Psychosocial Impact of Stigma on Schizophrenic Clients and their Family Members

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Signature
III

الإهداء

إلى من علمتني النجاح والصبر
إلى من كلت آمالها لتقدم لنا لحظة سعادة
إلى من حصدت الأشواك عن دربي لتمهد لي طريق العلم
إلى القلب الكبير والدتي العزيزة

إلى روح والدي الطاهرة... دانما نذكرك فما زلت بيننا
إلى رفيق دربي وتوأم روحي إلى من ساندني بلا حدود... أنا معك أكو وايودنك
أنا مثل أي شيء

إلى القلوب الطاهرة الرقيقة والنفوس البريئة إلى رياحين حياتي
والد: دعا شهد محمد سناء ومصطفى

إلى كل من ساندني وساعدني وكانوا ولا زالوا بمدوني بالحب والخير، لهم مني كل
الحب والتقدير إكويتي وأهل زوجي الأعزاء
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Psychosocial impact of stigma on schizophrenic clients and their family members

Declaration

The work provided in this thesis, unless otherwise referenced, is the researcher's own work, and has not been submitted elsewhere for any other degree or qualification

Student's Name: 
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اسم الطالب: 
التوقيع: 
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Psychosocial Impact of Stigma on Schizophrenic Clients and their Family Members
Nida Jawabreh
Supervised by
Dr. Adnan Sarhan

Abstract

Introduction: Stigma acts as a barrier for schizophrenic clients and their family members. In fact, it prevents clients and family members from getting the help they need. To date, there are limited studies regarding the impact of stigma on the social life of the schizophrenic clients and their family members in Palestine. This study aims to investigate the extent of stigma on schizophrenic clients and their families, and to investigate the effect of stigma on the interviewees in accordance with their demographic variables.

Methods: By following a descriptive non-experimental design, mainly by using face to face structured interviews and a questionnaire methodology for quantitative part of the study, and narrative interviews for qualitative part. This study sample consists of 150 schizophrenic clients and 150 of their family members from the Northern cities of Nablus, Jenin and Tulkarm of the West Bank, Palestine.

Results: The quantitative results show that the most prevalent stigma among schizophrenia clients was moderate with a degree of 48% and the least prevalence was severe with a degree of 2%. There is no significant correlation between the extent of stigma and: education, and gender, but in relation with age and educational status we found that there is a significant
correlation. Also the prevalence of stigma among family members was found to be a round medium and low level with a degree of 21.3%, 40.6% respectively. Which revealed a normal distribution of family impact of stigma and come to the lower impact than their patients.

The qualitative results show that the impact of stigma centralized on: inadequate support, burden of caring, and knowledge deficit.

**Conclusion:** The study concluded that schizophrenic clients and their family members experience stigma in their life and this negatively affected their quality of life in different aspects. The findings show that caring for a client with schizophrenia is stressful for the family members so there is need for financial and social support and training programs for the family members.
Chapter One
Introduction
1.1 Introduction

1.1.1 Schizophrenia

Schizophrenia is a brain disorder which affects the way a person acts, thinks, and sees the world. People with schizophrenia have an altered perception of reality and often a significant loss of contact with reality (Smith & Segal 2012). Schizophrenia has a profound impact on clients, their family members and society (Chong et al 2004).

Schizophrenia is a complex mental illness which may prove to be devastating for those who have the illness and life-altering for their caregivers. Symptoms appear through various manners, but typically fall within a finite group consisting of positive symptoms like delusions, hallucinations, bizarre behavior, disorganized speech and “Negative Symptoms”. Negative symptoms consist of a decrease or deficit in cognitive functioning, overall motivation, as well as a lack of interest in personal hygiene and social interaction. Positive Symptoms are treatable whereas Negative Symptoms may prove to be more resistant to medications (Smith et al 2011).

Schizophrenia is a relatively common disorder, with a lifetime prevalence of about 1%. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR). Symptoms are typically identified in adolescence or young adulthood, significantly disturbing the educational, social and professional lives of those suffering from the disease (Kadri et al 2004).

The living conditions of schizophrenics do not solely depend on the severity of the illness, but also on the level of acceptance within their
communities. Schizophrenics face a considerable amount of stigma, which can limit their access to treatment and cause community exclusion (Buizza et al. 2007). Schizophrenics are branded with a mental illness stigma, a negative marking of undesirable characteristics, even a notion that the mentally ill deserve reproach due to their mental illness (Deckerson et al. 2002).

1.1.2 Stigma

Stigma has been defined as an identifying mark of shame or discreditation (Goffman 1963). Stigma has been defined in the literature as a prominent factor negatively affecting individuals with mental illness and their families (Lam et al. 2010).

The effects not only harm people with mental illness, including those with schizophrenia, but it may cause psychological harm to the family members who are associated and are acting as caregivers (Corregan & Miller, 2004). Families assume a major role in the lives of their mentally ill relatives, causing them to experience stigma from just their association with the mentally ill. (Larson et al 2008).

1.2 Aim of the study

This study aims to investigate the extent of stigma and its psychosocial impact on schizophrenic clients and their families.

1.3 Problem statement

Mental illness is a double-edged sword. On one hand the general distress and significantly lessened opportunities that accompanies mental illness may be a direct result of psychiatric symptoms and a deficit of social skills.
On the other hand, lessened opportunities and personal demoralization occur due to stigma itself (Corrigan & Wassel 2008). Schizophrenics is not only associated with the symptoms of the illness itself, but also it is accompanied with what is called “Second Illness”. This “Second Illness” is comprised of the social environment in relation to the stigma associated with the mental illness (Vauth et al 2007).

A problem statement of this study may note the need to know more about schizophrenic patients, their family members and caregivers, how they are affected by stigma, and how stigma affects their quality of life?

The research findings will help to address the problem of stigma and how patients and their family members can cope with it. Additionally, finding will also illustrate the role of community mental health centers assess in decreasing stigma.

1.4 Background of the study:

Many mentally ill people, including those with schizophrenia, are target groups for stigmas such as social stigma. Social stigma is a phenomenon which influences how we think about and behave towards people who are targets of stigma (Smith et al 2011). Those with mental illness are stigmatized by others, which results in a number of negative consequences such as increasing familial stress, reducing employability and income, and hindering the ability to live an independent life (Penn et al 2000).

The stigma attached to ‘mental illness’ can have a lasting impact on the person who is labeled with the stigma. Often this can result in low self-esteem, a diminished quality of life, impairments within social relationships
and early treatment discontinuation. Coping with the stigma through general avoidance and withdrawal is common, but may result in demoralization, social isolation and lost opportunities for education, employment and housing (Chung & Wong 2004).

Relatives of clients with schizophrenia are often unaware of the social construct of mental illness, and this is referred to lack of awareness or poor insight. One explanation is that the impact of the acceptance of schizophrenia depends on the meanings relatives attach to schizophrenia. For example, if one believes the illness means that he or she is not capable of achieving valued social roles, then awareness could lead to hopelessness and less motivation to persevere, and this support the stigma impacts on effect of insight on outcomes on the illness (Lysaker et al, 2007).

The public stigma of mental illness affects many people who are in contact with schizophrenic clients, such as family members and friends. It has been documented that family members of persons who have persistent mental illness must successfully cope with many problems in order to be good caregivers, and these problems faced by family members are closely connected to the fear of violent behavior from their schizophrenic relatives. Consequently, the family's attitudes toward their schizophrenic family member may have a significant impact on the patient's social adjustment and their achievement of affective goals (Hanzawa et al, 2010). Understanding how stigma affects schizophrenic clients and their families, as well as understanding how those patients and families cope with the mental illness itself, has an important role in decreasing such behaviors.
Moreover, the proposed findings will be of great significance for the strategic planning of the future of community mental health, as well as the Palestinian family and the individual.

1.5 Demography of the study:

The total Palestinian territory population is 2.58 million. The Palestinian population consists of 1.3 million males and 1.27 million females, with a sex ratio of 103.2 males per 100 females, according to the Palestinian Central Bureau of Statics (PCBS, 2011).

Nablus:

Nablus is Northern governance in the West Bank, located in a strategic position between Mount Ebal and Mount Gerizim, approximately 63 kilometer north of Jerusalem. Nablus has a population 348,020 according to the Palestinian Central Bureau of Static's (PCBS, 2011).

The number of schizophrenic outpatients who are referred to the community mental health center in Al-Makhfeya is 4,867 (2011) according to the local clinic’s census.

Jenin:

Jenin is Northern governance in the West Bank; it overlooks both the Jordan River Valley to the East and Palestinian Marj Ibn Amer to the North. Jenin has a population of 281,156 according to the Palestinian Central Bureau of Static's (PCBS, 2011).

The number of schizophrenic outpatients who are referred to the community mental health center is 3,060 (2011) according to the local clinic’s census.
Tulkarm:
Tulkarm is Northern governance in the West Bank; it's located in the Northern Samarian mountain range. Jenin has a population of 168,973 according to the Palestinian Central Bureau of Static's (PCBS, 2011). The number of schizophrenic outpatients who are refer to the community mental health center is 3,208 (2011) according to the local clinic’s census.

1.6 Study Questions:

- Do demographic variables affect the extent and degree of stigma for schizophrenic clients and their family members?
- Are there significant amount of stigma toward schizophrenic clients and their family members?
- Are there any psychosocial impact of stigma toward schizophrenic clients and family members?
Chapter Two

Literature Review
**Literature Review:**

**2.1 Introduction**

Many studies discussed the effect of schizophrenia on patients and their families. In this part we are proposing the main literature results relating to schizophrenia, stigma, and the impact of stigma for the schizophrenic clients and their family members.

**2.2 Epidemiology of schizophrenia**

Mcgrath & Susser (2009) conducted a study about the new directions of the epidemiology of schizophrenia; they found that the prevalence and incidence of schizophrenia showed prominent variation in the locations. Males are more likely to develop schizophrenia than females (4:1). Migrant status, urban birth or residence, and advanced paternal age are associated with an increased risk of developing schizophrenia. Also individuals with schizophrenia have a 2-3-fold increased mortality risk compared with the general population.

Messias et al (2007) discussed the prevalence of schizophrenia, they found that the range in prevalence is from 2.7/1000 to 8.3/1000.

Tandon et al (2008) founded that the risk of developing schizophrenia over one's lifetime averages 0.7%. Schizophrenia runs in families and there are significant differences in the incidence of the disease. Genetic factors and environmental interactions contribute to over 80% of the likelihood for developing the disease. The numbers of chromosomal regions and genes have been linked to the risk of developing the disease.
2.3 Psychosocial factors and schizophrenia

The definition of ‘psychosocial’ is ‘pertaining to the influence of social factors on an individual’s mind or behavior, and to the interrelation of behavioral and social factors (Oxford English Dictionary, 2013).

Kern et al (2009) discussed and reviewed the psychosocial treatments that enable schizophrenics to cope with the disabling aspects of their illness and achieve personal goals are a necessary complement. They found that psychosocial treatments for schizophrenia include social skill training, Cognitive Behavioral Therapy (CBT), cognitive remediation, and social cognition training, among others. These treatments are reviewed and discussed in terms of how they address key components of functional recovery, such as symptom stability, independent living, work functioning, and social functioning.

