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Faculty of Graduate Studies

The experiences of Mothers caring for adults affected by schizophrenia in Hebron district – Palestine: A descriptive phenomenological study

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الإهداء

لأن وراء طريق طويل تملؤه العثرات كما النجاحات حلم لا بد أن يتحقق ،فلولاكم أنتم من كنتم بجانبي لحظه بلحظه، من ساندني طيله سنوات من التعب والسهر والدراسه لم يكن عملي هذا سيظهر للنور

إلى مناره العلم والامام المصطفى، الى سيد الخلق الى رسولنا الكريم (ص)

إلى من جرع الكأس فارغا ليسقيني قطره حب، الى من حصد الاشواك من دربي ليمهد لي طريق العلم، الى القلب الكبير (والدي العزيز)

إلى الينبوع الذي لا يمل العطاء، الى من حاكت سعادتي بخيوطٍ منسوجةً من قلبها (والدتي العزيزة)

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الى من أشرقت شمسك في سماء حياتي.. وكنت نورا قد غطى على أحزاني وبدلها أفراح ... كم هي رائعة عيناك التي أرى بهما الحياة . . حفظك اللـــــــه لـــي ومتعك بالصحة والعافية . . . ودمت لـــــــــي .... (زوجتي العزيزة)

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الإقرار

أنا الموقع أدناه مقدم الرسالة التي تحمل العنوان:

The experiences of Mothers caring for adults affected by schizophrenia in Hebron district – Palestine: A descriptive phenomenological study

خبرات الامهات اللواتي يقمن برعاية أولادهن البالغين المصابون بمرض الفصام العقلي في محافظة الخليل – فلسطين / دراسة وصفية

أقر بأن ما اشتملت عليه هذه الرسالة إنما هو نتاج جهدي الخاص، باستثناء ما تمت الإشارة إليه حيث ما أن هذه الرسالة كاملة، أو أي جزء منها لم يقدم من قبل لنيل أي درجة أو لقب علمي أو بحث لدى أي مؤسسة تعليمية أو بحثية أخرى.

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: **اسم الطالب:**

Signature: **التوقيع:**

Date: **التاريخ:**

Abbreviation

APA : American Psychiatric Association

WHO: World Health Organization

NGO: Non-Governmental rganizations

DSM-5: Diagnostic Statistical Manual of Mental disorders version 5

PBCS: Palestinian Central Bureau of Statistics

NAMI: National Alliance on Mental Illness

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Abstract

Introduction: Schizophrenia is a mental illness which cause severe disability and considered as major cause of suffering for clients affected with it. Diagnosis with Schizophrenia affects functioning within the family and caregivers, this manly resulted because the caregivers have to take their role in caring.

Aim: This study aimed at understanding the experience and management's practices that used by mothers of client affected by schizophrenia include difficulties and barrier that mother of face, and investigate both the positive and negative experiences of care giving, mother coping strategies, supportive factors, attitudes and perceptions Design :The study used a qualitative descriptive phenomenological method.

Data collection: Face to face, in-depth, semi-structured interviews were conducted with participants – 11 mothers of client affected with schizophrenia included.

The interview guide allowed mothers to express their experiences with caregiving of client affected with schizophrenia.

Sample: Purposive sampling was used

The setting of data collection was Hebron Community Mental Health Center. In Hebron district – West Bank- Palestine.

Data Analysis: The data was analyzed by using Giorgi's phenomenological psychology method (1985).

The result: From the experiences narrated by the mothers, 4 main themes and 18 sub themes emerged from the analysis of the data. The data obtained from mothers were transcribed verbatim. Which include **Coping with new situation, Knowledge deficit, Emotional and social experience and Ongoing Struggle**

Conclusion:

Each mother had unique experiences of their journey of caring and living, most of mothers experienced varies of difficulties and burden while caring for their client affected with schizophrenia include, psychological, Emotional, social and economic factors.

Most of mothers experienced lack of knowledge and information regarding schizophrenia and how to manage or deal with symptoms. Also early experiences with the illness include feeling of loss, sadness, crying. Mothers experienced many lifestyle change include being socially isolated due to they had to be always with their client who become dependent.

Mothers reported many needs to help them handle new situation, which included enough information and education, and counseling center,

also they needed center for rehabilitation and entertainments activity for their clients supported with mental health professional's.

In this study coping mechanisms of mothers explored, which they used to overcome challenges introduced by their client affected with schizophrenia. Mothers developed themselves with coping strategies to handle with challenges and new situation that they obligate to be with, lastly, some mothers also reported positive, character building experiences arising from their caring for their relative with schizophrenia, that they feeled satisfied when their client become better, and some mother's become closer and give more love to their client.

Key words: Schizophrenia, Mother, Burden, Coping mechanism, Phenomenology.

Chapter One

Introduction

Chapter One
Introduction

1.1 Introduction

This chapter describes and gives an overview of the problem under investigation. It starts the background of the study then aims and purpose and statement of the problem and significant of study, conceptual and operational terms of the study.

1.2 Background of the Study

Schizophrenia is a mental illness which causes severe disability and considered as the major cause of suffering for clients affected with it. Diagnosis with Schizophrenia affects functioning within the family and caregivers, this mainly resulted because the caregivers have to take their role in caregiving that was in the past performed through psychiatric institutions (Chan, et al, 2009).

Schizophrenia affects about 0.7% of the adult population, most ages affected between15 and 35 year. The World Health Organization (W.H.O, 2010) estimates that globally about twenty-nine million clients affected with schizophrenia. Despite its incidence each year 0.03%, this percentage is low but the prevalence is high because schizophrenia is chronic disorders (WHO, 2010). The onset of signs and symptoms of schizophrenia occurs usually in adolescence stage and early adult life (Fujino, and Okamura, 2009), so, diagnosis with schizophrenia is chronic, long term and often a

debilitating mental disorder that affects the all aspects of life for the caregivers and for the clients.

One meta-analysis proposed that about twenty percent of clients affected with schizophrenia show increasing disability and unremitting symptoms while around thirty-five percent of clients report that they had both remission and relapsing times with different length (Chien, et al,. 2013).

According to a study by Iseselo, et al. (2016) caregivers living with children affected with schizophrenic face complex difficulties. This includes, for example, emotional difficulties, lack of support from the community, and financial difficulties. The review report that mothers were affected by the diagnosis for her loved one in a variety of ways: household routines are upset, mother's life becomes disorganized, and family members fear psychotic episodes.

Previous studies focused on what has come to be known as the "family burden" of caring for a client affected with schizophrenia and has focused on the negative part of care-giving (Biegel et al., 1997). The Current studies attempt to approach to the new issue and explore previous aspects with neutrality and to focus on positive aspects of caring in the mother's experiences, such as the financial support, emotional support, caregiving role they provide to client affected with a schizophrenia (Bulger, et al, 2009).

Schizophrenia is chronic mental disorder, severe and disabling that causes major consequences of all aspects of life for those with the illness, as well as those caregivers. (Perkins, et al,. 2013).

Schizophrenia had consequences on a variety of domains in the patient, this mostly affected areas include emotion of clients, affect, perception, behavioral and motor functioning، and talking (Esan, et al,. 2012). Also, clients affected with schizophrenia mostly experience signs of cognitive impairment, apathy mood, fluctuations mood، and psychosis. Consequently, schizophrenia may take its characteristic on the psychological, biological, and social areas of individuals function within his life (Asmal, et al,. 2014).

Schizophrenia is a severe mental illness that prevalence range approximately from 0.3-0.7% of the adult individual worldwide, this disorder mostly appears between 15 to 35 years of a population (McGrath، et al., 2008). The onset of diagnosis with schizophrenia with an average in mid-twenties of age also estimated to be in late adolescence hood and early adulthood, (APA, 2013).

1.2.1 Background about mental health in Palestine

In Palestine Mental health problems remain under-treated, underreported and mental health services underfunded, under-resourced, for that mental health services in Palestine can't meet the client's caregivers need. Also, there are big shortages of infrastructure and human resources,

in 2002, the first situation analysis was undertaken by WHO in West Bank and Gaza revealed no mental health policy and a lack of public mental health services (WHO, 2003). The mental health system was still more hospital-based than community-based. Psychiatric hospitals in Bethlehem and Gaza were still the main assets to mental health care, while community mental health provision was extremely patchy and rooted in a traditional and biomedical-oriented approach. Services were fragmented, underdeveloped, poorly resourced and, in many areas, no services were available. Mental health human resources were extremely scarce, and existing staff were overworked, burnt out, poorly trained and demotivated. The public was unaware of the nature of mental illness, had misconceived views and held very stigmatizing and fixed beliefs surrounding mental illness. There was a lack of knowledge of mental health at primary health care level, no referral system or cooperation between different parts of the public health sectors or between the public health sector and the private sector or NGO sectors. (WHO, 2007)

Some non-governmental organizations were, indeed, providing good mental health services but in an uncoordinated way; therefore these fragmented good practices were not able to influence the general mental health system and actually were leaving untouched the culture of public sector services. in this situation, a traditional and sometimes archaic, biomedical model was prevailing and actually preventing innovative approaches taking place. This led to a lack of an integrated service system and the waste of resources in some situations, as the real needs of people

with mental health problems were not addressed, in addition, the 2002 situation analysis revealed no concept of holistic mental health care, high levels of stigma and no consumer support or advocacy groups. (Jabr, et al,. 2013).

1.3 Background to schizophrenia

1.3.1 Diagnosis of schizophrenia.

The diagnostic statistical manual version 5 (DSM-5) (2013) by APA give criteria for the diagnosis of schizophrenia.

The symptoms of schizophrenia classified according to DSM-5 as positive or negative symptoms. The Positive symptoms of schizophrenia include hallucinations, delusions, disorganization of cognitive abilities and disorganized behavior. And the Negative symptoms include abnormal expression of emotion, lack of motivation, anhedonia, and asociality. In addition, there are more symptoms for example decrease of cognitive abilities, remission, and relapse (APA, 2013).

The diagnosis with schizophrenia is typically chronic ،with times of relapses, but also around one-third of clients affected with schizophrenia will gain complete recovery within the first year of diagnosis, but mostly of clients require continuous caregiving and support (Fleischhacker & Stolerman, 2014).

Schizophrenia in male more than female and the symptoms more sever in man than in women, like cognitive impairments and negative

symptoms, also they experience poorer outcomes (Fleischhacker & Stolerman, 2014).

1.3.2 Symptoms of Schizophrenia

1.3.2.1 Hallucinations.

Hallucinations consider as one of the core symptoms of schizophrenia according (APA, 2013) hallucinating defined as false external stimuli that the client with schizophrenia feel while there is no physical input of stimuli of such in their environment and it non-existing or inaccurate for others persons who do not have schizophrenia. Clients experience hallucinating simply through their sense organs like, hear a sound, see things that not present, smell odder and taste things that not found in reality (Jordaan, 2012).

1.3.2.2 Delusions

Delusions are one core symptom for clients affected with schizophrenia (APA, 2013). Which can define as false beliefs or thoughts held in the client mind during a period of psychosis. However, these beliefs or thoughts consider as the symptoms of schizophrenia if this thought not shared by other people in the client's environment, religion or culture. Thus, delusional thoughts that client held usually deviate greatly from societal normative behavior (APA, 2013). There are different forms of delusions such as grandiosity delusion, delusion of persecutory, delusions of control, and delusion of reference.

1.3.2.3 Disorganized speech

Disorganized speech is the third core symptom that mentions as part in schizophrenia diagnosis (APA, 2013). These results due to clients difficulty concentrate or expression of thoughts (APA, 2013).

1.3.2.4 Catatonic behavior

This symptom related to the motor functioning of the client characterized by a state of stupor, lethargy and impaired in the level of consciousness (APA, 2013). In a state of catatonic the client does not answer any external stimuli. Client appear disoriented, waxy flexibility, and most of the time their body appear rigid and mute, they only focus on the interesting stimuli for them only without any concern to other stimuli.

1.3.2.5 Negative symptoms

The fifth core symptoms determine the diagnosis of schizophrenia is multiple symptoms that DSM-5 called negative symptoms of schizophrenia, negative symptoms include symptoms that affect daily and human function of the client, This result that the client may not function at a level expected from him as human behavior (APA, 2013). According to the DSM-5, a client with negative symptoms experience mostly have "emotional blunting" or, (Jordaan, 2012). In diminished emotional expressions, the client lacks the expected emotional behavior, like person poor or shy eye-contact, low voice, and flat affect to reactions are most of the signs of these characteristic symptoms of schizophrenia. For example, a

client affected with schizophrenia can't show pleasure and happiness when there is reason make them feel happy. Other negative symptoms include avolition, which defined as the inability to start or continue actions.

Schizophrenia characterized that symptomology of it has a significant emotional burden and socio-economical costs for the client themselves and for their caregivers (Awad &Voruganti, 2008). Direct economic costs include hospitalization and continuous mental and medical care, as well as provisions for economic and social support. Schizophrenia typically managed through antipsychotic drugs، which reduce the positive symptoms (APA, 2013). However, antipsychotic drugs have adverse side-effects and low tolerability, Psycho-social support and rehabilitation are also important to address negative symptoms, although these options are frequently underfunded or not available (Awad & Voruganti, 2008).

