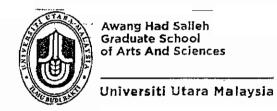
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INFLUENCE OF CAREGIVING AND PERSONALITY ON THE STRESS LEVEL OF CAREGIVERS OF CANCER PATIENTS: ROLE OF SOCIAL SUPPORT AS A MEDIATING VARIABLE



DOCTOR OF PHILOSOPHY UNIVERSITI UTARA MALAYSIA 2017



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Abstrak

Penjaga tidak formal merupakan antara sumber yang menyediakan penjagaan kepada individu yang menghidapi penyakit kronik seperti kanser. Peningkatan kadar kanser pediatrik telah menyebabkan peralihan pesakit daripada hospital kepada penjagaan di rumah. Peralihan ini mengakibatkan penjaga pesakit kanser pediatrik menghadapi cabaran dari segi sosial dan emosi yang berterusan sehingga mengakibatkan tekanan berkaitan penjagaan pesakit kanser. Menggunakan Stress Process Theory sebagai kerangka teoritikal asas, kajian ini bertujuan mengukur tahap pembolehhubah dan mengkaji korelasi serta kesan aspek penjagaan, dimensi personaliti serta sokongan sosial ke atas tekanan penjaga pesakit kanser di Pakistan. Ia juga bertujuan untuk mengukur kesan pengantara sokongan sosial dan peramal terkuat kepada tekanan penjaga. Sejumlah 286 penjaga keluarga telah dipilih sebagai responden dari lapan hospital yang memberikan rawatan kanser. Teknik persampelan rawak berstrata dan mudah digunakan dalam proses ini. Statistik deskriptif dan inferensi telah dijalankan untuk mencari hubungan antara pemboleh ubah bebas (penjagaan dan personaliti), pemboleh ubah pengantara (sokongan sosial) dan pembolehubah bersandar (tekanan penjaga). Dapatan kajian menunjukkan bahawa tiada sebarang hubungan secara langsung yang signifikan antara aspek penjagaan serta tret-tret personaliti extraversion, neuroticism dan openness dengan tekanan. Manakala, tret personaliti conscientiousness dan agreeableness menunjukkan hubungan yang signifikan dengan tekanan yang dihadapai oleh penjaga. Keputusan kajian juga mendedahkan bahawa sokongan sosial merupakan perantara di antara aspek penjagaan dan tekanan serta tret-tret personaliti extraversion, openness, agreeableness dan tekanan. Dapatan kajian juga mendapati bahawa agreeableness merupakan peramal terkuat kepada tekanan penjaga. Kajian ini memaparkan maklumat baharu kepada para penyelidik dan pengamal untuk mengenal pasti peramal kuat tekanan untuk penjaga di sepanjang proses tekanan. Ia menunjukkan impak yang tersendiri bagi personaliti dan sokongan sosial ke atas tekanan penjaga. Oleh itu, bantuan bagi membangun dan mengimplementasikan intervensi yang efektif bagi memenuhi keperluan penjaga perlu ditingkatkan bagi mengurangkan tahap stres dan menambahbaik kualiti hidup mereka.

