

THE LIVED EXPERIENCE OF PATIENTS WITH DEPRESSION IN PSYCHIATRIC OUTPATIENT CLINIC IN KEDAH AND PULAU PINANG

by

NUR ZAFIFA KAMARUNZAMAN

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LIST OF ABBREVIATIONS

ACT	Assertive Community Treatment
APA	American Psychological Association
CAQDAS	Computerize Aided Qualitative Data Analysis System
CBT	Cognitive Behavioural Therapy
CEDAW	The Convention on the Elimination of all Forms of Discrimination against Women
CMHC/ MENTARI	Community Mental Health Center
CSDH	The Commission on Social Determinants of Health
DALY	The disability-adjusted life year
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
ECT	Electroconvulsive Therapy
GAD	Generalized Anxiety Disorder
HoDs	Head of Departments
JEPeM	The Research Ethics Committee (Human) of Universiti Sains Malaysia
KPI	Key Performance Index
KPWKM	Ministry of Women, Family and Community Development
MDD	Major Depressive Disorder
MDG	Millennium Development Goals
MMHA	Malaysian Mental Health Association
MOE	Ministry of Education

MOH	Ministry of Health Malaysia
MOHR	Ministry of Human Resources
MREC	Medical Research Ethics Committee
NEM	New Economic Model Malaysia
NGO	Non-governmental organization
NHMR	National Mental Health Registry
NIA	National Indicator Approach
NMRR	National Medical Research
OHCHR	United Nations Office of High Commissioner for Human Rights
OT	Occupational Therapy Department
POC	Psychiatric Outpatient Clinic
SDG	Sustainable Development Goals
UN	United Nations
WHO	World Health Organization

PENGALAMAN HIDUP PESAKIT KEMURUNGAN DALAM MENJALANI RAWATAN DI KLINIK PESAKIT LUAR PSIKIATRI DI KEDAH DAN PULAU PINANG

ABSTRAK

Kemurungan adalah satu keadaan tidak selesa yang melibatkan tahap ketidakaturan mental lazimnya menjejaskan emosi dan tingkah laku seseorang. Jenis kesakitan mental ini biasanya berkait rapat dengan ketidakupayaan, satu keadaan penderita terdedah kepada penindasan dan diskriminasi sosial. Kajian lampau menunjukkan tiada perbezaan gender dalam diskriminasi yang dideritai oleh pesakit sebaik sahaja didiagnos dengan kemurungan. Manakala di Malaysia, statistik untuk pelbagai jenis sakit mental telah menunjukkan kenaikan yang stabil saban tahun, dan diagnosis kemurungan merekodkan lebih ramai wanita berbanding lelaki telah mendapatkan bantuan. Terdapat juga kekurangan kajian dijalankan terhadap pengalaman pesakit di perkhidmatan psikiatri, dan kesejahteraan ketika pasca rawatan dengan menggunakan perspektif gender. Oleh itu, objektif utama bagi kajian ini adalah 1) mengenal pasti bentuk-bentuk intervensi untuk pesakit kemurungan di klinik pesakit luar psikiatri di Kedah dan Pulau Pinang; 2) mendokumentasikan pengalaman-pengalaman pesakit lelaki dan wanita semasa mendapatkan rawatan kesihatan dan pemulihan sosial; dan 3) meneroka hasil perkhidmatan pasca rawatan yang diterima oleh pesakit lelaki dan wanita yang menghadapi kemurungan. Kajian ini telah menggunakan pendekatan fenomenologi terhadap 29 orang pesakit (21 perempuan, 8 lelaki) menggunakan temubual separa berstruktur. Triangulasi dijalankan kepada pakar-pakar psikiatri, pegawai-pegawai perubatan, para jururawat, kakitangan pentadbiran, dan penjaga di kajian lapangan. Data dieksplikasi menggunakan perisian kualitatif, Atlas.ti, versi 7.0. Penemuan utama kajian

mendedahkan bahawa struktur dan aktor patriaki masih mendominasi dalam membentuk pengalaman hidup pesakit. Terdapat tiga penemuan untuk menyokong penemuan utama ini. Pertama, farmaterapi dan psikoterapi adalah intervensi primer yang memberi faedah kepada kesejahteraan informan. Tiada perbezaan gender dalam penemuan ini dan kedua-dua gender berpendapat intervensi-intervensi ini dapat mengurangkan simptom-simptom kemurungan mereka. Keyakinan terhadap intervensi ini telah membina kepatuhan dalam rawatan. Kedua, terdapat peralihan paradigm daripada keraguan dalam rawatan psikiatri kepada mempercayai doktor-doktor dan sistem klinik. Namun, perbezaan gender dilihat dalam penemuan ini kerana terdapat kekurangan sokongan sosial dari keluarga dan rakan di kalangan informan wanita. Manakala majoriti informan lelaki mempunyai sokongan pasangan. Oleh itu, peralihan ini perlu untuk mencari sokongan luar bagi menerima keadaan kehidupan mereka terutamanya informan wanita. Tambahan, hubungan doktor-pesakit merekodkan proses tawar-menawar aktif dilakukan oleh kedua-dua gender bukan sahaja untuk mewujudkan kepercayaan dalam rawatan, tetapi untuk mencapai hasil dan makna yang berlainan. Ketiga, dalam pasca rawatan, identiti-identiti baru telah dibentuk oleh informan-informan wanita, iaitu pemerksaan dan berdaya tahan. Namun, hasil ini didapati bercanggah dengan nilai wanita tradisional di negara ini. Identiti-identiti ini adalah hasil daripada proses tawar-menawar yang dilakukan dalam hubungan doktor-pesakit yang akhirnya telah memberi manfaat kepada kedua-dua belah pihak. Penemuan kajian ini telah menyumbang kepada dua aspek utama, iaitu implikasi teoretikal dan praktikal. Dalam implikasi teoretikal, sebuah rangka teoretikal baru telah dibentuk oleh penemuan-penemuan utama kajian ini. Selain itu, penemuan-penemuan utama kajian ini telah memformulasikan cadangan untuk menambahbaik perkhidmatan psikiatri dan kesejahteraan pesakit yang meliputi

