DISEASE STATE PSYCHOLOGICAL KNOWLEDGE AND HEALTH BELIEF ON CANCER AND MINDFULNESSBASED STRESS REDUCTION (MBSR) AND ITS EFFECTS ON MINDFULNESS, ANXIETY, DEPRESSION AND HEALTH RELATED QUALITY OF LIFE (HRQOL) AMONG CANCER PATIENTS IN PENANG, MALAYSIA: A MIX METHODOLOGY APPROACH

CHE NORIAH BINTI OTHMAN

UNIVERSITI SAINS MALAYSIA

DISEASE STATE PSYCHOLOGICAL KNOWLEDGE AND HEALTH BELIEF ON CANCER AND MINDFULNESSBASED STRESS REDUCTION (MBSR) AND ITS EFFECTS ON MINDFULNESS, ANXIETY, DEPRESSION AND HEALTH RELATED QUALITY OF LIFE (HRQOL) AMONG CANCER PATIENTS IN PENANG, MALAYSIA: A MIX METHODOLOGY APPROACH

by

CHE NORIAH BINTI OTHMAN

Thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

September 2022

ACKNOWLEDGEMENT

First and foremost, I'd like to thank Allah S.W.T for the gift that has finally allowed me to finish my thesis on time. I am writing to convey my gratitude to Prof Dr Syed Azhar Syed Sulaiman, my supervisor, for agreeing to take me on as a student in the first place. His strength and encouragement inspired me to go on till now. May Allah provide him good health and great returns (Amin).

This thanks also go to my second supervisor, Dr Maryam Farooqui, who is currently far away in Saudi Arabia. However, never leave me alone with tight online supervision. She is the most encouraging person and working hand in hand toward the start of the concept of getting my PhD. Her words of encouragement were motivating.

My third supervisor, Dr Wan Ismahanisa Ismail, has been extremely supportive throughout my trip and has assisted me with thesis writing. Her never-ending efforts to see that I finish my thesis are outstanding. May Allah bless her health for her to take on more challenging projects in the future.

Last but not least, I'd like to thank Dr Phang Cheng Kar, my field supervisor, for his advice on the study's intervention approach. His generosity in allowing me to utilise his programme for my research is appreciated.

I'd also want to thank Puan Azlina Abdullah, MAKNA's Northern Region representative, for her unwavering assistance during the patient recruitment process. To patients who have taken part in this study, I hope God may bless them with good health, long life, and a quick recovery.

My PhD adventure would not be possible without my parents' blessing and my husband's unwavering support, willing to drive me throughout Malaysia for courses and other things relating to my studies at USM. His steadfast support keeps me going till the very end. Not to mention my children and grandkids, who have come to terms with mom/nanny absence on several occasions owing to my studies. May Allah provide Jannah to every one of my loved ones.

My gratitude should also go to the academic and non-academic staff at the USM School of Pharmaceutical Sciences, as well as to the dean of the USM School of Postgraduate and all staff, for the superb services rendered in providing entertainment for the students. May Allah grant everyone of you with good health and prosperity in all that you do.

TABLE OF CONTENTS

ACK	NOWL	EDGEMENT	ii
TAB	LE OF	CONTENTS	iv
LIST	OF TA	BLES	xiv
LIST	OF FIG	GURES	xvii
LIST	OF AB	BREVIATIONS	xviii
LIST	OF AP	PENDICES	xix
ABS	ΓRAK		XX
ABS	ГRАСТ		xxii
СНА	PTER 1	INTRODUCTION	1
1.1	Overv	iew	1
1.2	Resear	rch Background	2
	1.2.1	Cancer and Stress	2
	1.2.2	Traditional and Complementary Medicine (T&CM) For Stress Coping	3
	1.2.3	Mindfulness-Based Stress Reduction (MBSR) Program	4
	1.2.4	The Components of MBSR	4
	1.2.5	Patients' Counselling in Malaysian Clinical Setting	5
	1.2.6	MBSR Program in Malaysia	6
1.3	Proble	em Statement	7
1.4	Resear	rch Objectives	9
	1.4.1	Phase I (Qualitative Research)	9
	1.4.2	Phase II (Quantitative Research)	9
	1.4.3	Phase III (Intervention Research)	10
1.5	Resear	rch Questions	10
	1.5.1	Phase I (Qualitative Research)	10

	1.5.2	Phase II (Quantitative Research)			
	1.5.3	Phase III (Intervention Research)			
1.6	Significance of The Study				
	1.6.1	Primary Outcome			
	1.6.2	Secondary Outcome			
СНА	PTER 2	LITERATURE REVIEW12			
2.1	Introd	action			
2.2	Cance	r			
	2.2.1	The Definition of Cancer			
	2.2.2	Cancer Burden World-Wide			
	2.2.3	Cancer Burden in Malaysia			
2.3	Conve	ntional Cancer Treatment			
2.4	Compl	ementary and Alternative Medicine (CAM)21			
2.5	T&CM	M in Malaysian Term22			
	2.5.1	The Prevalence of T&CM Use among Cancer Patients Worldwide			
	2.5.2	The Prevalence of T&CM Use Among Cancer Patients in Malaysia			
2.6	Theory	y of Health Belief29			
2.7	Health	Belief Model (HBM)			
	2.7.1	HBM Utilization for Cancer Patients31			
	2.7.2	Knowledge, Attitude and Health Belief Among Cancer Patients 33			
	2.7.3	Knowledge, Attitude and Health Belief and The Impact on MBSR			
2.8	Theory	y of Mindfulness			
	2.8.1	T&CM and Mindfulness			
	2.8.2	Utilization of Mindfulness-based Program For Health Problem 38			
	283	Mindfulness-Based Stress Reduction Program (MBSR) 40			

	2.8.4	MBSR Use Among Cancer Patients World-Wide	42
	2.8.5	MBSR in Malaysia	44
2.9	Anxie	ty and Depression	46
	2.9.1	Anxiety and Depression Among Cancer Patients Worldwide	47
	2.9.2	Anxiety and Depression Among Cancer Patients in Malaysia	49
	2.9.3	Hospital Anxiety and Depression Scale (HADS)	51
	2.9.4	HADS for Cancer Patients	52
2.10	The Q	uality of Life (QOL)	53
	2.10.1	The Health-Related Quality of Life (HRQOL)	53
	2.10.2	The HRQOL Among Cancer Patients	56
	2.10.3	CAMS-R For Cancer Patients	58
	2.10.4	Stress-Coping Strategy Among Cancer Patients	59
2.11	Ration	al and Justification of Study	62
2.12	Conce	ptual Framework of the Study	63
CHA	PTER 3	METHODOLOGY	64
3.1	Overv	iew	64
3.2	Qualit	ative Research (Phase I)	65
	3.2.1	Study Location	66
	3.2.2	Study Participants	66
	3.2.3	Sampling Method	66
	3.2.4	Interview Guide	67
	3.2.5	Interview Style	68
	3.2.6	Data Recording	69
	3.2.7	Data Management and Analysis	70
		3.2.7(a) Transcribing Interviews	70
		3.2.7(b) Coding and Analysis	71
		3.2.7(c) Data Saturation	73

		3.2.7(d)	Validation and Reliability	73	
3.3	Quant	itative Reso	earch (Phase II)	74	
	3.3.1	Study Loc	cation	75	
	3.3.2	Study Pro	otocol	75	
	3.3.3	Study Pop	oulation	75	
	3.3.4	Sampling	Method	76	
	3.3.5	Sample S	ize Calculation	76	
	3.3.6	Study Ins	truments	78	
		3.3.6(a)	Quantitative Exploration on Knowledge, Attitude and Health Belief on Cancer, MBSR and the Treatment Received	79	
		3.3.6(b)	HADS, CAMS-R and EORTQLC-C30	85	
	3.3.7	Data Ana	lysis	88	
	3.3.8	Results P	resentation	90	
3.4	Intervention Research (Phase III)				
	3.4.1	Five Wee	ks of MBSR Intervention	91	
	3.4.2	Ethical A	pproval and Consent	93	
	3.4.3	Data Ana	lysis	93	
СНА	PTER 4	CANCEI AMONG	EDGE, ATTITUDE AND HEALTH BELIEF ON R ITS TREATMENT APPROACH AND MBSR CANCER PATIENTS: A QUALITATIVE RATION		
4.1	Introd		CATION		
4.1					
4.2					
		-			
4.4			alkia Data		
	4.4.1		phic Data	96	
	4.4.2		atients' Knowledge, Attitude and Health Belief on and Its Treatment Approach, and MBSR	98	