Kata Kunci: Kanser, Penjagaan, Personaliti, Sokongan Sosial, Tekanan

Abstract

Informal caregivers have always been a source of providing care to the individuals with chronic illness such as cancer. Increasing rate of pediatric cancer has shifted the patients from hospitals to the home settings. This shift involves the caregivers of pediatric cancer to face ongoing social and emotional challenges that may result in enduring illness and caregiving-related stress. Using Stress Process Theory as the foundation for the theoretical framework, the purpose of this research was to measure the level of variables and to examine the correlation and effects of aspects of caregiving, dimensions of personality and social support on the stress of caregivers of cancer patients in Pakistan. It also aimed to measure mediating effect of social support and the strongest predictor of caregiver's stress. A total of 286 family caregivers were chosen as respondents from eight cancer treatment hospitals. Stratified and simple random sampling technique was utilized for this process. Descriptive and inferential statistics were performed in order to find the relationship between independent variables (caregiving and personality), mediating variable (social support) and dependent variable (caregiver's stress). Findings showed that there were no significant direct relation between aspects of caregiving as well as extraversion, neuroticism and openness personality traits with stress. Whereas, conscientiousness and agreeableness personality traits were significantly related to stress of caregivers. Results also revealed that social support acts as a potential mediator between aspects of caregiving and stress as well as extraversion, openness, agreeableness personality traits and stress. Findings also found that agreeableness was the strongest predictor of stress of caregivers. This study presented new information to researchers and practitioners to identify strongest predictors of stress in caregivers along the stress continuum process. It illustrates the distinctive impact of personality and social support on caregiver's stress. Therefore, helps in developing and implementing effective interventions to fulfill caregiver's needs must be enhanced in order to reduce their stress level and improve their quality of life.

Keywords: Cancer, Caregiving, Personality, Social support, Stress

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This dissertation calls an end to my unforgettable journey of PhD. It has been kept on track and been seen through to completion with the guidance and support of numerous people. At the end of my thesis, it is a pleasant task to express my thanks to all those who contributed in many ways to the success of this journey. Thanks doesn't seem sufficient but it is said with appreciation and respect to all people for their encouragement, care, understanding and precious friendship.

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ANSA QURAT-UL-AIN

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CHAPTER ONE

INTRODUCTION

1.1 Introduction

Cancer as a generic term refers to a group of diseases characterized by the uncontrolled growth and spread of abnormal cells affecting multiple parts of the body (International Agency for Research on Cancer [IARC], 2016). One central feature of cancer, according to National Cancer Institute (2015) is the rapid metabolism of abnormal cells that enter into the adjacent parts of the body by growing beyond their usual boundaries and dispersing to other organs initiating a process of metastasizing which is considered as the major cause of death from cancer.

Worldwide, cancer has become a health burden enormously by reaching every region and socio-economic group. Today, about one in every seven deaths is due to cancer (American Cancer Society, 2016). It is the second and third leading cause of mortality in high-income countries and in low-income countries respectively. Cancer figures among the primary causes of mortality and morbidity, presenting around 14 million of new cases and approximately 8.2 million deaths due to cancer in 2012 with the alarming growth of about 21.7 million new cases by the year 2030 and 13.0 million deaths (American Cancer Society, 2016). This shows that the increase in new cases of cancer up to 70 percent in upcoming two decades is expected.

More than half of the cancer cases (60 percent) that are reported annually occur in Asia, Africa and Central and South America. World Cancer Report (2015) mentioned

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APPENDIX





UNIVERSITI UTARA MALAYSIA

06010 UUM Sintok, Kedah Darul Aman, Malaysia. Tel: 604 - 928 4000

21 October 2016

TO WHOM IT MAY CONCERN,

Dear Sir/Madam,

DATA COLLECTION FOR RESEARCH PURPOSE (PhD)

This letter confirms that Ansa Qurat-ul-ain (900377) is a PhD student at the School of Applied Psychology, Social Work and Policy, Universiti Utara Malaysia (UUM). Currently, she is doing a research under my supervision titled "Influence of Caregiving and Personality on the Stress Level of Caregivers of Cancer Patients: Role of Social Support as a Mediating Variable". The objective of her research is to examine the influence of caregiving, personality and social support of caregivers on their stress level.

The information collected from the participants through the survey process (questionnaire) will be kept private and confidential. Your cooperation in this regard is highly appreciated.

Thank you.