penekanan peranan klinik pesakit luar psikiatri; saranan untuk menangani stigma dan sokongan sosial; dan meningkatkan produktiviti dan peluang pekerjaan pesakit.

THE LIVED EXPERIENCE OF PATIENTS WITH DEPRESSION IN PSYCHIATRIC OUTPATIENT CLINIC IN KEDAH AND PULAU PINANG

ABSTRACT

Depression is a personal discomfort involving a degree of mental disorganization that usually affects the individuals' emotion and behaviour. This type of mental illness usually associated with disability, a condition where the sufferers are exposed to social oppression and discrimination. However, past studies indicate there are no gender differences in discrimination suffered by the patients after they are diagnosed with depression. While in Malaysia, statistics on various mental illnesses show steady increment across the years, and depression diagnosis recorded more female than men sought help. There is also a dearth study undertaken on patients' experiences in psychiatric care, and their wellbeing post-treatment using gender perspective. Thus, the main objectives for this study were 1)to identify the forms of interventions for patients with depression at the psychiatric outpatient clinic in Kedah and Pulau Pinang; 2)to document male and female patients' experiences towards the interventions while seeking medical and social rehabilitation treatment; and 3)to explore the post treatment outcomes perceived by male and female patients with depression. This research employed the phenomenology approach on 29 patients (21 female, 8 male) using semi-structured interviews. Triangulation was made with psychiatrist, medical officers, nurses, administrative staff, and care taker in the studied sites. Data were explicated with the assistance of qualitative software, Atlas.ti, version 7.0. The major finding revealed that patriarchal structure and actors still dominate in shaping the psychiatric patients' lived experience. There were three key findings indicated to support the major findings. Firstly, pharmacotherapy and

psychotherapy were the primer interventions benefitting the informants' wellbeing. There were no gender differences in this finding and both genders regard these interventions able to reduce their depression symptoms. Hence, these interventions had built their compliance in the treatment. Secondly, there was a shift of paradigm from scepticism on the psychiatric care to trusting the doctors and psychiatric outpatient clinic system. Gender differences were displayed in the finding primarily due to lack of perceived social support from family and friends in female informants. While a majority of male informants had their spouse support. Thus, this shift was necessary to seek for external support to sustain their life especially among female informants. Moreover, the doctor-patient relationship recorded active bargaining process undertaken by both genders not only to establish trust in the treatment, but also to achieve different intended outcomes and meanings. Thirdly, in the post-treatment, new identities were formed in female informants, namely the self-empowerment and resilience. The outcome however, contrasted with traditional women values in the country. These new identities resulted from the bargaining process made in doctor-patient relationship that eventually benefitted both parties. The findings had contributed to two major aspects, which are theoretical and practical implications. In theoretical implication, a new theoretical framework was shaped based on the key findings in this research. Besides, the key findings had formulated suggestions to improve the psychiatric care and the patients' wellbeing, which include emphasizing the role of the psychiatric outpatient clinic; addressing social stigma and social support; and uplifting the patients' productivity and employment.

CHAPTER 1

INTRODUCTION

1.1 Background of Study

According to WHO (2010a), mental health has become an emerging issue for both developed and developing countries. For example, depression has been ranked among the top global burden that contributes to disability. In 2020, this pathology is expected to be the second most common cause of disability, and it will be placed at the head of the charts by the year 2030. A similar trend is expected in Malaysia as the country faces a gradual increase in the pathology statistics of depression. Records show the presence of psychiatric morbidity of 10.7 percent in 1997; depression alone was recorded at a rate of 2.6 percent in 2002; with 40.9 percent of patients are Indians. Meanwhile, the suicidal ideation in young people has emerged to be the highest in 2007, with the overall morbidity of 9 percent in 2011 (Abdul Kadir, 2011). In a more recent statistics, the Health Morbidity and Mortality survey stated that the prevalence of mental health problem among adults in Malaysia has shown to increase by almost three folds compared to the previous report collected in 2008 (Institute for Public Health, 2015).

