

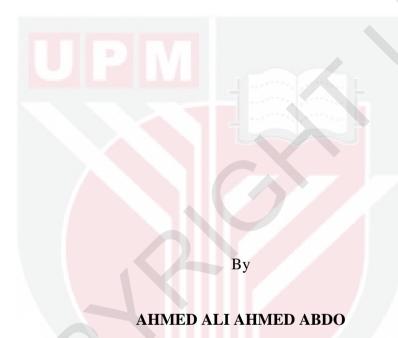
EFFECTS OF HEALTH EDUCATION AND COUNSELLING INTERVENTION ON STRESS AMONG WOMEN DIAGNOSED WITH BREAST CANCER IN YEMEN

AHMED ALI AHMED ABDO

FPSK(p) 2020 20



EFFECTS OF HEALTH EDUCATION AND COUNSELLING INTERVENTION ON STRESS AMONG WOMEN DIAGNOSED WITH BREAST CANCER IN YEMEN



Thesis Submitted to the School of Graduate Studies, Universiti Putra Malaysia, in Fulfilment of the Requirements for the Degree of Doctor of Philosophy

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DEDICATION

THIS IS DEDICATION TO

Associate Professor Dr Muhamad Hanafiah Juni

For his advice, his patience, and his faith, and for his extraordinary support in my research

"May Allah bless him with endless happiness, May Allah fulfil all his dreams, aspirations, bless him long life with good health, prosperity, and May Allah reward him with Jannah"



Abstract of thesis presented to the Senate of Universiti Putra Malaysia in fulfilment of the requirement for the degree of Doctor of Philosophy

EFFECTS OF HEALTH EDUCATION AND COUNSELLING INTERVENTION ON STRESS AMONG WOMEN DIAGNOSED WITH BREAST CANCER IN YEMEN

By

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December 2019

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The breast cancer is the most common type of cancer, accounting for 32.3% of all reported cancers in Yemen. It is the most frequently diagnosed life-threatening illnesses in women; it is greatly affect all spheres of women's life. Being diagnosed and living with cancer is a very stressful experience and having a serious impact on many aspects of women' daily life. Which make them prone to psychological and emotional disturbances, low quality of life, and leaves dramatic and adverse effects on their life. However, no cancer center in Yemen provide psychosocial support to the cancer patients. Moreover, there is high illiteracy particularly among women, and limited knowledge and understanding of breast cancer and its psychosocial implications.

The aim of this study is to develop, implement and evaluate the effect of the educational and counseling intervention on the stress, mental adjustment and quality of life in Yemeni breast cancer.

The study design is a quasi-experimental repeated measure with a comparison group. The study had been conducted in Yemen, in which 56 participants were placed in each of the two groups, a control and intervention group. The participants in intervention group had been selected randomly from the National Oncology Center in Sana'a, while the participants of control group were selected from the National Oncology Centers in Aden and Hadhramaut by using purposive sampling method. To evaluate the effects of the intervention, data were collected at baseline, 2 months and six months after intervention in both intervention and control groups. The outcomes were measured by using the PSS-10 item scale, Mini-MAC scale, QLQ-C30 questionnaires and QLQ-BR23 questionnaires.

The analysis had been conducted on 102 out of 112 participants (91%); 50 (89%) control group, and 52 (93%) intervention group. The results showed that the education and counseling intervention reduced the perceived stress score (p value < 0.05), improved the mental adjustment score (p value < 0.05) of all domains except for the fatalism (p = 0.54). As well as, the intervention has affected on the QoL in three domains; global health status, emotional functioning and future perspective (p value < 0.05), but the intervention did not show any effect on three QoL domains; the physical functioning, role functioning and body image domains were statistically non-significant.

The findings showed that the intervention reduced the level of stress, improved the mental adjustment with breast cancer and the most of the quality of life domains, with less non-significant effect on the body image, role functioning and physical functioning domains of quality of life, in particular, in the first three months of breast cancer diagnosis.

Keywords: Breast cancer, education, counseling, perceived stress, mental adjustment and quality of life

Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia sebagai memenuhi keperluan untuk ijazah Doktor Falsafah

KESAN PENDIDIKAN KESIHATAN DAN INTERVENSI KAUNSELING TERHADAP TEKANAN YANG DIALAMI OLEH WANITA YANG MENGHIDAP BARAH PAYUDARA DI YEMEN

Oleh

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Barah payudara adalah di antara barah paling lazim, menyumbang kepada 32.3% semua kes barah yang dilaporkan di Yemen. Ia adalah penyakit yang seringkali dikesan sebagai pembawa maut dalam kalanwan wanita; ia memberi kesan yang besar kepada semua aspek hidup mereka. Dikesan sebagai pengidap barah adalah satu pengalaman yang sangat memberi tekanan dan memberi impak yang serius kepada banyak aspek hidup wanita. Ini menjadikan mereka cenderung untuk terganggu secara psikilogi dan emosi, mempunyai mutu hidup yang rendah, dan ia meninggalkan kesan negatif yang dramatik ke atas diri dan hidup mereka. Namun demikian, tidak ada pusat barah di Yemen yang menyediakan sokongan psikososial kepada pesakit-pesakit barah ini. Namun demikian, terdapat banyak ketidaktahuan, malahan pengetahuan dan kefahaman yang terhad ke atas barah payudara dam kesan-kesan psikososialnya.