Pilling et al (2002) in a study regarding psychosocial treatment in schizophrenia, used social skills training and cognition remediation as psychosocial techniques for the treatment of negative symptoms of schizophrenia. The findings suggest no clear evidence for any benefits of social skills training on relapse rate, global adjustment, social functioning, quality of life or treatment compliance. Cognitive remediation had no benefit on attention, verbal memory, visual memory, planning, cognitive flexibility or mental state.

Felicia et al (2012) conducted a study in regards to the influence of demographic factors on Functional Capacity (FC) and every day functional outcomes in schizophrenia. The study examined the correlation of
demographic factors (race, age, and education) neuropsychological (NP) measures, the relative ability of FC performance, and demographic factors to predict real-world outcomes in social, vocational, and residential domains in 194 outpatients with schizophrenia. Age, education, sex, and racial status were reasonably associated with performance-based measures of everyday functioning, while in addition, age and education had a similar modest relationship with social competence. Age, but none of the other demographic variables, contributed to the prediction of all three domains of everyday functioning.

Another study concluded that perception of mental illness within cultural dynamics may affect the diagnosis, treatment, and reintegration of an individual with schizophrenia. As culture influences the ways individuals communicate and manifest symptoms of mental illness, style of coping, support system, and willingness to seek treatment may be affected as well (Versola-Russo, 2006).

2.4 Schizophrenia and the role of family

The family and its’ role can affect the attitude toward itself and the schizophrenic family member.

A study focused on the families living with severe mental illness found that schizophrenia is a stressful disease not only for those who directly suffer from it, but also for their family members. The researcher demonstrated that the families of those with severe mental illness are also suffering from significant stresses, while experiencing high levels of burden, and are often receiving inadequate assistance from mental health professionals. Effective
family functioning of schizophrenia may be influenced by a variety of psychosocial factors (Suanders 2003).

Rungreanqkulki et al (2002) conducted a study in Thailand; the aim of the study was to assess the impact of family factors on psychological morbidity of the mothers and relatives of a person with schizophrenia. Results suggest that in a stable stage of illness, other stresses of family life may have a stronger impact on the psychological status of family members, in comparison to the illness. The implications for clinical nurses and researchers are presented within the study as well.

Bustillo et al (2001) suggests that family therapy and assertive community treatment have clear effects on the prevention of psychotic relapse and re-hospitalization; long term psycho-educational family therapy should also be included in the treatment of the majority of persons suffering from schizophrenia.

2.5 Stigma

2.5.1 Definition

Stigma has been defined as a deep sense of worthlessness that demeans and diminishes those who experience it (Goffman, 1963). Different social groups have been and continue to be stigmatized due to race, sexual orientation, religion, and physical or mental illness (Munoz, et al 2011).

Stigma is associated with mental illness, especially with those suffering with schizophrenia, and seriously affects the lives of schizophrenics, their families, their friends and their communities. Stigma is considered to act as
an obstacle toward the mentally ill, especially schizophrenic outpatients, and severely affects the treatment of these patients (Fontain, 2009).

With references to a study carried out by Verhaeghe et al (2008) on peer support among clients and whether it could decrease negative links, outcomes of the study showed that stigma is negatively related to self-esteem, and peer support is positively related to stigma.

Macinnes & Lewis (2008) examined the impact of a six week group program designed to reduce self-stigma in a group of service users with serious and enduring mental problems. In addition to self-stigma, assessments for self-esteem, self-acceptance and psychological health measures were also undertaken. Researchers recorded a significant reduction in stigma and insignificant increase in self-esteem, self-acceptance and general psychological well-being.

Ohayon et al (2010) found that Self-stigma mediates rather than moderate the relationship between insight and burden. Accordingly, parents’ insight into the mental illness of their child appears to increase parent burden due to the increase of parent self-stigma.

Ritsher et al (2003) reported that the internalized stigma of mental illness had positive correlations with measures of stigma beliefs and depressive symptoms, and it had negative correlations with measures of self-esteem, empowerment and recovery orientation.

Dickerson et al (2002) found that clients were worried about being viewed unfavorably because of their mental disorder, and avoided telling others about it. Socioeconomic variables were related to the extent of stigma and
discrimination, but symptoms and social functioning were not measured. These results documented the extent to which persons with mental illness experience negative reactions from others.

Rush et al (2010) designed a study to investigate negative implicit attitudes toward mental illness and low implicit self-esteem using two brief Implicit Association Tests in 85 people with mental illness. Their findings suggest that self-stigma is a measurable construct and is associated with negative outcomes.

2.5.2 Stigma and Schizophrenia

One of the most important issues included with schizophrenia is stigma and its effect on quality of life of schizophrenic outpatients and their families. Kadri & Sartorius (2005) suggested that the stigma attached to mental illness is the greatest obstacle to the improvement of the lives of people with mental illness and their families. This stigma has effects which are true for all mental illnesses and in particular for schizophrenics. Such stigmas result in a lower priority for mental health services, difficulty achieving high quality of services, continual difficulties in finding employment and housing opportunities for people who have had an episode of mental illness, social isolation of people who suffer from mental illness and their families, and poor quality of care for physical illnesses occurring in people diagnosed as having had psychiatric illnesses. With reference to a study carried out by Shrivastava, et al. (2011) on the origin and impact of stigma and discrimination in schizophrenia patients
found that stigma and discrimination have a significant impact on the lives of patients.

Loganathan & Murthy (2008) assessed the experiences of stigma and discrimination among schizophrenic outpatients from rural and urban areas, using a semi-structured instrument. The results of the study showed a significant difference between rural and urban respondents.

Another cross-sectional study was conducted in twenty-seven countries, by the use of face-to-face interviews with 732 participants with schizophrenia. The researchers found negative discrimination was mostly experienced by participants in making or keeping friends, then from family members, in finding or keeping a job and in intimate or sexual relationship (Thorneycroft et al, 2009).

In one study, Sibitz et al (2011) found that stigma resistance is a new and promising concept. The development of stigma-resisting beliefs may help individuals in their hope of living a fulfilling life and in their recovery from mental illness.

Loch et al (2011) conducted a study to assess Brazilian psychiatrists’ attitudes toward patients with schizophrenia. 1,414 psychiatrists agreed to undergo the survey. Face–to–face interviews were conducted using a questionnaire that assessed stigma in three dimensions: stereotypes, social distance and prejudice toward a person with schizophrenia. Their opinion on psychotropic drugs and tolerance of side-effects were also assessed. The analysis of the data showed that the Brazilian psychiatrists tend to
negatively stereotype patients with schizophrenia. Older age was correlated with positive stereotyping and with less prejudice.

2.5.3 Stigma and family

Larson and Corregan (2008) had defined family stigma as the prejudice and discrimination experienced by individuals through associations with their relatives. Furthermore, it was found that many studies focused on stigma and discrimination toward people with schizophrenia and their family members. For instance, Gonzalez-Torres, et al. (2006) reported that patients and relatives describe a great variety of stigma and discrimination experiences in all areas of life, including health care.

In addition, Kadri, et al (2004) in their study conducted in Morocco explored whether family members of clients with schizophrenia are affected by stigma and whether areas of their lives are affected. They also intended to explore knowledge of the illness and their attitudes toward patients. They found that most families suffered from stigma and discrimination against schizophrenics.

According to Philips, et al. (2002) stigma had a moderate to severe affects on the lives of clients and their family members, and significantly greater if the respondent had a high level of expressed emotions.

Larson and Corregan (2008) describe family stigma which is experienced by family members and relatives of mentally ill patients and propose strategies to eliminate stigma.
Wong et al (2009) modified opinions on mental illness and he conducted interviews regarding families’ experiences. The results showed low levels of stigma as families endorsed many supportive initiatives. For example, patients should be encouraged to vote, they should be exposed to employment opportunities, and mental illness should be protected legally as a disability, including parity with in insurance coverage. Families also expressed that prayer and belief have a role in helping someone get better. Only ethnic minority families of individuals with recent onset psychosis endorsed a sense of shame and felt a need to conceal the patient's illness.

Parle (2012) explored the attitudes and beliefs of the general public toward people with mental illness, as well as the experiences and feelings of service users and their relatives. She found that despite national campaigns, there had not been a significant change in public awareness regarding mental illness. While a lot of research has been carried out to explore the public’s perception of mental illness, future research should examine the experiences of service users, their families, their careers and people they are close to in order to understand and measure the impact of stigma on their lives.

Ostman and Kjellin (2010) in their study aimed to investigate factors of psychosocial significance related to stigma of relatives. The results showed that the majority of relatives experienced psychosocial factors associated with stigma. 18% of relatives had, at times, thought that the patient would be better off dead, and 10% had experienced suicidal thoughts. Stigma by association was greater in relatives experiencing mental health problems of
their own, and was unaffected by patient background characteristics. They recommended that interventions are needed to reduce the negative effects of psychosocial factors related to stigma by association in relatives of people with mental illness.
Chapter Three
Methodology
Methodology of the study

3.1 Introduction
This chapter discusses the study design, sampling technique, and the tools used for the purpose of gathering data. Setting, inclusion, exclusion criteria, and other important titles clarifying its process are also included.

3.2 Study design
A quantitative descriptive non-experimental research design was implemented utilizing face-to-face structured interviews and questionnaire methodologies. Another part of the study was done using the narrative methodology.

Quantitative research based on traditional scientific methods, which generates numerical data and usually seeks to establish causal relationships between two or more variables, using statistical methods to test the strength and significance of the relationships (Dictionary of nursing 2008).

Narrative Inquiry emerged as a discipline within the broader field of qualitative research. It is an approach to understanding/researching the way people make meaning of their lives as narrative (Clandinin & Connelly 2000).

3.3 Study population and sample
3.3.1 Study Population
With reference to the Palestinian Ministry of Health, the population of the study consisted of 150 schizophrenic clients from the West Bank (Nablus, Jenin, Tulkarm) and 150 family members of these clients. The distribution of the schizophrenic clients was: 34 clients and 34 family members from
Tulkarm, 53 clients and 53 family members from Jenin and 63 clients and 63 family members from Nablus.

3.3.2 Sampling Technique

We took the convenient sample from the population of the study, all patients or their family members who agree to participate was taken, but it was limited number of patients to participate in our study in comparison with the number of schizophrenic clients, because the clients in our population and in other populations are difficult to be accessed and to accept participation in research due to the stigmatized effect of schizophrenia and they intended to hide themselves from social exposure. In spite the number of the total registries schizophrenia clients is large; like 3208 in Tulkarm, very few of them generally visiting the mental health clinics, also very few family members come to the mental health clinics to take their patients prescribed medications. For that we can see that very few clients refer to clinics like what seen in Tulkarm. This can be considered a clear evidence for the effect of mental illness stigmatization.

The study sample consisted of all schizophrenic clients and their families from the Northern West Bank cities’ mental health clinics, with an estimated sample size of 150 clients and 150 of their family members. Within the qualitative part of the study we used 20 participants. The qualitative part of the study used 20 narrators, 10 clients and 10 family members.
Table 3.1 Distribution of the sample according to the geographic area.

