0</td>
</tr>
<tr>
<td>Relationship with mental health workers</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>Consultation and control</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>Advocacy</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>Stigma and discrimination</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>Medication</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>Access to physical health services</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>Relationship with physical health workers</td>
<td>19</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 4.1 Comparison of situation with ideal scenario – Time 1 and time 2 frequencies
**Patient satisfaction**

The results obtained during the first interviews illustrate the positive responses given by the majority of the patients (n=18-20) to 8 of the life issues explored. Furthermore, an increase in ‘Yes’ ratings in two additional life issues (‘Help with finances’ and ‘How the day is spent’) can be observed when observing Time 2. ‘Family and Friends’ and ‘Social Life’ prove to be dissatisfactory for half of the patients interviewed in Time 1. These same issues re-appear in Time 2 at a lower frequency, with 7-8 patients being unsure or dissatisfied in relation to these respective issues. One can note that the all the ratings in Time 2 are identical to or more positive than Time 1 (Table 4.2).

<table>
<thead>
<tr>
<th>Category</th>
<th>Time 1</th>
<th></th>
<th></th>
<th>Time 2</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>Unsure</td>
<td>No</td>
<td>Yes</td>
<td>Unsure</td>
<td>No</td>
</tr>
<tr>
<td>Living place</td>
<td>12</td>
<td>3</td>
<td>5</td>
<td>15</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Money</td>
<td>12</td>
<td>1</td>
<td>7</td>
<td>14</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Help with finances</td>
<td>16</td>
<td>3</td>
<td>1</td>
<td>18</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>How the day is spent</td>
<td>15</td>
<td>1</td>
<td>4</td>
<td>19</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Family and friends</td>
<td>10</td>
<td>1</td>
<td>9</td>
<td>13</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Social Life</td>
<td>10</td>
<td>5</td>
<td>5</td>
<td>12</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Information and advice</td>
<td>19</td>
<td>1</td>
<td>0</td>
<td>20</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Access to Mental Health Services</td>
<td>20</td>
<td>0</td>
<td>0</td>
<td>20</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
### Table 4.2 Satisfaction with situation – Time 1 and time 2 frequencies

<table>
<thead>
<tr>
<th>Category</th>
<th>Time 1</th>
<th></th>
<th>Time 2</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>Unsure</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Choice of mental health services</td>
<td>20</td>
<td>0</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Relationship with mental health workers</td>
<td>19</td>
<td>0</td>
<td>1</td>
<td>19</td>
</tr>
<tr>
<td>Consultation and control</td>
<td>19</td>
<td>0</td>
<td>1</td>
<td>19</td>
</tr>
<tr>
<td>Advocacy</td>
<td>18</td>
<td>2</td>
<td>0</td>
<td>19</td>
</tr>
<tr>
<td>Stigma and Discrimination</td>
<td>12</td>
<td>2</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Medication</td>
<td>16</td>
<td>2</td>
<td>2</td>
<td>17</td>
</tr>
<tr>
<td>Access to physical health services</td>
<td>18</td>
<td>1</td>
<td>1</td>
<td>18</td>
</tr>
<tr>
<td>Relationship with physical health workers</td>
<td>19</td>
<td>1</td>
<td>0</td>
<td>19</td>
</tr>
</tbody>
</table>

4.3.2 Statistical Tests

The Wilcoxon Signed Ranks test was used to compare the data obtained during Time 1 and Time 2. This was aimed at detecting and analysing any differences between the set of data pairs. The resultant P value (also termed as two-tailed asymptotic significance) determines whether any difference between the two data collection periods is significant enough for acknowledgement. The Z score represents a standardised value that indicates the total sum of rankings obtained regarding their proximity or deviation from the mean.
Descriptor comparisons

Table 4.3 illustrates the mean scores of the participants’ ratings of their situation with the descriptor. Results show no significant difference between Time 1 and Time 2.

<table>
<thead>
<tr>
<th>Category</th>
<th>Wilcoxon Signed-ranks test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Z</td>
</tr>
<tr>
<td>Living place</td>
<td>-1.342</td>
</tr>
<tr>
<td>Money</td>
<td>-1.134</td>
</tr>
<tr>
<td>Help with finances</td>
<td>0.000</td>
</tr>
<tr>
<td>How the day is spent</td>
<td>-0.447</td>
</tr>
<tr>
<td>Family and friends</td>
<td>-1.823</td>
</tr>
<tr>
<td>Social life</td>
<td>-0.707</td>
</tr>
<tr>
<td>Information and advice</td>
<td>0.000</td>
</tr>
<tr>
<td>Access to Mental Health services</td>
<td>0.000</td>
</tr>
<tr>
<td>Choice of Mental Health services</td>
<td>0.000</td>
</tr>
<tr>
<td>Relationship with mental health services</td>
<td>0.000</td>
</tr>
<tr>
<td>Consultation and control</td>
<td>0.000</td>
</tr>
<tr>
<td>Advocacy</td>
<td>0.000</td>
</tr>
<tr>
<td>Stigma and discrimination</td>
<td>0.000</td>
</tr>
<tr>
<td>Medication</td>
<td>-0.447</td>
</tr>
<tr>
<td>Access to physical health services</td>
<td>0.000</td>
</tr>
<tr>
<td>Relationship with physical health workers</td>
<td>0.000</td>
</tr>
</tbody>
</table>

Significant p ≤ 0.05

Table 4.3 Wilcoxon Signed Ranks Test for Comparison of Participants’ situation with descriptor: Statistical differences between Time 1 and Time 2

Patient satisfaction
The Wilcoxon Signed Ranks test was used again to compare the participants’ satisfaction with their situation in Time 1 to that in Time 2. Findings show a significant difference in the ‘Family and Friends’ issues as well as borderline significance in ‘Money’ and ‘How the day is spent’ (Table 4.4).

<table>
<thead>
<tr>
<th>Category</th>
<th>Wilcoxon Signed-ranks test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Z</td>
</tr>
<tr>
<td>Living place</td>
<td>-1.518</td>
</tr>
<tr>
<td><strong>Money</strong></td>
<td>-1.897</td>
</tr>
<tr>
<td>Help with finances</td>
<td>-1.134</td>
</tr>
<tr>
<td><strong>How the day is spent</strong></td>
<td>-1.890</td>
</tr>
<tr>
<td><strong>Family and friends</strong></td>
<td>-2.251</td>
</tr>
<tr>
<td>Social life</td>
<td>-1.633</td>
</tr>
<tr>
<td>Information and advice</td>
<td>-1.000</td>
</tr>
<tr>
<td>Access to Mental Health services</td>
<td>0.000</td>
</tr>
<tr>
<td>Choice of Mental Health services</td>
<td>0.000</td>
</tr>
<tr>
<td>Relationship with mental health services</td>
<td>-1.000</td>
</tr>
<tr>
<td>Consultation and control</td>
<td>0.000</td>
</tr>
<tr>
<td>Advocacy</td>
<td>-1.000</td>
</tr>
<tr>
<td>Stigma and discrimination</td>
<td>-1.000</td>
</tr>
<tr>
<td>Medication</td>
<td>-1.141</td>
</tr>
<tr>
<td>Access to physical health services</td>
<td>0.000</td>
</tr>
<tr>
<td>Relationship with physical health workers</td>
<td>0.000</td>
</tr>
</tbody>
</table>

Significant p ≤ 0.05

*Borderline/Significant

**Table 4.4 Wilcoxon Signed Ranks Test for Participants’ Satisfaction:**

Statistical differences between Time 1 and Time 2
4.4 Qualitative data

The qualitative findings were classified and presented in a tabulated manner, as follows in Table 4.5 and Table 4.6.

4.4.1 Perception of participants

Table 4.5 summarizes the participants' account of their QoL in relation to the sixteen life issues explored. Unlike the quantitative data, it can be noted that the number of responses does not always add up to 20. This can be explained by the fact that in some instances, some participants chose not to comment about a particular life issue. However, at other times, each participant attributed several different types of comments to the same issue, making it possible to classify each comment under different themes. During the first interview, “Help with finances”, “Social Life” and “Medication” were the most commonly cited areas that need improvement. A shift is from Time 1 to Time 2, with “Family and Friends”, “Money” and “Stigma and discrimination” being the issues with the highest frequency of criticism by the subjects, during the second data collection period. These observations are also consistent with the quantitative data obtained during the study.
Table 4.5 Content analysis of CUES-U factors affecting QOL in Time 1 and Time 2 (Items 1-16 in CUES-U)

<table>
<thead>
<tr>
<th>Items</th>
<th>Categories</th>
<th>Excerpts</th>
<th>Category Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living place</td>
<td>House</td>
<td>“The interior of the flat is not pleasant...needs refurbishing”</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>interior</td>
<td>“I would like the place to look nicer, maybe new furniture and painting the walls.”</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Location</td>
<td>“The place is not in a central area”</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I need to catch 2 buses to go to most places.”</td>
<td>2</td>
</tr>
<tr>
<td>Money</td>
<td>Lack of</td>
<td>“I pay the flat rent and buy a cigarette...not much money is left to buy other things.”</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>money</td>
<td>“I have to count every cent because I end up spending a week with no money until the next cheque arrives.”</td>
<td>8</td>
</tr>
<tr>
<td>Help with finances</td>
<td>Budgeting</td>
<td>“Maybe I can learn to make money last longer throughout the month”</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Cigarettes cause my poverty. I can’t live without them, they are more important than food. If only I manage to resist”</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Employment</td>
<td>“I would like to find a way of making more money, like getting help to find a job.”</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Shopping knowledge</td>
<td>“I wish to learn the price of shop items so that I can compare prices and choose the cheapest products.”</td>
<td>4</td>
</tr>
</tbody>
</table>
### Table 4.5 Content analysis of CUES-U factors affecting QoL in Time 1 and Time 2 (Items 1-16 in CUES-U)

