

**A QUALITATIVE STUDY ON ELDERLY DEPRESSION AND
THEIR HELP SEEKING BEHAVIOUR IN KELANTAN**

DR ARUNAH A/P SANGGAR

DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE
REQUIREMENTS FOR THE DEGREE OF MASTER OF MEDICINE
(PSYCHIATRY)



UNIVERSITI SAINS MALAYSIA

2018

ACKNOWLEDGEMENT

I would like to thank all those involved throughout the journey of my thesis completion. First of all, I would like to thank my supervisor, Prof Madya Dr Asrenee Abd Razak who had been an amazing, enabling, supportive and responsive guidance from the beginning of this journey. Her expertise, supervision and persistence has been crucial in me completing this thesis.

I am extremely grateful to my study participants who had welcomed me with open arms and treated me as a they would a guest and opened up to share with me their experiences, thoughts and knowledge. This study would not have been possible if it was not for their active participation.

My family has also been a constant support and a place to unwind myself. My father, Sanggar Seerangan, and mother, Suppamah Kaliappen had always been a phone call away throughout the years I have been away to pursue my masters and complete this thesis. My sister, Ommathy Sanggar has also been encouraging and motivating me to carry on with the thesis on the days I needed a pick me up support.

Last but not least, my utmost gratitude to the Lord Almighty, as without him none of this would have been possible.

TABLE OF CONTENT

ACKNOWLEDGEMENT	ii
ABSTRAK (BAHASA MALAYSIA)	iv
ABSTRACT	v
CHAPTER 1 : INTRODUCTION	1
CHAPTER 2 : LITERATURE REVIEW	4
Depression in the elderly	4
Prevalence and risk factors for depression among elderly	6
Help Seeking Behaviour for depression	8
CHAPTER 3 : OBJECTIVES	13
General Objectives	13
Specific Objectives	13
CHAPTER 4 : MANUSCRIPT	14
Title page	14
Abstract	15
Introduction	16
Method	19
Results	21
Discussion	40
Conclusion	43

References	45
Additional file	47
Guidelines / Instructions to Authors of Selected Journals	49
CHAPTER 5 : STUDY PROTOCOL	58
Study protocol and consent form submitted for ethical approval	58
Ethical approval letter	107
REFERENCES	109
APPENDICES	113
Abstract presented in conference	113
Soft copy of transcribed interview	115

ABSTRAK (BAHASA MALAYSIA)

KAJIAN KUALITATIF TENTANG KEMURUNGAN DI KALANGAN WARGA EMAS DAN CARA MEREKA MENDAPATKAN BANTUAN DI KELANTAN

Walaupun kadar kemurungan di Malaysia tinggi, namun ramai di kalangan mereka tidak mendapatkan bantuan profesional. Kajian ini bertujuan untuk mendalami luahan gangguan emosi di kalangan warga emas di Kelantan, cara cara mereka mendapatkan bantuan dan pengetahuan mereka tentang kewujudan bantuan profesional. Kajian kualitatif fenomenologi interpretasi menerusi temu bual bersemuka di kalangan 19 warga emas Melayu yang disaring positif untuk kemurungan. Gangguan emosi muncul dalam tema ‘Hidup ini Sengsara’, ‘Kemurungan adalah tanda Kelemahan’ dan ‘Takdirku telah Ditentukan’. Manakala cara mereka mendapatkan muncul dalam tema ‘Berdikari’, ‘Rangkaian Sokongan Sosial’ dan ‘Bantuan Profesional bukan dari Kepakaran Kesihatan Mental’. Kesemua peserta kajian tidak mempunyai pengetahuan tentang kewujudan bantuan profesional kepakaran mental dan juga tidak akan memerlukan bantuan pakar kesihatan mental walaupun disaring positif untuk kemurungan. Oleh yang demikian, kesedaran kesihatan mental di kalangan warga emas perlu dipertingkatkan dan sokongan sosial mereka perlu diperkukuhkan.