Also One of the barriers in caring for client affected with schizophrenia is a lack of insight that makes them noncompliance with various way of treatment or medication and relapse (Huxley, et al., 2000).

family members have unique experiences with Mental disorders because of the cultural and social atmosphere of secrecy، discrimination, and stigma, and also cultural tendency to perceive persons affected with mental illness as a dangerous mad man, weak, ، and unpredictable behaviors (Ganguly, et al., 2010).

Studies of experience of caregiver have increased since the appearance of institutionalization which means mental illness community-

based care (Saunders, 2003). Many studies have reported that the challenges of caring for a family member with severe mental illness is associated with reduced quality of life and has significant impacts on the mental health and functioning of caregivers (Zauszniewski, et al. 2009).

1.3.3 Types of schizophrenia

According to DSM-5 Schizophrenia divided subtypes that including

- Catatonic schizophrenia
- Disorganized schizophrenia
- Paranoid schizophrenia
- Residual schizophrenia
- Undifferentiated schizophrenia
- And schizoaffective disorder.

1.3.4 Prevalence of schizophrenia

Schizophrenia affects around 0.3–0.7% of people at some point in their life, or 24 million people worldwide as of 2011. It occurs 1.4 times more frequently in males than females and typically appears earlier in men, the peak ages of onset are 25 years for males and 27 years for females. Onset in childhood is much rarer, as is onset in middle or old age (Zegwaard, et al., 2013).

Families of client affected with schizophrenia often experience major challenges when it comes to dealing with this mental health problem. Caregivers often take on the task of caring for their client with limited support and resources. Also, mental health professionals often not include the caregivers in the care plan or treatment of their relatives (Boydell et al., 2013).

Further understanding experience and management's practices that used by mothers of their children affected by schizophrenia include barrier and difficulties that mothers face, and investigate both the positive and negative experiences of care giving, mother coping strategies, supportive factors, attitudes, and perceptions.

1.4 Aim of the study

- This study aimed at understanding the experience and management's practices that used by mothers of client affected by schizophrenia include difficulties and barrier that mother of face, and investigate both the positive and negative experiences of care giving, mother coping strategies, supportive factors, attitudes and perceptions

1.5 Objectives of the study

- Explore and describe the experiences of mothers caring for their client affected by schizophrenia.
- Identify challenges and coping mechanisms utilized by mothers to deal with their client affected by schizophrenia.

- Develop a conceptual map to depict a pattern of the experiences of mothers caring for their client affected by schizophrenia.
- Determine supportive recourses and needs that help in coping with this situation.

1.6 Research Questions

This study's research questions emerged from the literature review regarding of mother's experiences who are caring for client affected with a schizophrenia:

1.6.1 Main Research Question:

What is the lived experience of mothers as a caregiver for her client affected by schizophrenia?

1.6.2 Subsequent Questions:

- What are the lived experiences of mothers caring for their client affected by schizophrenia?
- How mothers are involved in the care and treatment of their client affected by schizophrenia, loved one؟
- What perspectives do mothers have regarding mental health professional's roles and the provided services to help mothers cope effectively with their adult offspring affected by schizophrenia?

- What are the challenges and coping mechanisms utilized by the mothers when dealing with their client affected by schizophrenia and how they manage?

1.7 Statement of the problem

Caring for a client affected with schizophrenia that characterizes with severe, long-term and disabling mental disorder has considerable major consequences for caregivers. Clients affected with Schizophrenia has low global functioning and a high level of required care also associated with a number of barriers to managing their symptoms. The literature on caregiver's burden has documented the significant social, psychological, and economic consequences on caregivers for an individual with this illness. In addition, stress is largely unrecognized and unacknowledged by a caregiver and mental health professional.

Having a client with a diagnosis of schizophrenia is stressful for families, and primary caregivers in particular (Tans, et al., 2012). Generally, the diagnosis of a major mental health problem is a severe stressor in itself, eliciting negative responses such as anxiety, fear, anger, guilt, and depression (Tiihonen, et al, 2011).

According to WHO,2015 report regarding the field assessment of health conditions in the occupied Palestinian territory the service users who treated in community mental health clinics or centers the rate of mental health problems were as following ; the neurotic disorders (24.2

%), learning disability (mental retardation) (14.6 %), schizophrenia (12.2 %), epilepsy (10.7 %), affective disorders (9 %), other mental disorders (7.8 %), organic disorders (4.4 %), personality disorders (3.3 %) and substance abuse disorders (1.7 %). The quality and quantity of care need improvement in these community mental health services. Palestine is a low-income country with scarce resources, which is seeking independence.

1.8 Significant and justification of study

This study conducted to generate an understanding of mother's experience that will directly influence or improve clinical practice (Burns & Grove 2011). This study should generate knowledge that will enable health care professionals working in psychiatric units to understand the mothers' experiences when caring for their client affected by schizophrenia and to give them professional and supportive services in managing mental illness at home. This may assist health care providers to improve the support and care for such families. The findings should contribute to clarifying the role of the family member's in the continuity of care for the mentally ill care users to prevent relapses and re-hospitalizations.In-service education programmers, health education talks with family members and mothers, and the training of students should also benefit from this study. Finally, the findings should assist in the formulation of protocols, policies, and documentation of discharge plans and approaches to caring for affected patients and mothers at home.

1.9 Definitions of terms

Experience

"Experience constitutes the process of meaning construction whereby people think about themselves and their position in relation to others, and the world around them" (Haung, et al,. 2007).

Schizophrenia

"Schizophrenia is a psychiatric diagnosis that characterized by abnormalities in the perception or expression of reality.At least symptoms last for more than one year" (APA, 2013).

Operational Definitions

Mother: primary career for the client affected with schizophrenia.

Client affected with schizophrenia: the client who has been diagnosed with schizophrenia since at least 1 year.

Experience: everyday encounters in life.

Chapter Two
Literature review

Chapter Two
Literature review

2.1 Introduction

This part of the study presents the synthesis of literature that includes Mothers experiences of caring for client affected with schizophrenia, challenges of the care provision, and impacts of the disorder on the mother as caregivers.

The literature part concludes with an identification of the gaps in our knowledge base that prompted this study and that the proposed study seeks to address.

Literature review develops one's understanding of the literature in a field of study through a synthesis of critical analysis and a narrative defined by guiding concepts.

2.2 The Search

Search of the literature performed to obtain original studies that investigated experience of mother caring for their client affected by schizophrenia in all aspects. The relevant studies were identified by the use of the PubMed database and EBSCO host. In primary search, two different strategies used with the following key words: first, experience of mother care of schizophrenic client; and second, barrier and facilitator of mother in care, mother burden. Afterwards, we attempted additional search using a combination that included the following key words as well: factor affect

mother care, dealing with schizophrenia, caregiver of schizophrenia, consequences of schizophrenia, burden among caregivers,

Literature review included original studies, reviews, books, written in English. Thus, reviews, editorials, letters and case reports were excluded from our study. Studies included in the review contained quantitative and qualitative research regarding the mother experience. Limitations not use regarding any study sample size did, study design, and specific measures of outcomes used in the various studies.

2.3 Care giver experience

2.3.1 Quantitative studies

Setsuko Hanzawa. Et al. (2008) conducted quantitative cross sectional study that aimed to identify factors that contribute to burden among mothers caring for clients affected with schizophrenia, the study include 57 mothers of the Federation of Families of People with Mental Illness in Nagasaki Prefecture, the mothers evaluated using well-validated scales to evaluate burden of care that include general health status (General Health Questionnaire 12-item version), , coping strategies, difficulty in life, understanding of mental illness and disorders and emotional support, the finding indicate that no difference according to sociodemographic variables to be associated with burden. Burden significantly associated with general health status and difficulty in life, also On multiple regression it was found that resignation' and ‘social interests' are both of most coping mechanisms used by mothers.

Aggarwal, et al. (2011) conducted quantitative study that aimed to investigate experience of caregiving in schizophrenia, the study include Fifty caregivers of clients affected with schizophrenia, the study concludes that coping strategies used by the caregivers, education of caregivers and available social support influence the final appraisal of caregiving.

Doval, et al. (2016) conducted a quantitative study that aimed to assessment of the 'experiences of' coping strategies and caregiving' of the caregivers of clients affected with schizophrenia, and to study associations. The study was quantitative, cross sectional, included 102 caregivers of clients affected with schizophrenia using 'COPE Inventory' (COPE) and Experience of Caregiving Inventory' (ECI). The result of the study showed that the negative experience of caregiving was 'effects of illness on a family' as a whole while the term of 'stigma' was the lowest. Other domains had moderate scores of positive experiences are good aspects of a relationship. Also, care giver used a wide range of coping strategies which was adaptive and maladaptive. There are significant positive correlations emerged between adaptive coping strategies and positive experiences of caregiving, and between maladaptive coping strategies and negative experiences of caregiving and.

Boyer, et al. (2012) conducted a quantitative study that aimed to assess QoL of the caregivers of individuals with schizophrenia in two countries characterized by different social, economic and cultural conditions, namely Chile and France. The Methods was quantitative using

short-form health survey scale - 36 items (SF36). QoL of 41 Chilean caregivers to assess QoL. The finding of the study showed that Despite differences between Chile and France, especially in terms of quality and quantity of mental health services and economic supports, caregivers' QoL levels remain particularly low for both countries. Future support needs for caregivers.

Bharati, et al. (2015) conducted descriptive exploratory research that aimed to assess the coping strategies among the caregivers of patients with schizophrenia. This study adopted a descriptive exploratory research design. 100 adult caregivers were recruited from the psychiatric wards of selected tertiary care hospital of Nagpur, India, by non-probability purposive sampling method. Necessary permission and approval were obtained from the competent authority. The tools used to collect data were a socio demographic profile and Family Crisis Oriented Personal Evaluation Scale (FCOPES). The result shows the majority of the caregivers were male and parents above the age 50 yrs. The majority of the caregivers were non-literate and unemployed. Most of the caregivers used ‘seeking spiritual support' as the strongest coping strategy and ‘mobilizing family to accept help' as the weakest coping strategy. There was no association found between the selected demographic variable and the caregivers' coping strategies.

To’meh, (2013) conducted study that aimed to assess family Burden among Caregivers of Mentally Ill Patients in Nablus District, The study

finding indicates that burden significantly linked with the level of educational, gender, and economic status. Also, there are no differences found between age and mental disorder type. The study Conclude that Higher burden was linked to female, low level of educational, and low economic status. While higher objective burden scores were correlated with being male, high educational level, and high economic status.

Goodman, et al, (2007), conducted a quantitative study that aimed to find out the burden of care of caregivers of patients with schizophrenia, their finding suggests that despite such negative experiences, most caregivers did, at times, experience support from a few people who understood or tried to understand. Caring for a loved one who is ill often creates a deepened sense of closeness and connection between the caregivers and the person with schizophrenia. Family caregivers may also experience increased intimacy, satisfaction, and pride in the course of caring for their loved one with schizophrenia. However, the anxiety that comes with dealing with serious illness, combined with the burden of caregiving, can create strain in the relationship potentially stress caregivers. Similarly, in some situations, caregivers may feel guilty, angry, beset, anxious, resentful, and even depressed. The aforementioned varied and complex emotions in caregiving for a person with schizophrenia are among the most common. Thus, feeling both positive and negative emotions when providing care for a loved one who is ill is normal.

2.3.2 Qualitative studies

Yi, et al. (2014) conducted descriptive qualitative study that aimed to explore experiences of mothers' in caregiving for their adult children affected with schizophrenia in Korea. The method was descriptive qualitative research design used to explore, explain and understand the caring experience of mothers using and one focus group and in-depth interviews with 11 mothers, qualitative thematic analysis used to analyze the data. The finding identifies 3 themes the first was "emotional debris from the disease," the 2^{nd} "the disease that makes mothers dumb" the 3^{rd} "space of rational reason." The most thing that mother need is education, information and deeply understanding the process of recognition and acceptance of their children affected with schizophrenia.

Suryani, (2015) conducted a qualitative study that aimed to understand the experiences of Indonesian family care provider member with schizophrenia within the family, 9 primary care provider selected, data collected through in-depth interviews with each caregiver. Analysis of data using Colaizzi's approach. The finding of this study emerged 6 themes: living with a family, losing a loved one, challenges in interpersonal relationships, member experiencing paranoid thoughts, living with hopeful expectations of recovery, the need for respite care for family members and the need for appropriate support from health professionals. The study Conclude that there is need to focus on the family as a whole not only on the person have schizophrenia. Also, theirs need for further research needs

to identify the specific mental health care providers interventions which effective in helping care providers of a client with schizophrenia.