<table>
<thead>
<tr>
<th>Items</th>
<th>Categories</th>
<th>Excerpts</th>
<th>Category Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>How the day is spent</td>
<td>Suitable activities</td>
<td>“Some activity to fill the day, maybe work (must be suitable for me).” “I spend too much time home alone. I should make myself go out and join a club or something.”</td>
<td>6 5</td>
</tr>
<tr>
<td>Family and friends</td>
<td>Support</td>
<td>“My children drift in and out of my life...the ‘out’ periods make me so sad. That’s not support; I’m better off without them.” “Sometimes they [family members] do not trust me and treat me as if I were a child. I am ill, not crazy, and I am not a child”.</td>
<td>5 3</td>
</tr>
<tr>
<td>Social Life</td>
<td>A good friend/partner</td>
<td>“I need a friend whom I can meet and go out with. And maybe I can find a girlfriend.” “I like to dine out and to go out everyday...but I cannot afford it, as I have to pay for the transport too”.</td>
<td>7 4</td>
</tr>
<tr>
<td></td>
<td>Affordable and accessible leisure places</td>
<td>“I have to make myself go out, even if I don’t feel like it. How else can I make friends?”</td>
<td>3 0</td>
</tr>
<tr>
<td>Information and advice</td>
<td>Medication information</td>
<td>“What is the function of each pill? I’d like someone to explain to me.”</td>
<td>2 2</td>
</tr>
</tbody>
</table>
### Table 4.5 Content analysis of CUES-U factors affecting QoL in Time 1 and Time 2 (Items 1-16 in CUES-U)

<table>
<thead>
<tr>
<th>Items</th>
<th>Categories</th>
<th>Excerpts</th>
<th>Category Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and advice</td>
<td>Mental Health information</td>
<td>“I don’t really know what’s wrong with me.”</td>
<td>1</td>
</tr>
<tr>
<td>Access to mental health services</td>
<td>Nocturnal difficulties</td>
<td>“Night time is my only problem because community mental health workers cannot be contacted.”</td>
<td>2</td>
</tr>
<tr>
<td>Choice of mental health services</td>
<td>Hospital-based</td>
<td>“Many services e.g. psychologists and social workers are based at the hospital. I hate going there.”</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Lack of knowledge</td>
<td>“I know there are services, but I don’t know which of them are suitable for me.”</td>
<td>0</td>
</tr>
<tr>
<td>Relationships with mental health workers</td>
<td>Judgment</td>
<td>“I know it’s wrong to spend too much money, but I hate being judged by my keyworker. It makes me feel like I’m a bad person with no good in me.”</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
<td>“I feel anxious before the Outreach worker’s visit. I would like to stop feeling this way.”</td>
<td>0</td>
</tr>
<tr>
<td>Consultation and control</td>
<td>Financial control</td>
<td>“Sometimes I feel like I should have more control over my money. It’s mine and I should spend it when and how I like”.</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I want to manage my money without any interference.”</td>
<td>2</td>
</tr>
</tbody>
</table>
### Table 4.5 Content analysis of CUES-U factors affecting QoL in Time 1 and Time 2 (Items 1-16 in CUES-U)

<table>
<thead>
<tr>
<th>Items</th>
<th>Categories</th>
<th>Excerpts</th>
<th>Category Frequencies</th>
</tr>
</thead>
</table>
| Advocacy      | Assistance during important appointments e.g. psychiatric outpatients | “Before I visit the doctor, I spend so much time planning what to say. And then when I’m there, I can’t find the words. I hate going alone.” “I prefer to have someone with me when I attend for appointments e.g. at the Social services departments. When I go on my own, I become confused and mess up things.” | Time 1: 4  
Time 2: 3 |
| Stigma and discrimination | Psychological abuse | “Do I look like different? Because sometimes people look at me in a strange way. They think I don’t notice, but I do.” “When I object, they [family and friends] remind me of my past and threaten to admit me to the hospital. It frightens me.” | Time 1: 8  
Time 2: 6 |
| Financial abuse |                           | “Sometimes they [shop assistants] give me the wrong change. I only notice it when my friend is with me and she counts my change for me.” | Time 1: 1  
Time 2: 0 |
| Exclusion     |                           | “In the past I had friends who would abandon me when they saw me in one of my bad days.” | Time 1: 0  
Time 2: 2 |
### Table 4.5 Content analysis of CUES-U factors affecting QoL in Time 1 and Time 2 (Items 1-16 in CUES-U)

<table>
<thead>
<tr>
<th>Items</th>
<th>Categories</th>
<th>Excerpts</th>
<th>Category Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>Side-effects</td>
<td>“I feel so tired after I take the injection. Sometimes it lasts for a whole week”.</td>
<td>7 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I wet my pillow case because I dribble so much at night. It makes me feel dirty.”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Too much pills</td>
<td>“Everyday I have to swallow more than twenty pills. They cause nausea and retching. I would like to have less pills.”</td>
<td>3 2</td>
</tr>
<tr>
<td>Access to physical health services</td>
<td>Accessing general practitioner</td>
<td>“The health centre doctor doesn’t always come. And I cannot go to the health centre if I’m feeling sick.”</td>
<td>1 0</td>
</tr>
<tr>
<td></td>
<td>Nocturnal difficulties</td>
<td>“I had to go to the health centre at night. The ambulance took me there but wouldn’t take me back. I don’t drive and had no one who could come for me. There are no buses at night.”</td>
<td>0 1</td>
</tr>
<tr>
<td>Relationships with physical health workers</td>
<td>Respect</td>
<td>“Sometimes I feel that they [health workers] do not take me seriously. They treat me like I’m stupid or crazy.”</td>
<td>2 0</td>
</tr>
<tr>
<td></td>
<td>Patience</td>
<td>“It takes me long to understand things. They [physical health workers] are busy and get angry when I don’t understand immediately.”</td>
<td>0 1</td>
</tr>
</tbody>
</table>
4.4.2 Additional Issues

Table 4.6 depicts additional issues identified by the individuals and their respective perception as regards the effect on the QoL. A striking finding is that the participants perceive their life as being greatly affected by “Fear”, such that this theme was merited with 33 comments. This places the issue at the lead of CUES-identified and participant-identified factors that affect the QoL. Another finding is that any concerns about currency conversion disappear by the time of the second interview (In January, 2008, during the data collection period of the study, Malta changed its currency from Maltese Lira to the Euro.)

Table 4.6 Content analysis of other factors that affect the QoL (Item 17 in CUES-U)

<table>
<thead>
<tr>
<th>Themes</th>
<th>Categories</th>
<th>Excerpts</th>
<th>Category Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Time 1</td>
</tr>
<tr>
<td>Fear</td>
<td>Admission to hospital</td>
<td>“I am anxious before psychiatric appointments because I am afraid that he [psychiatric consultant] will admit me to hospital again.”</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I live in fear of returning to hospital and staying there forever.”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Relapse</td>
<td>“Before I sleep, I always pray God that the following day is a good one. I am afraid that I will wake up feeling bad again.”</td>
<td>15</td>
</tr>
</tbody>
</table>

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### Table 4.6 Content analysis of other factors that affect the QoL (Item 17 in CUES-U)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
<th>Excerpts</th>
<th>Category Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Time 1</td>
</tr>
<tr>
<td>Anger</td>
<td>Self-directed</td>
<td>“Why am I like this? I am too weak and I hate myself.”</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I feel like a failure. I ruined my life and that of my family.”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anger towards others</td>
<td>“Some people treat me like I’m crazy and I hate them.”</td>
<td>3</td>
</tr>
<tr>
<td>Currency abuse</td>
<td>Abuse</td>
<td>“The prices will be much higher and I will be given incorrect change.”</td>
<td>2</td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td>“I hate changes. I don’t want to think about the Euro because it makes me anxious.”</td>
<td>2</td>
</tr>
<tr>
<td>Loneliness</td>
<td>Inclusion vs Belonging</td>
<td>“I live in this flat...I like it, but it’s not home.”</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I’m ok here and no one bothers me. But sometimes I wish I still live at hospital.”</td>
<td></td>
</tr>
</tbody>
</table>

#### 4.5 Conclusion

This chapter consisted of the presentation of the results obtained during the research study, as well as the noting of important issues, such as the recurrence of common challenges as regards the QoL of psychiatric patients in the community. The implications of these results are explored and discussed in the following chapter.
Discussion
5.1 Introduction

This chapter seeks to explore the findings obtained from the interviews, in relation to the research objectives and the literature surrounding this area of study. Furthermore, the Tidal Model will be introduced in an attempt to give meaning to the results produced. This will allow the emergence of the relevance and implications of the study. Fictitious names have been used in the report in order include some of the more important direct quotes given by the participants. The chapter is presented in 4 main sections, namely:

- Identification of the most challenging Quality of Life (QoL) issues and their perceived change over time
- Other QoL issues and perceived change over time
- Participant-identified QoL issues
- Does Outreach support result in a change of perceived QoL over time?

5.2 Identification of the most challenging Quality of Life issues and their perceived change over time

5.2.1 ‘Social Life’ and ‘Family and Friends’

Cultural differences may lead to the assumption that research in different countries necessarily produces different results as regards a particular issue. It is on the basis of this assumption that the findings reported in this study are felt to be surprising, as they are similar to those produced during studies in other cultures. The issues of ‘Social Life’
and ‘Family and Friends’ are an example of this phenomenon, since they are repeatedly perceived to be the least satisfactory in the life of the psychiatric patients in the community. Despite the fact that Malta is known for its hospitality and supportive family environment, half of the participants of the present study (n=10) initially admitted that they are not satisfied with their relationship with family and friends. The intensity of this perceived challenging issue led one of the respondents, Joanne, to describe herself as seemingly invisible in her family house and one of the younger patients, Michael, to sadly admit that:

“I’m better off without them [family members]...they just make me feel more anxious.”

Other researchers report similar patient reactions and the attributed meaning given to this finding is that although family relationships are considered important, a dysfunctional family might heavily bear on the ability of the psychiatric patient to lead a meaningful life (Erdner et al., 2002; Granerud & Seversinsson, 2006; Blenkiron et al., 2003).

In the Tidal Model, ‘The Others’ was identified by Barker (2000) as being one of the dimensions of utmost importance in holistic patient assessments. This term refers to the kind of support that the patient receives from a whole range of people present in the life of that individual. The important role of this dimension might be the reason for the strong wording used by the participants to describe their perception as regards their social life as well as family and friends.
Chapter 5 – Discussion

The Maltese participants offered other explanations amongst which feature lack of trust and labeling by family members. However, since most QoL research is patient-focused, one must be cautious not to judge the situation before considering other issues such as family burn-out and family inexperience in dealing with psychiatric problems.