		4.4.2(a)	Knowledge on Cancer, it's treatment Received and MBSR	98
		4.4.2(b)	Attitude Toward Cancer, The Treatment Received and MBSR	102
		4.4.2(c)	Health Belief on Cancer and its Treatment Effectiveness and MBSR For Cancer Healing	107
		4.4.2(d)	Stress experiences and stress-coping strategies on th cancer diagnosis	109
		4.4.2(e)	Barriers on Treatment Seeking	113
4.5	Discus	ssion		115
	4.5.1		ge on Cancer, Conventional Treatment Received and	115
	4.5.2	Attitude	Toward Cancer, The Treatment Received and MBSR	121
	4.5.3		elief Toward Cancer, Treatment Effectiveness and For Cancer Healing	124
	4.5.4	Stress-co	pping Strategies Upon Cancer Diagnosis	125
	4.5.5	Barriers	for Treatment Seeking	129
4.6	Concl	usion		130
СНА	PTER 5	CANCE AMONO	LEDGE, ATTITUDE AND HEALTH BELIEF ON R ITS TREATMENT APPROACH AND MBSR G CANCER PATIENTS: A QUANTITATIVE Y EVALUATION	132
5.1	Introd	uction		132
5.2	Partic	ipants		132
5.3	Results			133
	5.3.1	_	aphic and Socioeconomic Characteristics of ents	133
	5.3.2	Disease (Characteristic of The Respondents	135
		5.3.2(a)	Cancer Types Suffered by Respondents	135
		5.3.2(b)	The Duration of Cancer Since Diagnosis	136
		5.3.2(c)	The Cancer Stages of The Respondents	137

	5.3.2(d)	The Combination of Treatment Received by The Respondents	138
	5.3.2(e)	The Side Effects From The Conventional Therapies	138
	5.3.2(f)	Other Treatment Seeking Behaviour Among Respondents and Disclosure to Their Doctor Status	139
	5.3.2(g)	Stress-Coping Strategies Practiced by Respondents	. 140
5.3.3	Knowled	lge on Cancer	140
	5.3.3(a)	Perceived Knowledge on Cancer	. 140
	5.3.3(b)	Level of Agreement on Statements About Cancer Suffered by Respondents	. 141
5.3.4		d Effectiveness on The Cancer Treatment Received by	142
5.3.5		ness-Based Therapies Practiced by Respondents for oping	143
5.3.6		lge on Mindfulness-Based Stress Reduction (MBSR) Respondents	145
5.3.7	Perceive	d Effectiveness of MBSR For Cancer Healing	. 145
5.3.8	Mindful	Anxiety and Depression, Cognitive and Affective ness, and Health Related Quality of Life (HRQOL) of lents	146
	5.3.8(a)	Level of Anxiety and Depression of Respondents	. 146
	5.3.8(b)	Level of Cognitive and Affective Mindfulness of Respondents	
	5.3.8(c)	Level of Health-Related Quality of Life (HRQOL) of Respondents	146
5.3.9	Characte	rall Correlation of Demographic Data, Disease eristic and Socioeconomic Status of The Respondents ADS, CAMS-R and EORTQLC-QLC30	. 147
	5.3.9(a)	Correlation of Demographic Data, Disease Characteristic and Socioeconomic Status of The Respondents with Anxiety and Depression Scores	147
	5.3.9(b)	Correlation of Demographic Data, Disease Characteristic and Socioeconomic Status of The Respondents With CAMS-R Scores	. 148

		5.3.9(c)	Correlation of Demographic Data, Disease Characteristic and Socioeconomic Status of The Respondents With EORTQLC-QLC30 Scores	. 148
	5.3.10	MBSR an	nd non-MBSR Users of Respondents	. 148
		5.3.10(a)	Demographic Characteristics of MBSR and Non-MBSR Users	. 148
		5.3.10(b)	Disease and Treatment Related Characteristics of MBSR and Non-MBSR Users of Respondents	. 153
		5.3.10(c)	Knowledge on The Cause of Cancer Among MBSR and Non-MBSR Users	. 157
		5.3.10(d)	Level of Agreement on Statements About Cancer Suffered Among MBSR and Non-MBSR Users	. 160
		5.3.10(e)	Perceived Effectiveness Cancer Treatment Among MBSR and Non-MBSR Users	. 161
		5.3.10(f)	Knowledge on MBSR Among MBSR and Non-MBSR Users	. 164
		5.3.10(g)	Perceived Effectiveness of MBSR For Cancer Healing Among MBSR and Non-MBSR Users	. 169
		5.3.10(h)	Disclosure of MBSR Use To Their Doctors Among MBSR Users	. 170
		5.3.10(i)	Anxiety and Depression Among MBSR And Non-MBSR Users	. 171
		5.3.10(j)	Cognitive and Affective Mindfulness Scale Revised (CAMS-R) Level Between MBSR and Non-MBSR Users	. 171
		5.3.10(k)	EORTQLC-QLC30 Level Between MBSR and Non-MBSR Users	. 172
5.4	Discus	sion		. 172
	5.4.1		ographic, Socioeconomic and Disease Characteristic of ents	. 172
		5.4.1(a)	The Demographic Characteristic of Respondents	. 172
		5.4.1(b)	The Socioeconomic Characteristics of Respondents	. 174
		5.4.1(c)	The Disease Characteristics of Respondents	. 175

		5.4.1(d)	Cancer and Perceived Effectiveness of Cancer Treatment and MBSR For Cancer Healing	. 177
		5.4.1(e)	The Stress-Coping Strategy Taken by Respondents Upon Cancer Diagnosis	. 185
		5.4.1(f)	HADS, CAMS-R And EORTQLC-C30 Level and Their Correlation with The Demographic, Disease and Socioeconomic Characteristic of Respondents	. 187
		5.4.1(g)	The Comparison of Demographic, Socioeconomic and Disease Characteristic Among MBSR And Non-MBSR Users	. 190
		5.4.1(h)	Perceived Knowledge and Effectiveness of MBSR For Cancer Healing Among MBSR and Non-MBSR Users	. 192
		5.4.1(i)	Perceived Effectiveness of Cancer Treatments Among MBSR and Non-MBSR Users	. 193
		5.4.1(j)	The Comparison of The Level Of HADS, CAMS-R and EORTQLC-C30 Among MBSR and Non-MBSR Users of Respondents	. 194
5.5	Chapte	er's Summ	nary	. 194
СНА	PTER 6	BASED	MENT ON THE EFFECT OF MINDFULNESS- STRESS REDUCTION (MBSR) PROGRAM ON HRQOL, CAMS-R AMONG CANCER PATIENTS	. 197
6.1	Introd	uction		. 197
6.2	Study	Variables	and Instruments.	. 197
6.3	Partici	pants		. 197
6.4			sed Stress Reduction (MBSR) Program's	. 198
6.5	Statist	ical Analy	rsis	. 199
6.6	Result			. 199
	6.6.1	_	aphic, Socioeconomic and Disease Characteristic of The	. 199
	6.6.2	Disease (Characteristic of the Participants	. 203
	6.6.3	and EOR	parison Pre and Post Anxiety and Depression, CAMS-R RTC QLC-C30 Between the MBSR Intervention Group tlist Group	. 205
			-	