Huang, et al. (2008) conducted qualitative research that aimed to gain understanding the experiences of coping for care giver of a client with a schizophrenic. The design was qualitative descriptive phenomenological research to understand the experiences of coping of carers living with a client with schizophrenic. The result showed that there are two coping mechanisms most commonly which are social coping strategies (professional support, religious and social) and psychological coping strategies (behavioral, emotional and cognitive). Also, 3 factors identified in the study, including feelings of shame, low social status, and traditional help-seeking behaviors. Also, result demonstrate the importance of understanding the coping experiences of care givers who care with relative affected by schizophrenia.

Bidisha & Shikha (2016) conducted a Qualitative study that aimed to find the meaning of care-giving experiences in the Indian context. The method was qualitative Narratives in-depth unstructured interviews from 10 families of diverse mental illness types. An interview guide was used for data collection. Interviews were taped and transcribed and discussed under three broad categories: resilience acceptance and suffering. The findings depict sufferings of family caregivers who were watching their loved ones suffer from illness; the gradual detachment in the relationship, and no reciprocity in caring along with meeting the financial and other demands.

The study demonstrates that gradually the family caregivers accept their role as carers and consider their work as part of their lives or ‘dharma' (the social responsibilities towards others, which are mandatory). Finally, the study sketches the family caregivers' journey towards becoming resilient over time. They could not separate their suffering from the patients' suffering but accepted the difficulties of their role. In the long run, they became resilient in handling the caregiving demands. This study can have a major impact on developing a culture centric intervention for family caregivers.

Johansson, et al. (2010) conducted a qualitative study that aimed to describe everyday life experiences of mothers who have an adult child with a long-term mental illness. 16 mothers included, by interview. Data analyzed used content analysis, the finding showed one main theme: My adult child who is struggling with mental illness is always on my mind, and three subthemes: (1) living with an emotional burden, (2) seeing light in the darkness despite difficulties and (3) living a life under constant strain. The study concludes that everyday life experiences are of great importance in order to support them and thereby increase the possibility of these mothers being a source of strength for their child.

Kılıç & Saruc (2015). Conducted qualitative study that aimed to reveal life experience of mothers with children with schizophrenia in Turkey. The method was qualitative. It was understood that children with schizophrenia vary pre morbid such as introverted, jealous, an inability of

socializing and failure at school. For mothers, onset period of the illness is quite painful and troubled. Mothers' basic idea about the cause of their children's illness is physical violence. The most important effect of the illness on the mothers is anxiety about the future of their children.

Wiens, (2015) conducted study aimed to explore and describe the experiences of personal growth and change of six mothers of adult children with schizophrenia, resulted in four common themes (Enduring sadness and loss, Distress and struggle, Commitment to helping/action, Personal and relational change); four significant threads (What will happen when I am no longer able to care for my child?, Impact on siblings who are well, Fluctuations in hope, Regret/Guilt); and four broader dimensions (New normal mothering, Changes in mothering over time, Involvement in the mental health system, Adaptation and engagement with life in new and meaningful ways).

Azwihangwisi, (2013) conducted study was to explore the experiences of mothers whose children were diagnosed with childhood schizophrenia. Participants consisted of eight mothers of children with schizophrenia from a rural village in the district of Vhembe, South Africa. They were interviewed at their homes, using in-depth, phenomenological interviews. Eight themes emerged from the participating mothers articulations. They were identified as poverty and unemployment, emotional reactions of mothers, blaming witchcraft, dealing with the children s violence, aggression and destructiveness, financial and social

support, an effect of schizophrenia on the mother-child relationship, and the loss that mothers go through. The study reconfirmed that caring for individuals with schizophrenia is not an easy task for mothers. Recommendations were advanced on the basis of the findings.

Rafiyah & Sutharangsee, 2011 conducted Qualitative study about experience of caregiver of individual with schizophrenia, finding suggest that Mother is the most important person who cares for the person with schizophrenia and mother usually helps the client affected with schizophrenia in performing their daily living activities such as, dressing, bathing, cooking, eating; taking medications, and going for checkups. Mother's personal needs for rest and attention to their own health may be neglected though not well addressed. This leads to dealing with multiple responsibilities, some of which may conflict with one another, caregivers face many difficulties of both making sure the person they care for has access to treatment and services, as well as taking care of themselves.

Summerville and Atherley, (2012), conducted qualitative studies that aimed to explore caregivers experience to have person diagnosed with schizophrenia at home, their findings showed that care-giving for a person with schizophrenia demands a variety of activities and roles. Thus, the caregivers not only had to deal with the demands and stresses related to the care for the ill relative, they also had to battle the health care system and the professionals who worked on it. In his message for family caregivers indicated that the feelings of frustration, guilt, and powerlessness due to

underestimation of the caregiver's role by health professionals may hurt caregivers. The cumulative impact on the caregivers could be devastating and admit to such anger and despair is not easy.

Jeon & Madjar (2004) conducted phenomenological study conducted in Australia aimed to explore experience of caring for a client with schizophrenia, the results indicated that support from the community for caregivers for a client with schizophrenia decrease the caregivers' feelings of isolation and increasing their feelings of confidence and was particularly meaningful.

2.4 Care giving Challenges

Findings from on line survey conducted by National Alliance on Mental Illness (NAMI, 2008), in the United States, that aimed to find out effect of having person with mental disorder within the family, The findings indicated that; mental illness affects the entire family, -More than two-thirds of caregivers (68%) are the parents or step-parents of the person living with schizophrenia to which they provide care. Brothers and sisters comprised12% of caregivers and 7% are spouses or significant others. Seven percent of caregivers are the children or grandchildren of the person under their care. The greatest challenge for all these family members is simply finding treatment, care providers, and services for their loved ones. In addition, the most concern /worries for families was the future of their relatives, also caregivers face various challenges can be as significant as those affecting people living with schizophrenia. Most caregivers of

persons with schizophrenia worry about the future of their loved ones when they die. An especially stressful challenge encountered by family caregivers caring for family members with schizophrenia is high-risk behaviors. These create emotional stress for family members arising from constant worries that the family member is going to develop high-risk behaviors or is actually engaged in them (NAMI, 2008).

Summerville and Atherley, (2012) conducted a qualitative study that aimed to find out the experience of caregivers of mental illness person, the finding show that mental illness is not always the greatest challenge. Rather such barriers and difficulties resulted from factors that breed physical, psychological and financial stress and strains for family caregivers of persons with schizophrenia. These situations heavily bear on the family and may create disagreement among family members that too often goes unaddressed and as a result, the illness and tensions among the family unit are exacerbated.

2.5 Impact of Disorders

The impact of mental health problems is not a simple factor that only affects the individual with the disorder. Mental and behavioral disorders have a large impact on individuals, families, and communities at large. Individuals who provide care for their loved one with mental problems also suffer from the distressing symptoms of disorders. Family caregivers also suffer due to the fact that they are incapable to deal with their own businesses including work and leisure, which may result from

discrimination. They may be troubled about their unmet needs and may not be able to carry their responsibilities towards family and friends. Family care givers are fearful of developing dependency syndrome in which he/she may incline to depend on other individuals (Zauszniewski, et al. 2010).

The burden on families ranges from economic difficulties to emotional reactions to the illness, the stress of coping with disturbed behavior, the disruption of household routine and the restriction of social activities (WHO, 1998). Expenses for the treatment of mental illness often are borne by the family either because insurance is unavailable or because mental disorders are not covered by insurance.

A study conducted by Shibre et al,. (2003) that aimed to investigate the impact of schizophrenia on the families and caregivers in Ethiopia shows that the impact of schizophrenia on family members is high even in traditional societies such as where the family network and informal social control is said to be strong and important. This study also indicated that more burden is experienced by female relatives than male relatives.

Abu Subaih (2010) conducted quantitative study that aimed to identify burdens and stigma among Jordanian family caregivers of patients with mental illness, the findings showed that the northern region caregivers' experiencing highest burdens and stigma. The findings suggested several implications for nursing practice, education and nursing administration.

2.6 Coping strategies

Grover, et al. (2015) recent review explored coping strategies and caregiver burden in caregivers of people with schizophrenia. This review concluded that coping strategies are associated with caregiver outcomes, including burden, psychological morbidity, and quality of life. The review linked problem-focused coping with better outcomes, and stated that emotion-focused coping is less clear in terms of impact.

Aggarwal, et al. (2009) conduct a qualitative study that aims to explore caregiver of mental illness coping mechanism, they found that seeking social support and positive communication were the most commonly used problem-focused coping mechanism in their sample.

Kate et al. (2013) conducted a quantitative study that aimed to explore mothers caregiver of client affected with schizophrenia, the result found that 83% of caregivers reported that they used problem-focused strategies, and 73% sought social support as a method of coping.

Tan et al., (2012) conducted study aimed to investigate the experience of mothers caring for mental illness child, reported that acceptance (of the illness) appeared amongst most of the mothers and coping strategies identified as positive and has the lower level of burden. Also, he indicates that use of acceptance coping strategy was protective against distress. Through multiple regression analyses, they found that acceptance partially mediated the relationship between distress and illness identity and personal control.

Bharati, et al (2015) conducted study aimed to assess the coping strategies among the caregivers of patients with schizophrenia. The objective was to explore the strongest and the weakest coping strategies used by the caregivers and to associate their coping strategies with selected socio demographic variables. This study adopted a descriptive exploratory research design. 100 adult caregivers were recruited from the psychiatric wards of selected tertiary care hospital of Nagpur, India, by non-probability purposive sampling method. The result shows Most of the caregivers used ‘seeking spiritual support’ as the strongest coping strategy and ‘mobilizing family to accept help’ as the weakest coping strategy. There was no association found between the selected demographic variable and the caregivers’ coping strategies.

2.7 Theoretical framework

Phenomenology used as a theoretical framework for this study. The aim of phenomenology studies is to describe particular phenomena, or the lived experience (Carpenter & Speziale, 2007). According to Giorgi, (1997) "Lived experiences involve the immediate consciousness of life's events prior to reflection and without interpretation، and are influenced by those things that are internal or external to them. It is the lived experience that gives meaning to each individual's perception of a particular phenomenon and thus presents to the individual what is true or real in his or her life" (Giorgi, 1997).

The role theory states that every person is considered as an actor of social relationships. There are categories of persons more or less similar in some aspects. These categories are called positions: father, mother, son, and others. Accordingly mother has different rolls; in general and once the family have member with chronic

A person in a certain position displays expectations about the form in which he/she is going to behave with other persons in the same position. This set of expectations is called role sector. In many occasions, schizophrenia makes family expectations regarding the patient, unfulfilled. This produces discomfort in all family members implied (Martínez, 2002).

The stress theory establishes that hardships associated with the disorder function, as environmental stressing factors or chronic tensions, originate the subjective aspects of burden. This produces a number of changes in the caregiver as the result of the interaction among the assessment of their coping strategies (Veltman, et al. 2002).

The systemic theory establishes that although burden refers to a family phenomenon, it is necessary to consider family in its social context to understand this concept. Hierarchically, the following subsystems can be recognized: individual, familiar, social network, and community and/or culture. Each subsystem has its own features and dynamics. The family would be a dynamic system affected by its subsystems and by external systems with a continuous input and output of information. In some cases,

family burden generates a closure in its external and internal limits to prevent the family from changing.

This study nevertheless used a descriptive phenomenological approach in order to provide a structure for understanding the phenomena of experiences among mothers. Therefore, in this study, the researcher's aim was to understand experience and management's practices that used by mothers of children affected by schizophrenia include difficulties and barrier that mother face, and investigate both the positive and negative experiences of care giving, mother coping strategies, supportive factors, attitudes, and perceptions.

Chapter Three

The Method

Chapter Three
The Method

3.1 Introduction

This chapter clearly defines the research methods used to conduct the study. The researcher explains how the necessary information and to data address the research objectives and questions was collected, presented and analysed. Reasons and justifications for the research design, research instruments, data sources, data collection techniques, data presentation techniques and analytical techniques used are given.

3.2 Design

Heppner et al (2004) describe a research design as a master plan which indicates the strategies for conducting research or as a structured plan include a list of procedure and specifications for controlling and performing a research project.

The design used in this study is qualitative phenomenological descriptive design.

Qualitative Research is primarily exploratory research. It is used to gain an understanding of underlying reasons, opinions, and motivations. It provides insights into the problem or helps to develop ideas or hypotheses for potential quantitative research. Qualitative Research is also used to uncover trends in thought and opinions, and dive deeper into the problem. Qualitative data collection methods vary using unstructured or semi-

structured techniques. Some common methods include focus groups (group discussions), individual interviews, and participation/observations. The sample size is typically small, and respondents are selected to fulfil a given quota (Englander & Robinson, 2007).

This design used to study the experience of mothers include describing the aspect of their caregiving role also will be an indicator for the mothers thought and feelings. (Barroso,. 2010). Semi-structured interviews conducted with mothers of each client.

Mothers chosen primarily was based on a descriptive approach where our primary goal is to provide some explanation how the mothers are experiencing their daughter/sons with schizophrenia in their homes and describe the experience with care.

3.3 Giorgi – Phenomenological psychology

The research method used here is Giorgi descriptive phenomenological. This design suitable here is phenomenological psychology following Giorgi (1971) because this method allows researcher to produce accurate descriptions of people experience.