During the second period of data collection, it was noticed that perceptions regarding the ‘family and friends’ issue were more positive. Although the respondents had similar descriptor comparisons during the two data collection sessions, a significant positive difference was detected in the participants’ satisfaction between the two points in time. These findings were similar to a study carried out by McGrew et al. (1994), where patients supported by an Outreach Team showed improved family and social support over time. One cannot conclude that this improvement was solely attributed to Outreach support, however, the system of care of the local Outreach Team strongly emphasizes the involvement of the patient’s family in the care plan. Hence, one cannot exclude the contribution of the Outreach Team to this positive difference.

The participants of the study noted that their social life was another area that may prove to be testing. This corresponds closely with the findings of Cresswell, Kuipers & Powers (1992) who noted that the social networks of community psychiatric patients suffering from schizophrenia consist of four to five people when compared to a network of 40 people for a person with no psychiatric problems. One significant aspect that the informants discussed was the need to find a friend or a partner; a significant person with whom to share the joys and sorrows of life. This need is echoed in similar studies, which support the current findings in noting that psychiatric patients are more prone to social exclusion and isolation than the average person (Curtis et al., 1998; Taylor et al.,
Challenges within the social life of the participating patients confirm the same issues illustrated in the quantitative research carried out by Blenkiron et al. (2003). The main issues, which were therefore listed as being causative factors of this reported isolation, include financial inadequacies and lack of motivation. One must acknowledge that financial difficulties are common amongst patients that are currently being supported by the Outreach Team. Whilst most of the individuals are unable to hold gainful employment, their income solely depends on social benefits. This usually caters for the individual's basic needs, which include accommodation, food and transport but excludes leisurely activities such as outings with friends. As regards the motivation issue, it is imperative to mention a comment by one of the participants, John, who succinctly pointed out that:

"I have to make myself go out, even if I don't feel like it."

This suggests that psychological factors play an important role in addition to the physical factors previously discussed.

Unlike the ‘family and friends’ issue, there was no significant difference in the ratings of the participants between the two periods of data collection. Interestingly, this correlates to research carried out by Curtis et al. (1998), which concluded that patients being supported by an Outreach Team do not exhibit significant improvement in their social life over time. While it can be positively noted that locally there was no regression in the perception of the participants as regards their social life, it is an area that requires more attention, since the findings show that a number of respondents are not satisfied with their QoL related to this issue ($n_1=10$, $n_2=8$).
5.2.2 ‘Stigma and Discrimination’

The present research study serves to aggregate more evidence towards the belief that when mentally ill individuals are reintegrated into the community, they become visible in different ways than other individuals. Kelly and McKenna (1997) insisted that this makes them highly prone to stigma and discrimination. During the first interview, more than half of the participants agreed that their situation compared well to the ideal scenario ($n_1=12$). The same number of individuals consequently described their QoL as being satisfactory as regards the issue of stigma and discrimination. However, the qualitative aspect of the study seems to have been more effective in capturing the in-depth feelings and perceptions of the participants about this issue. On analysing the data, it was noted that the informants clearly categorised the types of stigma and discrimination that they experienced. The three classes identified were psychological abuse, financial abuse and exclusion. Similar themes were visible in research studies such as the QoL research carried out by Kelly and McKenna (1997) and Wahl’s national survey (1999). While words can serve the purpose of depicting an individual’s story, one must note that in this particular issue, they fall short in picturing the atmosphere of hurt and shame that could be sensed during this part of the interview. In the Tidal Model, Barker (2000) described how the act of helping each other and acting humanely is the building block of the Tidal Model. Conversely, discrimination is considered as an act that can have a detrimental effect on the healing and reintegration process of the individual. Once again, the findings of the study may seem rather surprising in a country where 98 percent of the population is Roman Catholic – one of the religions which strongly discourages acts of discrimination.
One has to investigate what causes community psychiatric patients to attract this unwanted attention. Perhaps, it is related to ‘stigma of appearance’, an issue that was raised by Sam, a long-term sufferer of schizophrenia, who indignantly queried:

"Do I look different? Because sometimes people look at me in a strange way..."

Another reason for this finding might be related to the patients’ self-doubt, as a by-product of the mental illness. This can mean that the fact that patients felt different from others resulted in their mistaken perception that others treated them differently.

It is acknowledged that existing misconceptions regarding psychiatric patients and misconduct, such as violent behaviour, may further fuel the negative view of the public as regards the mentally ill. Cutcliffe & Hannigan (2001) suggested that media sensationalization of psychiatric disorders may have produced untold harm in influencing the public’s perception. On comparing the respondents’ answers during the first and second interviews, statistical tests showed no significant difference. This supported the findings obtained during a similar European study, namely the PriSM Psychosis study (Taylor et al., 1998) that showed no improvement or worsening in the QoL as regards this issue. One might tentatively suggest that the presence of an Outreach key worker may give signs to the public that the patient has a ‘protector’. This may reduce the risk of potential discrimination and abuse. Conversely, the fact that an individual requires Outreach support may label him as being fragile, which may serve to attract stigmatisation. Hence, one might hypothesize that these effects balance each other out and produce the results obtained in this study. However, McGrew et al. (1994) contradicted these results by producing evidence that stigma tends to improve with
Outreach support. Since that study was carried out in India, it might be argued that cultural differences might have contributed to the different findings.

5.2.3 ‘Money’ and ‘Help with Finances’

The findings of the study indicate that financial issues may partially influence the QoL of psychiatric patients who are leading a life in the community. Initially, 12 of the respondents affirmed that their financial situation compared quite well to the ideal scenario. Only one participant described his financial status as being much worse than the descriptor. Contradictingly, when the informants were subjected to the second quantitative question, which involved the rating of their satisfaction, seven of them stated that they were not satisfied with their financial situation.

On reflecting upon this finding, it can be noted that the descriptor in Carers’ and Users’ Expectations of Services (CUES-U) questionnaire described the ideal situation as ‘the owning of enough money for basic needs such as staying out of debt and eating’. Hence, it may be the case that the participants’ perceived ideal situation was different than that described in CUES. The qualitative responses obtained might serve to confirm that the sample perceived differences in the meaning of the ideal descriptor. On the other hand, there were several complaints about the lack of money to buy cigarettes and to pay for travelling fees. This discrepancy between the patient’s ideal and the professional’s ideal was also identified in the Tidal Model. Barker (2000) advised professionals to practice the art of active listening and allow patients to tell their life story as well as discuss their needs and goals. Since the patient is an expert in his own life, the carer must learn to ‘care with’ rather than ‘care for’ the patient. Barker explained how this can be practiced
by being cautious that the wishes of professionals, however well meaning, do not override those of the patients. The participants in the study were aware that they need practical help in finances and more than two thirds of the patients were satisfied with the help that they were receiving ($n_1=16$). Moreover there were several wise suggestions as regards more assistance in budgeting and shopping. Such personal wisdom can be appreciated in a reflection shared by one of the elder participants, Peter, who concluded that:

"...having enough money is not the problem. It's the way you use the money that can be difficult."

A degree of financial dissatisfaction was similarly evident in the work of Kelly et al. (2001), where one third of the participants reported a financial problem. The authors of this study claimed that the fact that the income of the cohort relied exclusively on social benefits might be an explanation for the perceived lack of money. Likewise, the research sample of the present study consisted of 18 patients deriving their income from social assistance and only 2 of the participants being gainfully employed.

Various researches provided valuable data and arguments as regards the effect of employment on financial status and QoL (Hatfield et al., 1992; Perkins & Repper, 1996). A particular study by Van-Dongen (1996) showed that non-working psychiatric patients had a lower general QoL score which was mainly attributed to perceived feelings of low self-esteem as well as actual lack of money. It seems as if the patients who were interviewed in the present local study were not aware of the importance of
employment since only one of them mentioned the employment issue and suggested Outreach help to find jobs for patients.

On comparing the participants’ responses over time, it can be noted that there is no significant difference in descriptor comparisons, albeit a borderline positive significance in patient satisfaction (Refer to Table 4.4). These findings fit in with the rest of research regarding this topic, where results range from positive to negative extremes as regards improvement of financial situation over time of patients being supported by an Outreach Team (McGrew et al, 1994; Curtis et al., 1998).

5.2.4 Living place

Living place was another surprising element in this research study as it was rated by the participants as having as much effect on the QoL as the financial issue. This contradicts most QoL research that does not classify the living place amongst the top QoL effectors. Although there was no significant difference between responses given over time, one can note that during the second interviews, there seemed to be a slight shift towards a more positive perception and no increase in negative answers. This was noted both in descriptor comparisons and patient satisfaction ratings. However, it was rather alarming that 2 of the respondents consistently described their living situation as being much worse than the descriptor, which causes them dissatisfaction in this area of their life. On referring to the descriptor in CUES, such a negative reply indicates that the place might not meet the individual’s needs, might be causing him to worry about losing the living place, might be out of the way or subject to harassment. The qualitative data sheds light on this challenge by identifying house/apartment interior and location as being the
causative agents of dissatisfaction. Although literature on the effect of living place on the QoL seems to be lacking, a particular study that was located, featured similar problems as regards challenges in the living place of psychiatric patients in the community (Johnson & Montgomery, 1999). As regards living place interior, the Outreach Team often liaises with other services in order to assist the patient in maintenance and in obtaining house appliances. Living place location and accessibility prove to be more challenging because oftentimes, the choice of house/apartment structure and location depends heavily upon the financial situation of the patient. On being asked about his satisfaction with his living place, Sam shared a somewhat philosophical reflection that is worth investigating. He stated that:

"..I like it [the flat]... but it's not home".