Tujuan kajian ini ialah membangunkan, melaksanakan dan menilai kesan strategi intervensi pendidikan dan kaunseling ke atas tekanan, pengubahsuaian minda dan mutu hidup terhadap barah payudara penduduk Yemen.

Rekabentuk kajian adalah kuasi-eksperimen, dengan pengukuran berulang dengan kumpulan yang dibandingkan. Kajian ini telah dijalankan di Yemen, dengan 56 orang peserta ditempakan dalam dua buah kumpulan, satu kumpulan kawalan dan satu lagi kumpulan intervensi. Peserta-peserta dalam kumpulan intervensi telah dipilih secara rawak dari Pusat Onkologi Negara di Sana'a, sementara peserta-peserta kumpulan kawalan telah dipilih dari Pusat Onkologi Negara di Aden dan Hadramout menggunakan kaedah persampelan bertujuan. Untuk menilai kesan-kesan intervensi, data telah dikumpul pada garis asas, 2 bulan dan 6 bulan selepas intervensi, kepada

kedua-dua kumpulan, kawalan dan intervensi. Dapatan diukur menggunakan skala 10 item PSS, skala Mini-MAC, soal-selidik QLQ-C30 dan soal-selidik QLQ-BR23.

Analisis telah dijalankan ke atas 102 dari 112 peserta (91%); 50 (89%) kumpulan kawalan, dan 52 (93%) kumpulan intervensi. Keputusan menunjukkan bawa pendidikan dan intervensi menurunkan skor persepsi tekanan, meningkatkan skor pengubahsuaian minda kesemua domain kecuali fatalisme. Strategi intervensi juga menjejaskan QOL (kualiti hidup) dalam tiga domain; status kesihatan global, kefungsian emosi dan perspektif masa hadapan, tetapi intervensi tidak menunjukkan apa-apa kesan ke atas tiga domain QOL; kefungsian fizikal, kefungsian peranan dan imej tubuh.

Dapatan menunjukkan bahawa intervensi menurunkan aras tekanan, meningkatkan pengubahsuaian minda terhadap barah payudara, dan meningkatkan domain mutu atau kualiti hidup, dengan kesan tidak signifikan ke atas imej tubuh, kefungsian peranan dan kefungsian fizikal, khususnya dalam tiga bulan pertama diagnosis barah payudara.

Kata kunci: Barah payudara, pendidikan, kaunseling, persepsi tekanan, pengubahsuaian minda dan kualiti hidup

ACKNOWLEDGEMENTS

In the name of Allah the most Merciful and Beneficent

First and foremost praise is to ALLAH, the Almighty, the greatest of all, on whom ultimetly we depend for sustenance and gudance. I would like to thank Almighty Allah for giving me opportunity, determination and strength to do my research. His continuous grace and mercy was with me throughtout my life and ever more during the tenure of my research.

Now, I would like to thank and express my deep and sincere gratitude to my main supervisor Dr. Aidalina Mahmud Department of Community Health Faculty of Medicine & Health Sciences Universiti Putra Malaysia, for her continuous support, guidance, and encouragement to make my PhD experience productive and stimulating, I ask May Allah reward her with Jannah.

I would like to thank and express my deep and sincere gratitude to my ex-main supervisor Associate Professor Dr. Muhamad Hanafiah Juni, Department of Community Health Faculty, Medicine & Health Science Universiti Putra Malaysia. I am in debtful to him, for his provided guidance, mentoring, and continued support.

I would also like to express my gratitude to my co-supervisors; Associate Professor Dr Nor Afiah Mohd. Zulkefli, Dr Hayati Kadir @ Shahar, Dr Lim Poh Ying and Dr Zubaidah Jamil Osman. Indeed, their valuable feedback and constructive comments were realy inspiring and helpful. Also, great thanks to the Assoc. Prof. Dr Huda Omer Basaleem, my external supervisor, she did the best and facilitated the implementation of field research, without her help and support, it would have been impossible to carry out the field research.