Simultaneously, most of the studies revealed that mental health patients' rights are systemically denied. The discrimination existed in the forms of employment, lack of accessibility to mental health care, insufficient facilities and expertise, stigmatized treatments, denial in social insurance, rigid welfare application, and others (Ashencaen Crabtree & Chong, 1999; Parameshvara Deva,

2004; Koyanagi & Bazelon, 2007; Saxena et al., 2007; Mohamad et al., 2011; Ito et al., 2012). In a study conducted at a Malaysian hospital, discriminating treatments were found to be commonly received by patients with mental illness due to the stigmatizing attitudes among health professionals and nurses, which eventually affect the health professional-patient relationship and treatments given (Minas et al., 2011). Another study managed to identify the health professionals' prejudice in predicting patients' behaviour, in which the patients were labelled as "difficult" (Koekkoek et al., 2011), which caused a negative impact such as unclear onset diagnosis.

Given the fact that both sexes are oppressed in the realm of mental illness, it is worth to note that the degree of repression is different (Garland-Thomson, 2002). In diagnostic measures, males were always associated with behavioural disorders such as aggressiveness, antisocial, and substance abuse, whereas women were usually mistaken to be suffering from physical somatization rather than depression (ZamZam et al., 2009; Hill & Needham, 2013). Physical somatization refers to the tendency of a patient to communicate their psychological disturbances with physical illness such as having migraine, back ache, or gastritis. For example, Marchand et al. (2016) had indicated that there is a great heterogeneity between genders on mental disorders and work related stress. According to the author, women higher rate of depression is caused by a gendered social structure and gendered organization, hence experiencing different social experience than men.

Other than that, help seeking behaviour was also found to be different between sexes, in which a study by Janardhana et al. (2011) posits that men will ask for help almost immediately after the onset problem occurred, while women were

forced to suppress their emotional abyss until they displayed social and mental dysfunctions. In this regard, men are perceived as economically significant who bring foods to the household compared to women; hence, the imbalance of care is usually traced in a patriarchal family. A self-rated study undertaken by Ojeda and McGuire (2006) exerted that two-third of the respondents identified themselves as poor users of health facilities due to the social and financial barriers. However, no gender differences were observed. Many patients reported the feeling of helplessness in getting the cure that they needed with no hope of recovery reflected in the poor services provided. On the contrary, women were observed to seek help more compared to men in developed countries. This situation is strongly related to different social roles that were present in the social environment. However, biologically, males have the propensity to be referred to specialist care as a result of depression (Culbertson, 1997; Bertakis et al., 2000). Tanenbaum (2009), Conrad (2005), and Dickerson (1998) identify that a majority of the service users seem to experience unsatisfactory services where their needs were not met. In this realm, the health professionals who functioned as the gatekeepers to the hospital and medication access, worked based on a tight budget and tend to be insensitive to their patients' needs.

Most often than not, many literature are inclined to focus on the recovery process, but only a limited number of studies had been conducted at the program level for the purpose of understanding how mental health care operations work in the country by also considering the patients' experience related to the services. It is also appropriate to note that most of the symptoms alone is not mere problem, but a combination of many other factors from the social environment contributing to the

disability experiences (Mubarak et al., 2003). With the above arguments, the purpose of this phenomenological study is to discover the experience of pursuing psychiatric outpatient clinic for male and female patients with depression.

1.2 Problem Statement

The augment of psychiatric statistic of depression is worrisome in this country. According to Malaysian Ministry of Health, the prevalence of mental pathology faced by different genders has been found to be significant (MOH, 2011). In one of the self-reported surveys in Malaysia, 3.1 percent of female was diagnosed with depression and required treatment, whereas the percentage of male was only 1.9 percent (Abdul Kadir et al., 2002). Simultaneously, the National Health Morbidity and Mortality Survey acknowledges that mental health problems significantly contribute to the total disease burden in the country (Institute for Public Health, 1997; Abdul Kadir et al., 2002). In this case, the report states that a total of 21 percent of both male and female tend to lose their total years living with disability, while 38 percent of the female was discovered to suffer DALY¹.

In the Third National Health and Morbidity Survey, mental illness embodies the percentage of 12.1 percent and 10.4 percent for female and male respectively, which recorded a ten-fold of increment in the statistics compared to the previous national survey (Maniam et al., 2008). Concurrently, the report in 2011 signifies the prevalence of generalized anxiety disorder (GAD) in female recorded at 2.2 percent,

¹According to WHO (n.d.), one DALY is equivalent of 'one lost year of "healthy" life'. This measurement is intended to calculate the cleavage between current health status with the ideal health status, across the population, taking into account the age, disease free and disability.

which is almost twice as high as of male (1.3 percent). Meanwhile, in 2011, similar findings were obtained for the state of depression, whereby the percentage of female was almost doubled than male (2.3 percent to 1.4 percent). On top of that, female is also leading the chart for suicide attempts (Abdul Kadir et al., 2011). The recent Malaysia prevalence study that was released in 2015 indicated that 30.8 percent of females and 28.8 percent of male adults were found to have mental health issues, which is nearly three-fold compared to the statistics recorded in 2008 (Institute of Public Health, 2015).