	6.6.4	The Comparison of Pre and Post Anxiety and Depression, CAMS-R and EORTQLC-QLC 30 Within the MBSR Intervention Group and The Waitlist Group	207
	6.6.5	The European Organization for Research and Treatment (EORTC) QLC-C30 (EORTC QLC C30) Sub Scales of Pre and Post MBSR Intervention Groups	209
6.7	Discus	sion	211
	6.7.1	Demographic, Socioeconomic and Disease Characteristic of The Patients	212
	6.7.2	The Between Group Comparison of Pre and Post HADS, CAMS-R and EORTC QLC-C30 of MBSR Intervention Group and Waitlist Group	216
		6.7.2(a) The Hospital Anxiety and Depression Scale (HADS)	216
		6.7.2(b) The Cognitive and Affective Mindfulness Scale-Revised (CAMS-R)	218
		6.7.2(c) The European Organization for Research and Treatment of Cancer (EORTC) QLC-C30 (EORTC QLC-C30)	220
		6.7.2(d) The Sub-scales of EORTC QLC-C30	222
	6.7.3	The Within Group Comparison of Pre and Post HADS, CAMS-R and EORTC QLC-C30 of MBSR Intervention Group and Waitlist Group	226
6.8	Chapte	er's Conclusion	227
6.9	Chapte	er's Limitation	228
СНАР	TER 7	THESIS CONCLUSION AND FUTURE	222
7 1	Canal	RECOMMENDATIONS	
7.1		asion	
	7.1.1	Conclusion from Qualitative Research (Phase I)	
	7.1.2	Conclusion from Quantitative Survey Research (Phase II)	237
	7.1.3	Conclusion from Intervention Research (Phase III)	243
7.2	Overal	l Thesis Conclusion	243
7.3	Implic	ation of the Study Findings	245
	7.3.1	The Implication to The Patients	245

APPE	NDICI	ES	
REFE	CRENC	ES	255
7.6	Suggestion for Future Research		
7.5	Limitation		
7.4	Recon	nmendations	250
	7.3.5	The Implication to The Researcher	250
	7.3.4	The Implication of Malaysian Policymakers in The Health Care System	249
	7.3.3	The Implication to The Health Caregivers	247
	7.3.2	The Implication to Family Members and Caregivers	246

LIST OF TABLES

		Page
Table 2.1	Number of new cases in 2018 in both sexes of all ages in	
	Malaysia 2018 (Globocan 2018)	18
Table 2.2	Cancer types versus number of cases in males for all ages in	
	Malaysia in 2018 (Globocan Cancer Statistic, 2018)	18
Table 2.3	Cancer types versus number of cases in females for all ages in	
	Malaysia in 2018 (Global Cancer Statistic, 2018, WHO)	19
Table 2.4	The summary of all cancer sites in Penang state for bot sexes.	
	Data is after age standardized (ASR) (Penang Cancer Registry	
	from 2007-2011 and Global Cancer Statistic 2018	19
Table 2.5	Distribution of anxiety and depression in different types of	
	cancer	48
Table 2.6	Distribution of anxiety and depression in different types of	
	cancer treatment	49
Table 3.1	Items tested for the measurement of level of knowledge on	
	cancer	82
Table 3.2	Items tested for the measurement of perceived on cancer	
	severity	83
Table 3.3	Items tested for perceived effectiveness of conventional	
	treatment for cancer	83
Table 3.4	Items tested for perceived benefit of Mindfulness-Based Stress	
	Reduction (MBSR) for cancer healing	84
Table 3.5	Timetable for a 5 weeks of MBSR program	92
Table 4.1	Demographic Characteristics of The Respondents	97
Table 4.2	Socioeconomic Characteristics of The Respondents	98
Table 4.3	Disease Characteristic of Respondents	98
Table 5.1	Demographic and socioeconomic characteristics of the	
	respondents	134
Table 5.2	The summary of the HADS, CAMS-R and EORTQLC-C30 of	
	cancer patients	147

The demographic characteristic of the MBSR and non-MBSR	
users of the respondents	150
Disease and treatment related characteristics of MBSR and non-	
MBSR users of respondents	154
Knowledge on the cause of Cancer between MBSR and non-	
MBSR users of the respondents	158
Level of agreement on statements about cancer suffered among	
MBSR and non-MBSR users of respondents	160
Perceived effectiveness of cancer treatments among MBSR and	
non-MBSR users of respondents	162
Knowledge on MBSR among MBSR and non-MBSR users of	
respondents	164
The MBSR Related Own-Practised of MBSR and Non-MBSR	
Users of Respondents	166
Perceived effectiveness of MBSR for cancer healing among	
MBSR and non-MBSR users of respondents	169
Disclosure of MBSR use to their doctors among MBSR users of	
respondents	170
Anxiety and depression level among MBSR and non-MBSR	
users of respondents	171
Cognitive and Affective Mindfulness Scale Revised (CAMS-R)	
level among MBSR and non-MBSR users of respondents	171
EORTQLC-QLC30 level among MBSR and non-MBSR users	
of respondents	172
Demographic and Socioeconomic Characteristic of participants	201
Disease Characteristic of The Participants	204
The comparison of Pre and Post Anxiety and Depression	
(HADS), CAMS-R and EORTQLC-C30 between MBSR	
Intervention Group and the Wait-list Group	207
The Within Group mean Comparison of Pre and Post MBSR	
Intervention of HAD, CAMS-R and EORTC QLC-C30 of	
MBSR Intervention group and Waitlist group	208
	users of the respondents

Table 6.5	The European Organization for Research and Treatment
	(EORTC) QLC-C30 (EORTC QLC C30) sub scales of Pre and
	Post MBSR Intervention 21

LIST OF FIGURES

	Page
Figure 2.1(a)	The estimated number of new cases in 2018 worldwide for both
	sexes, all ages
Figure 2.2	The incidence of cancer for both sexes all ages in Malaysia
	2018 (Globocan 2018-WHO)17
Figure 2.3	The traditional and complementary medicine definition and
	components
Figure 2.4	The components of behaviours in Health Belief Model31
Figure 2.5	Conceptual Framework of the whole study
Figure 3.1	Coding and analysing quantitative data (Broom, 2005)72
Figure 3.2	The summary of the study design
Figure 5.1	Types of cancer suffered by respondents
Figure 5.2	Duration of cancer since diagnosed
Figure 5.3	The cancer stages of respondents
Figure 5.4	The combination of treatments received by respondents
Figure 5.5	The treatment seeking types of respondents
Figure 5.6	The stress-coping strategies of the respondents and the
	disclosure to their doctors
Figure 5.7	Perceived knowledge on the cause of cancer among respondents 141
Figure 5.8	Level of agreement on the statement about cancer characteristic
	of respondents
Figure 5.9	Level of agreement on the perceived effectiveness of cancer
	treatment by respondents
Figure 5.10	Mindfulness-based therapies practiced by respondents for their
	cancer 144
Figure 5.11	Perceived effectiveness of Mindfulness-based therapies for
	cancer healing

LIST OF ABBREVIATIONS

(EORTC) European Organization for Research and Treatment of Cancer

QLC-C30

CAM Complementary and Alternative Medicine

CAMS-R Cognitive and Affective Mindfulness Scale-Revised

GLOBOCAN Global Cancer Statistic

HADS Hospital Anxiety and Depression Scale

HBM Health Belief Model

HRQOL The Health-related Quality of Life

MAKNA Majlis Kanser Negara

MBSR Mindfulness-based Stress Reduction

QOL Quality of Life

T&CM Traditional and Complementary Medicine

USM Universiti Sains Malaysia

WHO World Health Organization

LIST OF APPENDICES

Appendix A Semi-Structured Interview Guide Appendix B1 Patient's Validation (P1) Appendix B2 Patient's Validation (P2) Appendix B3 Patient's Validation (P3) Appendix C1 Validated Patient's Questionnaire and Informed Consent (English Version) Borang Soalselidik Pesakit Yang Telah Divalidasi dan Borang Appendix C1 Persetujuan Pesakit (Versi Bahasa Malaysia) **EORTQLC** Approval Form Appendix D Appendix E Application For Ethics Approval Surat Permohonan Kelulusan Dari Makna Kawasan Utara Appendix F Appendix G1 Consent Form English Appendix G2 Borang Persetujuan Pesakit (Bahasa Malaysia) MBSR Intervention Plan Appendix H Appendix I Participation Certificate Appendix J Conference and Publication Appendix K **MBSR** Activities

PENGETAHUAN PSIKOLOGI KEADAAN PENYAKIT DAN
KEPERCAYAAN KESIHATAN TERHADAP KANSER DAN PENURUNAN
TEKANAN SECARA MINDA SEDAR (MBSR) SERTA KESAN MINDA
SEDAR KE ATAS KEBIMBANGAN, KEMURUNGAN DAN KUALITI
HIDUP YANG BERKAITAN DENGAN KESIHATAN (HRQOL) DALAM
KALANGAN PESAKIT KANSER DI PULAU PINANG, MALAYSIA:
PENDEKATAN METODOLOGI BERCAMPUR