This can be interpreted by realising that although a living place might be materially equipped to serve as a home, there are other patient-related psychological issues that can contribute to the patient’s overall satisfaction with his/her QoL as regards the place where s/he lives. In the Tidal Model, Barker (2000) acknowledged the existence of the 'Self Domain' and the important role that it plays in planning for physical and emotional security. Once again, this author encouraged professionals to assess what part the individual might play in improving the QoL related to issues such as the living place. Although one can locate studies that partly investigate the effect of Outreach support on living conditions, as part of QoL, they yield opposing results, which makes the issue debatable (UK700 Group, 2000; Taylor et al., 1998; Lafave et al., 1996; McGrew et al., 1994).
5.2.5 ‘How the day is spent’

In accordance with other research, this particular study placed ‘Daily activities’ amongst the main determinants of the QoL of the psychiatric patient living in the community. Initially, more than two thirds of the participants described their way of spending the day as being as good as the descriptor. Consequently, feelings of satisfaction were reported by most of the respondents. Whilst this QoL area was rated as being slightly more challenging than certain other areas, one must view these local results in relation to other research studies. One can conclude that the Maltese psychiatric patients who participated in this study, reported greater levels of satisfaction in the way they spend their day than patients in other countries (Pinkney et al., 1991; MacGilp, 1991; Steinholtz-Ekecrantz, 1997 as cited in Erdner, Nyström, Severinsson & Lützén, 2002). However, one must reflect upon this conclusion while taking into consideration the fact that these studies did not mention whether the patients are being supported in any way.

An additional finding of the present study showed that while there was no significant difference between descriptor comparisons in the 2 different periods of data collection, a borderline significance was evident in the satisfaction of the participants. The difference was a positive one with increased reported feelings of satisfaction by the respondents. This is a replication of the results produced in part of the UK700 Study, which showed that patients receiving Outreach Support show an improvement in daily activities over time, when compared to a control group (Huxley et al., 2003). Once again, one must mention that other studies that included an exploration of daily activities as related to QoL produced contradicting results which showed no improvement in this area (Curtis et al., 1998; Taylor et al., 1998).
Locally, it may be possible to explain the satisfaction experienced by the participants by reference to the policy of the Outreach Team, which places emphasis on the importance of assisting referred patients to engage in meaningful daily activities. Suggestions by the participants included the need for assistance in finding employment in order to fill the day. When asked about his views on daily activities, Louis described how:

"...time passes slower at home. I do the cleaning and cooking and then I start to worry and think. I think too much then. That's why I want go to the day centre. So I can occupy my time and avoid thinking."

This statement is felt to echo the advice given by Erder et al., 2002, which emphasized the importance of directing patients towards activities in the community. It is also in line with the Tidal Model, as the participants of the current study appeared to be aware of their limitations and were being guided to work with their resourcefulness in order to improve their life (Barker, 2000).

5.3 Other Quality of Life issues and perceived change over time

5.3.1 Medication

The majority of the participants of the study considered their medication as beneficial in reducing the symptoms of mental illness. Consequently, findings show that during the first interview, 19 of the respondents agreed that their medication was as good as the descriptor situation. A slight shift towards a more negative perception was noticed during the second data collection session. However, statistics showed that the difference was of no significant relevance. It is interesting to note that despite the positive comparisons to the descriptor, some of the participants were then reluctant to rate their
medication as totally satisfactory. In fact 2 of the respondents felt that they were unsure about their level of satisfaction and another 2 individuals contradictingly rated their medication as completely unsatisfactory. The second interview sessions showed no significantly different results as regards satisfaction with medication.

Probing for an explanation revealed that the participants seemed to have a love-hate relationship with the medication they are prescribed. While the subjects seemed to be well aware and even grateful for the symptomatic relief of the medication, some individuals commented that the side-effects were annoying and can cause an amount of disruption. Such was the feeling of Thomas, one of the younger participants who stated that:

"I feel so tired after I take the injection....makes me feel like an old, weak man."

Other participants criticised the fact that they have to take too many pills, with some of them stating that the medication amounted to more than 20 tablets daily. One cannot effectively compare these findings to other studies because there is a dearth of research which links QoL and medication to Outreach support. One related study is that carried out by Desplenter, Simoens & Lackeman (2006) where findings showed that patient education regarding medication resulted in a positive change in attitude. This might serve to provide another possible explanation for the participant ratings in the present study - since Outreach keyworkers educate the patient about medication, the overall QoL rating in this area compares very well to other areas. Perhaps education needs to be on-going and directed towards the specific areas mentioned by the patients, such as understanding side-effects. This might increase patient satisfaction over time.
5.3.2 Relationship with physical and mental health workers

Relationships with physical and mental health workers were perceived as being ideal and satisfactory by the majority of the participants ($n_1, n_2 = 19$). Furthermore, this positive response remained consistent over time. The results are congruent to those obtained in a study carried out by Blenkiron et al. (2003), who also utilised the CUES questionnaire. The findings of both the latter-mentioned study and the present study also show that relationships with physical and mental health workers were rated as the areas that were perceived to be the most satisfactory in the life of the participating patients. A limitation of the high overall levels of satisfaction expressed was that the participants knew that the researcher of this present study formed part of the Outreach Team. This may have inhibited some respondents from making negative comments. However, when the subjects were allowed to discuss in the free text section, some of them felt the need to be critical despite a previously positive answer. Two individuals stated that they felt as if the psychiatric keyworker was judging them as regards their spending habits. One comment that made an impact described the negative effect of judging which makes Sam feel:

"...like I'm a bad person with no good in me".

Another participant confided that prior to the keyworker's visit, she experienced great anxiety. These perceptions were discussed by Barker (2000) in the Tidal Model and included within the quest for professionals to be able to relate to patients in an ordinary way aimed at establishing a relationship and not a dictatorship. The Model guides the
carer to focus on empowerment as this can lead to the patient feeling responsible to carry out changes within his/her life.

Regarding relationships with physical health workers, the participants demanded more respect and patience. Several researchers attempted to explore what patients with a psychiatric illness consider as 'good care'. The attributes identified were similar to those discussed by the patients in the present study and necessarily involve approachability, a relationship of respect, empathy and a non-judgmental attitude (McCabe et al., 2007).

**5.3.3 Access to physical and mental services**

This is another area that was rated as being satisfactory during both periods of data collection. The majority of the participants stated that their situation compared well with the descriptor of the ideal scenario, and as a result reported feelings of patient satisfaction in this area were high as compared to other areas in the QoL. A comment regarding access to mental health services described the problem of nocturnal difficulties, as locally, Outreach Team workers do not carry out community night duties.

To a lower extent, this same problem features in accessing physical health workers. One respondent added that sometimes the doctor at the health centre refuses to carry out a home visit. This worried her because she cannot afford to pay for a private general practitioner. Okin and Pearsall (1993) discussed how intensive community care can help patients to gradually form social networks, including physical and mental services. The authors asserted that in San Francisco General Hospital, USA, this has resulted in a
perceived improvement of the QoL of community psychiatric patients as well as reduced readmissions.

5.3.4 Advocacy, Consultation and control

A positive rating was obtained from the majority of the participants during descriptor comparisons and perceived satisfaction of ‘advocacy’ and ‘consultation and control’. These ratings did not prove to change as time elapsed between the first and second interviews. Findings from the study carried out by Blenkiron et al. (2003) showed a similar pattern as regards consultation and control. However, there is a discrepancy in the results obtained for the advocacy issue as the respondents in the current study have shown to be more satisfied in respect to this QoL area. Perhaps the larger sample size and the different setting in the cited study contribute to this difference.

Johnson and Montgomery (1999) reported related findings which link patient satisfaction as regards consultation and control. The researchers added that most of the participants in their study had aspirations and goals, which further helped to fortify their sense of control. The current study did not attempt to explore whether the participants had any plan or goals for their future so only a limited comparison can be made to the cited study.

The qualitative question regarding these areas asked the subjects to identify aspects which required more attention and assistance. The comments reported as regards the issue of advocacy centered around the need for assistance during important appointments. However, it was noted that the respondents acknowledged that they were
already being assisted in this area but were mentioning it because of its importance. When discussing consultation and control, one participant chose to criticize the fact that he felt that he should have more control over his money. This complaint was joined by a similar one from another respondent during the second period of data collection. One might attempt to explain this situation by realizing that budgeting can be a sensitive and challenging issue for both the outreach worker and the patient. Whilst the keyworker might be too over protective to the extent of reducing the patient’s freedom of choice, it can prove to be difficult for the patient to understand the importance of effective financial management. Megens and Meijel (2006) claimed that probably the building of a trusting therapeutic relationship in the community takes a long time.

In the Tidal Model, Barker (2000) explained that one of the initial interventions within the building of the relationship should be the identification of the patient’s personal theory. This involves the understanding of how the patient views problems rather than giving the person a professional explanation of his difficulties. The next goal would be to empower the patient to challenge his perceptions and bring about a therapeutic change. This process can take much more than the two-month period allocated for detecting differences, during the present study. This might explain the presence of these complaints regarding lack of control

5.3.5 Information and advice

The patients who were included in this research study perceived themselves as being well informed about the mental health system. The majority felt confident that they were receiving helpful advice which was available and easy to understand. The
participants did not have much to discuss as regards advice and information. One comment was a plea for more information about medication. As revealed by the study carried out by Desplenter et al. (2006), providing patients with practical information was useful and over time, it can increase knowledge and adherence to care. Another interesting comment described how a particular participant did not know why he had been admitted to the psychiatric hospital. He felt that he was not well informed about his psychiatric disorder and would like to have access to more mental health information. Although there was no change in the QoL ratings over time in relation to this area, and the area was perceived to be satisfactory, it might be interesting to objectively test the participants’ actual knowledge about areas in their life in order to verify whether the patients are being supplied with enough information while being supported by the Outreach Team.

5.3.6 Choice of Mental Health Services

This area proved to be the most satisfactory area in the participants’ life and all the respondents rated their choice of mental health services as being as good as the descriptor and completely satisfactory. This result was obtained during both interviews. During the first data collection period, John pointed out that despite his satisfactory rating, he was irritated by the fact that many psychiatric services were based at the psychiatric hospital, which was a problem as he states that:

"...I hate going there."
This showed that this individual was not really aware of the choice of mental health services available, some of which being located outside the hospital setting. When being interviewed for the second time, another participant admitted that he lacked knowledge as regards the types of mental services available. In view of these comments, reference can be made to the lack of knowledge already commented upon in other QoL areas, such as the medication issue.