On the other hand, many postulate mental health services have unclear measures of success in their service of treating individuals with depression (Koyanagi & Bazelon, 2007; Wang, 2012). The measurement of success is merely based on the number of occupied beds in the hospital, which is usually tabulated and reported, instead of the quality of life of the patients. Patients who are diagnosed with depression are usually stigmatized by their surroundings and also subjected to a great misunderstanding of the disease (Ashencaen Crabtree & Chong, 1999). Generally, stigma is associated with the act of stereotyping, prejudice, and discriminative behaviour of the society which impedes the recovery of patients with depression (Corrigan & Shapiro, 2010). Moreover, the stigma drives the social deviance labelling which will curtail the opportunity of the patients to be independent, including the loss of employment and housing opportunity (Ashencaen Crabtree & Chong, 1999). It has been recognized that the service users' perspective is critical in improving the services provided as the patients are usually muted, voiceless, and powerless in the realm of the service reform (Syrett, 2011; Pyer & Campbell, 2012; El Enany et al., 2013; Lasalvia et al., 2013; Corrigan, Druss, et al.,

2014). As a result, patients tend to limit themselves from being in the social environment such as taking a sick-role² to maintain social exclusion (Seloilwe & Thupayagale-Tshweneagae, 2007; Boo et al., 2011). However, patients with depression may still be living in the community, but in reality, the patients are vigilance to let others know their illness as their counterparts who are diagnosed with physical illness (Umi, 2013).

Wang (2012) further argues that the experience and concept of mental health issues in the Eastern setting are not well documented and researched. Hence, the understanding of patients' everyday life in the particular context is relatively low. In addition, the definition of depression varies across cultures, which is dependent on how the culture describes and perceives the nature of the illness. This statement is supported by Foucault because he regards mental illness as a product of socio-history rather than pathology (Turner, 1987). He also addresses that the gap created by practitioners is to enhance control over the body through medical practices, which he termed as biopolitics.

There is still a limited number of systematic studies conducted to further understand the life conditions of patients with depression based on gender, especially in Malaysia (Kadir & Bifulco, 2011). Interestingly, depression among single mothers is apparent, in which the daily life events and material deprivation may be considered as the effects due to young age, increased responsibility in child rearing, work commitment, and lack of social support (Kadir & Bifulco, 2011). The

² This term was coined by Talcott Parson in 1950, in which he defined it as legitimacy given by a doctor to a patient in waiving all of his or her social roles and responsibilities to recover from illness. In return of this waiver, the patient is obliged to follow the doctor's instructions and medicalization to be cured of from the sickness (Turner, 1987).

social stigma on single mothers plays a pivotal role in ostracizing the women who have to undergo single parenthood in the society by labelling them as “husband snatchers” or bringing shame to the family, which always interplays with the effect of low social support. Furthermore, the mental illness experiences of embodiment and gender have not been extensively investigated, neither are the experiences of mental health interventions (Ussher, 2011; Bornäs & Sandell, 2016). With the exception of studies by Ashencaen Crabtree (2012), Kadir and Bifulco (2011), and Ong (1988), numerous researches were found to be focusing on the medicalization of the bodies by adopting the gender neutral stands to explore the prevalence of mental health problems instead of the subjectivity of the patients (Mohd Sidik et al., 2003; Zaid et al., 2007; ZamZam et al., 2009). This matter corresponds to Pescosolido et al. (2007), who state that the number of mental health and gender studies have significantly decreased compared to the 1990s. According to the authors, the findings have resulted in much underrepresented matters in mental health studies that use other perspectives than medical paradigm. On the other hand, Haque (2005) pointed out that mental health problems have yet to become a prime issue in Malaysia, which is reflected in the paucity of the research publication medium as well as the lack of grants offered to study this field. In contrast with reality, the government of Malaysia through its National Economic Policy (NEM) is harping on the theme of inclusivity with a promise that none of the citizens would be left out in enjoying its economic prosperity (National Economic Advisory Council, 2009). However, it is worth to note that NEM has yet to fully give voices and power to this vulnerable group, which is even far from delving into the specific gender needs of everyday life and mental health services.

On top of that, the paucity of research also expands the needs of research according to service users' perspective because it is critical in reconstructing the understanding, needs, and service arrangement for this particular vulnerable group (Syrett, 2011; Pyer & Campbell, 2012). The aforementioned underrepresentation also contributes to the mismatch of treatments; thus, causing certain unmet needs. In this context, both service users' perspective from gender lens is not only crucial in differentiating each gender's needs, but also in rooting for gender equality in the service provided. Gender lens in health has become the interest in magnifying the biological and social factors interactions, which at the same time are used in sensitizing how gender inequality could contribute to health status (Afifi, 2007). Therefore, with the above arguments, this study explored the lived experience of depression among the service users of government psychiatric outpatient clinic from the gender perspective in Kedah and Pulau Pinang.