I also appreciate the support of the Profesors, staff and lectures of Community Department. I fondly remember their support, assistance, advice, and teaching; Associate Professor Dato' Dr. Faisal Ibrahim, Professor Datuk Dr. Lekhraj Rampal, Professor Dato' Dr. Lye Munn Sann, Dr Samiah Md. Said, Associate Professor Dr. Hejar Abdul Rahman, Associate Professor Dr. Halimatus Sakdiah Minhat, Dr. Huda Zainuddin, Associate Professor Dr. Suriani Ismail, and Associate Professor Dr. Rosliza Abdul Manaf. As well as, Prof. Madya Dr. Bahaman Abu Samah, Faculty of Educational Studies, adminastrators, the dean and staffs of graduate school for their assistant during of my study at UPM University.

I realy like to thank all the participants of patients who had granted me their time, and bear their pain and suffering of, to share this research. As well as, all collegues who participated in collection of data and performance of the intervention strategy: Mr. Jamal, Ms. Eman Maqtari, Dr Wasilah Dubai, Dr Samirah Alshaibani, Mr. Ala'a

Meftah, Ms. Abeer Mubarak, Mr. Mujahed AlJwafi, Mr. Eiad and Ms Abeer. As well as, I am grateful to the Oncology Centers administration in Sana'a, Aden and Al-Mukula for their help and facilitate to implement the research.

I owe everthing to my family who had encouraged and helped me at every stage of my personal and academic life and who longed to see this achievement come true. I dedicated this work to my mother, my dead father, my brothers; Abdulwally Mareh, Muhammed, Fahd, and Basheer, my children; Aimn, Eiman, Rania, Ali, and Elaf. Last but not least, naturally the thanks goes to my beloved wife, Muna Alhidary, all of this, would not have been possible without her support and patience.



This thesis was submitted to the Senate of Universiti Putra Malaysia and has been accepted as fulfilment of the requirement for the degree of Doctor of Philosophy. The members of the Supervisory Committee were as follows:

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TABLE OF CONTENTS

			Page
ABS	ΓRACΊ	Γ	i
	TRAK		iii
ACK	NOWI	LEDGEMENTS	v
APPI	ROVAI	L	vii
	LARA		ix
LIST	OF TA	ABLES	xiv
		GURES	xvi
LIST	OF Al	BBREVIATIONS	xviii
			>
CHA	PTER		
1	INTE	RODUCTION	1
	1.1	Background	1
	1.2	Problem Statement	2
	1.3	Significance and Benefits of the Study	4
	1.4	Research Questions	5 5 5 5
	1.5	The Objectives	5
		1.5.1 General Objective	5
		1.5.2 Specific Objectives	
	1.6	The Research Hypothesis	6
	1.7	Definition of Terms	6
		1.7.1 Women diagnosed with breast cancer	6
		1.7.2 Breast Cancer Survivors (BCS)	6
		1.7.3 Perceived Stress	6
		1.7.4 Mental Adjustment to cancer	6
		1.7.5 Quality of life (QOL)	7
2	LITE	ERATURE REVIEW	8
	2.1	Breast Cancer Overview	8
	2.2	Breast Cancer Incidence	8
		2.2.1 Global Perspective	8
		2.2.2 Breast Cancer in Yemen	9
	2.3	Psychological Implications of Breast Cancer	10
		2.3.1 The Perceived Stress	10
		2.3.2 The Adjustment to breast cancer	11
		2.3.3 The Quality of Life	13
	2.4	Psychosocial Intervention Models	16
	2.5	The Potential Predictors	18
		2.5.1 Stress and Mental Adjustment	18
		2.5.2 Quality of Life	21
	2.6	Effect of Intervention on Stress, Mental Adjustment and QOL	22
		2.6.1 Introduction	22
		2.6.2 Method	23
		2.6.3 Results	28
		2.6.4 Discussion	45

		2.6.5 Conclusion	47
	2.7	Theoretical Framework	47
	2.8	Conceptual Framework	49
3	MAT	ERIALS AND METHODS	53
	3.1	Study Location	53
		3.1.1 The National Oncology Program	53
		3.1.2 Oncology Cancer Center Selected	54
	3.2	Study Design	55
	3.3	Study Population	56
	3.4	Sampling Frame	56
	3.5	Participants	56
	3.6	Study Flow	57
	3.7	Sampling	57
		3.7.1 Sample Size Estimation	57
	2.0	3.7.2 Sampling Method	58
	3.8	Study Variables	60
		3.8.1 Independent and Covariates Variables	60
		3.8.2 Dependent Variables	62
		3.8.2.1 Perceived Stress	62
		3.8.2.2 Mental Adjustment to Cancer	62
		3.8.2.3 Quality of Life	62 63
		3.8.3 The Education and Counseling Intervention 3.8.3.1 Brief Introduction	63
		3.8.3.2 Development of the Intervention	63
		3.8.3.3 Content of the Intervention	68
		3.8.3.4 Implementation of Intervention	70
		3.8.3.5 Fidelity Ensuring Intervention Fidelity	71
	3.9	Study Instruments	74
	3.10		78
	2.10	3.10.1 Data Collectors	79
		3.10.2 Follow-up Phases	79
	3.11	Data Analysis	81
	3.12	Ethical Considerations	83
4	RESU	ULTS	84
-	4.1	Pilot Study Results	84
	4.2	Sample Characteristics	88
		4.2.1 Response Rate	88
		4.2.2 Attrition Rate Assessment	88
		4.2.3 Missing Data and Per-Protocol Approach (PP)	89
	4.3	Participants' Characteristics	89
	4.4	Evaluating the Differences between Groups at Baseline	93
	4.5	Determining the Significant Predictors	98
		4.5.1 The Predictors of the Perceived Stress	100
		4.5.2 The predictors of the Mental Adjustment to Cancer	101
		4.5.3 The Predictors of the Quality of life	107
	4.6	Effects of the Education and Counseling Intervention	118