<table>
<thead>
<tr>
<th>Location</th>
<th>No. Clients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nablus</td>
<td>64 (43%)</td>
</tr>
<tr>
<td>Jenin</td>
<td>52 (34.6%)</td>
</tr>
<tr>
<td>Tulkarm</td>
<td>34 (22.4%)</td>
</tr>
<tr>
<td>Total</td>
<td>150 (100%)</td>
</tr>
</tbody>
</table>

3.4 Tools of the study

Quantitative part of the study consisted of a questionnaire which is consisting of two parts. The first part was the Inventory of Stigma Experiences which is composed of two scales: the Stigma Experience Scale for measuring the scope of stigma experienced (prevalence of stigma among clients and their family members) in different life domains (10 items), and the other Stigma Impact Scale assessing psychosocial impact (7 items) from Stuart, Milev and Koller (2005). The family version consists of declining 7 questions. The responses range from never, rarely, sometimes, often and always. These responses were converted into binary responses (yes, no), which was implemented by the original author. The internal consistency of these 7 scale questions was found by Cronbach alpha to be (0.76) which is considered to be a good internal consistency.

The second part was a narrative qualitative methodology using face-to-face interviews.

The questionnaire consisted of three parts:

1- Schizophrenic clients' and their family members related demographic variables (quantitative part).

2- Stigma prevalence among schizophrenic clients and their family members (quantitative part).
3- Stigma impact items in relation to schizophrenic clients and their family members (qualitative part).

Internalized Stigma of Mental Illness Inventory (ISMI) was used to explore the effect of stigma on schizophrenic clients (see Appendix 4).

Familial experience with Stigma of Mental Illness Scale was used to explore the effect of stigma on family members (see Appendix 5).

The essential personal information about participants was taken from mental health centers. The necessary modifications to the questionnaire were done to be applicable for the study. The questionnaire includes two sections. The first section was for the client and the second section was for family members.

3.5 Study Setting

The study participants were picked from the files of the Mental Health Clinics. Interviews were conducted in the clients’ homes.

3.6 Selection criteria

3.6.1 Inclusion criteria

Schizophrenic outpatient clients and their family members were from the Northern area of the West Bank.

The inclusion criteria included:

- Clients diagnosed with schizophrenia from the Northern area of the West Bank.

Clients who were diagnosed more than six months according to Diagnostic Statistical Manual of Mental Health (DSM-IV), prior to the start of the study, were competent, and could tolerate an interview
- Male and female clients
- Competent family members of the schizophrenic clients

3.6.2 Exclusion criteria
- Incompetent clients
- Clients not diagnosed as complaining of schizophrenia.

3.7 Data collection process
Data collection began on October 1, 2011. Two months prior to the data collection, certain initiatives, such as an agreement with the Ministry of Health, took place as preparation for the study. The data was collected via specific related schizophrenic clinical interviews and through a questionnaire methodology. Face-to-face interviews were conducted in clients’ homes and community mental health centers. The interview took approximately forty-five minutes with the patients and their family members. After determining the study population, study sample, and the development of data collection tools, the researcher personally approached each and every client and their family for the purpose of data collection. Face-to-face structured interviews were conducted with each schizophrenic client and their family member. In the description of the study, the researcher explained the importance to the participants. Then, the data was filled-in using a questionnaire reported in their native language (Arabic).

3.8 Data analysis
Statistical Package of Social Sciences (SPSS) Version 19 is a computer based software statistics program, which was used for analyzing
quantitative data; mainly for the calculation of frequencies, means, standard deviations, percentages, and all needed inferential statistics. Also, thematic narrative analysis was used to analyze the qualitative part of the study.

3.9 Pilot study

The pilot study was conducted to evaluate and test the suitability of the questionnaire for the Arab population. The questionnaire was translated to Arabic and was distributed to professions for their opinions. Some questions were modified according to their advice in order to be best understood by the respondents. It was carried out of 18 participants from the clients and family members of schizophrenic clients at the Al-Makhfya community mental health center. The agreement for the pilot study interviews was made available during the time at which the researcher interviewed the participants. It appeared that the participants had no difficulties in understanding the items of the questionnaire. This pilot study was done by the researcher, and it's not included in the study sample.

3.10 Ethical considerations

Permission to conduct the study was given from the Ministry of Health and Institutional Review Board (IRB) of An-Najah National University. A consent form was prepared at the first page of the questionnaire and the participants read the consent before the interview. They were informed that their participation was voluntary. The aim of the study was explained by the researcher and participants verbally agreed to cooperate before the interview began. A verbal agreement was taken versus a written agreement due to issues of suspiciousness of some clients. All applicable information could be found in the questionnaire. Participants were dealt with in a
professional and confidential manner. In addition, the researcher informed the participants that the information would be used for the purpose of study.

3.11 Reliability and validity of the study

The study tool used is a questionnaire from previous study entitled “The inventory of stigmatizing experience: its development and reliability” from (Stuart et al 2005). The Cronbach alpha reliability coefficient was found to be 0.83 in their study.

In the Stigma Experience Scales, the researcher used the Kuder–Richardson coefficient of reliability to measure the internal consistency of the scale scores when the data is binary. Spearman’s rank order correlation was used to assess the association between the two scales. A statistically significant but moderately low correlation of 0.66 (p = 0.001) indicated that the two scales share some common variance, but measure somewhat different constructs.

Both reliability and validity are inherent characteristics of a scale. They vary with the purpose for which it is used, the characteristics of the individuals being assessed, and the environmental context in which the assessment takes place.

The content of the questions clarify to address the most remarkable features of the respondents stigma experiences and the constructs appeared to map well onto those drawn in the theoretical literature.

In addition, the scale scores assumed good internal consistency. Finally, the Stigma Impact Scales demonstrated a factor structure consistent with a
single underlying construct. All the results suggest that in our application, these scales yielded reliable and valid data.

3.12 Limitation of the study

The researcher met many obstacles during the study:

- Many clients and family members refused to participate or to answer the questionnaire and some of them had difficulty in understanding the items due to their mental illness.
- Finding suitable scales for the study.
- This study was personally financed.
Chapter Four
Results
4.1 Introduction

The purpose of this study was to investigate the extent of stigma and its psychosocial impact on schizophrenic clients and their families. Moreover, this chapter analyzes the relationship between study variables (gender, age, residence, history of illness, etc.) and psychosocial impacts of stigma on schizophrenic clients and their families.

Results of Quantitative data:

4.2 Results of demographic data

4.2.1 Distribution of demographic variables for clients

The demographic variables were distributed as:

- Age, employment status, gender, educational background, and living situation.
  The most prevalent age group affected was 40-49 year olds with a degree of 30%. And the least prevalent was 60-69 year olds with a degree of 7.3%.

The gender of the clients was included and consisted of not equal number of both males and females; males: 53.3%, females: 46.7%.

Regarding the employment status: The affected schizophrenic clients were assessed on their employment status and results revealed that about 74.7% of them were not employed and the remaining 25.3% were employed.

In analyzing their education levels, the most (43.3%) were educated at the primary level or less, compared with high rate (16.7%) of those who achieved the university level.
The living situation was assessed to find that 49.3% living with parents and the least 5.3% were living alone.

4.2.2 Distribution of demographic variables of the family members

The demographic variables for family members were distributed as:

- Age, gender, age of the client in the beginning of the treatment, highest education, living situation, and employment status.

The most prevalent age group was 60-69 year olds with a degree of 29% and the least prevalent age group was 19-29 years old with a degree of 14.7%.

The gender of the family member was assessed and we saw that most were females with a degree of 72.7% and the males had a degree of 27.3%.

The most prevalent age of clients in the beginning of treatment was 19-29 with a degree of 64.0% and the least prevalent age of the client in the beginning of the treatment was 30-39 with a degree of 6.7%.

Their educational status was assessed there and we saw that most (42.7%) achieved primary education or less, compared with the 6.7% who obtained collage or technical training.

The living situation for the family member was also take into consideration. 59.3% lived with their spouse and at least 13.3% were living with others.

70.0% were unemployed and the remaining 30.0% were employed.
Table 4-1: Distribution of the sample according to the demographic variables of the clients & family members.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
<th>Variable</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in years</strong></td>
<td></td>
<td></td>
<td><strong>Age in years</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19-29</td>
<td>22</td>
<td>(14.7)</td>
<td>19-29</td>
<td>19</td>
<td>(12.7)</td>
</tr>
<tr>
<td>30-39</td>
<td>29</td>
<td>(19.3)</td>
<td>30-39</td>
<td>35</td>
<td>(23.3)</td>
</tr>
<tr>
<td>40-49</td>
<td>33</td>
<td>(22)</td>
<td>40-49</td>
<td>45</td>
<td>(30)</td>
</tr>
<tr>
<td>50-59</td>
<td>37</td>
<td>(24.7)</td>
<td>50-59</td>
<td>40</td>
<td>(26.7)</td>
</tr>
<tr>
<td>60-69</td>
<td>29</td>
<td>(19)</td>
<td>60-69</td>
<td>11</td>
<td>(7.3)</td>
</tr>
<tr>
<td>Total</td>
<td>150</td>
<td>(100)</td>
<td>Total</td>
<td>150</td>
<td>(100)</td>
</tr>
<tr>
<td><strong>Gender of family member</strong></td>
<td></td>
<td></td>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>41</td>
<td>(27.3)</td>
<td>Male</td>
<td>80</td>
<td>(53.3)</td>
</tr>
<tr>
<td>Female</td>
<td>109</td>
<td>(72.7)</td>
<td>Female</td>
<td>70</td>
<td>(46.7)</td>
</tr>
<tr>
<td>Total</td>
<td>150</td>
<td>(100)</td>
<td>Total</td>
<td>150</td>
<td>(100)</td>
</tr>
<tr>
<td><strong>Age of client at the beginning of treatment.</strong></td>
<td></td>
<td></td>
<td><strong>Employment status for the client</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 19</td>
<td>28</td>
<td>(18.7)</td>
<td>Employed</td>
<td>38</td>
<td>(25.3)</td>
</tr>
<tr>
<td>19-29</td>
<td>96</td>
<td>(64)</td>
<td>Not employed</td>
<td>112</td>
<td>(74.7)</td>
</tr>
<tr>
<td>30-39</td>
<td>10</td>
<td>(6.7)</td>
<td>Not employed</td>
<td>112</td>
<td>(74.7)</td>
</tr>
<tr>
<td>Total</td>
<td>150</td>
<td>(100)</td>
<td>Total</td>
<td>150</td>
<td>(100)</td>
</tr>
<tr>
<td><strong>Highest education for family member</strong></td>
<td></td>
<td></td>
<td><strong>Educational status of the client</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public school or less</td>
<td>64</td>
<td>(42.7)</td>
<td>Primary school or less</td>
<td>65</td>
<td>(43.3)</td>
</tr>
<tr>
<td>High school</td>
<td>46</td>
<td>(30.7)</td>
<td>High school</td>
<td>50</td>
<td>(33.3)</td>
</tr>
<tr>
<td>Collage or technical training</td>
<td>10</td>
<td>(6.7)</td>
<td>Collage or technical training</td>
<td>9</td>
<td>(6.0)</td>
</tr>
<tr>
<td>University</td>
<td>25</td>
<td>(16.7)</td>
<td>University</td>
<td>25</td>
<td>(16.7)</td>
</tr>
<tr>
<td>others</td>
<td>0.7</td>
<td></td>
<td>others</td>
<td>0.7</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>150</td>
<td>(100)</td>
<td>Total</td>
<td>150</td>
<td>(100)</td>
</tr>
<tr>
<td><strong>Living situation of the client</strong></td>
<td></td>
<td></td>
<td><strong>Living situation of the client</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>8</td>
<td>(5.3)</td>
<td>Alone</td>
<td>8</td>
<td>(5.3)</td>
</tr>
<tr>
<td>Wife/Husband</td>
<td>56</td>
<td>(37.3)</td>
<td>Wife/Husband</td>
<td>56</td>
<td>(37.3)</td>
</tr>
<tr>
<td>Parents</td>
<td>74</td>
<td>(49.3)</td>
<td>Parents</td>
<td>74</td>
<td>(49.3)</td>
</tr>
<tr>
<td>Total</td>
<td>150</td>
<td>(100)</td>
<td>Total</td>
<td>150</td>
<td>(100)</td>
</tr>
</tbody>
</table>
Table 4-2 Distribution of F ratio with reference to internalized stigma of schizophrenic clients, age and educational status variables.