ABSTRACT

A QUALITATIVE STUDY ON ELDERLY DEPRESSION AND THEIR HELP SEEKING BEHAVIOUR IN KELANTAN

Despite a high prevalence of elderly depression in Malaysia, professional help seeking is limited. This study aims to explore the expression of emotional distress among elderly in Kelantan, their help seeking behaviour and their knowledge on the availability of professional help. Qualitative interpretative phenomenological approach with face to face interviews were conducted in 19 Malay elderly who have been screened positive for depression. The emotional distress in the elderly emerged as 'Life is Miserable', 'Depression is a Sign of Weakness' and 'My Destiny is Predetermined'. The emerging themes for help seeking behaviours are 'Self Efficacy', 'Social Support Network' and 'Formal Non Mental Health Professionals'. All of the participants had no knowledge on the availability of professionals mental health services and claimed neither would they require these services despite being screened positive for depression. Therefore there is a need to improve mental health literacy among the elderly about depression and empower their social supports.

CHAPTER 1

INTRODUCTION

The global population has been seeing significant increase in the growth of the older population owing to the decline in fertility and successful increase in the longevity of the human population. It is projected that by the year 2025, the global aged population would rise to 798 million and this amount would double to a whopping 1.6 billion by the year 2050 (Wan He, Daniel & Paul Kowal, 2016)

Malaysia, like every other developing nation has also caught up with population ageing, and it is postulated that by the year 2020, the older population would represent 7% of the nation and this would double to 14% by the year 2043. Thus by the year 2020, as an aged nation, Malaysia has to be fully prepared to accommodate the demands of the aged population (Hamid, 2015). The nation would have to be prepared to face some inevitable challenges in terms of maintenance of good health, chronic diseases, independence, financial resources, employment and rising health care costs. A substantial burden is placed on policy makers and health care providers in facing the upcoming challenges.

The World Health Organisation has defined “health as not merely a state of absence of disease but rather a complete state of physical, mental and social well being”(Callahan, 1973). Mental health on the other hand is defined as a “state of well being whereby individuals realise their own potential, cope with normal stresses of

life, work productively and is able to make contribution to the community” (WHO, 2004). It would only be fair to assume that attaining this state of health is the right of every human being, including the elderly, whom are often associated with chronic illnesses, loneliness and loss of employment with subsequent socio economic disadvantage leading to the general assumption that elderly is synonymous with poor general well being and health.

According to the Gwatkin (1997) through the global burden of disease report, depression has been projected to be the second leading cause of disease burden in the year 2020 and was ranked as the number one cause of disability in the year 1990 worldwide. It would not be far fetched to assume that the elderly population would be at high risk of developing depression considering the disadvantages and life events they face in life following ageing however very little is known about the expectations of elderly about their expectations on quality of life as they age, their expression of their emotional distress and their help seeking behaviour. These are important aspects to be explored as it would determine and provide a guide to the healthcare professionals and policy makers on the appropriate interventions and programmes aimed at ensuring the optimal physical and mental health of the group of the population.

The current study took place in Kelantan, a predominantly Malay Muslim occupied state in the northern eastern region in Peninsular Malaysia which has its own unique culture owing to its relative isolation and largely rural lifestyle. It has a population density of about 1.83 million in the year 2017, with a majority of 95 % of the

population being Malay Muslims. The average life expectancy for a male is 69.2 years and a female is 75.2 years (Department of Statistics Malaysia, 2017). The Malay Muslim have their own culturally unique way of expression their emotions which is usually limited and done in moderation in relation to its strong Islamic influence, and psychological problems are often somatised to avoid stigmatization by the community (Razak, 2017). This study would shed light into the expression of emotional distress and the experiences and beliefs of the causes of depression among elderly in this region and their subsequent help seeking behaviour in managing their depression. We also aim to evaluate their usage and the knowledge of availability of local policy and program for elderly mental health.

This dissertation was arranged according to the new manuscript ready format as aligned by the faculty and follows the SAGE journals submission guidelines. The manuscript will represent the whole body of the dissertation with the title of “ A Qualitative Study on Elderly Depression and Their Help Seeking Behaviour in Kelantan.”

CHAPTER 2

LITERATURE REVIEW

This review of literature is aimed to cover the known literatures at the time of commencement till completion of this study. Research gaps were identified and subsequently the research guide and conceptual framework was formulated using the information obtained.