		4.6.1	Testing the Assumptions of RM-MANCOVA/RM-ANCOVA/ANOVA	118
		4.6.2	The Effects of the Intervention on the Perceived Stress	123
		4.6.3		120
			Adjustment	126
		4.6.4	The Effects of the Intervention on the QOL	134
5	DISCUSSION			142
	5.1	Brief (Overview of Research	142
	5.2	Attriti	on Rate	142
	5.3	Partici	ipants' Characteristics at Baseline	143
	5.4	The D	ifferences between Groups at Baseline Survey	152
	5.5	Predic	etors Related to the Stress, Mental Adjustment and	
		Qualit	y of Life	152
		5.5.1	Predictors of the Perceived Stress of Breast Cancer	
			Patients	152
		5.5.2	Predictors of the Mental Adjustment of Breast Cancer	
			Patients	153
		5.5.3	Predictors of the QOL of Breast Cancer Patients	157
	5.6		iveness of the Intervention	162
		5.6.1	Effect of the Intervention on the Perceived Stress	162
		5.6.2	The Effects of the Intervention on the Mental	
			Adjustment	164
		5.6.3	The Effects of the Intervention on the QOL	167
6	CON	CLUSIC	ON, STRENGTHS, LIMITATIONS AND	
	RECO	OMME	NDATIONS	171
	6.1	Conclu	usion	171
	6.2	Streng	ths of the Study	171
	6.3		ations of the Study	172
	6.4	Recon	nmendations	173
REFI	ERENC	ES		174
APPI	ENDIC	ES		216
BIOD	OATA C	F STU	DENT	279
LIST	IST OF PUBLICATIONS 28		280	

LIST OF TABLES

Table		Page
2.1	Overview of included studies	29
2.2	Critical appraisal of the included studies	38
3.1	The oncology cancer center selected	54
3.2	Assumptions used sample size estimation	58
3.3	The experts' comments on the guideline content and messages	64
3.4	The Experts' Judgement on the Content and Messages of Intervention	66
3.5	Table of the Intervention Sessions Content and Messages	69
3.6	Evaluation of Fidelity for the Intervention Content Implementation	72
3.7	Follow-up Phases Table of the Study	79
3.8	Statistical Analysis for the Study Hypotheses	82
4.1	Participants' Socio-Demographic Characteristics of the Pilot Study	85
4.2	The Differences of Pre and Post Intervention in the Study Groups	87
4.3	The Response Rate	88
4.4	Attrition Rate Assessment for the Three Trials	89
4.5	Sociodemographic Characteristics of the Study Population (n=102)	90
4.6	Clinical Characteristics of the Study Population (n=102)	91
4.7	PSS, Mini-Mac and EORTC QOL Results at Baseline Survey (n=102)	92
4.8	The Difference in Sociodemographic Factors between Groups	94
4.9	The Difference in Clinical Factors between Groups at Baseline	95
4.10	The Differences between the Intervention and The control groups at Baseline	96
4.11	Baseline Scale Scores of the Participants in the Groups	97
4.12	Correlation Matrix for The Dependent and Independent Variables	99