Sincerely,

niversiti Utara Malaysia PROF DR. NAJIB AHMAD MARZUKI

Professor of Psychology School of Applied Psychology, Social Work and Policy Universiti Utara Malaysia MALAYSIA



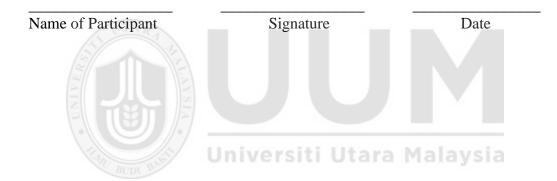




Informed Consent Form

I, the undersigned, confirm that I have read and understood the information about the thesis, as provided in the cover letter. I voluntarily agree to participate in the project. I understand I can withdraw at any time without giving reasons and that I will not be penalized for withdrawing nor will I be questioned on why I have withdrawn.

The procedures regarding confidentiality have been clearly explained to me as well as the use of the data in research, publications, sharing and archiving has been explained to me. I, along with the Researcher, agree to sign and date this informed consent form.



Influence of Caregiving and Personality on the Stress Level of Caregivers of Cancer

Patients: Role of Social Support as a Mediating Variable

Dear Respondent,

This is a survey regarding influence of caregiving and personality on the stress level of cancer patients. Only 10-20 minutes of your precious time are required to fill in the attached questionnaires. All the questions are to be answered. It is assured that all the information will be kept confidential and will be used only for the study purpose. It is also assured that anonymity will be maintained.

Please be honest in your response so true results in our research could be obtained. Your cooperation in this regard is highly acknowledged.

Ansa Qurat-ul-ain PhD Scholar

SECTION A: Demographic Information

Direction: Please tick in the relevant information.
1. Gender: Male: Female:
2. Age: 20-30 years 30-40 years
40-50 years Above 50 years
3. Marital Status: Single: Married: Other:
BUDI
4. Educational level:
Primary Secondary Intermediate
Graduation Masters Other
5. Occupation:
Govt. Sector
6. Relation of caregiver and care receiver:
Mother/Father Brother/Sister
Grandparent Other relation
7. Duration of illness: 0-3 years: 4-6 years: 7-10 years:

SECTION B

Caregiving Tasks Questionnaire (Physical Caregiving)

Direction: Please tick the columns that best describes about caregiving activities that you may or may not doing now for care-receiver.

Sr.	Items	Strongly	Disagree	Neutral	Agree	Strongly
No.		Disagree=1	=2	=3	=4	Agree=5
1	I help care-receiver with eating his/her food.					
2	I help care-receiver with					
	personal care (Dressing,					
	bathing or hair care)					
3	I help care-receiver use					
	the toilet, bedpan or					
	commode.					
4	I help care-receiver walk					
	across the room.					
5	I help care-receiver get in					
	and out of bed, chair or					
	couch.					
6	I plan care-receiver's					
	meals.				4	
7	I prepare care-receiver's					
0	meals.			_		
8	I take care of care-					
	receiver's banking, paying bills or other					
	financial matters.	iiversiti	Utara	Mala	ysıa	
9	I do shopping,					
	appointments, or run					
	errands for care-receiver.					
10	I help care-receiver with					
	writing letters, phone					
	calls, or other personal					
	communications.					
11	I help care-receiver with					
	laundry or other					
	household chores.					
12	I provide transportation					
	for care-receiver in					
	getting from home to					
	other places.					
13	I help care-receiver take					
	her medications and /or					
1.4	prescribed treatments.					
14	I contact doctor about					
	care-receiver's					

	medications and/or			
	treatment needs.			
15	I check on care-receiver			
	during the night.			

Berlin Social Support Scale (Emotional Caregiving)

Direction: Think about the patient. How did you interact with him during caregiving? Mark the columns that apply to you.

Sr,	Items	Strongly	Disagree	Neutral	Agree=	Strongly
No.		disagree= 1	=2	=3	4	agree=5
1	I showed him/her how					
	much I cherish and					
	accept him.					
2	I comforted him when					
	he/she was feeling bad.					
3	I left him/her alone.					
4	I didn't have much					
	empathy for him/her.					
5	I criticized him.					
6	I made him/her feel					
	valued and important.					
7	I expressed my concern					
	about his/her condition.					
8	I reassured him/her that					
	he can rely completely					
		iversiti	Utara	Mala	vsia	
9	I encouraged him/her		0 1010	1 1 01 1 01	,	
	not to give up.					
10	I was there when he/she					
	needed me.					
11	I did a lot for him/her.					
12	I took care of daily					
	duties that he could not					
	fulfill on his/her own.					