The purpose of Giorgi's phenomenological research is "to capture as closely as possible the way in which the phenomenon is experienced (Giorgi, 2003). Phenomenology is used to investigate for the psychological meanings that constitute the phenomenon in the life world of participants.

The idea of phenomenological research is to study how participant lives, that is how they behave and experience situations (Giorgi, 1985). Their experience is based on their life within the context in which the experience is taking place.

The process of research in phenomenology to starts with describe the situation as in daily life to give experience (Giorgi, 1985).

3.4 Study Participants

Participants were the primary mothers of clients affected by schizophrenia. The sample was purposive sample in order to achieve the study goals.

3.4.1 Sample size

The sample for this study is a purposive sample (Polit, 2006). We included 11 mothers and taken their consent to participate in the study. According to Giorgi method are three interviews sufficient to achieve the purpose of the study (Giorgi, 1985). Semi structured interviews conducted with mothers.

3.5 Inclusion criteria

- The mother of client age between 18 -30 years because the actual diagnosis can be done in this age period.
- The diagnosis of schizophrenia has been done at least 6 months prior to the interview.

- The client doesn’t have any co morbid disorder.

Exclusion criteria

- mothers can’t give consent form.

- mothers with mental or other disabling disorders

3.6 Setting

The setting of data collection was Hebron Community Mental Health Center. In Hebron district – West Bank- Palestine.

According to leaflet about the Center the Mission as proposed in it:

"Providing psychological service and awareness of all mental disorders, medical community, and treatment of mental illness, in addition to training the healthy to be better and to work for the prevention in the field of mental health and raise the awareness in the field of mental health"

Hebron is the largest city in the West Bank and has a population of around 729,193 (PBCS report, 2016). These people are the target centers of the service offered by the primary mental health care center operating in Hebron. In Hebron, the district divided to 3 area and have 3 major directors of primary health care, north, middle and south Hebron, but theirs one mental health center located in Hebron city for 3 major directors.

3.7 Selection of the study instruments

We have the interview process that has been followed a semi structured interview guide with different themes and underlying issues

designed from the essay purpose and question. Interview guide act as a support for that important issues not be forgotten during the interview. It also serves as a designated by the order in which different themes to be addressed. We use the interview guide as a checklist to ensure that all the themes were taken up instead of letting the interview wizard guide the conversation. This we believe contribute to the interviews generally feel relax and natural, rather than a form of hearing.

3.8 Data collection

3.8.1 Interview

Interview subjects include mothers to male and female clients affected with schizophrenia.

Comfortable, private room, free from interruptions in the clinic was used for the duration of the interviews, the participants were reassured that confidentiality would be maintained at all times. Participants were given

All interviews were audio taped with the consent of participants. The researcher kept a field note book to pen write participants ‘unspoken words, and mannerisms which could not be captured on tape to help during analysis.

The mothers obtained a consent form, which retained, and an information form, which they kept. The collection made through record interviews with a few people (11 women). Each interview was between 30-45 min, but even shorter descriptions exist, which in this study is that the

interview began with a question that the informant allowed to speak freely outside. We put as little questions as possible in order not to affect their own assumptions. About follow the questions asked there only to get a more detailed and deep description (Englander &Robinson, 2007).

Sound quality was good on all recorded interviews which allow that the interviews easily be transcribed without the pieces have fallen off because of noise. The interviews transcribed verbatim and all identifying features removed to ensure anonymity. All interviews first listen through. We printed the interviews and then summarized similarly to what calls meaningful merger operation. Some quotes saved in their original form.

Mother interview conducted the experiences of the mother's condition, its impact, handling (coping with life), perceptions of social support in everyday life and family patterns. Issues surrounding the clients day-to-day explored, focus on their styles to manage the behavior, and asked details of the history of the client's current problems, the nature of the symptoms (frequency, duration, situational variation). What is the importance of client's daily routines, interaction with family at home?

As a result, research focused on the holistic approach that provides to the client at home. The interviewer has to avoid asking leading questions, but rather seeking concrete descriptions of events, feelings, etc.

The initial question to the mother: What is your experience of being a parent of a client affected with schizophrenia?

Trustworthiness of the data ensured by appropriate sample selection to ensure credibility, show the logic flow of the data collection and analysis, and by verifying the findings with the informants to demonstrate fittingness or transferability of the findings.

3.9 Pilot study

The above method tested in the pilot study. The pilot study involves one informant. The researcher chooses One Mother of the schizophrenic client, who asked to participate in the study. The interviews were done in an isolated room in the clinic. The interview taped and the text treated in accordance with the above analysis, which this pilot interview might be included in the study sample.

3.10 Data Analysis

Giorgi Phenomenological psychologists analyses used. Data analysis according to Giorgi consists of four ordinal steps where each step is a prerequisite for the next (Giorgi, 1985b, 1997). Prior to the analysis transcribed each interview verbatim. All steps in the analysis must be performed within the phenomenological reduction (Englander & Robinson 2007). (Giorgi, 1997).

The research continuously for essay writing address theory, method, and purpose of the essay and the question as coherent and not as separate parts. The analysis of the material will be already in progress from the time we will start with the collection of material. The thought of how we will

analyze the collected material has been with us from the beginning of the choice of qualitative method. Designing the interview guide is a breakdown of the various themes in addition to background information has been about

Step 1: **Getting the sense of the whole statement by reading the entire description**

The entire interview protocol was read several times in order to get a sense of the whole experience. The idea was to obtain a description, not to explain or construct (Giorgi, 1989). Wertz (1985) suggest that readers should see raw data as well as processed data

The first reading is done in the natural attitude (i.e., the everyday attitude) told the researcher to more actively identify and critically examine their own interests, creditors learned, theories, hypotheses and existential assumptions about the phenomenon and then set them in brackets (Giorgi, 2005).

If certain passages of the collected material unclear, it is important that the author does not pad with their own interpretation, but instead goes back to the interviewee and ask for clarification descriptions. If the author is unable to collect further information about them will be later forced to describe the uncertainties that exist in the data. Ambiguities and contradictions in the data may not reduce or declared the basis of possible interpretations, but must always be described as such. (Robinson & Englander 2007), (Giorgi, 1985, 1997

Step 2: discriminating meaning units within a psychological perspective

After going through the first step, Giorgi (1986) suggests that the whole description should be broken into several parts to determine the meaning of the experience and these are expressed by the slashes in the texts (Giorgi, 1985) or by the numbering of lines (Wertz,1985). Parts that were relevant to the phenomenon that is being studied were then identified. The process of delineating parts is referred to as meaning units, they express the participant's own meaning of the experience, and they only become meaningful when they relate to the structure of all units (Ratner, 2001). A word, a sentence or several sentences may constitute a meaning unit.

Each meaning unit is constituent and therefore focuses on the context of the text (Giorgi, 1985). The meaning units are correlated with the researcher's perspective and therefore two researchers may not have identical meaning units (Giorgi & Giorgi, 2003a). This process takes place within what is called reduction. It is important in phenomenological psychology to withhold the existential judgment about the experience of the participant.

Step 3: Transforming the subject's everyday expressions into psychological language

The researcher returns to all of the meaning units and interrogates them for what they reveal about the phenomenon of interest. Once the

researcher grasps the relevance of the subject's own words for the phenomenon, Researcher expresses this relevance in an as direct manner as possible. This is called the transformation of the subject's lived experience into direct psychological expression. This step that makes it clears through the description of the intrinsic meaning in the material. Furthermore, the researcher must make clear the implicit meaning of meanings which the text points to, i.e., make explicit what is implicitly given. For that transformation must be kept at a descriptive level, it is essential, however, does not go beyond what is directly given in the data

Step 4: Synthesising transformed meaning units into a consistent statement of the structure of the phenomenon.

- Making the meanings units coherent and syntheses by relating them to each other to have meaning statements.

Specific statements are written for individual participants and a process of analysis is used whereby common themes across these statements are elicited and then form a general structural description which becomes the outcome of the research., the actual sentence structure on the investigated phenomenon described (Robinson & Englander 2007), (Giorgi 1985, 1997).

Sentence structure consists of the elements identified in the previous step and understood through their relationships and the way in which they are related to each other. Sentence structure is achieved by the researcher as

in step three make use of imaginary variations to arrive at the final sentence structure that cannot vary. All data must be considered and the researcher must also have been sticking to a purely descriptive language. If there are contradictions or ambiguities in the material shall be described but not explained or understood in terms of interpretations, theories, hypotheses or other existential assumptions. If the context and other contextual factors are relevant to the phenomenon must also be described. There are three levels of which the structure can be described. The first level is the individual structure that is based on a description of an informant. The second level is the general structure that can be achieved by having multiple descriptions (usually three). At the third level, we find the universal structure, which is located on a philosophical level. To find the general structure is always desirable when it can be generalized to other people experiencing the same type of phenomenon

Once the description of the psychological structure of each individual had been identified, the researcher looked at statements that can be taken as true in most cases.

3.11 Saturation of the Data

According to Polit and Beck (2008) saturation met in the time of qualitative data reach to a point where a sense of closure is met as further data yield as repetitive data. Also Burns and Groove (2005) state that saturation of data in a qualitative study is connected to the size of the sample which mostly dependent on the thematic analysis that follows each

interview transcribed or to continues until no more themes generated from the interview data.

In the current study, data saturation occurred at the 9th mothers. the researcher's conducted 2 more interviews to clarify the issue in the phenomena under study and to ensure saturation.

3.12 Credibility and dependability

Matters relating to the implementation of interviews and analysis can say something about the survey's reliability. Before the interviews, the authors write down what they expected to find in the survey and be conscious of how their backgrounds might be to color the survey. The authors could thus greater curb their expectations, bracketing (Englander & Robinson, 2007).

The authors may, by making themselves aware of their own attitudes, become a better listener who trying to put themselves aside and take the dialogue partner seriously.

All interviews recorded on a tape and transcribed verbatim. This makes the survey more credible than if the authors had only taken notes during the interview (Stebbins, 2001).

The credibility of the data may be related to whether respondents tell the authors truth (Stebbins, 2001). In this study authors are looking for experiences to mothers of caring for client affected with schizophrenia. An experience is subjective and thus true for the one who tells it.

The mothers asked if the authors really got something out of this when she had told its history. It is important that the analysis and presentation of findings made in a credible manner.

The authors follow analysis model to Giorgi (1985) as described and tried to be true to the stories of mothers and teachers. The authors selected in this study using a phenomenological approach to the theme, this give the authors more aspects of the findings. Using a developed analytical model, give an opportunity to test the analysis that is done (Stebbins, 2001).

3.13 Evaluating the quality of phenomenological research

When presenting phenomenological research, its value is established by honoring concrete individual instances and demonstrating some fidelity to the phenomenon (Jackson, et al., 2008). Research reports may, for example, contain raw data such as participants' quotations providing an opportunity for readers to judge the soundness of the researcher's analysis.

The quality of any phenomenological study can be judged in its relative power to draw the reader into the researcher's discoveries allowing the reader to see the worlds of others in new and deeper ways. Polkinghorne (1983) offers four qualities to help the reader evaluate the power and trustworthiness of phenomenological accounts: vividness, accuracy, richness and elegance. Is the research vivid in the sense that it generates a sense of reality and draws the reader in? Are readers able to recognize the phenomenon from their own experience or from imagining

the situation vicariously? In terms of richness, can readers enter the account emotionally? Finally, has the phenomenon been described in a graceful, clear, poignant way Developing trustworthiness of a qualitative study, credibility, dependability, confirmability, and transferability.

3.13.1 Credibility

Credibility focuses on the truth and value relating to the findings of the study and the representation of these (Topping 2006). The researcher, through the use of semi-structured interviewing techniques, tape recordings of the interviews and transcriptions of verbatim quotes, increased the accuracy of the descriptions of participants' experiences and therefore increased the credibility of the findings (Streubert & Carpenter 2010).

3.13.2 Dependability

Is concerned with the ability of the data to remain stable over time, would the study findings be replicated if undertaken with similar participants in a similar context. Credibility cannot be attained in the absence of dependability. The researcher used an audit trail to enhance the dependability of the study. It involved tracking and recording all decisions which could influence the study so an outside individual can examine the data (Streubert et al 2010). The researcher is keeping all recordings and of all decisions regarding the study with all other information under lock and key.

3.13.3 Conformability

Refers to the data representing the information participants provided. There were no biases or subjectivity in the study; the findings represented the participants voice (Polit & Beck 2010). The researcher upheld this principle by clarifying all information with the participants. The researcher made a follow up interviews to two participants.

3.13.4 Transferability

Involves the extent to which the findings of a qualitative study can be useful to similar groups or situations (Parahoo 2006). The study will enhance knowledge and subsequently result in the developments and practice of care giving. It should be understood that to achieve the robustness of study, accurate records were kept of all interviews and interactions with participants, as the careful recording of data was crucial to the study. The researcher considered at all times, strict attention to details, adhering to procedures and through consistency and accuracy throughout the research process.