1.3 Research Objectives

The research was conducted based on the following objectives:

1. To identify the forms of interventions for patients with depression at the psychiatric outpatient clinic in Kedah and Pulau Pinang;
2. To document male and female patients' experiences towards the interventions while seeking medical and social rehabilitation treatment; and
3. To explore the post treatment outcomes perceived by male and female patients with depression.

1.4 Research Questions

The research questions have been identified as follows:

1. What are the forms of interventions for patients with depression at the psychiatric outpatient clinic in Kedah and Pulau Pinang?
2. How do the female and male patients of depression experience the intervention process while seeking medical and social rehabilitation treatments?
3. To know how medical intervention and social rehabilitation experiences affecting both male and female in post treatment?

1.5 Significance of Study

This research aims to conduct a systematic study on the lived experience of patients with depression who underwent mental health care intervention. The importance of this study is in agreement with the study conducted by Pyer and Campbell (2012) which state that the perspective of service users is highly vital in reconstructing the service arrangement, especially in public hospitals. According to Syrett (2011), patients who use the service could serve as consultants and collaborators for service reform. Paradoxically, people who are diagnosed with mental illness are usually voiceless and powerless as well as deemed worthless, particularly in service reform (Kilian et al., 2003; El Enany et al., 2013; Lasalvia et al., 2013; Corrigan, Powell, et al., 2014). The underrepresentation of their perspective might further pronounce the marginalization of their roles as the member

of social institutions. It is important to explore and understand the perceived services based on the patients' perspective, which mainly involves their needs, the subjective understanding of how they experienced the treatment provided, and how they stride, thus the findings could be potent in formulating the recommendation to improve the service delivery for this particular group of patients. Furthermore, the incongruence between the nature of the services provided and the needed input from the patients could be mitigated by addressing the issues to the policy authority, which in turn will modify the treatment modules as well as uplift the patients' satisfaction.

At the same time, the research is targeting to expand the knowledge corpus by adding information related to depression experience through the gender lens due to the paucity of the research that ground the voices of gender. Most of the existing literature and research conducted on mental health issues employed the gender-neutral approach, in which the aspect of gender is not taken into account and perceived as less important (Hooyman & Gonyea, 1995). In fact, the gender neutral paradigm would only produce greatly biased and inefficient service reform and policy making (Afifi, 2007). Gender perspective is critical in deconstructing the dominant paradigm that has been holding the society, particularly the patriarchal power which treats the discrimination for both men and women as a norm. Hence, a gender perspective would easily enable the process of identifying and eradicating the oppression for both genders because the ultimate goal is to obtain gender equality in every aspect of life (Hooyman & Gonyea, 1995). One of the strategies of this study is to understand the context, which involves the studied sites because the system and methods of implementation vary in each country as usually cited in the literature (Thornicroft & Tansella, 2002; Jacob et al., 2007; Saxena et al., 2007; Drew et al.,

2011). Other than that, the study aims to put gender as the centre of discussion of the present research as well as the important intervening variable, which will greatly contribute in shaping human behaviour and experiences.

Finally, the research intends to contribute to the visualization of the themes and sub-themes due to the fact that the discussion was mainly conducted in the form of text and further supported by tabulation of figures to strongly support the explanation. In this study, the purpose of the visualization is to show the interconnection between sub-themes that shapes the whole theme, apart from helping the reader to easily track the discussion reviewed in the text.

1.6 Research Scope

The scope of the present study focuses on investigating the lived experience of patients who were diagnosed with depression while undergoing the outpatient mental health care. The study was conducted based on the experience of the patients in pre, during, and post-treatment at the attended hospitals to capture the whole understanding on how they went through the psychiatric treatments. The data were collected from two public and government run hospitals, namely Hospital Serenity in Kedah and Hospital Goodwill in Pulau Pinang. The study is interested to understand on how both genders undergone their lived experience, thus male and female were included in the research. Both genders were taken into account because for few reasons. Firstly, there is a limited study undertaken magnifying gender differences in mental health study in Malaysia (Kadir & Bifulco, 2011). The second reason was based on the Feminist Disability Theory that theorized both genders suffer discrimination for being mental health patients. Thus, this study could

contribute the understanding of representational system of this vulnerable group in Malaysian context. And finally, the researcher identified both studied hospitals did not maintain any statistic or name list specifying their patients diagnosis and treatment. This was a legitimate difficulty, which beyond the researcher's control to recruit a balance number of the informants in this study.

Thus the recruitment process was based on the following inclusive criteria:(a) age 18 years and above, (b) clinically diagnosed with depression or major depressive disorder, and (c) attended the follow-up treatments at the psychiatric outpatient clinics for at least 12 months. In this context, only remissive patients were being considered as the research subjects because they were clearer in their conversation and expression of experiences due to the absence of many depressive symptoms. In order to capture the lived experience of patients who underwent the psychiatric outpatient clinic (POC) service, the experience before, during, and after the mental health care were investigated to elicit the essence of the experiences.