<table>
<thead>
<tr>
<th>Age group</th>
<th>Sum of squares</th>
<th>df</th>
<th>Mean square</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between groups</td>
<td>477.545</td>
<td>4</td>
<td>119.386</td>
<td>2.161</td>
<td>0.076</td>
</tr>
<tr>
<td>Within groups</td>
<td>8012.239</td>
<td>145</td>
<td>55.257</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>8489.873</td>
<td>149</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational status</td>
<td>216.975</td>
<td>4</td>
<td>54.244</td>
<td>0.951</td>
<td>0.437</td>
</tr>
<tr>
<td>Between groups</td>
<td>8272.898</td>
<td>145</td>
<td>57.054</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within groups</td>
<td>8489.873</td>
<td>149</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>8489.873</td>
<td>149</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4-3 Distribution of t-test with reference to internalized stigma of schizophrenic clients, employment status and gender variables.

<table>
<thead>
<tr>
<th>Employment status for patient</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>P</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>38</td>
<td>68.7895</td>
<td>7.60923</td>
<td>0.313</td>
<td>-2.358</td>
</tr>
<tr>
<td>Not employed</td>
<td>112</td>
<td>72.0804</td>
<td>7.37678</td>
<td></td>
<td>-2.321</td>
</tr>
<tr>
<td>Gender Male Female</td>
<td>80</td>
<td>70.6375</td>
<td>7.96391</td>
<td>0.496</td>
<td>-1.057</td>
</tr>
<tr>
<td></td>
<td>70</td>
<td>71.9429</td>
<td>7.03590</td>
<td></td>
<td>-1.0</td>
</tr>
</tbody>
</table>
Table 4-4 Distribution of F ratio with reference to internalized stigma of family members, age and educational status variables.

<table>
<thead>
<tr>
<th>Age group</th>
<th>Sum of squares</th>
<th>df</th>
<th>Mean square</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between groups</td>
<td>4.172</td>
<td>4</td>
<td>1.043</td>
<td>0.270</td>
<td>0.897</td>
</tr>
<tr>
<td>Within groups</td>
<td>567.768</td>
<td>145</td>
<td>3.867</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>567.940</td>
<td>149</td>
<td>3.867</td>
<td>0.270</td>
<td>0.897</td>
</tr>
<tr>
<td>Educational status</td>
<td>9.176</td>
<td>3</td>
<td>3.059</td>
<td>0.798</td>
<td>0.497</td>
</tr>
<tr>
<td>Between groups</td>
<td>555.763</td>
<td>145</td>
<td>3.833</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within groups</td>
<td>564.940</td>
<td>148</td>
<td>3.833</td>
<td>0.798</td>
<td>0.497</td>
</tr>
<tr>
<td>Total</td>
<td>564.940</td>
<td>148</td>
<td>3.833</td>
<td>0.798</td>
<td>0.497</td>
</tr>
</tbody>
</table>

Table 4-5 Distribution of t-test with reference to internalized stigma of family members, employment status and gender variables.

<table>
<thead>
<tr>
<th>Employment status for patient</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>P</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>45</td>
<td>2.7556</td>
<td>1.72093</td>
<td>0.171</td>
<td>-0.924</td>
</tr>
<tr>
<td>Not employed</td>
<td>105</td>
<td>3.0762</td>
<td>2.03666</td>
<td>-</td>
<td>-0.988</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>41</td>
<td>2.6585</td>
<td>1.8222</td>
<td>0.979</td>
<td>-1.242</td>
</tr>
<tr>
<td>Female</td>
<td>109</td>
<td>3.1009</td>
<td>1.96235</td>
<td>-1.263</td>
<td></td>
</tr>
</tbody>
</table>

4.2.3 Prevalence of Stigma among schizophrenic clients

The prevalence of stigma for schizophrenic clients was measured using Internalized Stigma of Mental Illness Inventory (ISMI) to explore the internalized stigma of schizophrenic clients. The results were as the following:

- Minimal to none, mild, moderate, and severe.

The most prevalent stigma was moderate with a degree of 48.0%. The least prevalent stigma was severe with a degree of 2.0%.
Table 4-6 Prevalence of stigma among schizophrenic clients

<table>
<thead>
<tr>
<th>Degree of stigma</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal to non</td>
<td>7 (4.7)</td>
</tr>
<tr>
<td>Mild</td>
<td>68 (45.3)</td>
</tr>
<tr>
<td>Moderate</td>
<td>72 (48)</td>
</tr>
<tr>
<td>Severe</td>
<td>3 (2.0)</td>
</tr>
<tr>
<td>Total</td>
<td>150 (100%)</td>
</tr>
</tbody>
</table>

4.3 Comparison between the dependent variable – stigma among patients- and the independent variables: age, gender, education, and employment.

From the Least Significant Differences (LSD) results we can see that there is a significant difference between the age of 19-29 and the age of 50-59 (P: 0.006). The 50-59 age group reports more stigma than the 19-29 age group. There were no significant correlations between other age groups.

Table 4-7 Comparison between the dependent variable stigmas among clients-with the independent variables: age, gender and education using LSD analysis.

<table>
<thead>
<tr>
<th>(I) pat (J) patient age 2</th>
<th>Mean Difference (I-J)</th>
<th>Std. Error</th>
<th>P.</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-39 19-29</td>
<td>-5.07820&lt;sup&gt;*&lt;/sup&gt;</td>
<td>2.11827</td>
<td>0.018</td>
</tr>
<tr>
<td>40-49 19-29</td>
<td>-3.68772</td>
<td>2.03377</td>
<td>0.072</td>
</tr>
<tr>
<td>50-59 19-29</td>
<td>-1.39048</td>
<td>1.67533</td>
<td>0.408</td>
</tr>
<tr>
<td>50-59 40-49</td>
<td>0.71786</td>
<td>1.72053</td>
<td>0.677</td>
</tr>
<tr>
<td>60-69 40-49</td>
<td>-0.47532</td>
<td>2.56947</td>
<td>0.853</td>
</tr>
<tr>
<td>40-49 30-39</td>
<td>-3.68772</td>
<td>2.03377</td>
<td>0.072</td>
</tr>
<tr>
<td>30-39 30-39</td>
<td>1.39048</td>
<td>1.67533</td>
<td>0.408</td>
</tr>
<tr>
<td>50-59 30-39</td>
<td>2.10833</td>
<td>1.61536</td>
<td>0.194</td>
</tr>
<tr>
<td>60-69 30-39</td>
<td>0.91515</td>
<td>2.50027</td>
<td>0.715</td>
</tr>
</tbody>
</table>
The mean difference is significant at the 0.05 level.

In relation to stigma among patients with education and gender, we found that there are no significant differences.

The independent sample “t” test of employment revealed significant correlations between employed and unemployed patients. Unemployed patients (P. 0.02) have the highest mean and the highest rate of stigma.

Table 4-8 comparison of stigma among schizophrenic clients with their employment status.

<table>
<thead>
<tr>
<th>Employment status for patient</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>F</th>
<th>P</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>38</td>
<td>68.7895</td>
<td>7.60923</td>
<td>1.025</td>
<td>0.313</td>
<td>-2.358</td>
</tr>
<tr>
<td>Not employed</td>
<td>112</td>
<td>72.0804</td>
<td>7.37678</td>
<td>1.72053</td>
<td>0.194</td>
<td>-2.321</td>
</tr>
</tbody>
</table>

4.4 Prevalence of stigma among family members

The prevalence of stigma among family members was measured using the Stigma Experience Scale; to explore the internalized stigma of the family members. The results were ranged from (0-7), the most prevalent stigma was with 5 score with a degree 15.3%, and 0 score revealed no stigma with a degree 11.3%.
Table 4-9 Prevalence of Family Stigma

<table>
<thead>
<tr>
<th>Score</th>
<th>Frequency %</th>
<th>Score</th>
<th>Frequency %</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>17 (11.3%)</td>
<td>4</td>
<td>17 (11.3%)</td>
</tr>
<tr>
<td>1</td>
<td>26 (17.3%)</td>
<td>5</td>
<td>23 (15.3%)</td>
</tr>
<tr>
<td>2</td>
<td>18 (12%)</td>
<td>6</td>
<td>13 (8.7%)</td>
</tr>
<tr>
<td>3</td>
<td>32 (21.3%)</td>
<td>7</td>
<td>4 (2.7%)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td></td>
<td>150 (100%)</td>
</tr>
</tbody>
</table>

Figure (1):

Histogram: describes the distribution of stigma prevalence of family members.

From the histogram we can see that the family stigma prevalence score is distributed normally and most of the families feel stigmatized in about a medium level, with about a 3 score and also with a frequency of 32
(21.3%) of the family respondents. From about 61 (40.6%) of the family respondents reported a low level of stigma, and the remaining 57 (38%) reported a high level of stigma.

**Results of qualitative data**

A qualitative method of analysis was used to analyze the narrative part of the study through a thematic analysis. The responses of 20 schizophrenic clients and their family members were filled and gathered into themes. Also the respondent’s behavior toward themes and their answers were given to them in a form of their sample response to represent their full response.

**4.5 Impacts of Stigma for clients and family members**

From the schizophrenic clients and family members 20 participants were interviewed, three themes and seven sub themes emerged: inadequate support (lack of support from institutions, lack of support from legislations and lack of support from community), burden of care-giving (psychological and emotional burden and activity of daily living) and a knowledge deficit (lack of information about the disease and lack of information about the side effects of the medications). Themes and subthemes that emerged are presented in Table 4-6.
Table 4-10 Themes and subthemes that emerged from family and client interviews.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inadequate support</td>
<td>1- Lack of support from institutions.</td>
</tr>
<tr>
<td></td>
<td>2- Lack of support from legislations.</td>
</tr>
<tr>
<td></td>
<td>3- Lack of support from community.</td>
</tr>
<tr>
<td>Burden of caring</td>
<td>1- Psychological and emotional burden</td>
</tr>
<tr>
<td></td>
<td>2- Activity of daily living burden</td>
</tr>
<tr>
<td>Knowledge deficit</td>
<td>1- Lack of information about the disease</td>
</tr>
<tr>
<td></td>
<td>2- Lack of information about the side effects of medication</td>
</tr>
</tbody>
</table>

4.5.1. Inadequate support (First Theme):

The first theme was divided into three sub themes as mentioned below.

The 20 schizophrenic clients and family members were interviewed in a narrative way through face-to-face interviews. Their body language and facial expressions were observed to ensure responses reflected their ideas and opinions.