Depression in the Elderly

According to the Diagnostic and Statistical Manual For Mental Health (DSM 5) published in 2013 by the American Psychiatry Association, a diagnosis of Major Depressive Disorder is made when a person fulfils either one of the criteria of depressed mood or loss of interest in activities lasting at least two weeks followed by another four criteria of either change in appetite, change in sleep, change in activities, fatigue or loss of energy, feeling of worthlessness or inappropriate excessive guilt, loss of concentration and recurrent death thoughts or suicidality.

Depression in the elderly or commonly known as late life depression is depression that occurs after the age of 60 (Disabato & Sheline, 2012). It can either be a new onset of depression that occurs after the age of 60 or it could be a recurrent disease stemming from an earlier onset of the illness. The aetiological factors contributing

towards development of late life depression is different from early onset depression in that chronic medical illness and vascular lesions in the brain matter tend to be more common contributing factors and these people usually have less intense symptoms with better social support and more prominent cognitive impairments (Kessler et al, 2010).

Another important issue to consider in regards to elderly depression is the fact that Major Depressive Disorders fulfilling the criterion required is relatively low in prevalence and other forms of depression such as depression without sadness (Gallo et al, 1997), subsyndromal depression (Lavretsky & Kumar, 2002), mood disorder secondary to general medical condition, adjustment disorder with depressed mood, vascular dementia with depressed mood and substance or medication induced depression (DSM 5, 2013). Diagnosing these other forms of depression is as important as identifying and treating major depressive disorder as even the minor forms of depression tend to include impaired physical function, increased disability days, perceived low social support and increased health service utilisation (Lavretsky & Kumar, 2002 ; Alexopoulos et al, 2002 ; Beekman et al. 1995).

Diagnosing depression in the elderly also poses certain challenges that needs to be overcome. For example elderly male present with more of anger, apathy, anhedonia while woman present with more somatic symptoms and they tend to over express their somatic complaints and minimise psychological complaints. Overlapping symptoms such as cognitive impairment and medication side effects tends to cause confusion and ambiguity in establishing the diagnosis (Almeida et al, 2011).

Prevalence and associated factors of elderly depression

Prevalence of elderly depression in Malaysia ranges between 7.6% to 30.1% (Mohd Sidik, Mohd Zulkefli & Mustaqim, 2003 ; Sherina, Rampal & Mustaqim, 2004 ; Khan, Manan & Rohana, 2010 ; Abdul Manaf et al, 2016) depending on the screening tools used and is similar and comparable to the Asian prevalence of elderly depression which ranges between 10.5% to 23.5 % (Rajkumar et al, 2009 ; Cong et al, 2015 ; Majdi et al, 2011). This prevalence is almost comparable or perhaps slightly higher compared to a meta analysis done by Volkert et al (2013) comprising the European and North American countries which showed a prevalence of 19.47 % for dimensional depression.

There are many biological and psychological factors that contribute towards predisposing and perpetuating late life depression in the elderly that is unique to this group of population. Chronic medical illnesses such as diabetes mellitus, cardiovascular disease, cerebrovascular disease are found to be associated with a higher prevalence of depression among elderly (Rajkumar et al, 2009 ; Cong et al, 2015 ; Yaka et al, 2015 ; Mohd Sidik et al, 2003).

Psychosocial factors seems to play the main role in the development and maintenance of depression among the elderly as it has been found that most elderly describe loneliness (Khan, Manan & Rohana, 2010 ; Yaka et al, 2014 ; Yamin et al, 2016) , functional disability and dependency (Sherina et al. 2006 ; Glamcevski & Pierson, 2005 , Hairi et al, 2010 ; Yaka et al. 2014 ; Verhaak et al, 2014), unemployment and

low socioeconomic status (Khan, Manan & Rohana, 2010 ; Sherina, Rampal & Mustaqim, 2004) and stressful life events (Yamin et al, 2016) as the risk and associated factors for depression.

A few qualitative research efforts have been made locally to understand and explore the mental health of elderly in Malaysia. Dahlan et al (2010) , explored the life satisfaction of elderly people living in several institutions in Malaysia. A total of 20 participants were interviewed and a rather unexpected result obtained was the fact that these elderly were content and accepted their life in the institution which is not what would normally be expected.