5.4 Participant-identified Quality of Life issues

The final free text question of the interview proved to be valuable in discovering a number of additional issues that would have otherwise remained unexplored. One can note that during both the first and second interviews, most of the comments were rather negative, with the subjects choosing to discuss their challenges rather than satisfactory areas. Unarguably, the issue of 'fear' emerged outstanding from the rest of the findings, in that its high frequency of occurrence places it in the lead of CUES-identified and participant-identified factors that affect the QoL.

The majority of the issues present in the CUES-questionnaire are of a material type e.g. living place, money. Albeit challenging, plans can be made to address these issues and lessen their impact on the QoL. However, as regards the issue of fear, it was felt that the main cause is of a psychological nature which can prove to be harder to resolve. It was disconcerting that some of these individuals appear to be constantly haunted by the possibility of relapse and readmission. Sadly, Louise stated that:
"I cannot stop worrying. Will I always remain living here [at home]? I don’t want to go back [to the psychiatric hospital]. I am afraid I will go back and never recover and stay there forever."

It is understandable that this type of anxiety can be significant enough in affecting the perception of the QoL. Interestingly, the findings of this study correspond to the phenomenological findings of Johnson and Montgomery (1999). Supporting the trend that featured in the current study, these researchers commented that fear seems to be a major issue even for those individuals who have been leading a stable community life for a number of years.

It seems as if the study participants viewed themselves as having invisible ropes that might eventually and inevitably pull them back to the psychiatric hospital. Perhaps this can be possibly explained by the fact that patients who were referred to the Outreach Team were those who are most in need of help due to the disabling affect of their mental illness. Thus for these individuals, the task of overpowering challenges and mental obstacles was an everyday occurrence and not an occasional one. Similarly, the possibility of relapse never ventured too far away from reality. This emphasised the importance of ‘Transitional care’ – a type of care which is guided by the Tidal Model and which aims at creating a smooth passage from hospital care to community care. This involves the necessary provision of information and walking alongside the individual to offer reassurance and help when needed (Barker, 2000). On comparing the first and second periods of data collection, it can be concluded that the frequency and content of comments regarding the issue of fear were similar.
Other issues identified by a minority of respondents were those of anger and loneliness. Anger was described as being both self-directed and towards others. It was characterised by feelings of worthlessness and failure, self-perceived or projected onto the individual by the family/society. Barker (2000) asserted that with the implementation of 'the holistic assessment' based on the Tidal Model, emotions such as anger would be thoroughly identified and explored in order to empower the individual to find self-resources to deal with this distress. Although the issue of anger has featured in literature, it has to be noted that this emotion has been researched in relation to violence and aggression, rather than as a concept on its own (Doyle and Dolan, 2006).

Comments about loneliness all centred about lack of belonging in society. One of the participants notably explained how he felt that his living place was just a house and not a home. This data captures the fact that some patients felt as if they were outcasts in their neighbourhood, and worse still in their own home. Perhaps this is brought about by the labelling of the individual by society. Alternatively, it could have been induced by psychological elements within the individual which led to this perception. Literature showed that loneliness has been acknowledged as a common experience in psychiatric patients. However, this phenomenon has been studied in conjunction with other variables with the focus being on exploring the meaning of loneliness. Consequently, little effort has been made on identifying the cause-effect relationship that can lead to this experience (Rosedale, 2007). On a similar note to the issue of 'fear', there were no major changes between the first and second interviews.

Anxiety related to currency conversion was also detected during the first interview. The few comments about this issue described the possibility of higher prices and cheating
within the system. The incidence of an issue like the one of currency conversion, is described by Barker (2000) as a metaphorical storm, during which the individual might fear drowning and thus needs additional help. One can note that the issue of currency conversation did not feature at all during the second interview. This was probably related to the fact that the Outreach Team referred psychiatric patients in the community to Euro changeover training sessions. Additionally, anxiety might have been reduced by the knowledge that the conversion from Maltese lira to Euro was reported as a smooth, successful process within the country (Trichet, 2008).

5.5 Conclusion: Does Outreach support result in a change of perceived Quality of Life over time?

Ritsner, Kurs, Kostizky, Ponizovsky & Modai (2003) described QoL as being amorphous and heterogenous. This description is one of the few definite ‘QoL’ aspects that has been widely embraced by different researchers. Having gained first hand experience by carrying out the current study, it was felt that research was helping to form the central missing pieces in the ‘QoL’ puzzle. However, other pieces are being added to the edge of the puzzle, which render the concept as borderless and dimensionless. It was needless to elaborate on the fact that the introduction of other variables to this concept, such as the effect of professional interventions on the QoL, can increase the complexity of the scenario.

It is, therefore, of no surprise that it is debatable and yet inconclusive as to whether intensive care, such as Outreach Team support will affect the QOL of psychiatric patients living in the community. Certainly, the results of the current study showed
significant or borderline improvement in only 3 out of the 16 CUES issues, namely 'Family and friends', 'Money' and 'How the day is spent'. Improvement in these areas also occurred in research carried out by McGrew et al. (1994) and Lafave et al. (1996)

At first glance, the current results obtained might be regarded as somewhat negative. However, throughout the study, none of the QoL areas was characterised by a majority of negative ratings. This was shown by the fact that each area in CUES obtained 50% or more positive ratings, both in patient satisfaction and descriptor comparisons.

Therefore, one can tentatively suggest that this study was actually exploring individuals who appear to be already quite satisfied with their QoL. This may be one explanation for the lack of significant improvement between the first and second periods of data collection. In his report following a similar study with matching results, Taylor et al. (1998) described how a small sample size can result in a low power to detect differences. Additionally, they pointed out that lack of changes in the QoL over time can also be related to insensitivity of the research tool used or a true absence of effect of Outreach interventions. These possible reasons are felt to be also applicable to the current study.

Since this research was aimed at exploring 'change' and not simply 'improvement', it has to be mentioned that there was no regression in the QoL in any of the areas, as time elapsed. This sheds a more positive light on the findings obtained as it means that overtime, the QoL of the participants remained stable or improved. A notable finding is that the participants seem to be satisfied with the professional services that they are receiving. Hence, QoL challenges reported were specifically associated with areas
related to the social functioning of the individuals, such as ‘Family and Friends’ and ‘How the day is spent’.

This research study, based on the therapeutic philosophy of the Tidal Model, is felt to have reached its objectives and it was useful in giving the patients ‘a voice’ concerning their perceptions of the QoL within the community. In view of the interesting findings obtained, it is hoped to convey the message of the importance of using the Tidal Model in delivering patient-centred care that involves careful listening and analysing of the patient’s living experience.
Chapter 6

Conclusion
6.1 Overview of Study and Results

This study was aimed at exploring the perceptions of psychiatric patients living in the community, who are being supported by a psychiatric Outreach Team. The main interest of the researcher lay in the Quality of Life (QoL) of these individuals, as well as changes in perception over time. Twenty individuals chose to participate in the study, each of whom was interviewed twice with a period of two months between each interview. The Tidal Model formulated by Phil Barker (2000) was used to guide the research process and assist in analysing the findings.

The results showed that the participants under study seem to be already quite satisfied with their QoL in the community. On comparing different areas that comprise the QoL concept, it can be observed that several issues were perceived to be of more concern than others. Notably, challenging areas were the domains involving the social functioning of the individuals while patient satisfaction was attributed to the quality of the professional services being offered. The participants rated Social Life, Family and Friends, Stigma and Discrimination, Money, Help with Finances, Living place and How the day is spent as being the most challenging areas. Subjects clearly identified the satisfactory areas, as well as the challenging ones in their community life. Areas associated with a positive contribution to the life of the participants include Medication, Relationship with physical and mental health workers, Access to physical and mental services, Advocacy, Consultation and control, Information and advice and Choice of Mental Health Services. There were no reported dramatic changes in the QoL of the participants over time. However, the findings indicate that Family and friends, Money and How the day is spent were associated with borderline or significant improvement.
Apart from exploring the QoL areas identified within the Carers’ and Users’ Expectations of Services (CUES) questionnaire, the participants introduced other vital issues, namely fear, anger and loneliness. It could be argued that during the interview, the participants had already indirectly mentioned these emotions as regards each individual QoL area. For instance, participants had already discussed their perceived loneliness in relation to their social life and family and friends. However, it seems as if the impact of these emotions was important enough for the subjects to isolate them as individual factors that affected their QoL - referring again to the example of loneliness, it was observed that during the free text section, this emotion was discussed again as an issue on its own, with no particular relation to any of the other QoL areas.

Overall, the current findings firstly show that the participants had a satisfactory perceived QoL – however, there were issues, such as social life, family and friends and fear that were of particular concern to the respondents. Challenging issues involved the social functioning of the individuals whilst professional services offered were reported as being satisfactory. Secondly, minimal changes in perception were reported over time – one cannot exclude that these changes were brought into effect by Outreach support, although other factors might have been involved. Finally, the trends in the findings were consistent with other research in this field of study and can be associated with the philosophy of the Tidal Model (Barker, 2000). Indeed, this study served as an affirmation of the core belief of the Tidal Model – the importance of focusing on the personal experience of the individual in order to address the existing needs. Furthermore, important reflections and suggestions as regards the Outreach Team service and its effect on the QoL emerged from the study.
6.2 Critique of the Study

Despite the researcher's effort to eliminate possible flaws in the research study, one must acknowledge that certain issues might have nonetheless lowered the quality of the results obtained. Similarly, the study was characterised by strengths that enhance the validity of the findings obtained. This section is an acknowledgement and analysis of the main strengths and limitations that accompanied the research process.

It is felt that one of the limitations of this study was the absence of a comparative control group, which restricts one from concluding that the results obtained are solely attributed to the effect of the Outreach Team. In this sense, the qualitative aspect of the study proved to be a strength because it enabled the subjects to provide the researcher with rationale for their ratings. Additionally, it must be kept in mind that the design of the study was not experimental and thus the aim was to explore and not to identify relationships.