4.5.1.1 Lack of support from institution:

It was clear that there was lack of support from institutions for both clients and their family members. The lack of support for clients and their relatives makes it more difficult to find a chance for the clients to be included in institutions as a worker in any institution. The inadequate support creates a feeling of ignorant and unsympathetic. Some family members expressed this by the following:

**FM1**: "My brother tried to work to have a job, he went to many places to attend work at supermarkets or as a guard in any institutions, and he did not find any institution supported him".
The lack of support from institutions leads to further difficulties for the client. The clients feel that there is no cooperation between the institutions and clients, because they are seeing the clients as mad persons, and they haven't any ability to work.

C1 said about himself: “I worked in many places, but the employers when they discovered my illness they expelled me out”.

The family members experience a lack of support from institutions, because they did not find institutions that can include clients in work or training them to have a career.

FM 2: "Most of the time institutions prohibited my ill brother from having any training course due to his illness, I tried to talk to many institutions but there was no response”.

In the summary there are many misunderstandings on how to create cooperation between schizophrenic clients and their family members with institutions.

4.5.1.2 Lack of support from legislations

The schizophrenic clients and the family members mentioned that there are no legislations can keep the rights for the clients and their family members or to assist the clients to have their rights and to be a part from the community.

One family member expressed the following:

FM 3" Until now I don't find or hear about any legislation to guide the clients to live his/her life like any person in the community, or to give them their rights like to have work or to be included in the community".
One of the clients expressed this as the following:

C2 "All the people in the community think that the mentally ill persons are mad ones or mentally retarded there is no legislations give us our rights, no one give us chance to work, to learn or to get married".

4.5.1.3 Lack of support from the community

Schizophrenic clients and family members said that there is no specialized center to care for the clients. The community mental health centers only provided clients with medications, and most of the time the clients do not go there themselves, but rather family members pick up medications for them. In addition to the lack of society’s support and general misunderstanding of the clients themselves and the nature of the disease.

One family member expressed the following:

FM 4: "Most of the time, I went to the health center alone and brought the medication for my daughter. When I took my daughter with me, people thought that she was abnormal and may be mentally retarded or mad."

One client expressed the following:

C 3 "There are no specialized centers to include me or other clients in work or training courses".

Lack of community support for the clients and family members is caused by the lack of supportive centers in their communities. Clients require help doing important things in their lives like working and learning, and this lack of community support for clients and family members causes these dangerous misunderstandings. The needs of clients are not being met and
for family members, this may prevent some of them from accepting the clients as people.

**FM 5** One family member said: "I have not found any place or center to take my son to. He stays home, even though he is old enough to work, but there is no one helping us".

### 4.5.2. Burden of caring (Second Theme)

Caring for schizophrenic clients caused two types of burdens for family members: psychological emotional and activity of daily living burden.

#### 4.5.2.1 Psychological and emotional burden

The burden included the schizophrenic clients and family members’ experiences in dealing with the behavior of their schizophrenic relatives, as well as the diagnosis signs, symptoms and side effects of medications, including feelings of shame, anger, loneliness, a sense of powerlessness and have no one assisting them in caring-giving. These feelings emerged because the disease is chronic, and most clients’ behaviors are abnormal in comparison to social norms, so they need someone to follow up their needs, and help them develop a lifestyle that is realistic with their abilities, i.e. the inability to work. Family members are concerned with their relatives’ futures because they believe that clients’ conditions may worsen and the fact that most schizophrenics cannot live like normal people.

One of the clients **C 4** expressed the following:

"I spent all the time at home, doing nothing, only smoking, sometimes talking and sometimes laughing in a high voice or crying. When my family
asked me what I was doing I would say nothing." This makes and creates a high burden over the family.

Another family member FM 6 expressed the following:

"My wife cannot do anything at home. Most of the time she likes sitting down alone or sleeping. We have children and she cannot do the daily activities for them."

Another client C 5 said: "I feel angry, shame and stress due to my illness. I have daughters and no one wants to marry them because of my illness. People said you are a mad man." In this situation also the client considered a source of burden for his daughter.

In summary, the emotional burden was the main topic discussed by schizophrenic clients and family members. Most of them as expressed were shamed of the mental illness.

4.5.2.2 Activity of daily living burden and employment status:

Daily activity and employment status are other problems schizophrenic clients and family members face. Most schizophrenic clients cannot do their daily tasks without supervision and assistance. Also, they cannot stay at work for long time due to their illness.

FM 7: "My husband does not have any work. He cannot go to work every day and people don't like to help him. They think he is mad. One cannot do anything or have any responsibility."

C 6: "I am always at home. I don't like to do anything, I don't like to tidy myself, I also don't like to shave or bath, and refuse to help my family in
anything." This behavior of deficiency in activity of daily living also increases the burden over the family and client.

Another schizophrenic client C 7 mentioned the following: "I have the illness since ten years ago. I do abnormal things and cannot do anything for myself. I tried to help my family or find anything to do but i cannot continue any work."

In summary, schizophrenic clients face many difficulties in their daily activities and in working, which can cause burdens for clients and family members and bring more responsibility toward the schizophrenic clients.

4.5.3. Knowledge deficit (Third Theme)

Two types of knowledge deficit emerged: lack of information about the disease and lack of information about the side effects of the medication.

4.5.3.1 Lack of information about the disease

Most schizophrenic clients and family members do not have enough information about the nature of the disease. Most of them don't know much, if anything, about the disease or about its signs and symptoms. This issue makes it even more difficult for them to recognize a relapse. Therefore, clients and family members do experience difficulties in dealing with and taking care of the schizophrenic dependents.

One family member FM 8 mentioned the following: "When the doctor diagnosed my daughter, he said she had schizophrenia, the disease will continue for the rest of her life and she will take the medication continuously. Most of the time, I come to health center and take the
medication for her but I don’t know any information about the disorder more than what given firstly from the doctor.”

C 8 said: "After three years of marriage, I was diagnosed with schizophrenia. My husband took me to the doctor who gave me medication and said I would take the treatment for the rest of my life. I took the medication and I have children, but I cannot do housework or take care of the children. I don't know why I became like this.”

FM 9 mentioned the following: "When my son turned 22 years old, he started to behave abnormally. After one month we took him to many doctors they gave him medication, but he still continued the same behavior. Then, one doctor told us that he needed to see a psychiatrist, so we took him. The doctor said he has schizophrenia and gave him medication. He is still taking the same medication now. Sometimes I bring him with me to the health center and sometimes he refuses. We took the medication and went back. No one gives us enough information about the disease.”

It is clear in this study that schizophrenic clients and family members do not have enough knowledge about the disease process which causes difficulties in dealing with their relatives.

4.5.3.2 Lack of information about the side effects of the medication

During the interviews, the clients’ and family members mentioned that the medication the clients use had made some changes in behavior of the clients. Some noticed that the clients had an increase in sleeping time and others noted some of the clients became quieter with a decrease in activity.
One family member **FM 10** expressed the following: "My husband became less active and quiet after he took the medication. He likes to sit down and do nothing. I don't know if the medication has any relation with these things."

Also another schizophrenic client **C 9** said that medication prevented him from working: "Before I went to the doctor, I was sometimes going with my father to work, but after I took the medication I became lazy and stayed home. The medication affected my ability to work."

Another parent **C 10** expressed the following: "After I started the medication, I started to sleep most of day, sit down, do nothing and look outside. Do these things have any relation with the medication?"
Chapter five
Discussion
Discussion

5.1 Introduction

This study aimed to investigate the extent of stigma on schizophrenic clients and their families. It also attempted to link the affects of stigma on the respondents according to their demographic variables. It was very important to understand how stigma affects clients and their family members.

The study used a quantitative descriptive non-experimental design and qualitative descriptive phenomenological approach to analyze how stigma affects clients and their family members.

5.2 Stigma among schizophrenic clients in relation to socio demographic variables

The 50-59 age groups showed the highest percentage of stigma among schizophrenic clients. This may be due to the midlife age group in which clients are more likely to be affected by stigma. The result indicates no significant correlations between other age groups and stigma.

According to West et al (2011) clients in the midlife age distribution (35-54 year olds) had higher mean scale scores than older and younger clients, and this may be due to the midlife age in which clients are more likely to be affected by stigma as they consider their personal aspirations and barriers may exit toward achieving them, while older and younger clients are less interested with these issues.

In another study with convenience sample of 100 schizophrenic clients was done in Mumbai, India concerning their perceptions of stigma and
discrimination. The mean age was 39.2, which indicated that clients in this age are more affected with stigma (Shrivastava et al, 2011).

According to the gender of clients included in the study the highest level of stigma founded in males, which represent 53.3% of the total sample, while the females represent 46.7%. The difference refers to the type of sampling, which was taken in convenient way.

The result indicates no significant correlation between gender and stigma. A study done in China reported that the effect of stigma on schizophrenic clients is higher in males than females. In China, clients who develop schizophrenia earlier in life are less likely to obtain satisfactory employment and have difficulties in finding a spouse. Therefore, they are considered to be socially inferior because they cannot obtain the minimal needs of adults (Phillips et al, 2002).

Jenkins and Carpenter-Song (2009) result’s are not consistent with our results; they concluded that stigma is more prevalent in females than males in the interviews. This may represent a gender difference with respect to articulateness, but not necessarily to experience. It may also reflect the fact that all the interviewers were women, and that male participants might have been less comfortable than their female counterparts in discussing stigma related issues with female interviewers.

From this study, we can conclude that the independent sample “t” test of employment revealed significant correlations between employed and unemployed clients in favor of the unemployed (P. 0.02) who have the highest mean and the highest rate of stigma. The number of unemployed
clients was 112, which presented 74.7% of the total sample, while the number of employed participants was 38, which represents 25.3% of the total sample.

Our results are consistent with other studies. Marwaha et al (2007) concluded in their study, which was done in UK, France and Germany, that the large numbers of unemployed people with schizophrenia represent a significant financial cost to the welfare states of these three countries, and indicate considerable social exclusion among the mentally ill. In UK the employment rate sample was low standing at 12.9%, the rate in France was 11.5% and in Germany the rate was 30.03%.

Another study, done in Saudi Arabia, showed that 159 participants with schizophrenia were included in the study, 72 participants (45.3%) were employed, and therefore, 87 participants (54.3%) were unemployed. The differences in results can be explained that in Saudi Arabia people with schizophrenia and other mental illnesses are more likely to be employed because they receive supported from their families and are living in rich country (Al Showkan, 2012).

This study indicates that in relation to stigma among patients with education, there is no significant correlation.

Cechnick and Bielańska (2009) conducted a study in Poland for 202 schizophrenic clients. The results were not consistent with our study. They revealed that women had a stronger sense of stigmatization and they also found that the women were more educated and, often, married. This may be due to the fact that women stated that healthy people do not want to have a
relationship with a person who complains from mental illness, and they do so less than men. Also, they found that people with higher education have better ways of coping with the illness, have better social skills, and they tend to conceal their illness. Also, within the free labor market, they are able to protect themselves from their employer. They tend to not speak openly about their illness, so as to avoid the stigma and potential rejection. These dissimilarities may be due to the differences in culture and religion.

5.3 Stigma among family members in relation to socio-demographic variables

The results showed that most families feel stigmatized; 61 (40.6%) reported a low level of stigma 57 (38%) reported a high level of stigma, and the remaining 32 (21.3%) feel stigmatized on a medium level. The present study found that stigma is not significantly associated with demographic variables of the participant.