Evans et al (2017) interviewed 40 elderly participants explore their social support and care arrangements in rural Malaysia and found that all of the participants perceived themselves to be alone, and while the Malay participants considered their family for support, the Chinese participants preferred neighbours and friends for support as their children are usually overseas and these group of people despite having chronic medical illness avoided thinking about future consequence of their illness , care and death as these thoughts made them feel depressed. Meanwhile Mutalib et al (2016) explored interdependency and quality of life among Malay older people in the community and found that these group of people had high regards for meaningful social relationship, care of the sick and the need for companion while lonely amongst their neighbouring community and festive was an important way of maintaining their interdependency.

Help Seeking Behaviour for Depression

Help seeking behaviour is used interchangeably with health seeking behaviour and is an important tool in determining and understanding patients delay and promptness in seeking health care for a variety of health condition (Cornally & McCarthy, 2011).

There is no clear definition to explain help seeking behaviour for mental health but the closest definition is from The World Health Organisation which describes help seeking among adolescence, which defines it as,

“Any action or activity carried out by an adolescent who perceives herself/himself as needing personal, psychological, affective assistance or health or social services, with the purpose of meeting this need in a positive way. This includes seeking help from formal services – for example, clinic services, counsellors, psychologists, medical staff, traditional healers, religious leaders or youth programmers – as well as informal sources, which includes peer groups and friends, family members or kinship groups and/or other adults in the community. The “help” provided might consist of a service (a medical consultation, clinical care, medical treatment or a counselling session), a referral for a service provided elsewhere or for follow-up care or talking to another person informally about the need in question. We emphasize addressing the need in a positive way to distinguish help-seeking behaviour from behaviour such as association with anti-social peers, or substance use in a group setting, which a young person might define as help-seeking or coping, but which would not be considered positive from a health and well-being perspective.” (Barker & Gary, 2007)

There are many theories that have been developed to help us understand how a person seeks help for a particular illness. Some of the famous theories include Ajzen's theory of planned behaviour that is concerned with how a person's attitude towards the illness, their subjective norms and their perceived control over the illness influences their intention and subsequently the behaviour itself (Ajzen & Icek, 1991). The health belief model is another theory that informs us that the decision to perform a behaviour is dependent on how the individual appraises the perceived threat of the illness and its severity and the perceived barriers and benefits of the behaviour itself (Rosenstock & Irwin, 2005).

A very useful explanatory model developed by Arthur Kleinman called the Kleinman explanatory model of illness is particularly useful in mental health especially in the Asian population as it represents specific personal and social meaning that a person assigns to their experience of illness. It is derived from a person's belief, knowledge and perception about health and its causes, signs and symptoms, severity, transmission, options for treatment and prognosis. The source of their belief may include three main sectors namely the popular sector which includes beliefs shared by family, friends and their own personal experience, the folk sector where the belief originates from a traditional belief and professional sector which is from the person's exposure to teachings of health care professionals. This form of explanatory model is very culturally inclined and is suitable to explain help seeking behaviour for mental health which is still very much culturally rooted till date (Kleinman, Eisenberg & Good, 1978).

There has been many quantitative studies done to explore factors affecting help seeking in patients with mental illness. A study done exploring reasons and determinants of help seeking in people with subclinical depression in Netherlands in 2015, found that 40% perceived no need for care and claimed not to experience symptoms, could solve their own problems and could mobilise their own support and these group of people were much older than those who received care (van Zoonen et al, 2015). Whereas a study done in Germany in the year 2014 looking into the attitudes towards mental health service among older adults revealed that female, urban, personal experience with psychotherapy and increased in perceived social support showed more positive attitude towards mental health seeking (Kessler et al. 2015).

Meanwhile in the Asian context, in Korea in the year 2015, a community health survey looking into depression and professional mental health use revealed that only 17.4 % consulted mental health and elderly of both genders had lower percentage of consultation compared to the younger population. Those elderly with unmet healthcare needs, history of diabetes mellitus, lower education and income had lower mental health service use (Kim et al, 2015). Another study done by Park et al (2015) in Korea revealed that perceived stigma inversely affects mental health service use .