4.13	Patients Predictors of QOL in Breast Cancer	108
4.14	The Predictors to the Stress, Quality of Life, and Adjustment to Breast Cancer in the Study Sample	117
4.15	Correlation for the Dependent Variables (n=102)	118
4.16	Test Normality of PSS, Mini-Mac, QOL and BR23 (n=102):	119
4.17	Results of Mahalanobis distances of PSS, Mini-Mac, QOL, and BR23 (n=102)	120
4.18	Collinearity assumptions of PSS, Mini-Mac, QOL, and BR23 (n=102)	120
4.19	Box's test of equality of covariance matrices (n=102)	122
4.20	Levene's tests of equality of error variance (n=102)	122
4.21	Assessing the Sphericity of the Perceived Stress (n=102) Mauchly's test of Sphericity	123
4.22	Descriptive Statistics of the Perceived Stress Over Time (n=102)	124
4.23	Two-way RMANOVA for the Perceived Stress (n=102)	125
4.24	Normality and Sphericity Assumptions of the Mini-Mac domains	128
4.25	The Mean scores of the Mini-Mac domains in the three trials	129
4.26	Results of Two-Way Repeated Measures ANOVA for Mental Scores	132
4.27	Normality and Sphericity Assumptions of the Quality of Life	135
4.28	The Mean scores of the QOL domains in the three trials:	136
4.29	Results of Two-Way Repeated Measures ANOVA for QOL Scores	140
5.1	Attrition Rate Assessment for the Three Trials Period	142
5.2	The Age at Diagnosis Breast Cancer Patients from Different Studies	144
5.3	The Mini-MAC -29 Items Scores at Baseline Survey	150
5.4	The Number of Participants in Each Level of Stress at Three Consecutive Trials	163

LIST OF FIGURES

Figure	e	Page
2.1	PRISMA flow diagram explaining the methodology to select the eligible studies	25
2.2	Review of the authors' assessments concerning each risk related to bias	40
2.3	Risk of bias summary: Review of the authors' judgements about each risk of bias item for each included study	41
2.4	Funnel plot to assess publication bias for studies examining the effectiveness of educational and counselling support in female breast cancer patients during the trials; T1, T2 and T3, QOL	42
2.5	Forest plot: Educational and counseling support versus the hospitals' routine care, outcome; QOL	43
2.6	Forest plot: Intervention group vs control group, outcome; adjustment to cancer	44
2.7	A Transactional Model of Stress and Coping	48
2.8	Lazarus' Revised Model of Stress And Coping:	50
2.9	Conceptual Framework Effect of Educational and Counseling Intervention on Stress, Mental Adjustment and QOL	52
3.1	Map for the oncology cancer center selected	55
3.2	Diagram of the Quasi Experimental Study with Two Groups	56
3.3	Flow diagram of the study sample	60
3.4	Conceptual Framework for the Intervention Development Processes	73
3.5	Modified CONSORT Flow Chart	80
4.1	The Scatter Plot for The Normality, Linearity and Homoscedasticity	100
4.2	The Scatter Plot for the Normality, Linearity and Homoscedasticity	101
4.3	The Scatter Plot for The Normality, Linearity and Homoscedasticity	103
4.4	The Scatter Plot For The Normality, Linearity And Homoscedasticity	104
4.5	Plots of *ZRESID Against *ZPRED	106

4.6	Plots of *ZRESID Against *ZPRED	109
4.7	Plots of *ZRESID Against *ZPRED	111
4.8	Plots of *ZRESID Against *ZPRED	112
4.9	Plots of *ZRESID Against *ZPRED	113
4.10	Plots of *ZRESID Against *ZPRED	115
4.11	Plots of *ZRESID against *ZPRED	116
4.12	Scatterplot of Relationship between the Dependent Variables	121
4.13	Scores of Perceived Stress Across Three Trials between Groups	124
4.14	Profile Plot of the Mini-Mac Domains	130
4.15	Profile Plot of the Quality of Life Domains	137
5.1	The Percentage of Family History of Cancer in the Participants	148
5.2	Trend of Mean Stress Score in Intervention and Control Groups	163