Another study, which is consistent with our study, was done in Ethiopia. The results showed a high proportion of family stigma. Those with younger age were associated with fewer reports of stigma, possibly indicating a more tolerant attitude among the younger generation. In general, there was substantial concern about stigma among the family members, and stigma was commonly shared among nearly all community members and not related to socio-cultural factors (Shibre et al, 2001).

The results in relation to stigma among clients with education and gender showed that there are no significant differences.
A study in China by Pillips et al (2002) founded that the better-educated family members had an increased sensitivity to stigma. Such family members may feel that they have more to lose, which is inconsistent with our study. This perceived stigma is due to the level of urbanization, and may be linked to a higher level of external supervision of patients’ behavior in more densely populated urban districts, or a lack of close (supportive) ties in high-rise urban environments where neighbors are frequently strangers.

Magana et al (2007) revealed in their study that the relationship between lower levels of education among caregivers of schizophrenics and higher levels of caregiver depression are consistent with previous research of Latinos. In fact, they revealed that caring for schizophrenics with low levels of education, which is related to a lower socio-economic status, could mean that fewer resources are available to caregivers who are faced with challenging behaviors and other caregiver-related stressors.

5.4 Discussion of the prevalence of stigma among schizophrenic clients.

From our study we conclude that prevalence of stigma among schizophrenic clients was moderate with a degree of 48.0%. And the minimal prevalence of stigma was severe with a degree of 2.0%. In general, most clients had perceived at least some level of stigma.

A study was done by Ghanean et al (2011) in Iran discussed internalized stigma among patients with effective disorder or schizophrenia. The number of participants were 138; most participants had experienced at least some level of internalized stigma. minimal stigma was reported by 40%, mild stigma by 21%, moderate stigma by 27% and severe stigma by 12%.
A study in fourteen European countries by Brohan et al (2010) regarding self-stigma, empowerment and the perceived discrimination among schizophrenics, examined the degree to which mental health service users with schizophrenia, psychosis or schizoaffective disorder report self-stigma. 41.7% of the total sample reported moderate or high levels of self-stigma. The majority of participants felt that the public hold negative attitudes toward mental health service users (69.4% reported moderate to high levels of perceived discrimination) and the degree to which this belief held was significantly associated with an increase in reported self-stigma in both clustered and non clustered multivariate models. Our study appeared consistent with other studies; many studies revealed some significant levels of stigma from medium to above among schizophrenic clients also our study come to same results.

5.5 Discussion of the prevalence of stigma among family members

According to our study we concluded that prevalence of stigma among family members is distributed normally and most of family members feel stigmatized. 32(21.3%) with medium level of stigma, 61(40.6%) of the family members reported low level and 57(38%) reported high level of stigma.

In a study was done in Iran by Karamlou & Mottaghipour (2013) they discussed the experience of stigma among family members of psychiatric clients, 40% of the family members reported that stigma had moderate effect on their lives. Patients and their family members suffer from stigma
with negative attributions which may interfere with many aspects of their lives.

Discussion of the qualitative part of the study

5.6 Impact of Stigma among schizophrenic clients and their family members:

The themes emerged from the interviews of family members. They were three themes and seven sub themes.

5.6.1. Inadequate support

One of the themes that emerged from this is inadequate support. Clients and family members discussed three types of inadequate support; lack of support from institutions, lack of support from legislations and lack of support from their communities.

Lack of support for schizophrenic clients and their family members, which is typically provided by institutions, legislations and communities, may push the care of the client to be more difficult. This can cause the client to feel lonely no one defending him and the family members feel that there is no support or cooperation to help them in the caring of their ill relatives.

In a study with line with our study was done in Hong Kong (2004) by Chan & Yu discussed the deinstitutionalization of mental health care in Hong Kong many people with mental health problems are being cared for in the community. The majority of clients have a diagnosis of schizophrenia, and many have a long duration of illness and multiple readmissions. They discussed that People with mental health problems experiencing distressing mental symptoms; they had many difficulties, such as financial problems,
unemployment and lack of opportunities to participate in social activities which resulted from stigma and discrimination. These had a great impact on their quality of life.

5.6.2 Burden of caring:
One of the themes emerged from this study is the burden of caring. We found that schizophrenic clients and their family members experienced two types of burden; psychological and emotional burden, and also activity of daily living burden.

Family members of schizophrenic clients experienced burden in the form of feelings such as shame, anger, loneliness, powerlessness and having no one assisting them in caring of the clients. These feelings emerged because of the nature of this chronic disease. Relatives are often worried about the client's future because they believe that the client’s condition may worsen and that they cannot live like normal people.

Nirmala et al (2011) in their study explores the relationship between caregivers’ burden and level of expressed emotions by the patients with schizophrenia in India.

They interviewed 70 participants 35 caregivers and 35 schizophrenic clients, They found that the subjective burden of the caregivers was not associated with the level of expressed emotions among schizophrenic patients. The reasons could be that most of these clients are functional and have been attending to the daycare center regularly. But caregivers reported high rates of burden on the domain of impact well-being and perceived severity of the disease subscales of BAS (the burden assessment schedule).
A study in India, consistent with ours, by Sreeja et al (2009) compared levels of burden between schizophrenic clients and epileptic clients. They took a sample of 30 relatives of schizophrenic clients, and 30 relatives of epileptic clients. They discussed that relative caregivers of both groups share similar burdens; i.e. patient care, finance, physical and emotional stress, family relations and occupation, respectively. The burden of family members ranged from emotional reaction to the symptoms of the illness; i.e. the stress of coping with disturbed behavior, the disruption of household routine, the stigma they are confronted with and the restriction of social activities to economic difficulties. The condition of the ill relative requires that caregivers place their own needs and wishes after those of their schizophrenic relative.

In accord with our study a study was done in Australia (2013) by Sibitz et al, they discussed that internalized stigma has a negative impact on adherence to treatment, quality of life and recovery. The findings supported the idea that a day clinic program focusing on empowerment, recovery and stigma reduction made a positive contribution to reducing internalized stigma and promoting well-being in a clinical population diagnosed with a schizophrenia spectrum disorder.

Rafiya and Sutharangsee (2011), consistent with our study, discussed the burden of familial caregivers caring for patients with schizophrenia and its related factors showed that caregivers caring for patients with schizophrenia experience burden, which affects several aspects of the life of the caregiver ranging from emotional to physical, even interfering in
certain aspects of their social lives, and placing pressure on their financial situation.

They also found that in the case of severe illness, family members may feel burdened in dealing with the ill client due to characteristics of the illness, which require long term care. They found that schizophrenics who regularly visited community health centers experience a significant increase in the health function. Therefore, schizophrenics with a higher level of health functionality, also experience an increase in their ability to carry out daily activities. Thus, increasing health function is related to decreasing a family member’s burden.

5.6.3 Knowledge deficit of the schizophrenic clients and their family members:

The deficit of knowledge was one of the main themes which emerged in our study, with two sub themes emerging: lack of information about the disease and lack of information about the side effects of the medication. This lack of knowledge caused a gap in communication and interaction between the clients and their family members and the source of treatment for their schizophrenic clients, and this led to negative effects on how the family members can properly care for their relative.

In a study was done by Hooly (2010) discussed the family coping with schizophrenic clients, many family members challenge and the symptoms of the disease and the social deficit associated with it on daily bases. this study is consisting with our study.
Another study on line with our study was done on America (2010) by Kranke et al, adolescents who taking psychiatric medication reported stigma as a result for psychiatric medication use.
Conclusion

Schizophrenic clients and family members experience stigma in their lives and this negatively affects their quality of life in various aspects.

The findings show that caring for schizophrenics is stressful for family members, and there is a need for support and training programs for them.

Based on the results we make several recommendations. The most important of which is to include and integrate schizophrenics in their communities.
**Recommendations:**

Based on the result of the study we recommend the following:

1. Psychoeducation for the patients and their family members in Mental Health Centers and also by Outreach mental health members.
2. The media like T.V. and newspapers should held a positive view about mental health, mentally ill patients and their family members.
3. Create legislations to protect the mentally ill patients and their family members to save their rights and freedom.
4. Create financial and social support for the mentally ill patients and their family members.
5. Increase the distribution of mental health services by adding more mental health centers in the West Bank cities and villages.
6. Provide and supply the medicine and medical equipments in all mental health centers.
7. Held awareness courses in collaboration with medical relief and the Palestinian Red Crescent Society about mental illness and how to deal with them.
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Appendixes
Appendix (1)

Participant's Information Sheet

Title of the study:
Psychosocial Impacts of Stigma on Schizophrenic Clients
And Their Families.

The researcher:
Nida Tayseer Jawabreh, student of Community Mental Health Nursing, Master Program at An-Najah National University; Fourth Term.
Supervisor: Dr. Adnan Sarhan.

Synopsis:
For my thesis preparation I will do a research work on the psychosocial impacts of stigma on schizophrenic outpatients and their families. Because stigma affects all aspects of patients’ lives and the lives of their families the issue requires special attention. For this, I intend to study the impacts of stigma and how schizophrenic outpatients and their families can reduce the effects of stigma.

The purpose of the study:
To understand how stigma affects schizophrenic clients and their families, and how they cope with their situation.

What you are expected to do:
As a participant in the study you have a role in answering the questionnaire items honestly.
Privacy:
All data will be utilized exclusively for the purpose of the study.

Refusal to participate in study:
There is no obligation for you to participate in the study; you can refuse to participate from the study.

Harm:
No any harm will come to you due to answering this questionnaire.

Thank you for your participation.

Yours Truly,
Mrs. Nida Tayseer Jawabreh
Informed Consent Form

The under signed, … … … … … … … … … … (name), born in … … … … … … … … … … confirms to have been read/ explained requests to participate in the research project, entitled: 'Psychosocial impacts of stigma on schizophrenic clients and their families.'

I have been given a copy of your request/ project orientation and willing to participate in the project. I have received both verbal and written information about the study, and i am aware that my participation is voluntary.

Date:                                             Signature of informant:

The under signed confirms that she has provided her subject all needed information about the project and has handed over the above a copy of the request/ project orientation and consent to participation.

Date:                                             Signature of researcher:
نموذج معلومات المشترك

عنوان الدراسة:
التأثيرات النفسية والمجتمعية لوصمة المرض النفسي على المصابين بمرض الفصام الذهاني وعائلاتهم

معلومات الباحث:
أنا الطالبة نداء تيسير جوايرة في قسم الدراسات العليا قسم ترميض الصحة النفسية المجتمعية في جامعة النجاح الوطنية، الفصل الرابع، المشرف على البحث: الدكتور د عدنان سرحان.

عن ماذا تتحدث الدراسة؟
لإعداد رسالتقي العلمية، سأقوم بعمل بحث عن تأثير وصمة العار على مرضى فصام الشخصية المراجعين للعوائق النفسية المجتمعية وعلى عائلاتهم. حيث أن وصمة العار تؤثر على كافة مناحي حياة المرضى وكذلك على عائلاتهم، ولذلك فإنها تتطلب اهتمام وعناية خاصة، وبناءً على ذلك سوف أقوم بدراسة هذه التأثيرات وكيف يمكن للمريض وعائلاتهم التقليل منها.

الهدف من الدراسة:
تهدف الدراسة إلى استيعاب وفهم هذه التأثيرات على المرضى وعائلاتهم وكيفية التغلب عليها.

ماذا يتوقع منك فعله؟
كمشارك في هذه الدراسة، لديك دور مهم يتمثل بالإجابة عن أسئلة الاستبيان بصدق.