3.13.5 Autonomy

Participants were given clear unambiguous information regarding the research, comprehended the information and the option to consent or decline participation voluntarily as Polit and Beck 2010 stated. Informed consent was sought from every participant. Information sheet was also explained to all participants and were provided with copies of the consent

form. Polit and Beck (2010) advises the consent form should be clear, concise and easy to read with no jargon. These information sheets and consent forms were stored under lock and key and only the author and her two supervisors had access to. The researcher also explained to participants they have the right to withdraw from the study at any time.

3.13.6 Confidentiality

Confidentiality is essential; the researcher will safeguard participant's identities and responses from public disclosure (Stake, 2010). The researcher assured participants of confidentiality and was respected at all times. Pseudonyms were used throughout the study. Participants were assigned an identification number which was used throughout the study and no identifying information was entered onto computer files. Encryption technologies were used to protect electronic data in keeping with the Policy on Good Research Practice (Stake, 2010).

3.13.7 Beneficence

One ethical principle in research is beneficence, where the onus is on researchers to minimize harm and maximize benefits for the participants themselves, other individuals or society as a whole (Polit and Beck 2010). The sole aim of this study was to be of benefit. The researcher is certain that this study will be of benefit to the nursing profession and subsequently improve the lives of informal caregivers of individuals with schizophrenia.

3.13.8 Non-maleficence

Research should not cause any harm to participants either physical or psychological (Parahoo, 2006). The researcher, therefore, listened attentively to participants, provided an opportunity for them to voice any concerns or queries they have regarding the study.

3.14 Ethical consideration

The study approved by the Ministry of Education and An-Najah National University Research Ethics Boards (IRB). Consent obtained from informants to take part in the study. (Annex II).

The informants, who wish to attend, informed by the interviewer, both verbally and in writing (Annex I) for the purpose of the interview and study, at the same time, the agreement is made on the time of the interview. The participant informed that the interview conducted in a private room which just the informant and the interviewer present and that the interview recorded by tape recorder and that no individuals can be identified after text processing. Information on all bands and prints the text stored under the current rules in locked cabinets. The informants also informed of the voluntary nature to participate in the study and that at any time can stop the interview and that these not affect them in any way. The data stored until the investigation is completed. After that, all the material from the interviews be destroyed

On the information sheet, there are telephone numbers to interviewer and supervisor about any issues raised if the informant feels the need for

further discussion. These considerations are based on the Helsinki Agreement (World Medical Association. Helsinki Declaration, 2008) on ethical guidelines for nursing research on volunteerism, to withdraw from the project, potential risks or discomfort, anonymity, confidentiality, and contacts for any information needed.

Phenomenological studies are always retrospective (Parahoo, 2006). So it is with this study. The mothers tell their stories of adventures. To construct the stories seem to be a natural human process that assists individuals in understanding the experiences and themselves (Stake, 2010). How can it be a health effect for informants to participate in the survey? Several studies were done over the years and that says it is significant, positive, consistent and identifiable relationship between talking about emotionally difficult experiences and health. To construct their own history is a type of knowledge that helps to organize the emotional effects of experience as well as experience in itself.

"Being able to tell their history" can be experienced as healing in itself. At the same time, it might give some benefits for other parents and teachers in the same situation as a whole.

Confidentiality of the records and information mentioned in the beginning of the interview. The informants' identities protected fully. No names or other information that may reveal informants' identities reported.

Chapter Four

Finding of the Study

Chapter Four
Finding of the Study

4.1 Introduction

This chapter presents the results about the experiences of mothers of clients affected with schizophrenia in Hebron District. 11 mothers were interviewed (Appendix F) and take– about their experiences regarding care giving for their children client affected with schizophrenia. Data collected through In-depth interviews with mothers from November 2016 to February 2017. Gorgi phenomenological analysis was employed in addition to field notes on the behaviors during interview, some of the reactions like mannerism, tears of the participants that could not be

Reordered. The data were analyzed in order to provide deep interpretation to deeper understanding of mother's experiences, the transcribed written data was read more and more to identify ideas, words, concepts, memos, and themes that frequently appeared. The themes, concepts, and words were and checked and compared with all transcript and found to be saturated and consistent by the end of the ninth participant interview. After data become saturated, more 2 interviews were conducted as follow up interviews to ensure saturation and to clarify issues that were reported by some participants in earlier interviews. The themes and sub theme were grouped to reflect the experiences of the mothers (Table 4.2).

Four main themes were generated with multi sub themes. The themes identified from the interview discussed here using the mothers 'own words.

The mothers were interviewed using numerical arrangement and the findings are presented using M numerical arrangement to personalize the verbatim report and conceal the mothers 'identity. The mention of mothers using code name as the following, M1, M2, ……, M11

All mother included are main care giver for their children affected with schizophrenia,

4.2 Findings of the study

The result of the study presented in paragraphs according to theme and sub themes.

4.2.1 Description of the sample

The eleven (11) mother's caregivers were included aged between forty-three (43) and fifty-four (54) years. They were all main caregivers for their children affected with schizophrenia in Hebron District- Palestine, all of the mothers without any training or background education in mental health care.

10 of them were married, one widowed.

All mothers had formal education at least to 9^{th} grade, no one university educated. The period of care giving ranged between 2 years to 13 years. The general profile of the participants is provided in Table 4.1.

Giorgi phenomenological approach analysis method was used to emerging of themes and subtheme from interview data.

4.2.2 General profile of participants

The characteristics of the mothers obtained included the age, educational background, and marital status, length of care and age of their client (Table 4.1).

Table (4.1): Demographic characteristics of mothers and their client affected with schizophrenia

Mother	Age	Client age	Client gender	Duration of illness	Number of family members
M1	51	21	Male	4 years	7
M2	47	25	Male	5 years	5
M3	53	30	Female	8 years	6
M4	46	27	Male	4 years	7
M5	44	20	Male	3 years	6
M6	52	33	Male	7 years	5
M7	49	23	Male	2 years	9
M8	50	29	Female	10 years	11
M9	48	26	Male	3 years	10
M10	54	30	Female	6 years	9
M11	44	25	Male	7 years	8

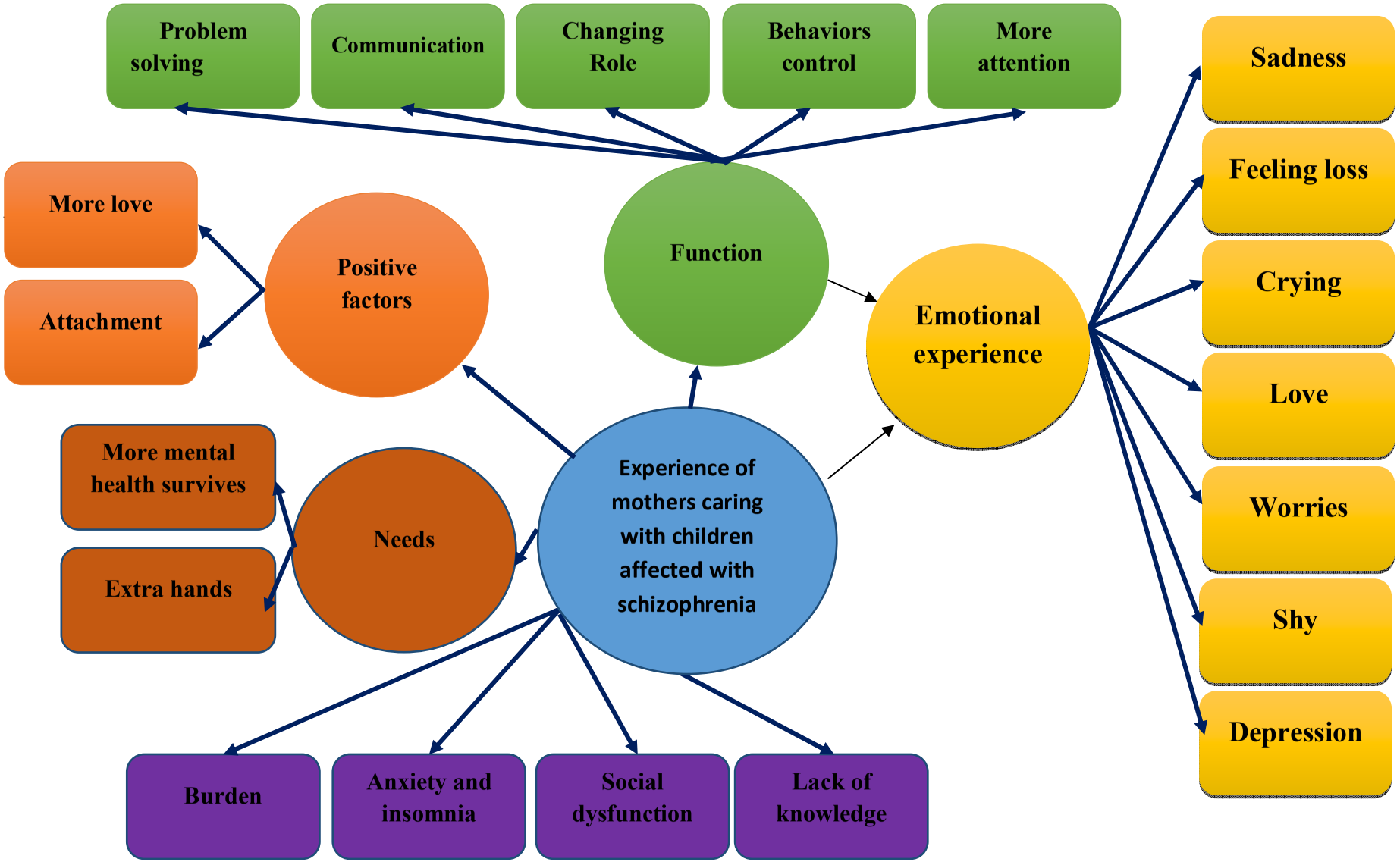
4.2.3 Themes and sub themes obtained from the interviews

From the experiences narrated by the mothers, 4 main themes and 18 sub themes emerged from the analysis of the data. The data obtained from mothers were transcribed verbatim. These are presented in the following table.

Table (4.2): Themes and categories

Major Themes	Sub themes
Coping with new situation	Depending on God for comforting Facing feeling of embarrassment and secluding self. Social stigma and Discrimination. Lacking support.
Knowledge deficit	Advocacy Seeking Learning about the illness
Emotional and social experience	Sadness Feeling Losses Thinking and worrying about future crying stressful situation strengthen family relationship
Ongoing Struggle	Difficult behaviors and accepting what can't be controlled Maintaining safety Facing challenging Affects all over daily life Relationships Changed priorities

4.3 Conceptual Map for mother's experience



The first theme was coping with a new situation:

Affects all over daily life, Relationships within the family, changed priorities, and facing challenging are another experience of mothers result as an impact of care giving on mothers.

This includes how mothers life changed than before diagnosing, how their care giving roles affect their relationships, due to the critical observations needed to handle client affect with schizophrenia ‘

Depending on God for comforting:

All of the mothers use spiritual and religious as a coping mechanism, because all of the mothers are Muslim, and in the religion of Islam there is Remuneration and reward from Allah, this gives them the power to be more patient. Here what mother stated related to spiritual and religious coping.

> M1: *We said, O Lord, Praise be to Allah, our Lord, we have patience, and we are patient.*
>
> M3: *Praise be to Allah for all things, the purpose of suffering from God and we need to be patient and say al-hamd lleah (tears):*

Facing feeling of embarrassment and secluding self.

In the first all participants feeling was denial to diagnosis of schizophrenia and no any participant accepts schizophrenia as a mental health problem of their offspring, all they consider it as Evil spirit or Magic. They go with their clients to "Shaiek" for a treatment of evil spirit,

After all their attempts, nothing changed and symptoms were worsening. They accept schizophrenia as mental illness it and they seek mental health professionals for help.

> M5: *I did not believe it (mean the Evil spirt and Jinn) but my son was normal. They took the "shaik'" and all the attempts not work. we believe this was mental illness and something psychological, So we took him to mental health center ……. we don't believe in that from the first because we don't accept my son as a mental patient.*
>
> *M9: he starts to shout at night, he walks fast until morning, he said strange things, in the first I think he was bewitched, we took him to Shaiek' in many countries, nothing help, also we have to accept the worst "my son is schizophrenic"*
>
> *M11: many times I ask our relative and neighbors to force him to take his medication, they all get tired from that. My child destroyed every thing, windowpanes of a neighbors houses. Most of our window is smashed, I must to be patient and try to control his behaviors".*
>
> *M4"my child all the time at home, Here at home he only smokes; some time he buys Hasheesh, he takes medicines only when he is in hospital".*

Stigma and discrimination

Stigma: Greek origin, refers to bodily sign or mark which signals something unusual or bad about a person (cuts/burns). It indicates that a

person is a slave, traitor or a criminal and is to be avoided especially in public places.

Goffman E. (Stigma. 1963) – stigma occurs when an individual is disqualified from full social acceptance because of possession of an attribute that is deeply discrediting.