LIST OF ABBREVIATIONS

AP Anxious Preoccupation

ASIR Age-Standardised Incidence Rate

ASMR Age-Standardised Mortality Rate

BCS Breast Cancer Survivors

BMI Body Mass Index

CBT Cognitive Behavioural Therapy

CA Cognitive Avoidanc

EDU Psychoeducational Interventions

EF Emotional Functioning

EORTC The European Organisation for the Research and

Treatment of Cancer

GHS Global Health Status

HH Helplessness / Hopelessness

FS Fighting Spirit

IARC International Agency for Research on Cancer

PF Physical Functioning

PSS-10 item scale Perceived Stress Scale 10 items

MBSR Mindfulness-Based Stress Reduction

Mini-Mac Scale Mini-Mental Adjustment to Cancer scale

MIND Mindfulness-Based

MoPHP Ministry of Public Health and Population

NCCF National Cancer Control Foundation

NOC National Oncology Centre

NOP National Oncology Program

QOL Quality of Life

QLQ-BR23 Quality Of Life Breast Cancer Questionnaire 24 Items

QLQ-C30 Quality Of Life Core Questionnaire 30 Items

RCT Randomized Controlled Trial

RF Role Functioning

SF Social Functioning

SRS Simple Random Sample

UNICEF United Nations Children's Fund

WHO World Health Organization

CHAPTER 1

INTRODUCTION

1.1 Background

Indeed, cancer receives little attention despite leaves an immense health burden on the health system and has significantly impact on the global economy (Organization, 2017). Around of 8.8 million patients die annually due to cancer, one out of six deaths globally and far exceeding the number of death from the HIV, malaria and tuberculosis combined. The cancer burden is greatest in developing countries, where 75% of cancer deaths occur, and the number of cancer cases is rising most rapidly (Organization, 2017; Prager, Braga, Bystricky, Qvortrup, Criscitiello, Esin, Sonke, Martínez, et al., 2018). The cancer is causing 196.3 million disability-adjusted life years (DALYs) worldwide, the incidence of cancer is expected to increase continuously and strain the world's healthcare resources owing to population growth and aging (Fitzmaurice et al., 2017; Ock, Choi, & Jo, 2018).

Cancer diagnosis is an extremely traumatic event, and causing psychological disturbances for patients (Leano, Korman, Goldberg, & Ellis, 2019). As well as, creates a unique set of physical and psychological threats, whose impact may extend far beyond the period of diagnosis and treatment to many years in post-diagnosis (Gieseler, Gaertner, Thaden, & Theobald, 2018; Voigt et al., 2017). In addition, there is a lack of public information and awareness on how to recognise the sign that a person has cancer diagnosis and premature cancer mortality (Prager, Braga, Bystricky, Qvortrup, Criscitiello, Esin, Sonke, Martínez, et al., 2018).

The cancer constitutes an enormous burden on society in both economically developed and non-developed countries (Torre et al., 2015). Where the cancer expenditures have increased, and expected to rise faster than any other related area of healthcare (Prager, Braga, Bystricky, Qvortrup, Criscitiello, Esin, Sonke, Martinez, et al., 2018). The economic burden of cancer also includes indirect costs, namely the value of time spent with the disease and loss of productivity for the survivor and society. The indirect costs and costs associated with support programs further increases the total economic cost caused by cancer (Guy et al., 2013).

The consequence has been significant physical, financial and emotional strain on individuals and families suffering from cancer around the world. Prolonged disability and premature mortality have a substantial economic impact. The high direct and indirect economic costs of cancer need particular considerations and a substantial portion of cancer patients are not accessing or receiving adequate care mainly because of weak health system, inadequate national services, disparities in access to cancer care and high financial costs (Prager, Braga, Bystricky, Qvortrup, Criscitiello, Esin, Sonke, Martinez, et al., 2018). Also concerning, is that the patients with cancer also

face some challenges in maintaining their employment if they are employees to pay for these costs (Jagsi et al., 2014).

Breast cancer is one of the most commonly diagnosed cancer 11.6 %, and the second leading cause of death 6.6% (Bray et al., 2018). It is the most commonly occurring cancer in women (Ferlay et al., 2015). It is the leading cause of death and disability among women, especially young women, in low- and middle-income countries (Peters, Woodward, Jha, Kennedy, & Norton, 2016). The incidence of breast cancer has been noticeably increasing (IARC, 2014), it is increasing by about 5% annually (Özmen, 2011).

Furthermore, the burden afforded by cancer is increasing in developing countries as a result of population ageing and growth as well as, through the adoption of cancer-associated lifestyle choices, such as; smoking, physical inactivity, and westernised diets (Jemal et al., 2011). The cancer costs nearly 20% higher than the other chronic-non communicable diseases. The breast cancer is considered one of the top three cancers that has significantly impact on the global economy (Dolgin, 2018; Gross, 2014). Undoubtedly, in this case, the high cost of cancer care and treatment will affect the patient's ability to meet their financial obligations or to continue their treatment (Carrera, Kantarjian, & Blinder, 2018).

Also concerning, is the fact that many patients living in countries do not have the opportunity or right to obtain access to health care services or in many cases do not have the ability to pay the exuberant costs afforded with medical care and cancer treatment (Gross, 2014). Furthermore, the psychosocial costs refer to the loss of quality of life (QOL) associated with having cancer. Women with breast cancer incur such costs in the psychosocial domain related to the QOL such as suffering from anxiety, depression, cancer burden, marital discord, negative changes in social and family relationships, and uncertainty of the future (Li et al., 2018; Tsai, Kuo, & Chung, 2017).

Once women affected by breast cancer, they are asked to recall the very moment of their diagnosis and cancer experience, a series of symptoms may appear including hyperarousal, emotional numbness. The sensation of the situation happening to a person other than self, and intrusive thinking together with nightmares and flashbacks that guide the clinician to understand how traumatic the cancer diagnosis was across the life span (Arnaboldi, Riva, Crico, & Pravettoni, 2017).