الخصائص:
كل المعلومات سوف تستخدم لأغراض هذه الدراسة فقط.
الرفض للمشاركة في هذه الدراسة:
ليس هناك ما يلزمك للمشاركة في هذه الدراسة, بإمكانيك رفض ذلك.

الضرر:
لن تتعرض لأي ضرر أو أذية لاجايتك هذه الاستبيان.
شكرا لمشاركتكم.
تفضلو بقبول فائق الاحترام.

السيدة نداء تيسير جوابرة.
نموذج موافقة عامة

أنا الموقع أدناه .....................................................، و المولد في -

أؤكد أنه تم قراءة و توضيح طلب المشاركة في هذه الدراسة التي تحت عنوان "الآثار النفسية و المجتمعية لوصمة العار على مرضى فصام الشخصية المراجعين للعيادات الصحية النفسية المجتمعية و على عائلاتهم".

وقد أعطيت نموذج من طلب الموافقة و على استعداد للمشاركة في البحث. و تلقيت كافة المعلومات التي تتعلق بالبحث سواء كانت شفهية أم خطية. وأنما مدرك تماما ان مشاركتي في هذا البحث طوعية.

توقيع المشارك:

التاريخ:

و تؤكد الموافقة أدناها أنها قدمت كافة المعلومات اللازمة حول البحث، و قد سلمت المذكور أعلاه نسخة من الطلب المقدم و نموذج الموافقة.

توقيع الباحث:

tاريخ:
Appendix (3)
التآثيرات النفسية المجتمعية لوصمة المرض النفسي على مرضى الفصام الذهاني وعائلاتهم المراجعين لمراكز الصحة النفسية المجتمعي

معلومات شخصية:
أولاً نود أن نعرف القليل عنك. أرجو تحديد الإجابة في المكان المخصص.
1- الجنس: _ ذكر _ أنثى
2- ما هو تاريخ ميلادك ؟ ____________________________.
3- ما هو أعلى مستوى علمي تلقيته؟
   - تعليم مدرسي أو أقل (حتى الصف الثامن).
   - بعض سنوات في الكلية أو المعهد التقني.
   - أنهيت المدرسة الثانوية (التجهيزي).
   - أنهيت الدراسة في الكلية أو المعهد التقني.
   - بعض من الجامعة.
   - أنهيت الجامعة.
   - تخرجت أو حصلت على درجة تخصص في مجال معين.
4- ما هو مقر إقامتك الحالي.
   - وجدتك.
   - مع زوج / زوجة أو شريك.
   - مع أقارب آخرين.
   - مع شخص لا تقربه.
   - أخرى ____________________________.
5- هل تعمل؟
   - لا عمل.
   - مديرة منزل.
   - متقاعد.
   - طالب.
   - متطوع.
   - عمل في دوام كامل.
   - عمل في دوام جزئي.
سواءً تقوم باستخدام مصطلح "مرض نفسي" في ما تبقى من هذه الاستبيان وقد يرجى التفكير بذلك كأنه أفضل مصطلح يستخدم.
**Internalized Stigma of Mental Illness Inventory (ISMI)**

We are going to use the term "mental illness" in the rest of this questionnaire, but please think of it as whatever you feel is the best term for it.

For each question, please mark whether you strongly disagree (1), disagree (2), agree (3), or strongly agree (4).

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel out of place in the world because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Mentally ill people tend to be violent.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. People discriminate against me because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I avoid getting close to people who don’t have a mental illness to avoid rejection.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I am embarrassed or ashamed that I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Mentally ill people shouldn’t get married.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. People with mental illness make important contributions to society.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I feel inferior to others who don’t have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Agree</td>
<td>Strongly Agree</td>
<td></td>
</tr>
<tr>
<td>-------------------</td>
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<td>------</td>
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<td></td>
</tr>
<tr>
<td>disagreement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>illness.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I don’t socialize as much as I used to because my mental illness might make me look or behave “weird.”</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. People with mental illness cannot live a good, rewarding life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. I don’t talk about myself much because I don’t want to burden others with my mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. Negative stereotypes about mental illness keep me isolated from the “normal” world.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. Being around people who don’t have a mental illness makes me feel out of place or inadequate.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. I feel comfortable being seen in public with an obviously mentally ill person.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. People often patronize me, or treat me like a child, just because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. I am disappointed in myself for having a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. Having a mental illness has spoiled my life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. People can tell that I have a mental illness by the way I look.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>---</td>
<td>-----------------</td>
<td>---------</td>
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</tr>
<tr>
<td>19. Because I have a mental illness, I need others to make most decisions for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. I stay away from social situations in order to protect my family or friends from embarrassment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. People without mental illness could not possibly understand me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. People ignore me or take me less seriously just because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23. I can’t contribute anything to society because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24. Living with mental illness has made me a tough survivor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25. Nobody would be interested in getting close to me because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26. In general, I am able to live my life the way I want to.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27. I can have a good, fulfilling life, despite my mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28. Others think that I can’t achieve much in life because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>موافق بشدة</td>
<td>موافق</td>
<td>غير موافق بشدة</td>
<td>غير موافق</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>1- أشعر بأنني لا أنتبه لهذا العالم لأنني أعاني من مرض عقلي.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2- يميل المصابون بأمراض عقلية إلى العدوانية.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3- يميز الناس بصرف النظر لاني أعاني من مرض عقلي.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4- أتجنب الاقتراب من الأشخاص البصري لإصابة بمرض عقلي.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5- أشعر أحيانا بالحرج و العار لأنني مصاب بمرض عقلي.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6- لا ينبغي للمصابين بأمراض عقلية الزواج.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7- للمصابين بأمراض عقلية إسهامات مهمة في المجتمع.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8- أشعر بأنني أقل شأنا من الناس غير المصابين بأي مرض عقلي.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9- لا اختلط كثيرا في المجتمع كما كنت أكثر من قبل لأن</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

29. Stereotypes about the mentally ill apply to me.

Strongly Disagree  Disagree  Agree  Strongly Agree

| 1 | 2 | 3 | 4 |
المرض يعطي أبدًا أو أتصرف بغرابة.

لا يمكن للأشخاص المصابين بمرض عقلي العيش حياة جيدة.

إذا لم يتحدث عن مرضي كثيرًا لأني لا أريد أن يتحمل الآخرين عبء مرضي.

الأفكار الأخلاقيات السلبية حول الامراض النفسية

تجعلني بحالة انعزال عن العالم الخارجي.

عندما أكون مع نفس أصدقاء أشعر بعدم الاتصال و التثبيت.

أشعر بالراحة عندما أكون في مكان عام مع شخص مصاب بمرض عقلي.

عادة ما يزاعني الناس و يعاملوني كظل بسبب المرض

أشعر بخيبة امل و احباط بسبب المرض العقلي.

المرض أفسدت لي حيائي.

يمكن للناس المعرفة بمرضي من خلال طريقة نظرتي.

أحتاج الآخرين لاتخاذ القرارات عني بسبب اصابتي بمصر عقلي.

بتجنب حضور المناسبات الاجتماعية و ذلك حتى لا أضع عائلتي لأصدقائي في موقف محرج.

لا يمكن للناس الإصحاء فهمي.

عادة ما يتم رفضي و عدم أخذني على محلاج الجد بسبب مرض العقلي.
- لا يمكنني المساهمة في المجتمع و ذلك بسبب مرضي.

- المعيش مع الإصابة بمرض نفسي جعلني أشك في عينًا وجودتي.

- لا تزداد مهتمة بالقربي الي لأي مصاب بمرضي.

- بشكل عام بإمكانى المعيش بالطريقة التي أريد.

- يمكنني المعيش حياة كبيرة بالرغم من مرضي.

- 27 يمكنني المعيش حياة جيدة ومرضية بالرغم من مرضي.

- الصورة المفيدة لمرضي المصابين بمرضي.

- تنطبق علي.
Appendix (4)

Family Experiences with the Stigma of Mental Illness

Information about you

First, we would like to know a bit about you. Please mark the correct box.

Gender :
Male-2 female-1

What year you were porn__________________ ?

What is your highest level of education ?

Public school or less (up to grade 8) -

Some high school–
☐-Completed high school (grade 12 or 13)
☐some College or technical training
☐Completed College or technical training
☐Some University
☐Completed University
Graduate or professional degree

What is your current living arrangement? Are you currently living ...
- Alone - With a Spouse/partner - With Parents - With another relative(s) - (With other unrelated person(s) - (others

Specify ________________________________

Family Experiences with the Stigma of Mental Illness

Are you employed?
- Not employed - Homemaker - Retired - Student
- Volunteer - Employed Full-time - Employed Part-time

Information about your relative’s mental health problems.

Does your relative currently have schizophrenia?

What is your relationship to this person?

Relationship ________________________________ :
Does your relative currently live with you?
- Yes - yes, but currently in hospital - no

How old is your relative?
Age at last birthday __________________________:

Are they …
-Male - Female

Compared to one year ago, would you say their mental illness is?...
-Better - about the same - worse

About how old were they when they first had symptoms?

About how old were they when they first received treatment?

Have they ever been hospitalized for a mental illness or suicide attempt?
-Yes - No - Don’t know

If yes:
*Have they ever been hospitalized in:
- □ □ A provincial psychiatric hospital
- □ □ A general hospital psychiatric unit
- □ □ A medical/surgical unit in a general hospital
- □ □ Don’t know

*Have they ever been committed under Provincial mental health legislation (the Mental Health Act)?
- Yes
- No
- uncertain

*Have they been hospitalized in the last year because of a mental health problem?
- Yes, as a voluntary patient
- Yes, as a committed patient
- No
- Don’t know

*Have you ever been personally involved in a family member’s commitment process?
- Yes
- No
- uncertain

*Have they ever been hospitalized in a forensic unit?
- Yes
- No
- uncertain
In the last year have they attended an outpatient or community mental health program?

Don’t know - No - Yes. If yes, about how often do they attend:

- Weekly or more often
- 2 or 3 times a month
- Once a month
- Once every 2 or 3 months
- Once every 6 months
- Once or twice a year

Experiences with Stigma.

The next section asks about experiences with stigma you or your family as a whole has had.

By stigma we mean negative feelings people have toward people with a mental illness.

Do you think that people think less of those who have a mental illness?

☐ Never - Rarely - Sometimes

- Often - Always

**The guiding questions for the interview with clients and family members:

Do you think that the average person is afraid of someone with a serious mental illness?

- Never - Rarely - Sometimes
Has your relative been stigmatized because of their mental illness?

Never - Rarely - Sometimes
- Often - Always

Please explain.

Have you felt stigmatized because of your relative’s mental illness?

Never - Rarely - Sometimes
- Often - Always

Please explain.

Have other members of your family been stigmatized because of your relative’s mental illness?

Never - Rarely - Sometimes
- Often - Always

Please explain

Interview guide questions for qualitative part of the study:
Could you give us an example of a stigmatizing experience your family has had in the last year?

Was this the worst experience of stigma your family has had?

☐☐ Yes
☐☐ No. If not, what was the worst stigmatizing experience you or your family has had?

When did this happen? ____________________________

What impact has stigma had on your family?

Have stigma affected your family’s ability to make or keep friends?

☐-Yes- No ☐-Not sure

Could you explain?

Has stigma affected your ability to interact with your other relatives?

☐-Yes- No ☐-Not sure

Could you explain?