The discrimination according to the Cambridge advanced learner's dictionary is to treat a person or particular group of people differently, especially in a worse way from the way in which you treat other people, because of their skin colour, sex, religion etc.

Stigma is the biggest obstacle to recovery, treatment and societal acceptance for people living with mental illness also for their families, stigma and discrimination against those living with mental illness is widespread and reaches into educational institutions, workplaces, homes, health care centers, in the media and even in the religious places. It causes shame, prejudice, apathy, and hopelessness and prevents over half of those living with mental illness from seeking treatment (Ronzoni, et al. 2014).

One of a problem for the care giver for mental illness client is Stigma and discrimination have some and many have face the issue of stigma in care giving. This makes caregiver‘s perceived negative feeling in caring that causes the caregiver to feel devalued and the feeling that people tend to distance themselves from them because of their care giving role. Most of Mothers said that most they had self-stigma in the first period of diagnosis,

then because here in Palestine the living is extended family and sociality is high, they will know and stigma time by time decrease, also discrimination not found in any case.

> *M2> I don't shy from my son illness, this from Allah, everyone asks me what he complains and I tell them, ……, I don't feel discrimination from any one because of my son diagnosis, but I think for example if he wants to get marred he will face this.*
>
> *M3> In the first I don't tell any one about her illness, but they ask me why she doesn't go to university, why she separated, I can't hide her illness, I don't feel stigma because of this like any illness, from Allah.*
>
> *M9> in the first period I Feel shy when I listen one call him mad, but I think a lot and when we bring him to mental health clinic I see many illnesses and case worse than him, so now I don't feel shy any more.*

Lacking support

All of the mothers stated limited resources including economic difficulties, lack of facilities, and lack of support mostly from outside the family like mental health professional and services that their role limited to provided medication for their clients, the mothers described a lack of services offered in the community for families coping with schizophrenia, such as counselling.

The main concern as mother's states was a lack of suitable care, they mention that care here depends only on medication and sometimes social

worker inside the clinic only. Because of this, the mothers found that they were required to take all of the responsibility of providing a high level of day-to-day care, supervision, financial support. Also, the mothers weren't provided with information or support to help control serious issues and deteriorating symptoms like violence, self-harm aggression, regression, and nervousness. Also, mothers mention their concern for the well-being of their clients and their wishes to give the best possible care and safety for their clients.

M1 > No one help me in care when his father at work, he tried to suicide many times, I can't control his behaviors, he force me to give him money to buy "Hashish" that recently he starts to smoke, I don't know what to do, our economic status don't let me give him what he wants, there is no one help, I need thing make him stop smoking Hashish, "tears" . if there is agency can you tell me to go for, no one gives me any information about his illness, no one educates me how to deal, they tell me just make him commit with his medication.

M3> I live with her alone in the home, her 2 brothers and 1 sister was married, they live beside us, but I am the only care giver, all the responsibility on my back, she needs a lot of things, her expenses are very high, she all the time want to eat chocolates, she prefer expensive types, her brothers help me, but not enough, some time her personal fees more than 100 Nis, if I tell her to stop that she becomes very nervous, you see her weight, she was 50kg, now she more than 120 kg, no one tell us

about how to manage this, they sit with social worker, but no benefit, I don't know what to do.

Theme 2: Knowledge deficit:

Knowledge deficit makes the situation for mothers in their caring journey difficult they reported that they lacked knowledge in aspects of how to control the situation and how to manage the condition in crisis. Also, they didn't have knowledge of what should be done when their clients affected with schizophrenic exhibited symptoms of the illness. For that matter, it was striking that all the mothers did not know how to protect themselves and how to absorb the revelation.

Also, mothers beliefs about schizophrenia in the first connected to be a spiritual illness caused by supernatural powers can't be seen or touched by a human. The majority of the mothers have the belief in that after symptoms appear, all mother interviewed went in the first to "Shaiek" because of their beliefs but after that, they went to mental health care provider. Mothers also stated that they don't know until now what is the cause or what is the schizophrenia,

The mothers we interviewed don't know or give a false meaning of schizophrenia, this indicates lack of knowledge about their clients illness, this as many mother mention due to no one educates or teaching them about this.

M6: *His illness is the separation of personality, no one talk with us about his disease or what is the extent, nature or cause.*

M8: *I don't know what she complains of, they said to me it a psychological disorder.*

M4: *you can tell me what my child has, what he complain, how to manage his symptom, how to deal with him.*

M7: *I want one tell me in details about, my son illness, what will happen, how it happened what cause this.*

Theme 3: Emotional experience

The caregiver emotional burden consisted of psychological burden involving feelings Feeling Losses, Sadness, Economic burden, thinking and worrying about the future, Stigma, and Discrimination.

The emotional worries and feelings resulted from the stressors of caring, fear, and panic that their client could be harmed from and for his behaviors and actions that could be on himself or on other. Part of these emotional worries and difficulties result from the process of caring its self as they describe it is difficult.

The mothers expressed that they sadness feeling start from the day knowing that their client diagnosed as schizophrenia client. Mothering client with schizophrenia drained their energies from the period of childhood to adulthood then suddenly that client to diagnose as a schizophrenic client was a huge lost to most of the mother. The term of schizophrenia alone was a major loss to most of the mothers.

Sadness

Findings of the study revealed that mothers of the client with schizophrenia experience sadness in their roles as a caregiver. Mothers said that they go through lots of feelings of sadness from the first day they know that their client was diagnosed with schizophrenia.

> M10> *when she diagnosed, I feel very very sad, I want to leave the house and wander in the mountains, I was too much shocked. I feeling very very sad because when she married about 2 years ago, she was normal not like this, but now "with crying" now she become psychologically illness. I can't stop thinking, now she was divorced, no one help me, now I must to do everything; I am now aging I don't have strength as before, her father in prison since 14 year, These big responsibilities make me feel sad deep inside me, worry, all time thinking, I can't sleep. I feel I am sinking.*
>
> M7: *I can't express my feeling, but you can imagine caring for your child from childhood to adulthood to end up as psychosis is very sad feeling, feeling of loss.*

Thinking and worrying about the future:

Thinking and worrying were emotional burdens for the mothers caring for a client affected with schizophrenia. The concept of thinking here can be described as a cognitive experience that involves meditating of the problem and to become aware of a problem. In point of view for the mothers who knowing well the stressful nature of care and the

characteristic and burden of the care make them thinking a lot and worry most about their days as they are always feeling afraid about their clients future there will be nobody to care for their clients in the event that they die or become unable to manage. The following mothers said how their minds are full of thoughts.

> M3> *I think a lot about my daughter's illness. It has affected me physically. I become very tired, I haven't strengthened as before, I can't concentrate on anything, she takes almost of my thinking. I ask myself, who will take care of her when I am not present or when I die, these thoughts control my mind, hoping for Solve the problem.*
>
> M6> *I think a lot, I am most of the time thinking, I pray, and fast all the time. Looking for my daughter with this condition make me think a lot, feeling sad. I have sleeplessness due to many thoughts. I feel worried about his future, I couldn't imagine what will happen to her, how his life becomes, how he will continue.*

Strengthen family relationship:

The finding from interview data indicates that's mothers generally felt affectionate and loving towards their clients. And most of the clients seems to be attached and loved to their mothers despite their problematic behavior. This relationship and feeling rewards give the mother more and more support in her journey of care as mother stated when they saw their clients better they feel very happy and hope increase.

M3 " I feel that She always attached with me, and she loved me so much, she feel happier when I'm around or when I'm next to her. The relationship between us very strong, when I saw her good and near to normal I feel very very happy, this what I hope to see her all the time"

Crying and feeling losses

Mothers experienced the fact of diagnosis their clients with schizophrenia as shocking, while others talk about they don't believe its medical diagnosis and believe this come from evil or Jinn. Shock, Denial, crying, and fear was first emotional response to the diagnosis:

M1 said *about* their first response to diagnosis *all the family starts crying, we don't believe in that, he was a good boy, we don't know what happened*, we are shocked.

M4: *in the first, I feel that I am psychosis, crazy, and my son 20 years old, what happened to him, he was normal, was working, I don't believe, we cried all the time.*

M10> *when she diagnosed, I feel very very sad, I want to leave the house and wander in the mountains, I was too much shocked.*

Theme 4: Ongoing struggle

This theme emerged from mother daily caregiving experience, the characteristics, difficulties, symptom, behaviors, of schizophrenia are making mothers struggle to be daily, the sub theme is difficult behaviors, maintaining safety, and accept what can't be controlled.

Difficult behaviors.

This subtheme emerged from all of the mother experience and talk about their clients unacceptable behaviors.

M5> he is heady, he wants to do what he thinks and he don't respond to any one, if I prevent him he hit me, and shout on me, if his father or his brother prevent him he will harm himself by wounding his hand, this is my life, all the day I observe him because if he goes out he starts to shout and verbally threatened the neighbors.

M10> She threatens us at home and gets violent, she scares me and her small sons especially when relapses, she throws stones at peoples and cars, and we have to pay the cost. Have you noticed her hand has a big scar, this from windscreen glass that she was broke when the driver asks her to pay after service and she refused, she also insulted him. The driver didn‘t know she was ill.

M11> when he not taking his medication he becomes very nervous, he smashes everything, and neighbors get tired to help me force him to take his medications. he destroyed his brother's games, destroy the every thing in the street, windows of people's houses. Most of our window is smashed, It is him".

Difficult behaviors, Maintaining safety and Accept what can’t be controlled

Most of the mother put the safety of their client affected by schizophrenia and another family member in the first, most of them

mention that medication makes their client calm and less violence and harm, but some time they have to accept unacceptable behavior to ensure safety.

M2> all the time he wants to harm other, one time he tried to kill his brother, he smashes glass bottle on his head, we take him to the hospital, ..., when he takes his tablet he become less harm, but I should observe him all the time, I give him what he wants, if I don't he became very nervous and no one can imagine what he can do, no one can control him, he has magic power.

M1> many time he go to Al-Ibrahimi Mosque, "there are many checkpoints for the Israeli army" he want to let them kill him, but they know him because many time they tell them that he has psychological illness, now if I refuse any thing that he wants he went their……, he wants money to buy Hashish.

M8> much time we took her to the hospital, I called the police two times to control her, she started to hit her head with a stone, she harms her self-many time, if one becomes near her, she will harm, she didn't listen to any one, many time has bleeding. So we had to do what she wants to prevent her from harm her self or other. ……, most of the time she wants money to buy a musical instrument, also she starts to loud the speaker in the night at 3, 4 am.

Facing challenges

Affects all over daily life, Relationships within the family, changed priorities, and facing challenging are another experience of mothers result as an impact of care giving on mothers.

This includes how mothers life changed than before diagnosing, how their care giving roles affect their relationships, due to the critical observations needed to handle client affect with schizophrenia ‘

M8: Caring is not easy, all day is difficult. After she ate, she will try to upside down the bowl where she ate from. When I try to prevent her or complain she becomes very angry, shout. So no one can bear her behaviors, I can't go any place, I must all the time with her at home, if she goes out she will make me feel very shy, so I prefer to be with her at home. It makes caring very difficult for me.

M6: many things changed, my time from morning to evening is full, caring for person with psychological illness like to care for 20 people, it's very difficult because he is not weak or bed rode this is a high power man who not has insight, all the time I must monitor him,

M2: from the time of diagnosing, many things changed, relationship with my son become stronger, I love him more and more every day, but he took my time, fun go over. For now, those social responsibilities, I don‘t attend them my son life is

more important to me than weddings and funerals. There is no hand at the moment to continue the care

M11: I have to abandon activities like going to I don‘t get anyone who to take over the care, I can‘t leave. Caring is a big responsibility. Neighbors and Friends think I am not interesting. It is my son condition that has separated me like that.

M10: my life become up side down, many things changes "tears" I can‘t receive visitors because of my daughter illness. I have to refuse or ignore invitations to participate in any social events. I don‘t attend social functions. I must keep my daughter away from the people, no one can control her so I have no choice than to ignore social activities.

M3: the fact that there is this big caring responsibility on my shoulder it affects my daily activities, all over the day, I must be there, I can't keep her away from me, " ربنا قدرلها المرض وانا قدرلي اقعد جنبها بالبيت واضل اعتني فيها"

Chapter Five
Discussion

Chapter Five
Discussion

5.1 Introduction

The previous chapter consists of data that has been gathered from mothers of clients affected with schizophrenia. In this chapter, the themes and sub themes that mentioned in previous will be the basis for the discussion. The various themes and subthemes were examined and compared with available literature to determine areas of congruence or otherwise. Thus, the findings on the experiences of mothers of client affected with schizophrenia were used to build or confirm ideas from the literature.

Many researchers talk about different angles and aspects of Schizophrenia but it still a lot of undiscovered. Contributing to unveil these unknown aspects is hope of the researcher when begin, no matter how small or big contribution.

This study conducted among mother's to exhibit their life experiences and to listen to mothers who care for their client affected with schizophrenia in Palestine.