ABSTRAK

Kanser adalah satu penyakit yang mengancam nyawa diseluruh dunia. Di diagnosis dengan kanser memberi suatu tekanan yang hebat kepada pesakit secara psikologi dan jika tidak ditangani akan menjurus kepada kecelaruan psikologi seperti kebimbangan dan kemurungan yang akan mengganggu kepatuhan kepada rawatan dan hasil klinikal. MBSR telah dibuktikan secara klinikal berkesan untuk mengurangkan kesan tekanan psikologi seperti kebimbangan dan kemurungan dikalangan berbagai pesakit yang mengalami berbagai penyakit termasuk pesakit pesakit kanser. Pengetahuan dan kepercayaan menentukan keputusan pesakit untuk memilih sesuatu rawatan yang ditawarkan. Walaubagaimanapun selepas satu carian menyeluruh belum ditemui sebarang dokumen berkaitan kajian tentang tahap pengetahuan dan kepercayaan tentang kanser dan MBSR dikalangan pesakit kanser di Malaysia terutama di Pulau Pinang. Kajian tentang kesan MBSR keatas pesakit kanser juga belum pernah dijalankan di Malaysia. Sehubungan dengan itu kajian ini dijalankan untuk mengetahui tahap pengetahuan dan kepercayan kesihatan terhadap penyakit kanser dan MBSR serta mengukur kesan intervensi 5 minggu MBSR keatas pesakit kanser di Pulau Pinang, Malaysia. Kajian metodologi bercampur digunakan. Kajian

ini melibatkan tiga fasa. Fasa 1 adalah fasa kualitatif dimana 18 pesakit telah ditemubual sebelum ketepuan data dicapai. Fasa 2 adalah fasa soal-selidik kuantitatif melibatkan 136 pesakit. Fasa ketiga adalah Fasa Intervensi yang melibatkan 38 orang pesakit. Data yang terdiri daripada demografik, tahap HADS, CAMSR dan HRQOL dianalisa menggunakan SPSS versi 20 dan dipersembahkan dalam bentuk naratif, jadual dan carta. Kajian ini menunjukkan tahap pengetahuan pesakit tentang kanser dan MBSR adalah rendah dan memerlukan penambahbaikan. Walaubagaimanapun, tahap kepercayaan mereka seperti keberkesanan perawatan, sikap terhadap perawatan dan halangan halangan untuk menerima rawatan kanser sangat menggalakkan. Mereka menganggapkan rawatan yang diterima boleh menghilangkan gejala kanser namun masih percaya bahawa kesan rawatan akan bertambah baik jika rawtan moden dan tradisional seperti MBSR disatukan. Kajian ini juga mendapati intervensi 5 minggu MBSR dapat mengurangkan gejalan psikologi seperti kebimbangan dan kemurungan (HADS), meningkatkan kekuatan kognitif dan penumpuan pesakit (CAMSR) namun tidak meningkatkan keseluruhan kualiti kehidupan pesakit berkaitan kesihatan (HRQOL). Kajian ini merumuskan bahawa tahap pengetahuan pesakit tentang kanser dan MBSR perlu ditingkatkan melalui pembelajaran berterusan dan kempen kesedaran kanser dikalangan penduduk terutama pesakit kanser. MBSR dicadangakan diperkenalkan diklinik onkologi sebagai satu sokongan psikoonkologi untuk pesakit kanser supaya pengurusan pesakit kanser dapat diperbaiki dan membantu meningkatkan keberkesanan rawatan.

DISEASE STATE PSYCHOLOGICAL KNOWLEDGE AND HEALTH
BELIEF ON CANCER AND MINDFULNESSBASED STRESS REDUCTION
(MBSR) AND ITS EFFECTS ON MINDFULNESS, ANXIETY, DEPRESSION
AND HEALTH RELATED QUALITY OF LIFE (HRQOL) AMONG
CANCER PATIENTS IN PENANG, MALAYSIA: A MIX METHODOLOGY
APPROACH

ABSTRACT

Cancer is a death treatening disease world wide. Being diagnosed with cancer is a stressful event and if left unattended may lead to psychological distress and affect treatment compliance and clinical outcome. MBSR is proven clinically effective in reducing psychological distress problem among patients with various chronic diseases including cancer. Knowledge and health belief determine patients decission making. However to my thorough literatute search no study was conducted on cancer patients knowledge and health belief on cancer and MBSR in Malaysia especially in Penang. Also no data found that document the effects of MBSR on psychological distress including anxiety and depression among Malaysian cancer patients. So this study was conducted to explore the knowledge and health belief on cancer and MBSR and to measure the effect of MBSR program on HADS, CAMSR and HRQOL among cancer patients in Penang, Malaysia using a mix methodology approach. This study was conducted in three phases. Phase 1 is a qualitative phase which involved a face to face interveiewing the patients using a guided questionnaires and the saturation was reach at patients 18. Phase two was a quantitative survey using the questionnares developed from the phase 1 information. Upon validation 136 patients were managed to be consented to fill up all the questionnares which consist of demographic data, HADS,

CAMSR and HRQOL. The phase 3 was an intervention Phase where the pre and post intervention value of HADS, CAMSR and HRQOL were again measured after the 5 weeks of MBSR intervention. This study revealed that the knowledge of cancer patients on cancer and MBSR were still low and need improvement. However their health belief on cancer where the perceived effectiveness, cues to action and barriers for treatment seeking were very encouraging. They perceived conventional treatment as effective for their cancer treatment but still belief that the combination with TCM like MBSR would heal their cancer better. This study also found that the 5 weeks MBSR intervention on cancer patients have reduced the psychological distress state of the patients such as anxiety and depression (HADS), increased cognitive power (CAMSR) but not the total health related quality of life (HRQOL). This study concluded that the knowledge and health belief on cancer among cancer patients should be enhanced through education program. This study also found that MBSR is effective in reducing psychological distress among cancer patients. This study would like to suggest more education program on cancer knowledge and awareness should be introduced in general population and cancer patients. MBSR is suggested to be introduced in oncology clinic as a psychooncology support for cancer patients for better patients management and clinical outcome.

CHAPTER 1

INTRODUCTION

1.1 Overview

Being diagnosed with cancer is a stressful event and affects many dimension of individual's life (Barre et al., 2018). The treatment offered by many clinical settings especially in Malaysia focuses on the physical part of the disease but not much on the psychological wellbeing. Patients attempt many methods of modalities and treatment to cope with stress. However, there is no available data in Malaysia for stress-coping strategy among cancer patients in Malaysian healthcare system. Counselling is available in some cases, however there is no standardized counselling method dealing with cancer patients. Psycho-oncologists are available in some settings, but the number is small (Sherina Mohd Sidik et al., 2018).

Health belief is important in a patient's decision-making and attitude towards cancer and treatment offered. Patient's beliefs, behaviors, and values are shaped by factors such as ethnicity, gender, language, mental ability, nationality, occupation, race, religion, sexual orientation, and socioeconomic status (Diana & Romaine, 2020) Patient's who receive a strong support regardless of their ethnicity and socio-economic background for instance, have a positive believe and behaviour towards life and value the life more meaningful. This can be a major defense against negative psychological outcomes and can help to cope more effectively with the physical and psychological demands of cancer.

To get a general view of the incidence of cancer worldwide, this chapter presents a world statistic of cancer and zooms down to Asian countries including Malaysia.

Since the main focus of this study is on how cancer patients perceive cancer, its treatment effectiveness and mindfulness-based therapy, this chapter briefly describes the meaning of mindfulness, mindfulness-related therapies, and effect on anxiety and depression; and health-related quality of life in clinical setting.

This chapter then lists the objectives of the study and the research questions, followed by the significance of the study.

1.2 Research Background

Cancer is a major health problem worldwide and is the second leading cause of death. The World Health Organization (WHO) calculated the number of death due to cancer estimated to be 12 million by 2030 (Eisenberg et al., 1993). Low to middle-income countries contribute to almost 70% of the total cancer deaths. The prevalence of cancer was approximately 90000 when Malaysia's population was 21.4 million in 1998, (Kasri, 1993) and expected to be 9.8% increase in 2020 (Karim, 1997).