A few efforts has been taken globally and locally to ascertain help seeking behaviour for depression in a qualitative manner. For example, a study using 42 depressed elderly African American showed that these group of people attributed depression as a normal part of ageing and seek more culturally acceptable ways to cope with their symptoms through informal support system such as their family and religion and

believed that depression was a sign of weakness and thus obtaining professional treatment was viewed to be highly stigmatised (Conner et al, 2010). In Uganda, pathways of help seeking in hospitalised patients for depression revealed that somatisation, social meaning and help seeking, meaning and perceived consequence of illness, making sense of psychiatry admission and various causal attributions and role of significant others shaped their help seeking behaviour (Okello et al, 2007).

In the local context, the aspect that has been given importance in the recent past is the importance of religion and spirituality amongst the depressed Muslims and elderly. Minhat (2014), interviewed 20 elderly Malay female regarding the purpose of their religious activity during leisure and found that these group of female found serenity and calmness and considered praying as synonymous with being old and gave them means to socialize. Meanwhile, Md Rosli et al (2016), interviewed 10 patients amongst which 2 were elderly and found that spiritual elements was important in depressed Malaysian Muslim as it served their religious needs to worship and obtain guidance while it also served its purpose for existential needs for calmness, empathy, self discipline, hope and to explore the meaning of their illness. These finding may be able to assist in explaining the lack of help seeking among the Malay elderly in the local context.

This study aims to look into the expression of emotional well being and subsequent help seeking behaviour among community dwelling depressed elderly in the state of Kelantan as there is very limited data pertaining this issue. This study would shed light into the expression of emotional distress and the experiences and beliefs of the

causes of depression among elderly in this region and their subsequent help seeking behaviour in managing their depression. We also aim to evaluate their usage and the knowledge of availability of professional mental health services.

CHAPTER 3

OBJECTIVES

GENERAL OBJECTIVES

To explore the expression of emotional distress among depressed elderly in the state of Kelantan and how it subsequently shapes their help seeking behaviour.

SPECIFIC OBJECTIVES

1. To explore the expression of emotional distress and the experiences and beliefs of the causes of poor mental health among elderly
2. To explore the help seeking behaviours among elderly in managing their mental health problem
3. To evaluate the usage and availability of professional mental health services in the elderly

CHAPTER 4

MANUSCRIPT

4.1 TITLE PAGE

**TITLE : A QUALITATIVE STUDY ON ELDERLY DEPRESSION AND THEIR
HELP SEEKING BEHAVIOUR IN KELANTAN**

Authors : ARUNAH S ¹, ASRENEE AR ¹

¹ Department of Psychiatry,

School of Medical Sciences, Universiti Sains Malaysia,

16150 Kota Bharu, Kelantan.

Keywords : elderly, help seeking behaviour, depression

Abstract

Despite a high prevalence of elderly depression in Malaysia, professional help seeking is limited. This study aims to explore the expression of emotional distress among elderly in Kelantan, their help seeking behaviour and their knowledge on the availability of professional help. Qualitative interpretative phenomenological approach with face to face interviews were conducted in 19 Malay elderly who have been screened positive for depression. The emotional distress in the elderly emerged as 'Life is Miserable', 'Depression is a Sign of Weakness' and 'My Destiny is Predetermined'. The emerging themes for help seeking behaviours are 'Self Efficacy', 'Social Support Network' and 'Formal Non Mental Health Professionals'. All of the participants had no knowledge on the availability of professionals mental health services and claimed neither would they require these services despite being screened positive for depression. Therefore there is a need to improve mental health literacy among the elderly about depression and empower their social supports.