This chapter begins with a restatement of the purpose of the study and the guiding research question, followed by a brief overview of the research findings. Attention is then drawn to the convergence or divergence of the findings of the current study with the existing research on this parenting experience. This is followed by a discussion of the ways in which

the findings of this study are empirically and theoretically important. Implications for counseling psychology practice and future research are discussed and the limitations of the study are addressed.

As stated in before in chapter one, the aim of the study was to understanding the experience and management's practices that used by mothers of client affected by schizophrenia include difficulties and barrier that mother of face, and investigate both the positive and negative experiences of care giving, mother coping strategies, supportive factors, attitudes and perceptions.

- What are the experiences of mothers caring for their clients affected by schizophrenia?

5.2 Emotional experiences of mothers.

One of the interesting result in the study was emotional experience that was consist of shocking, crying, depression, Fear, Worry, distress, feeling ashamed at the time of diagnosis, Experiences of loss, The sense that life had become difficult, Guilt, Frustration, feeling of Disappointed, and sense of helplessness.

The emotional experience of mothers resulted from long term experience of caring.

In general, mothers described caregiving role for clients affected with schizophrenia as a difficult task. This consistent with a study of

Mhaule, (2009) that finding suggests being a caregiver for a mentally ill person is very difficult task.

According to interview data, many factors make mothers task difficult such as the accumulation stressors, challenging experiences by mothers, the consequences of schizophrenia on the client and on the mother. All of that makes mothers frequently experienced a sense of frustration throughout caregiving.

A body of literature has explored the emotional experiences of caregivers of clients affected with schizophrenia (Mhaule & Ntswane, 2009; Saunders & Byrne, 2002; Negota & Mashegoane, 2012). Many emotional reactions, such as distress, frustration, guilt, sadness, stigma, and worry, overlap with local findings by Mhaule and Ntswane-Lebang (2009). Other emotions, such as heartache, helplessness, and uncertainty, are in accordance with the work of Saunders and Byrne (2002). My findings suggest that caregivers react emotionally at two distinct stages – first, upon the diagnosis of their relative (Negota & Mashegoane, 2012), and thereafter, throughout the course of being a caregiver.

The feelings at the time of diagnosis were similar, they don't believe in the first, denial stage, then they feel loss, sadness and crying, this because the client with schizophrenia become a stranger in his behaviors, and mother reported that the period of diagnosis the situation like crises. This could be due to caregivers lack of knowledge on how to manage and handle their loved client who from short period normal one. All of these

feelings is normal response according to stages of grief, also can be mothers felt helpless in the situation because all in shock within family, more over most caregivers had not expected the diagnosis of schizophrenia for their client this can be concluded from mothers word because all mothers of the sample has only one client affected with schizophrenia. This result consistent with study Negota and Mashegoane (2012) reported that in the time of first diagnosed, family and primary caregivers have a lot of feelings which can be expressed as irritable, sadness, fear of what coming, nervousness and anger, and frustration.

Also, some of the mothers experienced shock and feeling of loss the possibly as mothers mention due to their ideals and hopes and dreams for their loved clients.

Mothers think a lot from the 1st day of diagnosis, continuous feeling that their child hasn't a good chance for normal life.

Negota and Mashegoane (2012) found in their study that caregivers have experienced sense and feeling of loss. They explained this feeling because caregivers had hope and ideas for their client to have good future, and all of this dream disappear and lost after diagnosis. Second is due to caregivers consider the person they knew before not exist they lost them and client became ill.

Mother's Emotional burden resulted with disruption, distress, depression, and anxiety for the whole family. The mothers experienced a

high level of Grief, which is consistent with a study of Eakes' (2005) that he found the feeling of grief is a major aspect of emotional burden among caregivers through caregiving responsibilities. Also, the findings of our study found that the mothers suffered from sadness and grief because of caring responsibility for her loved child who for long life dependent on her.

The mother's participant in this study described their own daily life to waver between despair and hope. Despite their role as a care giver for chronic illness, some mothers were feeling optimistic. Acceptance of the diagnoses and information how to deal with different situation seemed to be very important.

5.3 lack of knowledge about the illness

Another aspect of experience found by this study all of the mother's reported false understanding of schizophrenia and also reported lack of knowledge regarding dealing with their clients affected with schizophrenia, mother's mentioned that due to lack of information that they take from mental health professional about the illness of their clients. Lack of knowledge considers as challenges that mothers experienced, after their child diagnosis. Mothers struggle daily to gain enough information and to understand, mainly with regard to the main cause of schizophrenia, dealing with symptoms, prognosis, treatment. This consistent with Meta-analysis by Murray et al., (2007) suggests that psychoeducation for caregivers are often not included in the care plan for their clients Furthermore, care givers often report lack of support from mental health providers As a result

caregivers report a lack of understanding of how to deal or manage symptom. Another study by Asmal and her colleagues (2014) explored various topic of psychoeducation needs for caregivers of client affected by schizophrenia, their finding concludes educating caregivers regarding the possible causes of schizophrenia, communication techniques, problem-solving and crisis management strategies and side effects of antipsychotic medication.

All the mothers would like to know more about the illness of their clients. Also, many of them report that it's difficult for them to self-education because they don't know where to find and what kind of information to search for. Also, mothers mention that limited understanding of schizophrenia and the consequences increased conflict with their clients.

Some of the possible reasons for problems in communication between mental health professionals and mothers as I understand form interview that Some of the mental health professionals may communicate with the mothers using medical phrases, another reason that the mental health care provider supposed that mothers know every thing.

5.4 Mother’s Burden

According to Awad & Voruganti, (2008) burden conceptualized through the Objective and Subjective Burden, Also mothers mention term of a burden as challenges. The main finding in this study was the mothers' experience of long-term responsibility for their dependent client affected

with schizophrenia, this expressed by mother much time in many places, such as emotional, physical, economic burden.

The best description for mother management practices during caring that "mothers permanently on-call". They strived to be constantly available when their client needed them. The mother's experiences of challenges and burden in various aspects of their daily lives. As stated in result part, also mothers had experienced multiple of emotional consequences from the first day of their clients diagnosis, and during care for the client affected with schizophrenia.

Mother’s burden can explain due to the client's inability to perform daily tasks, client affected by schizophrenia may have no choices to perform certain tasks, they depend on their caregiver to assist them. Consequently, as mothers mention they assist their clients with "most aspects of the patient's daily care, such as overseeing compliance with medications and treatment, ensuring safe and calm environment, controlling their behaviors, helping their clients to deal with everyday difficulties. This consistent with many studies, Gutiérrez M et al. (2005) mention that clients with schizophrenia are highly dependent on their caregivers and caregiving of client affected by schizophrenia introduces a significant burden.

Another study by Iseselo et al. (2016) investigate forms of disruption that may be caused for caregivers of mentally ill clients. First, caregiving can disrupt daily routines of caregivers. Second mention that Caregivers

also experienced a sense of obligation to provide care. Another aspect of experience here thinking in future.

Mothers' thinking always for their dependent client future, many questions with no obvious answers in mind of mothers, they attempt to make their clients less dependent. This is the normal concept of mothering which targets to make the client independent and gradually abandon the asymmetry of the childhood years. Perhaps it would be better for the clients affected with schizophrenia if their mothers don't make them feel that or have this worries to increase their self-esteem.

One of the important finding that increase burden which is most of mother’s experienced lack of support, but in fact according to finding the majority of mothers hadn’t support from the health care professionals.

Also theirs another aspects that made mother’s experience of burden include:

1) Life style changes for mothers.

2) Physical strain.

3) Client problematic behavior.

4) Distressing.

5) Client dependency.

6) Disruption.

7) Emotional impact on caregiver

5.5 Changing of daily life style

At the time of diagnoses, mothers experienced a depressing, sadness, feeling loss. Then they have to deal with clients behaviour (e.g., violence, nervousness, or aggression) this create big challenges and mother forced to change their daily life style to cope with new situation at home and in the community, many mothers reporting conflict with their clients affected with schizophrenia this consistent with study of Bauer et al. (2012), that conclude of present of client affected with schizophrenia at within family introduced many aspects of burdens for mother as primary care giver and for whole family and they should have many changes to daily life of caregiver and social environment at home.

5.6 Problematic behaviors.

Mothers mention multiple accounts of client's problematic behaviors. For eg: destructive behaviors, aggressive, nervousness, are common difficulty faced by many mothers. This result consistent with many recent studies has discussed problematic behaviors of the client with schizophrenia (Molefi & Swartz, 2011; Mhaule & Ntswane, 2009; Negota & Mashegoane, 2012).

This behavior had emotional and physical consequences, mothers experienced feelings of worry, fear, helplessness, and frustration.

Moreover, by being preoccupied with the demands posed by their clients, more over mothers forced to meet their requests.

5.7 Facing moments of distress.

Some mothers reported that they waiting the moments that their client experienced depression, anxiety, aggression, fear, or helplessness this consider as another challenge of caregiving client affected with schizophrenia. This consistent with findings by a study of Gutierrez-M et al. (2005) that intense heartache commonly experiences by mothers of client affected with schizophrenia.

The experience of Stigma cause a lot of burdens and sometimes caregivers could not escape, but here most of the mothers don't experience stigma as they mention. This result inconsistent with a number of studies have reported stigma among caregivers of mental illness (Kung, 2003; Koschorke et al., 2014; Magana et al., 2007; Von Kardorff et al., 2015).

According to Kung (2003) report, that stigma increases caregivers' burden directly. Additionally, also connected to with symptoms of mental disorders for example depression.

5.8 Caregiver Coping

Mothers can utilize emotion-focused coping mechanisms and/or problem-focused coping mechanisms. It is possible that mothers as caregiver can, at times, cope by utilizing a combination of these two mechanisms (Folkman & Lazarus, 1988); but,

This part will discuss the various coping mechanism and strategies used by mothers in this study independently.

5.8.1 Religious as coping.

Religious can be considered as an emotion-focused coping strategy. All mothers are Muslims and they use to pray and Duaa because caregivers were religious prior to the onset of their client schizophrenia, this obvious from their dressing– but relied on it throughout the mother's role.

The majority of mothers included in the study reported that their religion (being religious; or doing religious acts like duaa, pray) strong their coping and acceptance. This consistent with many studies of Rammohan et al. (2002), that he states religious belief and hope from Allah enhanced well-being and conceded as an effective coping mechanism for who caring of client with mental illness.

Study of De Wet et al., 2015 stated that, religion looks as an very effective coping mechanism for clients with schizophrenia.

5.8.2 Emotion-focused Coping Strategies

In Emotion-focused coping, people try to regulate their emotions stressfully. emotion-focused coping appear in many aspects among mothers in this study which include: acceptance, enhancing the positives; avoidance of conflicts and decrease the impact of caregiving.

Several studies have reported that caregivers of mental illnesses using emotion-focused as coping strategy, also they report its effectiveness in a stressful situation (Haung et al., 2008; Scazufca & Kruipers, 2011). However, Nehra, et al, (2005) report that emotion focused coping strategies are more common in caregivers of the client with schizophrenia.

5.8.3 Positive thinking and coping.

Mothers in this study have multiple methods of positive thinking, According to Huang et al. (2008), state that positive thinking decrease burden among caregiver of mental illness. This can be explained as positive thinking has direct effect on the psychology of the person and positive thinking increased self-esteem and also connected to more life satisfaction sense,

Findings also suggest that mother's positive thinking can be directed toward themselves – e.g, mothers hope their clients will recover, also positive thinking can foster resilience in mothers, which resulted in enhance coping and decrease burden (McCann et al., 2009; Zauznewski, et al., 2009).

5.8.4 Acceptance as a coping mechanism.

Most of the mothers stated that they had accepted their clients diagnosis, this enhanced caregivers-wellbeing, this result with relieve of guilt and shame. Various studies have reported that when caregivers haven't acceptance of illness this increased burden (Haung et al., 2008). According

to Haung et al. (2008), the Foundation for acceptance is positive thinking of caregivers.

5.8.5 Avoiding conflicts.

Most of Mother use Avoidance as a coping mechanism with several situations. Mothers mostly avoid actions or behaviors that can cause conflict, Hassan et al. (2011) suggest that caregiver burden increase for who avoid confronting difficulties. this could be explained that avoidance instead of an act not resolved or alleviated. E.g client problematic behavior.

Recommendations

Based on this study findings the following recommendations are made:

Recommendations For policy maker

- Counseling and Education centers should be available in the communities for informal the clients and their mothers to access with mental health professionals
- A social worker or mental health nurse should be available and work well for clients and also for their caregivers.
- Informal care giver with specialties and experience of dealing with clients affected with schizophrenia should help the mothers to decrease burden.

Recommendations for mothers

- Mothers should increase their awareness through learning and look for reliable information about schizophrenia and how to handle symptoms rather than accept problematic behaviors, or enter in conflict with their clients.
- The mother should be aware that there is varies methods of treatment rather than medication, and to be aware of places rather than services of MOH.

Recommendations for future research

- To study in deep the right and wrong ways used by caregivers to deal with client affected with schizophrenia.
- To study the experience of clients themselves with schizophrenia and their need according to in their point of view.
- To study fathers' and other family member experiences in order to broaden our understanding from a family-centered perspective.
- To do quantitative research that assess quality of life, depression, and burden among care givers.