1.2.1 Cancer and Stress

The diagnosis of cancer is a stressful event. Stress can trigger anxiety and depression. If the anxiety and depression is left unattended, they will affect the cancer treatment and may lead to worse clinical outcome (Nikbakhsh et al., 2014).

Stress affect patients physiologically and psychologically. The stress occurs during or even after they survive from cancer. The trauma of stress may remain unaddressed, becoming a lifelong memory and can destroy patient's quality of life (QoL). The stress are often due to the uncertainty of their future, disease severity, scared of treatment and worry of the physical difficulties and their body image (Alhusban, 2019). Family issue and economic burden also contributed to stress (Ashing-Giwa & Lim, 2009).

The various negative impacts of stress in cancer patients, either in compounding to psychiatric comorbidity such as anxiety, depression, post-traumatic stress disorder etc. or in deteriorating their quality of life, indicate the need for a holistic approach (Barre et al., 2018).

1.2.2 Traditional and Complementary Medicine (T&CM) For Stress Coping

Many people living with cancer use Traditional and Complementary Medicine (T&CM), which includes mind-body therapies (MBT). The most common reason given were for the improvement of emotional and physical well-being (Choi et al., 2012). In a study involving 393 cancer patients in Penang, Malaysia 46.8% were reported to use different type of T&CM to cope with their cancer. Out of these numbers 40.8% of them were reported to use Mind-body Complement Therapy (MBCT) which is one of the MBT type of therapy (Farooqui et al., 2012). MBT includes relaxation and imagery, hypnosis, yoga, meditation, tai chi, qigong, and art therapies to cope with stress. An example of MBT utilized by patients is Mind-body Cognitive Therapy (MBCT) for stress management and to improve health-related quality of life (HRQOL) (Carlson et al., 2017).

The effectiveness of these therapies was reviewed by assessing recent findings in the context of cancer care. These therapies show efficacy in treating common cancer-related side effects, including nausea and vomiting, pain, fatigue, anxiety, depressive symptoms as well as improving overall quality of life (Elkins, Fisher, & Johnson, 2010). Some of these therapies also have effects on biomarkers such as immune function and stress hormones (Rouleau et al., 2015). However, no structured MBCT are offered in Malaysian clinical setting (Sidik et al., 2018). MBCT was used more towards anxiety and to prevent cancer relapse (Hazlett-Stevens., 2019).

1.2.3 Mindfulness-Based Stress Reduction (MBSR) Program

Mindfulness-Based Stress Reduction (MBSR) program is another example of MBT. MBSR was started by Professor Kabat Zinn at University of Massachusetts in 1979 (Zainal et al., 2013). In the Islamic context exercising our mind to be mindful is known as *muragabah* (Parrott, 2017).

Compared to MBCT, MBSR program was found to be more effective in reducing anxiety and depression; whereas MBCT was more towards anxiety only and prevention of cancer relapse (Hazlett-Stevens et al., 2019).

MBSR program was brought to Malaysia in 2012 by Dr Phang Cheng Kar, a psychiatrist, and was tested in many clinical settings, (Phang et al., 2014; Skarstein et al., n.d.) and in general population including medical students (Phang et al., 2016), and nurses (Hee et al., 2013).

The program was found to be effective for psychological problems including anxiety and depression. Dr Phang later developed and validated his own program namely Mindful-gym. Mindful-gym has been utilized in clinical setting for psychiatric patients (Phang et al., 2014).

1.2.4 The Components of MBSR

Mindfulness-Based Stress Reduction (MBSR) is an eight-week evidence-based program that offers secular, intensive mindfulness training to assist people with stress, anxiety, depression and pain. MBSR is a practical approach that aims to train attention, allowing people to cultivate awareness and therefore enabling them to have more choices and take wise action in their lives.

MBSR program uses a combination of mindfulness meditation, body awareness, yoga and exploration of patterns of behaviour, thinking, feeling and action.

Mindfulness can be understood as the non-judgemental acceptance and "open-hearted" investigation of present experience, including body sensations, internal mental states, thoughts, emotions, impulses, and memories, in order to reduce suffering or distress and to increase well-being proposed by Kabat-Zinn (2003) (Feldman .et al., 2007).

MBSR program was utilized in the intervention part of this study to evaluate its effects on anxiety and depression among cancer patients. MBSR used by Dr Phang focuses the approaches based on Buddhism. This study is intended to modify some components of spiritual/religious approaches in the program.

1.2.5 Patients' Counselling in Malaysian Clinical Setting

Counselling is an important component of cancer care. Counselling sessions are offered to cancer patients before, during and after going through treatment. This is to increase cancer patient's self-esteem in order to cope with the post traumatic effects of cancer and its treatment. However, the counselling module used in most clinical settings in Malaysian government hospitals mostly covers the physical symptoms of the patients and not much on the psychological aspects. (Periasamy et al., 2015). In Malaysia, psycho-oncology service is available to provide a basic general consultation to cancer patients but the number is 0.83 per 100 000 population (MOH, 2016). Furthermore, the counselling module used is not standardized among the counsellors. Most of the counsellors conduct the case based on their own knowledge background and working experience (Sidik et al., 2018).

Thorough counselling of a cancer patient is essential for comprehensive medical care. It is concerned with complex needs surrounding the psychological, social, behavioural, and ethical aspects of cancer. A patient's feelings towards life

can be a major defence against negative psychological outcomes and patient's search for meaning in life may outweigh demographic or clinical factors.

MBSR if found effective can be utilized for psycho-oncology service in hospital setting, in line with the projection of the Ministry of Health Malaysia whereby there will be increasing number of counsellors/psychologists designated in the hospitals supporting patients. Moreover MOH also suggested a Multidisciplinary Team (MDT) management of handling psychological aspect of the patients consist of the oncologist, palliative physicians, psychiatrist, psychologist, rehabilitation therapist, medical social workers, spiritual/religious personnel and paramedics should regularly meet, to coordinate the information and updates the report to the ministry (MOH, 2016).

1.2.6 MBSR Program in Malaysia

MBSR has attracted the attention in the domains of emotion research at international level; clinical intervention for anxiety and depression made this mindfulness-based exercise more popular in the clinical setting (Allen et al., 2006).

MBSR started in Malaysia since 2012. It was brought to Malaysia by Dr Phang Cheng Kar a Psychiatrist at Sunway Medical Center, Sunway, Selangor. He has started a MBSR clinic for psychological related problem in his clinic and is proven effective. MBSR has never been utilized in government hospital in Malaysia, however studies were conducted among medical students and health care personals (Phang et al., 2012; Phang et al., 2014; Phang et al., 2016).

Not many study are found in the literature search related MBSR and cancer patients especially for anxiety and depression. On the other hand unfortunately, role of MBSR on cancer patient has not been well investigated in Malaysia.

1.3 Problem Statement

MBSR is clinically proven world-wide for the treatment of anxiety and depression among cancer patients (Hazlett-Stevens et al., 2019). MBSR program has been validated and tested on a few groups of medical students and healthcare professionals and was found to be effective to reduce anxiety and depression (Lan et al.,2014).

Since patients' knowledge, attitude and belief on cancer and its treatment have great influence on clinical outcome (Aflaksair, Abbasi and Parinez, 2012), it is pertinent to assess these parameters before the introduction of MBSR program to cancer patients. However, from the thorough literature search, there is no study has been conducted on the exploration of the knowledge, attitude and health belief on MBSR among cancer patients in Malaysia especially in Penang.

Cancer patients experience tremendous stress upon cancer diagnosis (Nikbakhsh et al., 2014). However, no data available on the prevalence of anxiety and depression among cancer patients in Penang. Anxiety and depression were measured using HADS (Hospital Anxiety and Depression Scale).

The Health Related Quality of Life determine patients' state of physical and psychological well-being. The HRQOL is measured using (European Organization for Research and Treatment of Cancer) EORTQLC-QLC 30. No data available on the current state of health of cancer patients in Penang.

The Cognitive and Affective Mindfulness supports the strength of mindfulness and emotion regulation (Feldman G. et al., 2007). The cognitive and Affective Mindfulness are measured using CAMS-R (Cognitive and Affectiveness Mindfulness Scale-Revised). If patients have a high score of CAMS-R it shows that the mindfulness level of the patients are high and the chance of having a positive impact on MBSR is

high. However, no available data that assess the effect of MBSR program on HADS, CAMSR and EORTQLC-C30 among cancer patients in Penang Malaysia.