The initial fear of limitations resulting from the researcher being a member of the Outreach Team turned out to be unfounded. This can be seen from the fact that the participants provided a considerable amount of criticism during the data collection. It seems as if this potential limitation was in fact a strength, as it is felt that the researcher was able to offer possible explanations in the context of the results obtained. This would have been a difficult task for a researcher who did not have a substantial amount of knowledge about the mode of operation of the Outreach Team. However, one cannot exclude the possibility that some participants could have been uncomfortable with the fact that the researcher was a member of the Outreach Team.
The use of CUES as a guide to the interviews was probably the force behind the wealth of information obtained. It is acknowledged that collecting data by means of an interview served the purpose of the study as it allowed the researcher to clear any difficulties and enable the participants to express themselves freely. Furthermore, some of the individuals who were randomly selected to participate in the study were known to have literacy problems as well as impaired cognitive skills. Alternative data collection techniques, such as focus groups or questionnaires, would have placed undue pressure on these individuals. One limitation that was encountered during the use of CUES was caused by the fact that the qualitative questions related to each QoL area, prompted the participants to discuss any further problems in that particular area. This led to a lack of qualitative data as regards the positive aspects in the QoL of these individuals. The final free text question at the end of the interview was the only one of its type, in that it simply asked the participants if they had other issues that they would like to discuss. However, by then, the tone of the interview had been set and the participants continued to discuss their problematic areas only.

A possible limitation associated with the data collection process was the short period (2 months) between the two interviews. In view of the knowledge that the effect of community psychiatric interventions tends to be slow and gradual, it is felt that 2 months were not enough to capture true changes. However, time constraints imposed by the academic process made any extension of the intervening period between T\(_1\) and T\(_2\) impractical.

The sample of the study is considered as having been of good quality. The strengths lie in the fact that each gender was equally represented, the age of the participants was
widespread (from 29-62 years) and the participants came from different Maltese regions. These factors are felt to render the sample to be quite representative of the whole population. Consequently, this contributes to the generalisibility of the findings.

Sample limitations lie in the knowledge that the participants were characterised by several other variables which could have an impact on the findings. Some of these factors include psychiatric diagnosis, level of non-professional support e.g. by relatives and duration of life in the community (since the last hospital admission). Furthermore, the duration of Outreach support for each participant varied considerably, with 4 of the participants having been receiving support for less than 1 year, while 11 respondents being supported for longer than 2 years. This variable could have affected the reported perception of the individual as regards the QoL in the community.

Criticism may centre around the small sample size of the study. This is acknowledged as a limitation which was mainly influenced by lack of time required to recruit and study a larger sample. Nevertheless, the total population size of psychiatric patient living in the community and being supported by the Outreach Team is relatively small (60 patients). Thus, the the sample chosen in the current study forms one-third of the total population and thus it is thought that the results do have a degree of generalisibility (Sandelowski, 1995).

The process of data analysis is regarded as having been carried out in an effective and thorough manner. The fact that the researcher had limited experience in transcription and coding of qualitative data was considered a limitation. In order to control this challenge, concurrent analysis of the data was carried out by an independent practitioner, so as to confirm the themes identified. This process introduced the
additional strength of limiting the possibility of subjective interpretations, which can lead to biased results (Polit et al., 2001).

6.3 Recommendations

6.3.1 Recommendations for Clinical Practice

1. The findings, especially those of a qualitative nature, demonstrate how allowing the patients to express themselves yields copious amounts of information. This process is important both for research purposes and especially for clinical practice. While traditionally, the health care professional might have been portrayed as the leader and the expert, nowadays the trend is moving towards forming a partnership with the patient. Barker (2000) emphasized building a therapeutic relationship with the patient, where the power is shared and thus, the patient and the carer are equal partners united by having one common goal. This will enable the formation of personally-appropriate care plans. The study therefore recommends changes in the way that care planning is developed and implemented with more emphasis placed upon the partnership between the patient and the carer.

2. The findings of the study show that the participants have a lack of education as regards particular QoL areas. It is recommended that community services seek to include the aspect of education within care plans. It is suggested that education is continuous and provided verbally, practically and in a written form.
3. The study revealed that social networking and daily activities are two of the challenges in the life of the psychiatric patient in the community. The availability of further community services like day centers may be one way to address the challenge. Currently, there are two Maltese day centers, which are specifically targeted for mental health users - the availability of a day center in every town is recommended. An additional intervention might be the introduction of a peer-buddy system. The Buddy System involves individuals within the community, who may be other mental health service-users. The ‘buddy’ would assume the role of a friend to the individual and would be active in supporting the individual and assist in accessing community-based activities.

4. Some of the participants commented about the fact that the Outreach Team service is not available outside office hours. Therefore, there is the need for a 24-hour help-line in order to provide a means of direct help at any time. Moreover, another community team such as a Crisis Intervention Team could help to bridge the Outreach Team services outside office hours.

5. Another recommendation is the use of a QoL tool such as CUES in order to carry out regular outcome measures. This involves a systematic method of assessing the extent to which the team has achieved its intended objectives. Areas that require improvement will be identified with the aim of enhancing the performance of the Outreach Team.
6.3.2 Recommendations for Future Research

1. It would be useful to carry out a study, which compares a group of individuals receiving Outreach support to a control group. This can provide further information about the effect of the Outreach Team.

2. It is recommended that a needs-assessment analysis is undertaken in order to further explore the needs of the patients from community services.

3. A qualitative study including a larger sample of patients might help to ascribe more meaning to QoL issues and the way that they are being helped to address challenging issues.

4. A longitudinal study over a longer time span may be more useful in identifying changes in perceptions after several months of Outreach support.

5. A study comparing the perceptions of the patients to those of their professional carers might be of great value, considering that these two entities have to work together in a therapeutic relationship in order to reach a common goal. Collecting this type of data might offer a better view of the situation and identify means for improving the QoL.
References


http://socialwelfare.berkeley.edu/faculty/segal/Community%20Membership%20and%20Social%20Networks%20PRJ%2027%20Hardiman%20Segal%20Article.pdf


Appendices
Operational Definitions

Quality of Life (QoL)

It is the individual’s perception of his/her position in life within the cultural context and value system s/he lives in, and in relation to his/her goals, expectations, parameters and social relations (Kuyken, Orley & Power, 1995).

Outreach

It is a system of care aimed at maintaining contact and continuity of care in the patient’s home (Hassiotis, Tyrer & Oliver, 2003).

Tidal Model

A model developed for psychiatric nursing which seeks to reveal the meaning of peoples’ experiences and them to reclaim control of their life (Barker, 2000).

Carers’ and Users’ Expectations of Services (CUES) questionnaire

A questionnaire developed to evaluate the perception of psychiatric patients and their carers of their QoL in relation to the community services that they are receiving (Lelliot, Beevor, Hogman, Lathlean & Ward, 2001, 2003).

In-patient psychiatric care

It is the care for a patient who is formally admitted to a psychiatric institution for treatment and/or care (OECD Health Data, 2001).
Community Psychiatric Nurse

A speciality within nursing that targets the psychiatric community setting so as to provide care for people with mental health problems (Wallace, 2005).
Ethics Board Permission- University of Malta

To be completed by Faculty Research Ethics Committee
We have examined the above proposal and advise
Acceptance Refusal Conditional acceptance

For the following reason/s:

Signature Date 12/03/07

To be completed by University Research Ethics Committee
We have examined the above proposal and grant
Acceptance Refusal Conditional acceptance

For the following reason/s:

Signature Date 6/7/07

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1. Where you live

The place you live in should meet your individual needs. You should not have to worry about having to move out, and it should not be too out-of-the-way. You should be able to come and go when you want, be alone when you want and not be harassed by the people you live with, by staff or by neighbours.

a). How does the place you live in compare with this description?
   - As good as this
   - Worse than this
   - Very much worse than this

b). Are you satisfied with the place you live in?
   - Yes
   - Unsure
   - No

c). What would you most like to change about where you live?

2. Money

You should have enough money to pay bills, stay out of debt and not miss meals. You should not have to feel isolated or cut off from society because of lack of money.

a). How does your money situation compare with this description?
   - As good as this
   - Worse than this
   - Very much worse than this

b). Do you have enough money to meet your needs?
   - Yes
   - Unsure
   - No

c). What are your most serious money problems?

3. Help with finances

Many people find that they need help with claiming benefits, filling in forms and working out how to manage their money. You should get as much help as you need to do these things.

a). How does the help you get compare with this description?
   - As good as this
• Worse than this
• Very much worse than this

b). Are you satisfied with the level of help you get with your finances?

• Yes
• Unsure
• No

c). What aspects of your finances would you most like help with?

4. How you spend your day

You should have the opportunity to spend your day in some form of regular and meaningful activity. This could be working, studying, training or going to a day centre or day hospital.

a). How does the way you spend your day compare with this description?

• As good as this
• Worse than this
• Very much worse than this

b). Are you satisfied with the way you spend your day?

• Yes
• Unsure
• No

c). What would you most like to change about how you spend your day?

5. Family and friends

Mental illness can affect a person's relationships with the people that he or she cares most about. You should be able to maintain good relationships with the people closest to you.

a). How do your relationships compare with this description?

• As good as this
• Worse than this
• Very much worse than this

b). Are you satisfied with your relationships with the people closest to you?

• Yes
• Unsure
• No

c). What would you most like to change about your relationships?
6. Social life

You should have the opportunity to mix with people and form new friendships and relationships. To make this possible, you should have enough money, access to transport if you need it and the use of a telephone.

a). How does your social life compare with this description?

- As good as this
- Worse than this
- Very much worse than this

b). Are you satisfied with your social life?

- Yes
- Unsure
- No

c). What would you most like to change about your social life?

7. Information and advice

You should be given as much information as you want or need about the services and treatments available to you, about the Mental Health Act and how it works and about the mental health system generally. Some people find it helpful to have someone like them (such as another service user or a member of the same community) to explain things to them. The information you are given should be clear and easy to understand, and should be available as and when you need it.

a). How does the information and advice you get compare with this description?

- As good as this
- Worse than this
- Very much worse than this

b). Are you satisfied with the information and advice you get?

- Yes
- Unsure
- No

c). What issues would you more information and advice about?