Introduction

The global population is experiencing an increase in its ageing population owing to the increase in longevity and decrease in fertility. According to the World Health Organisation, depression would be the second leading cause of disease burden by the year 2020. Rowe and Kahn (1987) have coined the landmark term, successful ageing that incorporates low probability of disease and disability, high cognitive and physical functionality and active involvement with life, however, depression would undoubtedly hinder achievement of this state of life. Multiple risk factors have been identified to be contributing towards the development of depression in the elderly, namely loneliness (Yaka, Keskinoglu, Ucku, Yener & Tunca, 2014 ; Liu, Gou, Zho, 2016 ; Yamin & Kadir , 2016) , chronic medical conditions (Glamcevski, Pierson, 2005 ; Rajkumar et al, 2009 ; Yaka, Keskinoglu, Ucku, Yener & Tunca, 2014) , functional limitations (Sherina, Rampal, Hanim & Thong, 2006 ; Verhaak, Dekker, de Waal, van Marwijk & Comijs, 2014) , stressful life events (Yamin & Kadir , 2016) , unemployment and low socioeconomic status (Sherina, Rampal & Mustaqim, 2004 ; Yaka, Keskinoglu, Ucku, Yener & Tunca, 2014).

Depression in the elderly is associated with significant impairment in quality of life, increased morbidity, poorer health outcome (Bartels, Blow, Van Citters, & Brockmann, 2006) and yet they are commonly under recognised and treated. Sarkisian, Hays & Mangione (2002) conducted a study amongst community dwelling depressed elderly in California and found the elderly looked upon depression, dependency, less energy, reduced sexual ability and having more aches and pains as a normal part of normal ageing and that would naturally explain their lack in seeking professional mental health service. Similar results were obtained in another study using depressed elderly

African American showed that these group of people attributed depression as a normal part of ageing and seek more culturally acceptable ways to cope with their symptoms through informal support system such as their family and religion and believed that depression was a sign of weakness and thus obtaining professional treatment was viewed to be highly stigmatised (Conner et al, 2010).

In Malaysia, the prevalence of depression among the elderly in the community varies between 7.6% to 30.1% (Mohd Sidik, Mohd Zulkefli & Mustaqim, 2003 ; Sherina, Rampal & Mustaqim, 2004 ; Khan, Manan & Rohana, 2010 ; Abdul Manaf, Mustafa, Abdul Rahman, Yusof & Abd Aziz, 2016) depending on the screening tools used. It is possible that the local elderly adopt a certain explanatory model to explain their symptoms that is more acceptable to them socioculturally (Razali, Khan & Hasanah, 1996 ; Razali & Hasanah, 1999) , which subsequently shapes their help seeking thus indirectly acting as a barrier towards seeking professional help.

A very useful explanatory model developed by Arthur Kleinman called the Kleinman explanatory model of illness is particularly useful in mental health especially in the Asian population as it represents specific personal and social meaning that a person assigns to their experience of illness. It is derived from a person's belief, knowledge and perception about health and its causes, signs and symptoms, severity, transmission, options for treatment and prognosis. The source of their belief may include three main sectors namely the popular sector which includes beliefs shared by family, friends and their own personal experience, the folk sector where the belief originates from a traditional belief and professional sector which is from the person's exposure to teachings of health care professionals. This form of explanatory model is very culturally inclined and is suitable to explain help seeking behaviour for mental health which is still very much culturally rooted till date (Kleinman, Eisenberg & Good,

1978).

The current study took place in Kelantan, a predominantly Malay Muslim occupied state in the northern eastern region in Peninsular Malaysia which has its own unique culture owing to its relative isolation and largely rural lifestyle. The Malay Muslim have their own culturally unique way of expression their emotions which is usually limited and done in moderation in relation to its strong Islamic influence, and psychological problems are often somatised to avoid stigmatization by the community (Razak, 2017). This study would shed light into the expression of emotional distress and the experiences and beliefs of the causes of depression among elderly in this region and their subsequent help seeking behaviour in managing their depression. We also aim to evaluate their usage and the knowledge of availability of professional mental health services.

Method

Setting and participants

A qualitative interpretative phenomenological approach using face to face interviews were conducted in the homes of elderly in multiple districts in the state of Kelantan. Three community leaders were recognised as key informants to help the researcher gather the potential participants. Subsequent participants were recruited via snowball sampling from a few districts in Kelantan namely Machang, Tanah Merah, Pasir Puteh and Tumpat. These potential participants were required to be 60 years or more of age, with the ability to converse in either Malay or English language.