The patients at stress need counselling to gain their emotional and physical strength. However, the available setting in Malaysian clinical services does not provide enough psychological support for cancer patients with stress. Due to this lacking, patients seek various kinds of support including T&CM to cope with their stress.

The most popular T&CM sought by cancer patients is mindfulness-based therapy (MBT) in the belief that the mind has healing power (Theadom, 2015). MBT was shown to reduce anxiety and depression (Tran et al., 2020), however, there is no structured MBT offered in Malaysian clinical setting for cancer patients.

MBSR have started in a local private hospital however, there is no MBSR program offered in government clinical setting in Malaysia. (https://my.linkedin.com/in/dr-phang-cheng-kar-17313a168).

The MBSR currently in the private hospital however, uses components which might not be suitable for different socio-cultural and religious background in Malaysia. So the approach of this study was modified to suit cultural and religion belief of the patients.

This study was conducted in three phases. Qualitative Exploration in the Phase 1, Quantitative Survey as Phase 2 and Intervention Phase, as Phase 3. Qualitative exploration is suitable in the Phase 1 as we want to explore and understand the concepts, ideas and experiences of an individual in a particular cohort in depth as suggested by Holloway, (2005. Semi Structured interviews were used in this study as it is more flexibility of the research domain (Patton, 2002). The finding in Phase 1 help us to develop the questionnaire for phase 2 to gather the quantitative survey result. Phase 3 is an intervention phase.

1.4 Research Objectives

The research objectives of this study consist of three phases:

1.4.1 Phase I (Qualitative Research)

- i. To explore knowledge, attitude and health belief on cancer and its treatment approach among cancer patients.
- To explore cancer patients' psychological state on first cancer diagnosis and stress coping strategy taken by cancer patients.
- iii. To explore the barriers faced by the patients to go for their treatment of choice.
- iv. To explore knowledge, attitude and health belief on MBSR and its practice approach among cancer patients.

1.4.2 Phase II (Quantitative Research)

- To measure the knowledge, attitude and health belief on cancer and its treatment approach among cancer patients.
- ii. To measure the knowledge, attitude and health belief on MBSR and its practice approach among cancer patients.
- iii. To determine the prevalence of MBSR use, belief towards MBSR, monthly expenditure on MBSR and disclosure of the MBSR used to the health care providers among cancer patients.
- iv. To measure the level of anxiety and depression among MBSR users and non-users using HADS.
- v. To measure cancer patients mindfulness level among MBSR users and non-users using CAMS-R.
- vi. To measure HRQOL among MBSR and non-MBSR users using EORTQLC-C30.

vii. To correlate the anxiety, depression, Cognitive and Affective Mindfulness and Health Related Quality of Life with MBSR and non-MBSR users.

1.4.3 Phase III (Intervention Research)

To measure and compare the pre-and post-MBSR intervention of HADS,
 CAMS-R and EORTQLC-C30 among cancer patients.

1.5 Research Questions

1.5.1 Phase I (Qualitative Research)

- i. What are the knowledge, attitude and health belief on cancer and its treatment among cancer patients?
- ii. What are the knowledge, attitude and health belief on MBSR, its practice approach on cancer patients?
- iii. What are the prevalence of MBSR use, belief towards MBSR, monthly expenditure on MBSR and disclosure of the MBSR used to the health care providers among cancer patients?
- iv. What are the cancer patients' psychological state on first cancer diagnosis and the stress coping strategy taken by cancer patients?
- v. What are the barriers faced by the patients to go for their treatment of choice?

1.5.2 Phase II (Quantitative Research)

- i. What are the levels of knowledge, attitude and health belief on cancer and its treatment approaches among cancer patients?
- ii. What are the levels of knowledge, attitude and health belief on MBSR and its treatment approaches among cancer patients?
- iii. What are the levels of HADS, CAMS-R and HRQOL among MBSR and non-MBSR users?

iv. What are the relationships between the HADS, CAMS-R and HRQOL with MBSR and non-MBSR users?

1.5.3 Phase III (Intervention Research)

- What are the level of HADS, CAMS-R and EORTQLC-C30 before the MBSR intervention
- ii. What are the level of HADS, CAMS-R and EORTQLC-C30 after the MBSR intervention
- iii. What are the different between the pre-and post-MBSR intervention of HADS,CAMS-R and EORTQLC-C30 among cancer patients

1.6 Significance of The Study

1.6.1 Primary Outcome

This study will aid researchers in determining the amount of knowledge, health beliefs, and attitudes around cancer and MBSR among participants. The impact of the MBSR programme on the HADS, CAMSR, and EOTQLC can all be measured. This information is necessary for better patients' management.

1.6.2 Secondary Outcome

This study would benefit cancer patients; they can use the MBSR program and support their peer group members. This study would also benefit caregivers; they can learn about MBSR and use it to help cancer patients cope with stress.

Healthcare personnel can use MBSR to enhance the treatment effect with fewer side effects and better clinical outcomes, thus reducing patients' hospital stay.

For policymakers, MBSR can be considered introduced for stress reduction in oncology settings at other hospitals in Malaysia.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter describes cancer – the definition, the types, the burden of cancer worldwide and the situation in Malaysia. Since patients' perception of diseases, treatment choices and benefits are strongly associated with how people act and behave, the Health Belief Model is discussed.

This chapter also describes mindfulness and its utilization worldwide and in Malaysia. How MBSR intervention has benefitted cancer patients clinically is described briefly. How anxiety and depression affect patients' clinical outcomes is also discussed.

The tools of measurement are described, such as Hospital Anxiety and Depression Scale (HADS), Cognitive and Affective Mindfulness Scale-Revised (CAMS-R) and Health-Related Quality of Life (HRQOL).

2.2 Cancer

2.2.1 The Definition of Cancer

One defining feature of cancer is the rapid creation of abnormal cells that grow beyond their usual boundaries, and which can then invade adjoining parts of the body and spread to other organs, the latter process is referred to as metastasis. (Apn, 2019).

Cancer is a generic term for a large group of diseases that can affect any part of the body. Other terms used are malignant tumours and neoplasms. Metastases are a major cause of death from cancer (Zucca, 2017).

2.2.2 Cancer Burden World-Wide

Cancer is one of the major cause of death in the world (https://www.who.int/news-room/fact-sheets/detail/cancer. Low to middle-income countries contribute to almost 70% of the total cancer death. Most of the cancer cases were associated with behavioural and dietary risks such as high body mass index, low fruit intake, low vegetable intake, and lack of physical exercise, tobacco use and alcohol use. The highest risk was due to tobacco which contributes to almost 22% of cancer deathworld-wide (WHO, 2017). Cancer is expected to rank as the leading cause of death and the single most important barrier to increasing life expectancy in every country of the world in the 21st century. According to estimates from the World Health Organization (WHO) in 2015, cancer is the first or second leading cause of death before age 70 years in 91 of 172 countries, and it ranks third or fourth in an additional 22 countries (https://www.who.int/news-room/fact-sheets/detail/cancer.

Cancer also gives a bad impact on the economy. The cost of cancer treatment was estimated to be more than USD1.16 trillion in the United States in 2010 and is significantly increasing (Stewart & Wild, 2014). Only one in five low and middle-income countries have the necessary data to drive cancer policy (Zucca, 2017).

One in five men, and one in six women, worldwide develop cancer during their lifetime, and one in eight men and one in 11 women die from the disease. Worldwide, the total number of people who are alive within 5 years of a cancer diagnosis, called the 5-year prevalence, is estimated to be 43.8 million. The global cancer burden is estimated to have risen to 18.1 million new cases and 9.6 million deaths in 2018 reported by Global Cancer Observatory Malaysia (Global Cancer Statistic, 2018-WHO).

The increasing cancer burden is due to several factors, including population growth and aging, as well as the changing prevalence of certain causes of cancer linked to social and economic development. This is particularly true in rapidly growing economies, where a shift is observed from cancers related to poverty and infections to cancers associated with lifestyles and is more typical of industrialized countries.

Effective prevention efforts may explain the observed decrease in incidence rates for some cancers, such as lung cancer (e.g. in men in Northern Europe and North America) and cervical cancer (e.g. in most regions apart from Sub-Saharan Africa).