Limitations

There are several limitations identified in the current study. Generally, small sample sizes are not considered to be a drawback for qualitative studies as they do not aim to collect expansive data that is representative of whole populations (Morrow, 2005).

However, it must be acknowledged that qualitative studies are therefore limited in their generalizability. This study was undertaken with a small number of mothers in Hebron district who are providing long-term care for their clients affected with schizophrenia. The findings of this study may not be representative of caregivers from different populations,

The study also included only mother participant, it is likely that other family members have different experiences, perceptions and coping strategies that are not represented by this study.

Another area of potential limitation is that the participants were selected from mothers who come to the clinic, this could mean that mothers isolated at their home couldn't participate.

Conclusion

This study highlighted the experiences of mothers in caregiving of clients affected with schizophrenia in Hebron district, Palestine. A small and homogenous sample of 11 mothers participated in this study, according to this study, it became clear that diagnosis with schizophrenia is a complex and debilitating mental illness that introduces a wide range of challenges to the clients and their caregivers.

In summary, Each mother had unique experiences of their journey of caring and living, most of the mother's experienced vary of difficulties and burden while caring for their client affected with schizophrenia include, psychological, Emotional, social and economic factors.

Most of the mothers experienced a lack of knowledge and information regard schizophrenia and how to manage or deal with symptoms. Also, early experiences with the illness include the feeling of loss, sadness, crying. Mothers experienced many lifestyle changes include being socially isolated due to they have to be always with their clients who become dependent.

Mother report many needs to help them handle new situation, which includes give them enough information, and counseling center, also they

need center for rehabilitation and entertainments activity for their client supported with mental health professional's

In this study coping mechanisms of mothers explored, which they used to overcome challenges introduced by their clients affected with schizophrenia. Mothers developed themselves with coping strategies to handle with challenges and new situation that they obligate to be with, lastly, some mothers also reported positive, character building experiences arising from their caring for their relative with schizophrenia, that they feel satisfied when their clients become better, and some mothers become closer and give more love to their clients.

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Appendices

Appendix (1)

Interviews guide questions , English and Arabic

GENERAL INTERVIEW QUESTIONS

- How did your life change from the moment your son/daughter was diagnosed?
- What was the diagnosis/first access to mental health services experience like?
- What are the difficulties you experience caring for your son/daughter? Eg: emotional, financial, social, etc.
- How does this situation impact on your family?
- Have things changed for you over time? How?
- What support do you access/have you used in the past? Eg: mental health services, community services, family/social support etc.
- How would you describe your relationship with your son?
- What is the most difficult part about your relationship with your son?
- What is the most rewarding aspect of your relationship with your son?

أسئلة المقابلة العامة

- كيف تغيرت حياتك من لحظة تشخيص ابنك / ابنتك؟
- ما هو تشخيص ابنك / ابنتك ؟
- كيف كانت تجربتك باول زيارة لعيادة الصحة النفسية؟
- ما هي الصعوبات التي تواجهها اثناء عنايتك بابنك / ابنتك؟ على سبيل المثال: العاطفية، والمالية، والاجتماعية، وما إلى ذلك.
- كيف يؤثر هذا الوضع على عائلتك بشكل عام؟
- كيف تغيرت الأمور بالنسبة لك مع مرور الوقت؟ ماذا؟
- ما هو مصدر دعمك ومساعدتك في العناية بابنك؟
- ما هي الخدمات التي تستخدميها ومتوفرة لك مثال: خدمات الصحة النفسية، والخدمات المجتمعية، والدعم الأسري / الاجتماعي، الخ.
- كيف تصفين علاقتك مع ابنك؟
- ما هو الجزء الأصعب في عنايتك ابنك؟
- ما هو الجانب الأكثر سعادة لكي في علاقتك مع ابنك؟

Appendix (2)

consent form, English and Arabic

Participant's information sheet

Information to the mother

Title of the study

The experiences of Mothers caring for adults affected by schizophrenia in Hebron district – Palestine: A descriptive phenomenological study

Introduction:

I am Malik R. Duies, a student of community mental health nursing master's program at An-Najah National University.

My supervisor is Dr. MarimAltell

What is the study of?

For my thesis, I will make a research on the experience of the mothers of caring for client affected by schizophrenia, and their management practices for the behaviors of the patient that according to international research, is most common psychiatric disease. I will study the experience of primary care providers (mothers) and their methods for handling the situation.

The aim of this study is to investigate and describe the experience of mother that interact mostly on a daily client with schizophrenia.

This study aims also to understand managements practices that used by mothers to deal with the most prominent signs of schizophrenia in order to formulate of a care plan and investigate of difficulties and barrier that mother of schizophrenic patient face.

What you expected to do:

You as the mother of the patient has an important role in the interaction with the patient, because you have chosen for the study and your participation means that I will conduct an interview with you, if you are willing to participate, the interview will be recorded and the expected last 45-60 minutes.The interview will be implemented in your home at the appropriate time for you. the interview willbe conducted in a private room which just the informant and the interviewer present and that the interview will be recorded by tape recorder and that no individuals can be identified after text processing.

Privacy:

All data is recorded only for the purpose of the study, and will remain held in a locked cabinet during the study and destroyed after the study is complete. No real names will be mentioned in the study and you will be identified by codes.

Refusal to participate \ withdraw from the study:

There is no obligation for you to participate in the study, you can refuse to participate or withdraw from the study at any time, even without

giving reasons and this will never have a negative impact on you or your child.

Harm:

No harm will come to you from participating, and your name will never be mentioned to anyone.

We appreciate your participation

If after the interview still has something to convey, we are ready for more clarifications at the following telephone numbers

Malik R. Duies:0598501474

Dr.MarimAltell:0599836444

Appendix (3)

participant informant sheet to the family of the client, English and Arabic

Consent Form

Confirms to have been explained requests to participate in research project on **The experiences of Mothers caring for adults affected by schizophrenia.**

I have been given a copy of your request / project orientation and are willing to participate in the project. I have received both verbal and written information about the study, and I'm aware that my participation is voluntary. I am informed that at any time, without having to explain it might withdraw from study if I wish. If needed I can be contacted for a new interview or clarification.

Address……..Telephone number …… Email……Academic level ……..

The undersigned confirms that he / she provided information about the project and has handed over the above a copy of the request/ project orientation and consent to participation.

Date…….

Signature of informant ……..

Signature of the project leader ……

(Signature of informant)

بسم الله الرحمن الرحيم

جامعة النجاح الوطنية **An-Najah National University**

كلية الدراسات العليا **Faculty of Graduate Studies**

نموذج موافقة على المشاركة في الدراسة:

الاسم:.....

لقد تلقيت المعلومات المكتوبة والكلامية حول الدراسة التي ستكون حول تجربة الاطفال في مواجهة الاحداث اليومية والاسبوعية عندكم بالبلدة وما يترتب على على مشاركتهم. واوافق على مشاركة طفلي في هذه الدراسة بشكل طوعي، وقد تم ابلاغي انه بامكاني ان اسحب طفلي من هذه الدراسه في اي وقت قبل وخلال الدراسة بدون اعطاء اي اسباب.

التوقيع **التاريخ**

جامعة النجاح الوطنية
كلية الدراسات العليا

خبرات الامهات اللواتي يقمن برعاية أولادهن البالغين المصابون بمرض الفصام العقلي في محافظة الخليل – فلسطين / دراسة وصفية

إعداد
مالك ربحي حسين دعيس

إشراف
د. مريم الطل

قدمت هذه الأطروحة استكمالاً لمتطلبات الحصول على درجة الماجستير في تمريض الصحة النفسية والمجتمعية بكلية الدراسات العليا في جامعة النجاح الوطنية في نابلس، فلسطين.

2017م

خبرات الامهات اللواتي يقمن برعاية أولادهن البالغين المصابون بمرض الفصام العقلي في محافظة الخليل – فلسطين / دراسة وصفية

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إشراف

د. مريم الطل

الملخص

مقدمة: الفصام هو مرض نفسي يسبب إعاقة شديدة ويعتبر السبب الرئيسي للمعاناة للمرضى المتأثرين به. التشخيص بمرض الفصام يؤثر على كامل الأسرة ومن يعتنون بالمريض، لان المريض يصبح معتمد على غيره في الرعاية بسبب طبيعة المرض ولا يمكن ان يعتمد على نفسه بشكل كامل وهذا يسبب الارهاق للعائلة.

الهدف: تهدف هذه الدراسة إلى فهم خبرات الامهات اللواتي يقمن برعاية اولادهن المصابون بمرض الفصام العقلي، وتشمل الصعوبات التي تواجهها الأم، التجارب الإيجابية والسلبية لتقديم الرعاية، استراتيجيات التأقلم ، العوامل الداعمة، والمواقف و التصورات

تصميم: استخدمت الدراسة المنهج الوصفي النوعي الوصفي

جمع البيانات: أجريت مقابلات شبه منظمة، شفهية، وجها لوجه، منظمة مع المشاركين – شملت 11 من الامهات اللواتي يقمن برعاية اولادهن المصابون بمرض الفصام.

وقد سمح دليل المقابلة بالتعبير عن خبراتهم في تقديم الرعاية للأطفال المصابين بالفصام.

عينة: تم استخدام أخذ العينات الهادفة، وكانت عملية جمع البيانات هي مركز الصحة النفسية في منطقة الخليل – الضفة الغربية – فلسطين.

تحليل البيانات: تم تحليل البيانات باستخدام طريقة علم النفس الظواهر لجورجي (1985).

النتيجة: من التجارب التي روى عنها الأمهات، ظهرت 4 مواضيع رئيسية و 18 موضوعا فرعيا من تحليل البيانات. البيانات التي تم الحصول عليها من الأمهات كتبت حرفيا. والتي تشمل **التكيف مع الوضع الجديد** "البكاء، المواجهة الروحية، دعاء، الصلاة، القبول" **العجز المعرفي** " البحث عن المعلومات، التعلم عن المرض" **التجارب العاطفية والاجتماعية** "الحزن، الشعور بالخسائر، التفكير في المستقبل، الوضع المجهدة، الوصمة والتمييز والمكافآت الإيجابية ". **النضال المستمر** "السلوكيات الصعبة، والحفاظ على السلامة، وقبول ما لا يمكن السيطرة عليها" "مواجهة التحدي، يؤثر في جميع أنحاء الحياة اليومية، والعلاقات، والأولويات المتغيرة".

خلاصة البحث:

لكل أم خبرات فريدة من نوعها في رحلتهم من الرعاية والمعيشة مع ابنها المصاب بمرض الفصام، فإن معظم الأمهات يعانين من صعوبات وأعباء، في حين أن رعاية ابناهن المصابون بالفصام تشمل عوامل نفسية وعاطفية واجتماعية واقتصادية.

وتعاني معظم الأمهات من نقص المعرفة والمعلومات فيما يتعلق بالفصام وكيفية التعامل مع الأعراض أو التعامل معها. كما أن التجارب المبكرة مع المرض تشمل الشعور بالخسارة والحزن والبكاء.

عانت الأمهات من العديد من التغييرات في نمط الحياة بما في ذلك العزلة الاجتماعية نظرا لأنها يجب أن تكون دائما مع ابنها المصاب بمرض الفصام الذي اصبح يعتمد عليها بشكل كامل لانه لا يمكن تركه وحده.

ذكرت الأمهات العديد من الاحتياجات التي من شأنها مساعدتهم على التعامل مع الوضع الجديد بعد تشخيص ابنائهن بالفصام، والتي تشمل التثقيف الصحي حول مرض الفصام من حيث المسببات، الاعراض، العلاج وكافة المعلومات المتعلقة بالمرض، وتطالب الامهات بوجود مركز للاستشارات النفسية، كما أنهم بحاجة إلى مركز لإعادة التأهيل والترفيه الأنشطة لابنائهم مع وجود اخصائيين نفسيين على مدار الوقت للتخفيف من اعباء الرعاية والترفيه عن اطفالهم وتخفيف الغضب لديهم.

هذه الدراسة ايضا استكشفت آليات التأقلم لدى الأمهات، التي استخدمنها للتغلب على التحديات التي أدخلها ابنائهم المتضررين من مرض انفصام الشخصية. حيث طورت الأمهات أنفسهن باستراتيجيات جديدة للتكيف للتعامل مع التحديات والوضع الجديد.

وأخيرا بعض الأمهات أفادت أيضا عن تجارب بناء الشخصية الإيجابية عن رعايتهن لابنائهن المصابون بالفصام، وأنهن يشعرن بالارتياح عندما يصبح أطفالهن أفضل ، وبعض الأمهات اصبحن أقرب وقدمن المزيد من الحب لابنائهم

توصيات الدراسة: تشمل التثقيف الصحي للامهات حول كل ما يتعلق بالفصام وانشاء مركز للاستشارات النفسية والترفيه والتاهيل المهني للمرضى ومقدمي الرعاية لهم.