They were then further screened with the Malay version of Geriatric Depression Scale (M-GDS) and the Malay version of Elderly Cognitive Assessment Questionnaire (M-ECAQ). Inclusion criteria for recruitment is a score of 5 or more in the Malay version of Geriatric Depression Scale and a score of 4 and above in the Malay version of Elderly Cognitive Assessment Scale. The Geriatric Depression Scale has 89% specificity and 92% sensitivity and its validity and reliability in detecting depression has been supported by various researches and in the clinical practise. A score of 0-4 is considered normal depending on age, education and complaints, 5-8 indicated mild depression, 9-11 indicates moderate depression and 12-15 indicated severe depression (Kurlowicz & Greenberg, 2007). The Elderly Cognitive Assessment Questionnaire was administered to exclude elderly with possible dementing illness as cognitive impairment would interfere with the interview process. The participants who fulfilled the required criteria and consented for the study were then given appointments for subsequent in face to face interviews.

Data collection

The interviews were conducted in the participants respective homes or a prior agreed upon place of meet such as 'pondok' located in the community setting. 'Pondok' in the state of Kelantan acts like a halfway home for most elderly whereby they stay in these places during weekdays to study and perform their religious duties and studies under the guidance of a religious teacher and they return to their respective homes over the weekends to live with their family. Permission was obtained from the authorities in charge of the 'pondok' prior to visit. A total of nineteen face to face interviews were conducted with each interview lasting for a minimum duration of forty five minutes to an hour. The interview explored the patterns of belief, normative expectations, behaviours and meanings of their emotional well being and distress in old age. Help seeking behaviour pertaining their emotional distress involving their family and relationship issues, perceived social support, religion, networking, religious beliefs and practise, knowledge and utilisation of mental health services were identified.

We used a semi structured interview guide developed using the Kleinman Explanatory Model of Illness which employs specific open ended questions that reveals how people make sense of their illness and and allows us to understand how people experience their lived experience (Additional file 1). The model proposed by Arthur Kleinman explores the how, why, when, what next of an illness within socio cultural context. While help seeking includes three main sectors namely the popular sector which includes beliefs shared by family, friends and their own personal experience , the folk sector where the belief originates from a traditional belief and professional sector which is from the person's exposure to teachings of health care professionals (Kleinman, Eisenberg & Good, 1978). The entire conversation was audio recorded

and transcribed verbatim in the language of the participants.

Data analysis

The transcripts were read and reread by the author to familiarise with the data that was collected. The author then developed initial coding of the earlier transcripts using open and inductive method which subsequently provided the basis for subsequent iterative coding during concurrent data collection and analysis. The transcripts and field notes were managed using the N Vivo Pro 11 qualitative data analysis software (QSR International Pty Ltd, 2016). The software aided in labelling codes which were described as nodes which were then organised into hierarchies and formed the basis of emerging themes. The emerging themes then allowed further exploration of the phenomenon in the subsequent interviews. The codes and themes were compared and discussed among the authors to arrive at the final themes and sub themes. Data collection was stopped once saturation was achieved. The trustworthiness of the study was ensured by using triangulation of data and researcher to ensure credibility, the use of thick description to ensure transferability, dependability via proper audit trail, and reflexivity that was applied at each stage of the analysis.

Ethical approval

The study was approved by the Human Research Ethics Committee of Universiti Sains Malaysia (USM/JEPeM/15110493)

Results and Discussion

Nineteen depressed elderly were interviewed between September 2016 to July 2017. All the participants were Malay Muslim in origin and their age was between 61 to 91 with a mean age of 70.5 years. 15 out of the total participants were female while 4

were male. The M-GDS score ranged between 5 to 13, ensuring that participants with mild to severe depression were all covered in the study. Table 1 describes the socio demographic characteristics of each participant in the study.