However, the new data show that most countries are still faced with an increase in the number of cases being diagnosed and requiring treatment and care (Gobal Cancer Statistic, GLOBOCAN, 2018-WHO).

Figure 2.1(a) presenting the estimated number of new cases in 2018 worldwide for both sexes, all ages.

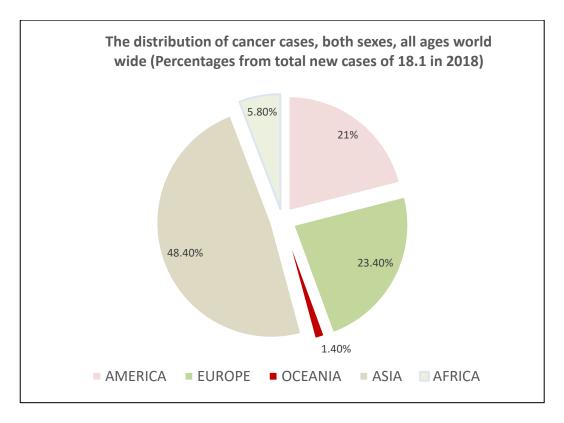


Figure 2.1(a) The estimated number of new cases in 2018 worldwide for both sexes, all ages

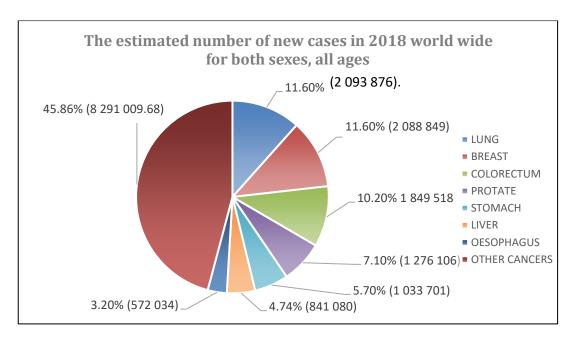


Figure 2.1(b) The estimated number of new cases in 2018 world wide for both sexes, all ages (Global Cancer Statistic 2018-International Agency for Research on Cancer 2020, WHO)

There will be an estimated 18.1 million new cancer cases (17.0 million excluding nonmelanoma skin cancer) and 9.6 million cancer deaths (9.5 million excluding nonmelanoma skin cancer) in 2018. In both sexes combined, lung cancer is the most commonly diagnosed cancer (11.6% of the total cases) and the leading cause of cancer death (18.4% of the total cancer deaths), closely followed by female breast cancer (11.6%), prostate cancer (7.1%), and colorectal cancer (10.2%) for incidence and stomach cancer (5.7%), and liver cancer (4.7%) for mortality. Lung cancer is the most frequent cancer and the leading cause of cancer death among males, followed by prostate and colorectal cancer (for incidence) and liver and stomach cancer (for mortality). Among females, breast cancer is the most commonly diagnosed cancer and the leading cause of cancer death, followed by colorectal and lung cancer (for incidence), and vice versa (for mortality); cervical cancer ranks fourth for both incidence and mortality. The most frequently diagnosed cancer and the leading cause of cancer death, however, substantially vary across countries and within each country

depending on the degree of economic development and associated social and life style factors (Freddie, 2018).

2.2.3 Cancer Burden in Malaysia

Cancer is one of the leading causes of morbidity and mortality worldwide. In 2012, there were approximately 14.1 million new cases, 8.2 million cancer deaths and 32.6 million people living with cancer worldwide. (Globocan, 2018). Cancer remains a threat among the Malaysian society nowadays. According to the Malaysian National Cancer Registry Report (MNCR) (2007–2011), there were 103,507 new cancer cases reported from 2007 to 2011. Females made up 46,794 cases (54.8%) of these reported cases, while males 56,713 cases (45.2%) (Ahmadi et al., 2019).

Despite the Health Ministry's strategy of promoting early screenings to avoid late detection, which is associated with worse survival, the recently released Malaysia National Cancer Registry Report (MNCRR) 2012-2016 also discovered, alarmingly, that the percentage of cancer cases detected in Stages 3 and 4 increased from 58.7% from 2007 to 2011 to 63.7% in 2012 to 2016 (CodeBlue, 2020).

In Globocan (2018), it was reported that the incidence of cancer in Malaysia was 43,837 in 2018 as the ASR (World) per 100,000 was 139.9 as in Figure 2.2.

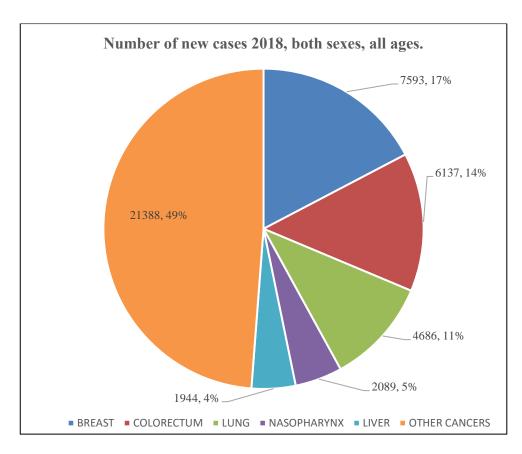


Figure 2.2 The incidence of cancer for both sexes all ages in Malaysia 2018 (Globocan 2018-WHO)

Number of cases in both sexes for all types of cancer is presented in Table 2.1. Since the incidence of cancer depends heavily on the age structure of the population, there is a need for age adjustment for comparative analysis. The age-standardised incidence rate is a summary measure, indicating the rate that a population would have if it had a standard age structure (National Cancer Registry of Malaysia, 2018).

Table 2.1 Number of new cases in 2018 in both sexes of all ages in Malaysia 2018 (Globocan 2018)

Cancer type	Number of cases			
Breast cancer	7593 (17.3%)			
Colorectal	6137 (14%)			
Lung	4686 (10.7%)			
Nasopharynx	2089 (4.8%)			
Liver	1944 (4.4%)			
Others	21 388 (48.8)			

(Global Cancer Statistic, 2018)

As reported by the cancer registry survey, the ten leading cancers among males were lung, nasopharynx, stomach, urinary bladder, rectum, non-Hodgkin's lymphoma, larynx, liver, colon and oesophagus; whereas among female, cervix, breast, ovary, lung, nasopharynx, oesophagus, thyroid, colon, rectum and non-Hodgkin's lymphoma. (Figure 2.5 and 2.6).

Number of cases for males of all ages were led by lung cancer, followed by prostate and nasopharynx cancers as in Table 2.2.

Table 2.2 Cancer types versus number of cases in males for all ages in Malaysia in 2018 (Globocan Cancer Statistic, 2018)

Cancer type	Number of cases		
Lung	3426 (16.6%)		
Colorectal	3342 (16.2%)		
Prostate	1802 (8.8%)		
Nasopharynx	1600 (7.8%)		
Liver	1460 (7.1%)		
Others	8984 (43.6%)		

Number of cases for males of all ages were led by lung cancer, followed by prostate and nasopharynx cancers as in Table 2.3.

Table 2.3 Cancer types versus number of cases in females for all ages in Malaysia in 2018 (Global Cancer Statistic, 2018, WHO)

Cancer type	Number of cases		
Breast cancer	7593 (17.3%)		
Colorectal	2795(14%)		
Uterine cervix	1682 (10.7%)		
Ovary	1271 (4.8%)		
Lung	1260 (4.4%)		
Others	8167 (37.1%)		

In Malaysia the rate of cancer incidence is projected to reach a figure of 57 000 in 2025, a 38% increase from reported cancer incidence figures in 2015 (Malaysian Oncological Society, 2018). The projection of cancer incidence in Malaysia are expected to be 56,932 in 2025 (Malaysian Oncology Society, 2018).

Table 2.4 The summary of all cancer sites in Penang state for bot sexes. Data is after age standardized (ASR) (Penang Cancer Registry from 2007-2011 and Global Cancer Statistic 2018

	No	CR	ASR	(ASR 95% CL)	CumR
MALE	5245	144.1	150.5	(146.4, 154.6)	15.9
FEMALE	6085	166.6	157.8	(153.8, 161.8)	16.1

As far as race is concerned, the distribution of cancer is various depending on the types of cancer (Penang Cancer Registry, 2004-2007).