1.2 Problem Statement

As mentioned earlier, breast cancer is reported to be one of the significant public health problems worldwide. It is the most commonly diagnosed cancer, contributing 11.6 % of the total number of new cases diagnosis (Bray et al., 2018; Ferlay et al., 2015). In Yemen, it is the most common type of cancer in women, accounting for 32.3% of all diagnosed cancers (Bawazir;, 2018; Bawazir;, Bashateh, Jradi, & Breik, 2019). Breast

cancer is considered as a chronic, life-threatening illness that greatly impacts all spheres of women's life and well-being (Aydiner, İgci, & Soran, 2016). Sadly, the cancer attacks the most valuable thing in women's life; where, the breast constitutes a part of their aesthetic appearance, identity and symbol of motherhood, their femininity and affects their loved ones (Galjchen, 1999; Kunkel, Chen, & Okunlola, 2002; Lewis, Sheng, Rhodes, Jackson, & Schover, 2012; Ohaeri, Ofi, & Campbell, 2012). In addition, in Yemen, women who are diagnosed with breast cancer at a younger age, between 30 to 50 years (Alwabr, 2016; Bawazir, 2017).

Consequently, once a woman knows she has breast cancer, she often feels terrified, scared, worried, experience immense sadness (Al-Azri et al., 2014; J. Holland, Herdman, & Hewitt, 2004), the hopelessness and fear of dying (Fu, Xu, Liu, & Haber, 2008). Furthermore, the changes in her body structure, such as, hair loss, removal of one or both breasts, are terribly stressful issues for women suffering from this illness. This may be equivalent to the loss of their femininity and feeling of disfigured appearance, resulting in developing an inferiority complex (Enache, 2012). Moreover, the side-effects due to cancer treatment lead to a myriad of physical and mental disturbances (A Jassim & Whitford, 2014; Miller, Bowen, Croyle, & Rowland, 2009).

Therefore, the breast cancer remains an extraordinarily stressful experience for majority of women (Compas & Luecken, 2002), where 80% of the patients with breast cancer reported a high level of stress, in particular, immediately after diagnosis (Nordin et al., 2012). Being diagnosed with breast cancer is often equivalent to facing death (Cozaru, Papari, & Sandu, 2014). One of the most causes of stress in the breast cancer due to lack of information (Barre, Padmaja, Rana, & Tiamongla, 2018; Nordin et al., 2012). The breast cancer patients are keenly interested in receiving information about their illness, and its management and progression (Halbach et al., 2016; Shea-Budgell, Kostaras, Myhill, & Hagen, 2014). Provision of information will aid patients in their decision-making, thus reducing their stress and better their quality of life (Shea-Budgell, Kostaras, Myhill, & Hagen, 2014). As well as, the patients express the great need for counseling, and to confer with someone who has experienced the same disease and who has successfully overcome this crisis (Giese-Davis et al., 2006).

However, in Yemen, the psychosocial support cancer centers are often neglected, the patients do not receive any kind of the health education or counseling (Al-Naggar, Nagi, Ali, & Almuasli, 2011; Ba-Khubaira & Al-Kahiry, 2012). Moreover, there is a high illiteracy particularly among Yemeni women (MoPHP & CSO, 2013; Vandenberg et al., 2009), and limited knowledge and understanding of breast cancer (Ahmed, 2010; Al-Maweri et al., 2014; Bawazir;, Bashateh, Jradi, & Breik, 2019). Furthermore, a number of previous studies had highlighted that the most medical care providers might be unaware of the patients' concerns (Parker, Aaron, & Baile, 2009).

1.3 Significance and Benefits of the Study

The Arab world has an overall population around 380 million (5% of the world's population) and has enough financial resources (Sweileh, Zyoud, Al-Jabi, & Sawalha, 2015). However, their contribution in the research activities is still limited and less than the regional countries such as in Israel, Turkey or Iran, and far less than the developed countries (Sweileh, Zyoud, Al-Jabi, & Sawalha, 2015). As well as, there are a deficiency in the cancer research in the Arab countries (Hamadeh, Borgan, & Sibai, 2017). Moreover, there is inadequate research infrastructure and poor cooperation between industries institutions, governmental agencies and academic institutions (Hamadeh, Borgan, & Sibai, 2017; Sweileh, Zyoud, Al-Jabi, & Sawalha, 2015).

In Yemen, the situation much worse, where the health literature is still very limited (Bawazir, 2017), and has received very little attention (Qirbi & Ismail, 2017). Furthermore, there is a high illiteracy (Vandenberg et al., 2009) and limited knowledge and understanding of breast cancer and its psychosocial implications among women in Yemen (Ahmed, 2010; Bawazir;, Bashateh, Jradi, & Breik, 2019).