8. Access to mental health services

You should be able to get help from your local mental health when you need it, throughout the week, at any time of the day or night.

a). How does your ability to get help from local mental health services compare with this description?
Appendix C

9. Choice of mental health services

A range of services should be available to you, and you should be able to choose those that closely match your needs, including complementary/alternative therapies, counselling and psychotherapy. You should have a choice about the mental health workers you meet with regularly (for example, being able to choose their gender or ethnic background) and be able to change workers if you do not get on.

a). How does the range of choice you have compare with this description?

- As good as this
- Worse than this
- Very much worse than this

b). Are you satisfied with the range of choice you have?

- Yes
- Unsure
- No

c). What are your main concerns about the choice of mental health services available to you?

10. Relationships with mental health workers

Doctors, nurses, social workers and other mental health workers should show you respect, be honest with you and discuss things with you in a way in which you can understand. They should keep information about you confidential or ask your permission before passing it on to others. If they pass on information, it should be accurate and save you from having to repeat yourself to new mental health workers.

a). How does your situation compare with this description?

- As good as this
- Worse than this
- Very much worse than this

b). Are you satisfied with your relationships with mental health workers?
c). What would you most like to change about your relationships with mental health workers?

11. Consultation and control

Mental health workers should not pressurise you to do anything that you do not want to, or take decisions on your behalf without getting your permission first. Even if you have been 'sectioned', people should show you respect, listen to you and take your opinions seriously.

a). How does your situation compare with this description?

- As good as this
- Worse than this
- Very much worse than this

b). Are you satisfied with the level of consultation and control you have?

- Yes
- Unsure
- No

c). What would you most like to change?

12. Advocacy

You should be able to put your views across to people in authority. This can be difficult for several reasons, such as the effects of medication, if English is not your first language or if the situation is frightening or intimidating. If you want, you should have somebody (an advocate) to help or support you, or speak for you. You should feel that this person really understands what you want and genuinely represents your views when he/she speaks on your behalf.

a). How do your circumstances compare with this description?

- As good as this
- Worse than this
- Very much worse than this

b). Are you satisfied with the help you get in dealing with difficult situations?

- Yes
- Unsure
- No

c). What situations do you most want help with?
13. Stigma and discrimination

You should feel safe and other people should not harass, exploit, victimise or be violent towards you. You should not experience stigma or discrimination at home, at work or from mental health workers, police or any other section of the community. People should not discriminate against you because of race, culture, religion, gender and sexual orientation, physical or mental disability or for any other reason.

a). How do people treat you compared with this description?

- As good as this
- Worse than this
- Very much worse than this

b). Are you satisfied with the way other people treat you?

- Yes
- Unsure
- No

c). What situation would you most like to change?

14. Your medication/drug treatment

Medication should be given only to relieve the symptoms of mental ill health and to reduce your distress. All medication can have unwanted effects, but these should not cause more disruption to your life than improvement.

a). How does your medication compare with this description?

- As good as this
- Worse than this
- Very much worse than this

b). Are you satisfied with your current medication?

- Yes
- Unsure
- No

c). What would you most like to change about your medication/drug treatment?

15. Access to physical health services

You should be able to get the treatment and care that you need for your physical health when you need it, whether you are in hospital or living at home. You should be able to be registered with a general practitioner and have regular check-ups from a dentist. You should have access to other types of care, such as opticians, chiropodists, physiotherapists and so on.

a). How does your physical health care compare with this description?

- As good as this
• Worse than this
• Very much worse than this

b). Are you satisfied with your access to these services?

• Yes
• Unsure
• No

c). What type of health care do you have problems getting?

16. Relationships with physical health workers

The people who give you physical health care should listen to you, show you respect and take your condition seriously.

a). How does your situation compare with this description?

• As good as this
• Worse than this
• Very much worse than this

b). Are you satisfied with your access to these services?

• Yes
• Unsure
• No

c). What would you most like to change about your relationships with physical health workers?

Other issues

There may be other issues that are important to you, in addition to those that the questionnaire has already asked about. Please use the space below to write down anything else that is important to you that you would like help with or that you would like to change.
Appendix C

CUES-U Maltese Version

1. Il-Post fejn Toqghod


b) Il-post li toqghod fih jaqbel ma’ din id-deskrizzjoni?

• Il-post tajjeb daqs din id-deskrizzjoni
• Il-post aghar minn din id-deskrizzjoni
• Il-post aghar hafna minn din id-deskrizzjoni

c) Inti sodisfatt bil-post li qed tghix fih?

• Iva
• Miniex ċert
• Le

d) X’ tixtieq tbiddel l-aktar fil-post li tghix fih?

2. Flus

Inti ghandek flus biżżejjed biex thallas il-kontijiet, ma jkollokx dejn u ma toqghodx lura mill-ikel minhabba nuqqas ta’ flus. Ma thossokx isolat u maqtugh mis-socjeta minhabba nuqqas ta’ flus.

a) Is-sitwazzjoni finanzjarja tieghek taqbel ma’ din id-deskrizzjoni?

• Tajba daqs din id-deskrizzjoni
• Aghar minn din id-deskrizzjoni
• Hafna aghar minn din id-deskrizzjoni

b) Ghandek biżżejjed flus ghall-bżonnijiet tieghek?

• Iva
• Miniex ċert
• Le

c) X’ inhuma l-akbar problemi li ghandek bil-flus?

3. Ghajnuna fil-Finanzi

Hafna nies ikollhom bżonn ghajnuna biex iqassmu il-flus taghhom, hekk kif ukoll biex jakkwistaw beneficiċji u jilmew formoli. Inti issib ghajnuna biżżejjed biex taghmel dawn l-affarijiet.

a) L- ghajnuna li tinghata lilek taqbel ma’ din id-deskrizzjoni?
Appendix C

• Tajba daqs din id-deskrizzjoni
• Aghar minn din id-deskrizzjoni
• Hafna aghar minn din id-deskrizzjoni

b) Inti sodisfatt bil-livell ta' ghajnuna li qed tinghata biex tigi meghjun fl-aspett finanzjarju?

• Iva
• Miniex ċert
• Le

c) F' liema aspetti finanzjarji ghandek bzonn l-iktar ghajnuna?

4. Kif tqatta' il-ġurnata tieghek

Ghandu jkollok l-opportunita li timla l-ġurnata tieghek b' attivitajiet regolari u ta’ valur. Dawn l-attivitajiet jistghu jikkonsistu f'xoghol, studju, mawra f' xi day centre jew mawra l-isptar matul il-ġurnata.

a) Il-mod kif inti tqatta il-ġurnata tieghek jaqbel ma’ din id-deskrizzjoni?

• Tajjeb daqs din id-deskrizzjoni
• Aghar minn din id-deskrizzjoni
• Hafna aghar minn din id-deskrizzjoni

b) Inti sodisfatt bil-mod kif tqatta' il-ġurnata tieghek?

• Iva
• Miniex ċert
• Le

c) X’ tixtieq li tbiddell-aktar fil-mod kif inti tqatta' il-ġurnata tieghek?

5. Familja u Hbieb


a) Ir-relazzjonijiet tieghek jaqbel ma’ din id-deskrizzjoni?

• Tajbin daqs din id-deskrizzjoni
• Aghar minn din id-deskrizzjoni
• Hafna aghar minn din id-deskrizzjoni

b) Inti sodisfatt bir-relazzjonijiet tieghek man-nies li huma ghezież ghalik?

• Iva
• Miniex ċert
6. Il-Hajja Soċjali


d) Il-hajja soċjali tieghek taqbel ma' din id-deskrizzjoni?
   - Tajba daqs din id-deskrizzjoni
   - Aghar minn din id-deskrizzjoni
   - Hafna aghar minn din id-deskrizzjoni

e) Inti sodisfatt bil-hajja soċjali tieghek?
   - Iva
   - Miniex ċert
   - Le

f) X’ tixtieq li tbiddel l-aktar fil-hajja soċjali tieghek?

7. Informazzjoni u pariri

Inti ghandek tinghata biżżejjed informazzjoni fuq servizzi u trattamenti li jista’ jkollok aċċess għalihom, fuq il-Mental Health Act u l-mod kif tħadem u fuq is sistema tas-sahha mentali. Xi nies isibuhu ta’ ghajnuna li jkollhom xi hadd bħalhom (ezempju xi hadd li juża wkoll is-servizzi mentali jew membru ta’ l-istess komunita) li jispjegalhom l-affarijiet. L-informazzjoni li tinghata ghandha tkun faci biex tiftiehem u ghandu jkollok aċċess għal din l-informazzjoni meta jkollok bżonnha.

a) L-informazzjoni u l-pariri li jinghataw lilek jaqblu ma’ din id-deskrizzjoni?
   - Tajbin daqs din id-deskrizzjoni
   - Aghar minn din id deskrizzjoni
   - Hafna aghar minn din id-deskrizzjoni

b) Inti sodisfatt bl-informazzjoni u l-pariri li qed tirċievi?
   - Iva
   - Miniex ċert
   - Le

c) Liema huma l-affarijiet li tixtieq iltkar informazzjoni jew pariri fughom?

8. Aċċess għas-Servizzi tas-Sahha Mentali

Ghandek tkun tista ġġib ghajnuna mis-servizzi tas-sahha mentali, kull meta jkollok bżonn, matul il-ġimgha, f’ kull hin, kemm fil-ghodu u kemm matul il-lejl.
Appendix C

a) Il-mod li inti jirnexxien ikkigib ghajnuna mis-servizzi tas-sahha mentali, jaqbel ma' din id-deskrizzjoni?
   - Tajjeb daqs din id-deskrizzjoni
   - Aghar minn din id-deskrizzjoni
   - Hafna aghar minn din id-deskrizzjoni

b) Inti sodisfatt bil-mod li tista' ikkigib l-ghajnuna jekk ikollok bżonn?
   - Iva
   - Miniex cert
   - Le

c) X' diffikultajiet tiltaqa' maghhom biex ikkigib l-ghajnuna mis-servizzi, meta jkollok bżonn?