2.3 Conventional Cancer Treatment

The National Cancer Control Program (NCCP) 2016 to 2020 aimed to develop standard clinical management, including improving the accuracy, efficiency, accessibility and timeliness of cancer diagnosis and streamlining the diagnosis using state-of-the-art technologies. NCCP also was set to provide comprehensive diagnostic services to support cancer patients in all aspects of care, including recurrence, complications and secondary effects of cancer and its treatment outcome. The program also expanded the type and widened the range of SPECT, PET and therapeutic

radiopharmaceuticals used in nuclear medicine for this country. Strengthening haematology services and providing psycho-oncology services in all cancer centres.

In terms of treatment, the NCCP aims to enhance the delivery of cancer therapy services which are timely, equitable and accessible for cancer patients throughout the country (National Cancer Program, 2016-2020).

Malaysia is currently facing the prospect of an ageing population and is predicted to cross the 15 per cent threshold in 2030 (Hirshman, 2019). The increasing number of ageing populations in Malaysia due to modernization and the growing adoption of unhealthy lifestyles increase cancer risk. The cancer control program in Malaysia is carried out quite independently by various agencies from governments, private sectors and non-government organizations. There is some duplication in the services, but no doubt, there are still lacking in certain areas such as prevention, rehabilitation and palliative care (National Strategic Plan for Cancer Control, 2016-2020).

Eventhough cancer is now better managed, the integration and coordination across all organizations should pursue systematically to ensure substantial reduction and better prevention, early detection and treatment.

The strategy of treatment is to detect cancer as early as possible. Psychooncology service could be one of the important modalities in the multidisciplinary approach to successful cancer management, other than surgery, anti-cancer drugs, and radiotherapy. Evidence-based guidelines and protocols are needed to optimize the services (National Strategic Plan for Cancer Control Program, 2016-2020).

Early detection, seeking proven treatment at curable stages, and patient adherence to the cancer treatments are important steps in prolonging cancer patients' length and quality of life and reducing the cancer burden on the healthcare system.

Malaysia is a country of multi-ethnic populations with different cultural and educational backgrounds. Thus, the evaluation of knowledge and perceptions of cancer and its treatment will be both fascinating and time-consuming but necessary for a greater understanding of the causes of the late presentations (Farooqui et al., 2011).

2.4 Complementary and Alternative Medicine (CAM)

Complementary/alternative medicine (CAM): often refers to a broad set of healthcare practices that are not part of a country's tradition and are not integrated into the dominant healthcare system. Other terms sometimes used to describe these healthcare practices include "natural medicine", "nonconventional medicine", and "holistic medicine".

Herbal medicine: plant-derived material or preparations with therapeutic or other human health benefits, which contain either raw or processed ingredients from one or more plants. In some traditions, the material of inorganic or animal origin may also be present. Traditional medicine (TM): is the total of knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illnesses. (National policy on traditional medicine and regulation of herbal medicines Report of a WHO global survey World Health Organization. Programme on Traditional Medicine (2005).

The World Health Organisation (WHO) defines CAM as "a comprehensive term used to refer to both traditional medical systems such as traditional Chinese medicine, Indian Ayurveda, Arabic Unani medicine, and to various forms of indigenous medicine" (WHO Traditional Medicine Strategy: 2014-2023). In Malaysia, CAM is referred to as Traditional and Complementary Medicine (T&CM).

2.5 T&CM in Malaysian Term

In Malaysia, non-conventional medicines are usually referred to as Traditional and Complementary Medicine (T&CM). They are classified into six main types, namely Traditional Malay Medicine (TMM), Traditional Chinese Medicine (TCM), Traditional Indian Medicine (TIM), Complementary Medicine (CM), Homeopathy and, recently included, Islamic Medical Practice (IMP). In the year 2001, the Malaysian government established National Policy on T&CM with the vision of integrating the use of these non-conventional medicines into the Malaysian healthcare system. The policy aimed to ensure the quality and safe use of T&CM practices and products to attain optimal potential in healthcare delivery (Hasan et al., 2011).

However, the definition of T&CM worldwide is not easy. There is no exact clear-cut definition of T&CM between countries (Lewith et al., 2002). According to Cancer Backup, T&CM can be divided into three different categories. The first category is psychological and self-help therapies, which help patients, deal with their illnesses' emotional and psychological aspects like stress, anxiety, and depression. Among these therapies are counselling, relaxation, healing, visualization, meditation, art therapy, and hypnotherapy. The second category is known as physical therapies. Example of them is reflexology, and shiatsu, where the sense of touch is used as the main tool for the treatment. The last category is those classified as unconventional medicine or drugs, including Homeopathy, Herbal medicine, Essiac, and Bach flower remedies (Cancer Backup).

However, Montbriand, 1994 in his study on the overview of complementary therapies chosen by cancer patients, had a different grouping for complementary therapies and described the three types of T&CM as psychological, physical and spiritual (Farooqui et al., 2016). The psychological therapies involve distraction

strategies to take the mind of patients of the illness with a positive attitude towards life and finally cure. The physical therapies include herbal tea treatment, injection of thyme enzyme to enhance the immune system, diet alteration, and megavitamins. Spiritual therapies involve prayer and healing.

"While scientific medicine focuses on cures of diseases, complementary medicine is concerned with helping us to heal ourselves". Complementary therapy emphasizes the restoration of health rather than the removal of sickness (Smith, 2013).

Attitude is one of the fundamental differences between complementary therapies and orthodox medicine. While orthodox or conventional medicine views symptoms as hostile and treats them accordingly, complementary therapies "use a symptom of illness which a person presents merely as a tool, guide or instructor, to discover more basic imbalances in the person's body, mind or spirit" (Adam & Jewels, 2007).

In Malaysia, the term Traditional and Complementary (T&CM) medicine is used officially by the Ministry of Health, Malaysia. "T&CM is defined as a form of health-related practice to prevent, treat or manage the ailment, or illnesses and to preserve the physical and mental wellbeing of an individual. T&CM excludes medical or dental practices used by a medical or dental practitioner respectively" (Traditional and Complementary Medicine Blueprint 2018-2027 (Health Care), Malaysia).

T&CM in Malaysia is divided into Traditional Chinese Medicine, Traditional Indian Medicine, Traditional Malay Medicine, Islamic Medical Practice, Homeopathy, Osteopathy and Chiropractic (T&CM Act 2016). The definition and components of T&CM are illustrated in Figure 2.5.

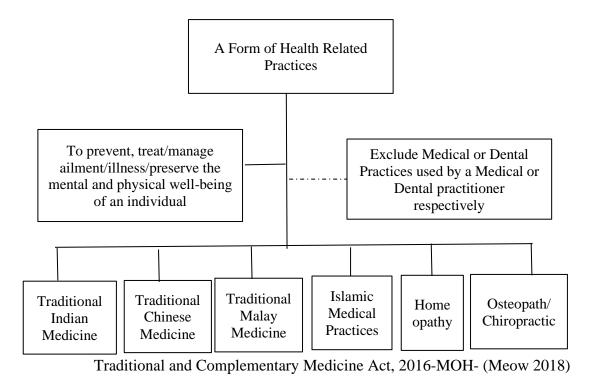


Figure 2.3 The traditional and complementary medicine definition and components

However, The National Centre of Complementary and Alternative Medicine (NCCAM) in the United States of America classified CAM into five categories for ease of standardization: whole medical system, mind-body medicine, biologically based practices, manipulative and body-based practices, and energy medicine (The NCCAM-United States, 2013).

Another grouping of T&CM is based on the types of therapy applied. The groups are biologically based therapies (BBT), mind-body therapies (MBT), whole system therapies (WST), and energy and manipulative body-based therapies (EMBT). BBT includes nutritional supplements (vitamins, minerals, and enzymes) and a special diet (herbs, animal products, juices). MBT comprises prayers for health, spirituality and others (meditation, Tai chi, music, yoga, Qigong, hypnotherapy, Reiki etc. WST includes Traditional Chinese Medicine, Malay therapies, Homeopathy, Ayurveda, light therapy and ozone therapy. EMBT involves energy medicines, massage, herbal baths, aromatherapy etc (John et al., 2016).