As can be seen from the meta-analysis study in the second chapter, there are only five (5) studies had been undertaken in Arab countries out of 5,464 (0.09%), and none of those studies had been conducted in Yemen. To the best of our knowledge, the education and psychosocial support was not found in the breast cancer treatment protocol in cancer center in Yemen.

Therefore, this study sought to address that deficit, and in so doing, enrichment the paucity of studies in this particular field. The study will be as an additional value to the existing body of Arabic literature, in particular, the Yemeni research library. Moreover, the findings of the study will help to determine the significant predictors of the sociodemographic characteristics that are associated with the coping with the cancer and QOL in breast cancer patients. To this end, predictive modelling was constructed to determine which of the sociodemographic characteristics predict of perceived stress, mental adjustment and QOL scores in the breast cancer patients. Moreover, it is hoped that this research will encourage the researchers in Yemen to conduct more studies in this field, thus enrichment the research process in breast cancer field.

Furthermore, the results of the study will give an evidence base for the stakeholders of decision makers and donors in the Yemeni health system to integrate the health education and counseling support into the patient medical provided care. The results will be useful for the physicians to ensure that their patients receive a comprehensive health care. The cancer centers who will implement this intervention will improve their patients' adaptation to cancer.

1.4 Research Questions

This study attempted to answer the following questions:

- a) What are the socio-demographic and clinical characteristics in women who was diagnosed with breast cancer?
- b) What are the level of perceived stress, mental adjustment and quality of life in women who was diagnosed with breast cancer?
- c) What are the differences in participants' characteristics between intervention and control groups at the baseline survey?
- d) What are the potential predictors that influence perceived stress, mental adjustment and quality of life in women who was diagnosed with breast cancer?
- e) What are the differences in the perceived stress, mental adjustment and quality of life between and within intervention and control groups at baseline, two months and six months after intervention?

1.5 The Objectives

1.5.1 General Objective

The study aimed to develop, implement and evaluate the effect of education and counselling intervention on the stress, mental adjustment and quality of life in Yemeni women who was diagnosed with breast cancer.

1.5.2 Specific Objectives

- a) To assess the participant's socio-demographic and clinical characteristics in the study sample.
- b) To assess the baseline level of perceived stress, mental adjustment and quality of life in the study sample.
- c) To determine the differences in participants' characteristics between intervention and control groups at the baseline survey.
- d) To identify the potential predictors that influence perceived stress, mental adjustment and quality of life in women who are diagnosed with breast cancer.
- e) To develop and implement the educational and counseling intervention based on the Stress and Appraisal Coping Theory for the breast cancer patients in Yemen.
- f) To determine the differences in the perceived stress, mental adjustment and quality of life between and within intervention and control groups at baeline, two months and six months after intervention.

1.6 The Research Hypothesis

- a) There are higher levels of stress, and low in adjustment to cancer and quality of life in breast cancer patients in Yemen.
- b) There are no statistically significant differences in the participants' characteristics between intervention and control groups at the baseline survey in Yemeni breast cancer patients.
- c) The patients' socio-demographic and clinical characteristics significantly predict changes the scores of perceived stress, mental adjustment, and quality of life in breast cancer patients based on the baseline survey outcomes.
- d) There are significant differences in the perceived stress, mental adjustment and quality of life between and within intervention and control groups at baseline, two months and six months after intervention.

1.7 Definition of Terms

1.7.1 Women diagnosed with breast cancer

All women who have been diagnosed with breast cancer for the first time, and have been pathological confirmed.

1.7.2 Breast Cancer Survivors (BCS)

The National Coalition for Cancer Survivorship (NCCS) pioneered the definition of survivor as being any person diagnosed with cancer, from the time of initial diagnosis until his or her death (Stovall, Greenfield, & Hewitt, 2005), including those who have recovered from the disease (Norat, Aune, Navarro, & Abar, 2014).

1.7.3 Perceived Stress

Stress is the mental and physical condition that occurs when a person must adjust or adapt to the environment (Coon & Mitterer, 2014). In this study, stress was measured using the Perceived Stress Scale (PSS-10), developed by Cohen, Kamarck, and Mermelstein (1983). It assesses the degree to which participants evaluate their lives as being stressful during the past month.

1.7.4 Mental Adjustment to cancer

Adjustment to cancer may be defined as cognitive and behavioural responses the patient makes to the diagnosis of cancer. (Watson et al., 1988). In this study, mental adjustment refers to strategies such as feeling helpless/hopeless, anxious preoccupation, fighting spirit, cognitive avoidance and fatalism that cancer patients

use to adapt to the stress associated with having a cancer diagnosis (Watson et al., 1994).

1.7.5 Quality of life (QOL)

It is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning. It goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on quality of life. A related concept of QOL is well-being, which assesses the positive aspects of a person's life, such as positive emotions and life satisfaction" (Philpott, 2015).



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