Have your experiences with stigma affected your family’s quality of life?

☐-Yes- No ☐-Not sure
Could you explain?

**What does your family do to cope with stigma?**

Do you try to avoid situations that may be stigmatizing to your family?

- Yes  
- No  
- Not sure

Could you explain?

**Have you ever tried to reduce stigma by educating your friends or relatives about mental illness?**

- Yes  
- No  
- Not sure

Could you explain?

**Have your experiences with stigma motivated a member of your family to speak out about the rights of the mentally ill?**

- Yes  
- No  
- Not sure

Could you explain?
Have your experiences with stigma motivated a member of your family to participate in programs to educate the public about mental illness.

☐-Yes-  No  -Not sure

Could you explain?

What do you think causes stigma?

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

What should we do to fight stigma?

_________________________________________________________________

Thank you for taking your time to complete this survey. Is there anything else you would like us to know about your experiences with stigma that we have not yet asked?

Additional Comments:
خبرة العائلة مع وصمة الأمراض النفسية

معلومات شخصية :
أولا نود أن نعرف القليل عنك. أرجو تحديد الإجابة في المكان المخصص.

1- الجنس : □ ذكر □ أنثى

2- ما هو تاريخ ميلادك؟ ________________________________

3- ما هو أعلى مستوى علمي تلقيته؟

* تعليم مدرسي أو أقل (حتى الصف الثامن).
* بعض صفوف المدرسة الثانوية.
* أنهيت المدرسة الثانوية (<الصف 12 أو 13>).
* بعض السنوات في الكلية أو معهد تقني.
* أنهيت الدراسة في الكلية أو معهد تقني.
* بعض من الجامعة.
* أنهيت الجامعة.
* تخرجت أو حصلت على درجة تخصص في مجال معين.

4- ما هو مقر أقامتك الحالي ؟ هل تسكن حاليا ...............؟

- مع أقارب آخرين
- مع زوج / زوجة أو شريك
- مع شخص لا تقربه

عدد _____________________________

5- هل تعمل ؟
لا أعمل
- متقاعد
- مدرسة منزل
- طالب
- متطوع
- أعمل في دوام كامل
- أعمل في دوام جزئي

معلومات حول المشاكل النفسية التي يعاني منها الأقارب:
6- هل يعاني قريبك حالياً من أي مرض من الفصام الذهني؟

7- ما هي علاقتك بهذا الشخص؟

العلاقة: * أب * أم * أخ * أخت * غير ذلك حدّد

8- هل يعيش قريبك معك حالياً؟

نعم
- نعم، ولكنه حالياً في المستشفى
- لا

9- كم عمر قريبك؟

العمر: __________

10- هل هو:

ذكر
- أنثى

11- مقارنة بما كان عليه قبل سنة، هل ستصف حالته المرضية ب:

أفضل
- كما هي تقريباً
- أسوء

12- كم كان عمره تقريباً عندما ظهرت عليه الأعراض لأول مرة؟
13 - كم كان عمره تقريبًا عندما تلقي العلاج لأول مرة؟

14 - هل تم نقله مرة إلى مستشفى الأمراض النفسية بسبب مرضه النفسي أو حاولة الانتحار؟

• نعم - لا - لا تعلم

إذا كانت الإجابة على سؤال 14 بنعم:

* هل تم نقله فيما مضى إلى:

• المستشفى النفسي في مستشفى الأمراض النفسية
• المستشفى العام قسم الطب النفسي
• قسم الجراحة أو الطب في مستشفى عام لا أعلم

هل تم نقله في الماضي إلى المستشفى بسبب أي مشاكل نفسية؟

• نعم, كمريض دائم - نعم, كمريض دائم لا
• لا أعرف

في السنة الماضية هل حضرالي أي برنامج للصحة النفسية المجتمعية أو أي مراكز للمعالجة؟

• لا أعلم - نعم

إذا كانت الإجابة نعم, كم مرة جاء فيها؟

• أسبوعياً وأحياناً أكثر
• 2 أو 3 مرات في الشهر
• مرة كل شهرين وثلاث شهور
• مرة كل ست شهور
- مرة أو مرتين في السنة

التجارب مع وصمة المرض النفسي:

القسم التالي يحتوي على أسئلة حول تجربتك وعائلتك التي مررت بها بسبب وصمة المرض النفسي.

و نقصد بوصمة المرض النفسي الشعور السيء تجاه الأشخاص المصابين بمرض نفسي.

هل تعتقد بأن الناس يفكون بالإعشاق المصابين بمرض نفسي بأنهم لأقل شانا

- أبداً
- نادراً
- أحياناً
- غالباً
- دائماً

الأسئلة التوجيهية التي تم استخدامها في المقابلة مع المرضى وعائلاتهم:

- هل عاني قريبك من الوصمة بسبب المرض النفسي؟

- أبداً
- نادراً
- أحياناً
- غالباً
- دائماً

من فضلك أن توضح: -------------------------------------------------------------

- هل شعرت انت بوصمة المرض النفسي بسبب مرض قريبك النفسي؟
الاسئلة التوجيهية المستخدمة في الجزء النوعي السردي من الدراسة:

20- هل عانى أي أحد من أفراد عائلتك من وصمة المرض النفسي بسبب مرض قريبك النفسي؟

من فضلك أن توضح ________________________________

21- هل بامكانك أن تقدم لنا مثالاً على شعور عائلتك بوصمة المرض النفسي في السنوات الماضية؟

من فضلك أن توضح ________________________________

22- هل كانت هذه اسوة تجربة لوصمة المرض النفسي التي مرت بها عائلتك؟

من فضلك أن توضح ________________________________

- أحيانا
- نادرا
- أبدا
- دائما
- غالبا

- أحيانا
- نادرا
- أبدا
- دائما
- غالبا
23- متى حدث هذا؟

24- ما هو أثر هذه الوصمة على عائلتك؟

25- هل أثرت وصمة المرض النفسي على قدرة عائلتك في تشكيك علاقات صداقة أو المحافظة على الصداقات القديمة؟

- نعم
- لا - لست متأكدًا

هل بإمكانك التوضيح؟

26- هل أثرت وصمة المرض النفسي على قدرة عائلتك في التعامل مع أقاربك؟

- نعم
- لا - لست متأكدًا

هل بإمكانك التوضيح؟
27 - هل أثرت تجاربك مع وصفة المرض النفسي على نوعية حياتك العائلية؟

نعم - لا - لست متأكدًا

هل بإمكانك التوضيح؟

-----------------------------------------------------------------------

28 - ماذا فعلت عائلتك للتغلب على وصفة المرض النفسي؟

-----------------------------------------------------------------------

29 - هل تحاول أن تتجنب المواقف التي يمكن أن تسبب الوصمة لعائلتك؟

نعم - لا - لست متأكدًا

هل بإمكانك التوضيح؟

-----------------------------------------------------------------------
30- هل حاولت مرة أن تقلل من وصمة المرض النفسى من خلال تثقيف أصدقائك و أقاربك حول الأمراض النفسية؟

نعم - لا

هل بإمكانك التوضيح؟

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31- هل حفزت تجربتك مع الوصمة النفسية أحدًا من أفراد عائلتك في التكلم عن حقوق المرضى النفسين؟

نعم - لا

هل بإمكانك التوضيح؟

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32- هل حفزت تجربتك مع وصمة المرض النفسى أحدًا من أفراد عائلتك للمشاركة في برنامج

يساهم في تثقيف الناس حول الأمراض النفسية؟

نعم - لا

هل بإمكانك التوضيح؟

---------------------------------------------
---------------------------------------------
---------------------------------------------
---------------------------------------------
هل بإمكانك التوضيح؟

ما الذي تعتقد أنه السبب الرئيسي لوصمة المرض النفسي؟

ما الذي يجب أن نفعله لمحاربة وصمة المرض النفسي؟

شكراً لأخذك معي إلى هذا الإحصائية، هل هناك أي شيء آخر تود أن تعلمنا به حول تجربتك مع وصمة المرض النفسي ولم نسألك عنه.

تعليقات إضافية:
التأثيرات النفسية و المجتمعية لوصمة المرض النفسي على المصابين بمرض الفصام الذهاني و عائلاتهم

إعداد
نداء تيسير جوابرة

إشراف
د. عدنان سرحان

قدمت هذه الأطروحة استكمالا لمتطلبات درجة الماجستير في تمريض الصحة النفسية المجتمعية بكلية الدراسات العليا في جامعة النجاح الوطنية في نابلس، فلسطين 2013.
التأثيرات النفسية و المجتمعية لوصمة المرض النفسي على المصابين بمرض الفصام الذهاني وعائلاتهم

إعداد

نداء تيسير جوابرة

إشراف

د. عدنان سرحان

الملخص

يعود السبب الحقيقي وراء منع مرضى الفصام الذهاني من تلقي المساعدة التي يحتاجونها إلى شعورهم بوصمة المرض النفسي حيث تشكل هذه الوصمة حاجز منيعا يمنعهم من تلقي أي مساعدة.

حتى الآن ما زالت الدراسات محدودة فيما يتعلق بتأثير وصمة المرض النفسي على الحياة الاجتماعية للمريض وعائلاتهم في فلسطين.

تهدف هذه الدراسة إلى التعرف على مدى تأثير وصمة المرض النفسي على مرضى الفصام الشخصي وعائلاتهم، و جاءت نتائج البحث من خلال المقابلات وفقًا للمتغيرات الديموغرافية.

منهجية البحث:

و للوصول للأهداف المذكورة أعلاه تم اتباع منهج وصفي غير تجريبي يعتمد على المقابلات المنظمة وتوزيع الاستبيانات. وتضم عينات الدراسة 150 مريضا يعانون من المرض النفسي و150 عضو من أفراد عائلاتهم من المحافظات الشمالية للضفة الغربية جنين، طولكرم ونابلس.

وكذلك استخدم الأسلوب النوعي السردي وذلك لتبان تأثير وصمة العار على المريض وعائلته.

النتائج:

أظهرت النتائج الكمية أن معظم الحالات من وصمة المرض النفسي كانت متوسطة أي ما نسبته 48% ونسبة الحالات المستعصية 2%.

وأوضحت الدراسة أيضا عدم وجود أي علاقة بين انتشار وصمة المرض والتعليم والجنس، بينما توجد هناك علاقة كبيرة بين وصمة المريض والتقدم في السن والحالة التعليمية.
كما بينت الدراسة أيضاً أن انتشار وصمة المرض بين أفراد الأسرة جاءت بالمعتدلة والمنخفضة بما نسبته 21.3% و 40.6% على التوالي. والتي أظهرت وجود توزيع طبيعي حول تأثير وصمة العار على العائلات حيث أن نسبة على العائلات أقل من نسبته على المرضى أنفسهم. و كشفت النتائج النوعية أن تأثير وصمة المرض النفسي يتحور حول عدم وجود الدعم، عبء الرعاية، وقلة المعرفة.

الخلاصة:

توصلت الدراسة إلى أن مرضى الفصام الشخصي وعائلاتهم واجهون وصمة المرض النفسي في كافة مناحى الحياة مما أدى إلى التأثير السلبي على نوعية الحياة، كما أوضحت الدراسة أن رعاية مرضى الفصام الذهاني ما هو إلا عبء على عائلاتهم لذلك هم بحاجة للدعم وبرامج التدريب لكافة أفراد الأسرة.