The data were collected during the operation of the POC. The time-frame has been chosen to ensure the maximum opportunity could be gained to recruit the potential informants. Any potential recruitment was referred to health professionals during the POC period in order to confirm the inclusive criteria, especially from the psychiatrists and medical officers. This step was crucial in ensuring that only patients who fulfilled the inclusive criteria were included.

1.7 Terms and Definitions

For the purpose of reaching a common understanding of the studied elements, the following operationalized definitions are used:

1.7.1 Biomedicalization

Biomedicalization is a new transformation of medicalization. It involved expansion of techno scientific shift of biomedical organization, infrastructures, knowledge, and clinical treatment through privatization of research to their strategic partners, such as university and pharmaceutical industry (Conrad, 2005). Doctors do not have the control on the care system as indicated during medicalization era, however, they are governed by the institution which funding the mental health care (Clarke et al., 2003; Conrad, 2005).

1.7.2 Deinstitutionalization

Deinstitutionalization is a movement to shift psychiatric patients into the community to be treated (Lamb & Bachrach, 2001). The main objective is to reduce bedding in mental hospitals, release the patients from hospital and change the status of outpatients, minimize relapse and re-hospitalization, and promote recuperation process that is conducted in the community setting (Thornicroft & Tansella, 2002; Parameshvara Deva, 2004; Abdul Kadir, 2011).

1.7.3 Depression

Depression is a type of mood disorder that is categorized as a form of mental disorder by DSM-5 American Psychiatric Association (2013). According to the Malaysian Mental Health Association, depression is due to imbalance of chemical in the brain (MMHA, 2008). The Law of Malaysia defines mental disorder as "...any mental illness, arrested, or incomplete development of the mind, psychiatric disorder or any other disorder or disability of the mind however acquired; and "mentally disordered" shall be construed accordingly" ("Mental Health Act," 2001, p. 2). According to the medical model employed by the Diagnostic Statistical Manual V (DSM-V), depression is characterized by distinct episodes that last for at least two weeks, which are capable of showing the observable differences in feeling, cognitive functions, and ability to socialize (American Psychiatric Association, 2013). DSM-V is the manual used by the psychiatrist to plot the symptoms of mental illness to the disease categories during diagnosis. The symptoms include depressed mood or loss of interest in daily activities, weight loss, insomnia or hypersomnia, psychomotor dysfunctionality, fatigue, worthlessness or feeling of guilt, indecisiveness, and suicidal ideation.

Similarly, Gove and Tudor (1973) define depression as a disorder that involves personal discomfort and/or mental disorganization. Personal discomfort refers to the feeling of distress and anxiety, while mental disorganization exists in different forms such as confusion, thought blockage, motor retardation, hallucination, and delusion. The DSM-5 American Psychiatric Association (2013) further acknowledges the dysfunctional dimensions of depression, which is believed to be a long lasting illness. On this note, the severity of individual disorder might

also result in different symptoms, namely single or recurrent episodes, current severity, the presence of psychotic features, and the remission status. In the context of this study, only remissive patients are being considered as the research subjects because they are projected to be clearer in their conversation and expression of experiences due to the absence of depressive symptoms. However, they still require the doctor's supervision to get better.

The above impression describes depression totally as a medical problem. However, the main concern is the extent of depression being a biological defaulted. Is it possible for depression to be caused by external factors such as social environment and social relationship with others? Alternatively, the social model tends to contend the idea that depression is resulted by the biological defect; however, the social environment and its forces are considered to be significantly harmful towards individuals, regardless of genders (Aneshensel, 1992; Donaldson, 2002; Garland-Thomson, 2002). More alluring, the feminist scholars have provided an avenue for women or marginalized group to voice out and describe their experiences as well as the meaning of those experiences (Brooks & Hesse-Biber, 2007). For example, the study conducted by MacKay and Rutherford (2012) on the feminist activist accounts of their lived experience on depression had managed to discover that the construction of being depressed interplays with the social factors, material sufferings, and biological understanding. Hence, this imparts that the voices of women suffering from depression is very much embedded to their social condition. In other words, the original narratives provided by these women should be taken into account because it will particularly frame out their misery.

The misery differences between genders have been highly acknowledged through gender studies, which are also known as a psychosocial disability. The classification is vital to recognize the social sufferings and difficulties in daily life. According to Davar (2008), psychosocial disability is addressed by the radical scholars due to their doubt towards psychiatry, and its ability to contribute to the intellectual corpus. This indirectly contests the validity of psychiatric practices, which is considered as infant science as well as the lack of testing and science evidences to claim the classification made in the Diagnostic and Statistical Manual (DSM) (Dziegielewski, 2010). Apart from that, depression can be better understood by intersecting the onset with social condition, politics, economy, and culture of the individuals that could cause them to experience misery in everyday life (Davar, 2008; MacKay & Rutherford, 2012).