9. Ghażla ta' Servizzi tas-Sahha Mentali


a) L-ghazla li ghandek inti ghas-servizzi tas-sahha mentali, taqbel ma' din id-deskrizzjoni?
   - Tajba daqs din id-deskrizzjoni
   - Aghar minn din id-deskrizzjoni
   - Hafna aghar minn din id-deskrizzjoni

b) Inti sodisfatt bl-ghazla ta' servizzi li ghandek?
   - Iva
   - Miniex cert
   - Le

c) X' jinkwietak l-aktar fuq l-ghazla ta' servizzi tas-sahha mentali li jista' jkollok aċċess ghalihom?

10. Relazzjonijiet mal-haddiema tas-sahha mentali

Tobba, nurses, social workers u haddiema ohra li jahdu fis-settur tas-sahha mentali ghandhom juruk rispett, ikunu onesti mieghek u jiddiskutu mieghek b'mod li inti tifimhom. Dawn il-haddiema huma ta min jafdhom u huma jaghmlu dak li jkunu qalu li ha jaghmlu. Ghandhom ituk appuntamenti, u jzommuhom minghajr ma jhalluk tistenna. L- informazzjoni li ghandhom fuqek tinżamm kunfidenzjali u huma jitolbu il-permess tieghek qabel ma jghadduha lil persuni ohra. Jekk informazzjoni fuqek tinghata lil
persuni ohra, din tinghata b’ mod prećiż u minghajr il-bżonn li inti toqghod tirripeti ruħek meta titaqa ma’ haddiema godda.

a) Is-sitwazzjoni tieghek taqbel ma’ din id-deskrizzjoni?
   - Tajba daqs din id-deskrizzjoni
   - Aghar minn din id-deskrizzjoni
   - Hafna aghar minn din id-deskrizzjoni

b) Inti sodisfatt bir-relazzjoni li ghandek mal-haddiema tas-sahha mentali?
   - Iva
   - Miniex ċert
   - Le

c) X’ tixtieq tbiddel l-aktar fir-relazzjoni li ghandek mal-haddiema tas-sahha mentali?

11. Konsultazzjoni u Kontroll

Il-haddiema tas-sahha mentali ma jridux jisfurzawk biex taqghem xi haġa li ma tixtieqx taqghem jew jieħdu decożjonijiet ghalik minghajr ma tiġi kkonsultat. In-nies ghandhom jisimghuk u jieħdu l-opinjonijiet tieghek bis-serjeta, anke jekk xi darba ġejt miżmum fl-isptar psikjatriku.

a) Is-sitwazzjoni tieghek taqbel ma’ din id-deskrizzjoni?
   - Tajba daqs din id-deskrizzjoni
   - Aghar minn din id-deskrizzjoni
   - Hafna aghar minn din id-deskrizzjoni

b) Inti sodisfatt bil-livell ta’ kosultazzjoni u kontroll li ghandek?
   - Iva
   - Miniex ċert
   - Le

c) X’ tixtieq li tbiddel l-aktar?

12. Rapreżentanza


a) Iċ-ċirkostanzi tieghek jaqblu ma’ din id-deskrizzjoni?
   - Tajbin daqs din id-deskrizzjoni
   - Aghar minn din id-deskrizzjoni
   - Hafna aghar minn din id-deskrizzjoni
b) Inti sodisfatt bl-ghajnuna li qed tiehu meta tkun f’ sitwazzjonijiet diffiċli?

- Iva
- Ministria ċert
- Le

c) Liema huma is-sitwazzjonijiet li thoss li ghandek l-iktar bżonn ta’ ghajnuna fihom?

13. Stigma u diskriminazzjoni


a) Il-mod kif int tiġi trattat jaqbel ma’ din id-deskrizzjoni?

- Tajjeb daqs din id-deskrizzjoni
- Aghar minn din id-deskrizzjoni
- Hafna aghar minn din id-deskrizzjoni

b) Inti sodisfatt bil-mod kif jitrattawk in-nies?

- Iva
- Ministria ċert
- Le

c) Liema sitwazzjoni tixtieq li tbiddell l-aktar?

14. Mediċini

Inti ghandek tinghata mediċini biss biex ittaffi is-sintomi tal-marda mentali tieghek u biex tnaqqas it-tbatija tieghek. Kull mediċina jista’ jkollha effetti mux mixtieqa pero il-mediċini li qed tiehu ghandhom iktar itejbulek hajtek milli joholqulek problemi b’ dawn l-effetti mux mixtieqa li jista jkollhom.

a) Il-mediċina li qed tinghata taqbel ma’ din id-deskrizzjoni?

- Tajba daqs din id-deskrizzjoni
- Aghar minn din id-deskrizzjoni
- Hafna aghar minn din id-deskrizzjoni

b) Inti sodisfatt bil-mediċini li qed tieħu?

- Iva
- Ministria ċert
- Le
c) X’ tixtieq li tbiddel l-aktar fil-medicini li qed tiehu?

15. Aċċess ghas-servizzi tas-sahha Fiżika

Ghandek tkun tista ġġib trattament u kura ghas-sahha fiżika tieghek meta jkollog bżonn, kemm jekk inti tieghed l-isptar kif ukoll jekk tghix id-dar. Ghandu jkollok it-tabib privat tieghek (II-GP) u jkollok ukoll check-ups regolari minghand dentist. Ghandu jkollok aċċess ghal tipi ohra ta’ kura bhal optician, podologist, physiotherapist u servizzi ohra bhal dawn.

a) Is-servizzi ghas-sahha fiżika tieghek jaqblu ma’ din id-deskrizzjoni?
   • Tajbin daqs din id-deskrizzjoni
   • Aghar minn din id-deskrizzjoni
   • Hafna aghar minn din id-deskrizzjoni

b) Inti sodisfatt bl-aċċess li ghandek ghal dawn is-servizzi?
   • Iva
   • Miniex ċert
   • Le

c) Liema huma is-servizzi tas-sahha li jkollok problemi biex ikollok aċċess ghalihom?

16. Relazzjonijiet ma’ haddiema tas-sahha fiżika

In-nies li jaghtu kas is-sahha fiżika tieghek iridu jisimghuk, juruk rispett u jiehdu l-kondizzjoni tieghek bis-serjeta.

a) Is-sitwazzjoni tieghek taqbel ma’ din id-deskrizzjoni?
   • Tajba daqs din id-deskrizzjoni
   • Aghar minn din id-deskrizzjoni
   • Hafna aghar minn din id-deskrizzjoni

b) Inti sodisfatt bl-aċċess ghal dawn is-servizzi?
   • Iva
   • Miniex ċert
   • Le

c) X’ tixtieq li tbiddel l-aktar fir-relazzjoni li ghandek mal-haddiema li jiehdu hsieb is-sahha fiżika tieghek?

Affarijiet ohra

Permission to use CUES

Dear Mrs. George,

I am Paulann Spiteri, a Maltese psychiatric nurse working at the local psychiatric hospital. Currently, I am following a Masters course and the field I would like to explore by means of my dissertation, centers around the Quality of Life of Psychiatric patients living in the community. Since I form part of a psychiatric Outreach Team, I would also like to explore the effect that our service has on the Quality of Life of these patients. Thus, under the supervision of Mr. Martin Ward, whom I think you know, the title of the dissertation is: A study to explore patients' perception of their quality of life over time, while being supported by a psychiatric Outreach Team. The study sample will consist of 40 patients who are supported by the Outreach Team and data collection will take place over 2 times, using CUES as an interview tool. Several quality of life tools exist, however, on reviewing CUES-U, I consider it as being the most appropriate for the purpose of my research. Thus, I would please like to ask for permission to use CUES-U as a structured interview tool and also, to translate the tool to Maltese, since this would be easier to understand by the patients. Permission is needed since my university committee requires me to have permission for any tool that I use. I would be grateful if you could respond to this email address. I appreciate that I am using the tool in a way that was perhaps not originally intended but I feel that I am not deviating from the ethos it subscribes to. I look forward to hearing from you in due course.

Yours sincerely,
Paulann Spiteri

On 4/18/07, Emma George <egeorge@cru.rcpsych.ac.uk> wrote:

Dear Ms Spiteri,

I have spoken to Dr Lelliott and Maureen McGeorge who have said they are happy to give permission for you to translate CUES-U into Maltese. I would be grateful if you could send a copy of the translation for our records.

Best wishes

Emma
Patient Information Letter and Consent Form (English version)

Dear __________.

My name is Paulann Spiteri and I work as a nurse within the Outreach Team at ______. At the moment, I am following a Masters Degree in Health science (Nursing/Midwifery), and as part of this course, I am required to carry out a research study. My chosen study is: A study to explore patients’ perception of their quality of life over time while being supported by a psychiatric Outreach Team.

In order to collect information for the study, I will be carrying out 2 interviews for each person who will be participating in the study. The focus of the interview will be the experience of life in the community.

The interviews will take from 45-60 minutes and will be carried out at a place of the participants’ preference. I would like to record these interviews on a tape recorder, as well as write down notes during the interview. This will make it easier for me to gather information.

I would like to invite you to participate in my study. Your participation is voluntary and you are free to withdraw from the study at any time, without providing a reason. Withdrawing from the study will not have any effect on you or on the quality of care that you are given. No one but myself will have access to the information so that anything that is said during the interviews remains strictly confidential. Your identity
will not be available in the study report as pseudonyms will be used instead of names. After the study is completed, the audiotapes and notes will be destroyed.

Any queries regards the study can be discussed by contacting me at:

**Work tel.no.** 23304236

Thank you and regards,

Paulann Spiteri

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**Consent Form**

I have read and understood the information given to me about the research study. I hereby, give my consent for participation in the study.

Name: ______________________

Signature: _______________ Date: ___________________
Patient Information Letter and Consent Form (Maltese version)

Ghażiż/Ghażiża _______________.


Kull intervista ddum 45-60 minuta u ssir f 'post magħżul mill-partecipant. Hija ix-xewqa tieghi li nirrekordja l-intervisti fuq tape recorder hekk kif ukoll inniżżell xi noti. Dan jghinni biex niġbor l-informazzjoni.


Jekk ghandek xi mistoqsijiet dwar ir-ričerka tista tikkuntatjani:

**Numru tax-xoghol:** 23304236

Grazzi bil-quddiem,

Paulann Spiteri

\[------------------\]

Kunsens


Isem: ______________________

Firma: _____________________  Data: ______________