Table 1 : Sociodemographic characteristics

No	Age (years)	Race	Sex	M-GDS score	Living arrangement
A1	72	Malay	Female	13	Home with spouse
A2	75	Malay	Male	6	Home with spouse
A3	67	Malay	Female	8	Pondok/Alone
A4	91	Malay	Female	9	Pondok/Alone
A5	80	Malay	Male	7	Pondok with spouse
A6	86	Malay	Female	12	Pondok with daughter
A7	64	Malay	Female	6	Pondok/Alone
A8	65	Malay	Female	8	Pondok/Alone
A9	61	Malay	Female	7	Pondok/Alone
A10	74	Malay	Female	6	Pondok/Alone
A11	65	Malay	Female	5	Home with spouse
A12	74	Malay	Female	8	Home with spouse
A13	67	Malay	Female	6	Home with son
A14	61	Malay	Female	7	Home with spouse
A15	70	Malay	Male	6	Home with spouse
A16	65	Malay	Female	12	Home/Alone
A17	66	Malay	Male	8	Home with spouse
A18	77	Malay	Female	6	Home/Alone
A19	63	Malay	Female	8	Home with daughter

Expression of emotional distress

The elderly summed up their life experiences of emotional distress into three main themes namely (i) Life is Miserable, (ii) Depression is a Sign of Weakness and (iii) My Destiny is Predetermined.

Table 2 : Subthemes and themes for expression of emotional distress by the elderly.

Subthemes	Themes
1. Loneliness 2. Varying emotions 3. Loss of functionality	Life Is Miserable
1. I am still in control of myself 2. Laughter as the Pandora mask	Depression Is A Sign Of Weakness
1. Complacent 2. Content	My Destiny Is Predetermined

Theme 1 : Life is Miserable

Most of the participants had not voluntarily mentioned that their life was less than perfect and that they have their share of difficulties and struggles battling their own demons. However as they spoke, it was not difficult to pick up that they do experience their share of hardships and misery in the form of loneliness, varying emotions and loss of functionality.

Loneliness was a constant form of struggle experienced by the elderly in both forms of perceived and actual loneliness. Their context of loneliness almost always involved their children living far from them having to run their own life. Although most elderly tried to justify the lack of presence of their children in their life currently as a necessity for their children to thrive and survive and run their family, one of them, A13, did openly express her displeasure at the lack of effort shown by their children to visit them or at least communicate over the phone.

A13 , a widow with 12 children who lives with her youngest son describes;

“Terasa sangat lah sebab kita sore. Kita sakit pun, kita sakit sokmo kan. Demo tok tanyo kito pun. Tok caro kito, tok tanyo khabar kito. Banyak sangat teraso tu. Demo buat caro sangat demo tu. ni dah telepon ko dio suh maghi tok maghi. Duk beraso lah kito nyo.gitulah dengan anak kita, duk braso nok maroh. Berasa nak marah dia. Kito tok maroh, tapi berasa kito nok maroh. Tok rajin maroh ko anak, tok rajin kato gapo-gapo, tok rajin. Anak-anak ramai pun tak de pakso. Sore ko dio tak po pulok, dia sore sajo dio.”

“ I am hurt because I am lonely. I am always sick but they don't care about me. They don't ask about my well being. I am very hurt. They only care about things that matters to them. I have called them many a times asking them to visit me but they don't come. I feel angry and I feel like scolding them. I don't scold them although I feel like doing it.I don't force them even though I have many children. Its easier to have just one child.” -(A13)

Another participant, A2, a retired school headmaster described how he felt lonely despite having his spouse around with him;

“Saya kata rasa muram saya ni dalam tempoh 2-3 tahun kerana kesunyian. Sebab saya dengan isteri saya duduk di rumah, isteri saya bekerja lagi masa tu, sekarang ni isteri saya sudah bersara macam saya ni. Saya dan isteri saya berdua-duaan di rumah ni. Jadi, teringatlah kat anak-anak seramai 7-8 orang ada di Kuala Lumpur. Jadi, ingat kat cucu, ingat kat anak macam tu la. Muram sebab ingat. Daripada keluarga besar bising jadi sunyi.”

“ I say that I am upset over the past 2-3 years because of loneliness. My wife used to work but now she is retired just like me. Only the 2 of us live here. So, I think about my children in Kuala Lumpur. I think of my grandchildren and children. Upset because I think of them. From a big noisy family now it has become quiet.” - (A2)

Nine elderly female out of the total participants interviewed were widowed whereas one of them was a divorcee however none of these participants complained regarding the lack of a spouse in their life contributing to their loneliness and claimed that they were able to cope with it although they did occasionally miss them while those living with their spouse still perceived themselves to be lonely as they were missing their children and grandchildren.

The varying emotional experience among this elderly include a wide range of emotion