In Malaysia, a research conducted by Roziah (2000) identified that Malay women conceptualized illness in a form of dichotomy. Firstly, illness is defined as the intrusion of individual performance in daily life, which causes uneasiness to the disability. This situation is usually described in medical terms, which affects the physical body. Secondly, illness refers to the disturbances caused by supernatural spirit that is capable of weakening the soul. The second explanation is strongly related to psychosocial functioning, which is described as mental health problem. In relation to mental health problem, culture plays an important role in providing meaning to the onset of the disease. For example, the Malays' interpretation of the disease intertwines with the spiritual being and religious factors (Chong et al., 2013). Among the explanations to comprehend the occurrence of mental illness include the loss of one's soul, the blood vessels being blocked by wind or "angin", and the

possession by spiritual entity or also known as “Jinn” (Haque, 2005). These features are important in capturing the local experience that relate with depression since local meaning system and practices might differ in other context (Kirmayer et al., 2017).

The above arguments consistent are with Karim (1990b) that postulates the existence of emotions should be viewed based on the social labelling of emotional states and the effect of its expression within the cultural realm. In this sense, the friction between the emotions and the social sentiment (literally *adat*) would depersonalize the individual’s personal interest. The social labelling and the effect of the displayed emotion are significant when it is defined as uncontrollable. This definition would shift the meaning of the occurrence into illness, a kind of mental illness in which involved the intervention of supernatural beings. It is also interesting to note that certain types of mental illness such as amok and *latah* are socially constructed within the cultural framework of masculinity and femininity (Karim, 1990a).

Meanwhile, the Chinese would adopt the belief of *ying* and *yang* paradigm, but the Indian tend to perceive that mental state can be preserved with the practice of healthy diet, which describes the connection with the God and the Brahmins (higher caste) (Haque, 2005; Chong et al., 2013). These cultural explanations are regarded as an alternative way to comprehend the meaning of patients with depression who experience misery.

Therefore, the present study describes depression as a state of personal discomfort involving a degree of mental disorganization that usually affects the individuals’ emotion and behaviour, which is believed to be caused by one’s social environment, material sufferings, physical, and emotional irritations that could result

in misery of their everyday life. Social labelling, stigmatizing, and the barriers to be active individuals, employees, and part of the community members are among the method to discriminate patients with depression.

1.7.4 Disability

Disability is a form of social oppression that limits the activity of the impaired that include person with mental illness, which undermines their psycho-emotional wellbeing (Thomas, 2010). Disability is believed to be culturally constructed and fabricated in the language of everyday life on the body, where it is a “natural state of corporeal inferiority, inadequacy, excess, or a stroke of misfortune” (Garland-Thomson, 2002, p. 5).

1.7.5 Field

Field is a system of social hierarchy that had power relation embedded in the structure (Wallace & Wolf, 1999). *Field* or objective structure is a field of forces which provides struggles platform over social position within it (Mahar et al., 1990a).

1.7.6 Habitus

Habitus is a mental map, which is shaped by everyday experience and socialization, or an agent (Mahar et al., 1990b). The component of *habitus* is highly associated with internalized schemas that embody one’s social structure. On the

other hand, the internalized schemas is influenced by class structures, gender, age, and social class (Ritzer, 1996).

1.7.7 Illness

In the medical field, the research conducted on disease and illness has always been a major interest. Most often than not, disease is considered as a breakdown of biological functioning or structure, while illness represents the physical, emotional, and the essence of the perceived disease experiences (Kleinman, 1988; Roziah, 2000). Illness is socially constructed by the local cultural orientation that shapes the society's thought, behaviour, and the process of coping with the daily life of disability (Kleinman, 1988). Simultaneously, illness is also associated to sick role, a term introduced by Parsons (1991) that is connected to the act of deviant. A person who employs the sick role usually withdraws from work as a time off in order to take necessary medical treatment for the purpose of avoiding from being labelled as deviant (Gabe et al., 2004).

1.7.8 Intervention

Intervention refers to any course of treatment conducted to alter the course of events of an individual, which include the use of medicine, counselling, psycho-education and course of treatment (Segen's Medical Dictionary, 2011). In mental health nursing research, Smith (2012) postulates that psychological interventions should be employed to promote biopsychosocial functioning through therapeutic social connection between health professionals and patients. Biopsychosocial is a holistic approach employed by psychiatrist to examine psychiatric patients based on

their biology, psychology, and the social aspects that might contribute to the patients' depression. In this study, treatment and intervention were used interchangeably.

1.7.9 Lived Experience

The lived experience has always been a favourite unit of analysis in feminist studies. Dated back in the rise of the second wave of the feminist movement, feminist researchers have come together to create consciousness on the conspicuous contradiction on their lived experience with the mainstream theories taught in the academic fields (Brooks & Hesse-Biber, 2007). Apart from the lack of representation of women and the marginalized group, there are several goals of conducting feminist research, which is to expose the hidden aspect of the subject's life, challenge the existing structures and ideologies, and continue building new epistemologies and methodologies. According to Brooks (2007), it is best to study the lived experience because it could resonate the on-going project of the feminist research. The research is able to unlock the silence and the unknown knowledge offered by the oppressed group through the sharing of their own experience. Ultimately, the research findings aim to apply the oppressed group's vision and knowledge to social activism which is believed to promote social change in the society.

In order to seek understanding of lived experience, the definition of experience is broken down based on phenomenological approach, which is aligned with the research design employed in this study. Experience is defined as an accumulation of knowledge gained as an outcome of direct involvement in one

event. According to van Manen (1990), experience can be significant if an individual creates an unforgettable memory to any particular event. Similarly, Schutz (1970) postulates experience as the starting and the end point of phenomenological research. A subjectivity is an individual experience and it involves a flow of experience which creates consciousness towards other experiences. The interest in phenomenology is to investigate the shared meaning by the informants about a phenomenon, also known as intersubjectivity.

Experiences consist of unit of meaning or patterns as the foundation to lived experience. However, only experiences with reflective consciousness are able to create expression and meaning (Schutz, 1970). van Manen (1990) emphasizes that lived experience can be studied by transforming the lived experience into texts (transcribed data), which will also provide an expression of its essence that acts as a linguistic construct to describe a phenomena. Individuals accumulate the stock of experience across time, which could guide the individuals to think or act when they come across any similar situation (Schutz, 1970). It is also important to note that experience exists in a temporal structure, while it can only be defined as an experience if a person had gone through an event, in retrospect.

Ratcliffe (2015) postulates the accounts of predicament by the patients serve as a communication to reflect the changes in their lives, for example from healthy to illness. It is vital to acknowledge the involvement of time span, which involves the world before and after in order to allow the study to make sense of the changes in the experience of the patient's life. As quoted from Ratcliffe (2015), "we can let our subject matter guide us and – in the process – progressively refine our understanding of the sense of reality and belongingness" (p.23). Walby (1996) also concurs that

time plays an important role in the research of gender relations, particularly in the context of identifying the changes in the structure of patriarchy and women's biographies.

Therefore, lived experience in this study is considered as an accumulation of experiences that has been consciously reflected by an individual as a meaningful substance, which is expressed to create the essence of the experiences. In relation to the present study, the experiences before, during, and after the mental health care treatment will be investigated to capture the lived experiences in mental health care for both genders in order to elicit the essence of the experiences.

1.7.10 Medicalization

Medicalization is a term used to describe individual's health state as problematic and usually doctors would confirm the disease could be fixed through medical treatment (Conrad, 2005). It gives power to the doctors to control over the organization (hospital) where their medical practices were exercised.

1.7.11 Mental Health Care

The mental health care is one of the clinical programs conducted under MOH for the purpose of providing psychiatric treatments. According to Roziah (2000), a medical system emerges as a response to mitigate illness and sick role, which is further applied to overcome mortality in society. In this study, the mental health services are only provided as a secondary health care, which is described as psychiatric services that are based in general hospitals. This psychiatric services

possess the sub-specialization of psychiatry in which the service admission is upon the referral from primary care or private practices (MOH, 2011). The services provided involve in-patient and outpatients services, promotion, prevention treatment, home visits, and psychosocial rehabilitation (Thornicroft & Tansella, 2002; Parameshvara Deva, 2004; Abdul Kadir, 2011). However, the focus of the current research mainly revolves around the outpatient psychiatric clinic in public and government run hospitals.

1.7.12 Psychosocial Rehabilitation

Psychosocial rehabilitation is known as non-drug treatments and it promotes social skills development for patients with mental illness. Among the treatment included are talk therapy; social skills development such as improving communication, decision making and leadership; and vocational training. According to Merican et al. (2004), psychosocial therapy could potentially up-lift self-esteem and self-efficacy of patients however; it needs integrated support from the patients, family members, community members, and health professionals to make it a success. At this end, psychosocial rehabilitation could not run fully as other countries due to financial constraints. To overcome this problem, MOH has integrated rehabilitation into general hospital as the primary health care who serves patients with trainings, usage of equipment, and skills development (Jamaiyah, 2000). On the other hand, assistance from non-governmental organization and community support group on this matter has given advantages to the patients especially in reducing stigma (Kelly, 2006).

1.8 Organization of the chapters

The current study is organised into eight chapters. Chapter 1 covers the background of the study, problem statement, research questions, research objectives, the significance of the study, research scope, and the terms and definitions. Chapter 2 discusses the literature review that includes the clinical symptoms of depression, the management history of patients with mental illness, and depression that is treated as a public issue both globally and locally, which includes the discussion on mental health, particularly related to legislations and programs. The articulation of this section includes various social determinants of health inequities such as social status, prestige, and the access to health service that define the patients' social positioning in the society. The discussion is then continued by examining the social determinants of health, which comprise the material stands, adversity in life events, and lifestyles. In this realm, the experiences of the patients in mental health care will be presented to depict the current phenomenon being investigated. This chapter is concluded with the discussion on the theoretical approach as well as the framework used.

In Chapter 3, the approach employed in this study is highlighted, which is known as phenomenology in order to investigate the lived experience of the informants. Simultaneously, the study population, sampling techniques, data collection procedures, explication of data, and ethical consideration are also deliberately presented in the same chapter. On the other hand, Chapter 4 aims at introducing the informants and their adverse life events in which linked to the onset of depression. This chapter ends with the analysis of the demographic profiles of