SECTION C

Big Five Inventory (BFI)

Direction: Please tick each statement to indicate the extent to which you agree or disagree with that statement.

I see myself as someone who...

	Hyself as someone who						
Sr.	Items	Strongly	Disagree	Neutral	Agree	Strongly	
No.	T (11 ()	disagree=1	=2	=3	=4	agree=5	
1	Is talkative						
2	Tends to find fault						
	with others						
3	Does a thorough						
	job						
4	Is depressed, blue						
5	Is original, comes						
ļ	up with new ideas						
6	Is reserved						
7	Is helpful and						
	unselfish with						
<u> </u>	others						
8	Can be somewhat						
	careless						
9	Is relaxed, handles						
	stress well						
10	Is curious about						
	many different						
	things	Univer	siti Ut	ara M	alays	la	
11	Is full of energy						
12	Starts quarrels with						
	others						
13	Is a reliable worker						
14	Can be tense						
15	Is ingenious, a deep						
	thinker						
16	Generates a lot of						
	enthusiasm						
17	Has a forgiving						
	nature						
18	Tends to be						
	disorganized						
19	Worries a lot						
20	Has an active						
	imagination						
21	Tends to be quiet						
22	Is generally						
	trusting						
	Tends to be lazy						

24	Is emotionally					
2.	stable, not easily					
	upset					
25	Is inventive					
26	Has an assertive					
	personality					
27	Can be cold and					
	aloof					
28	Preserves until the					
	task is finished					
29	Can be moody					
30	Values artistic,					
	aesthetic					
	experiences					
31	Is sometimes shy,					
	inhibited					
32	Is considerate and					
	kind to almost					
	everyone					
33	Does things					
2.4	efficiently					
34	Remains calm in					
35	tense situations Prefers work that is					
33	routine					
36	Is outgoing,					
30	sociable					
37	Is sometimes rude					
	to others	Univer	siti Ut	ara M	alavs	ia
38	Makes plans and					
	follows through					
	with them					
39	Gets nervous easily					
40	Likes to reflect,					
	play with ideas					
41	Has few artistic					
	interests					
42	Likes to cooperate					
	with others					
43	Is easily distracted					
44	Is sophisticated in					
	art, music, or					
	literature					

SECTION D

Medical Outcomes Study- Social Support Survey

Direction: How often is each of the following kinds of support available to you if you need it? Tick one number on each line.

Sr.	Items	Strongly	Disagree	Neutral	Agree	Strongly
No.		disagree=1	=2	=3	=4	agree=5
1	Someone you can count	-				
	on to listen to you when					
	you need to talk.					
2	Someone to give you					
	information to help you					
	understand a situation					
3	Someone to give you					
	good advice about a					
	crisis.					
4	Someone to confide in					
	or talk to about yourself					
	or your problems					
5	Some whose advice you					
	really want					
6	Someone to share your					
	most private worries and					
	fears with					
7	Someone to turn to for					
	suggestions about how					
	to deal with personal	niversit	Utara	Mala	vsia	
	problem					
8	Someone who					
	understands your					
	problems					
9	Someone to help you if					
	you were confined to					
10	Same and to take your to					
10	Someone to take you to					
	doctor if you needed it					

SECTION E

Modified Caregiving Strain Index

Directions: Here is a list of things that other caregivers have found to be difficult. Please tick the columns that apply to you.

Sr. No.	Items	Yes, On a regular Basis=2	Yes, Sometimes =1	Never=0
1	My sleep is disturbed			
2	Caregiving is convenient			
3	Caregiving is a physical strain			
4	Caregiving is confining			
5	There have been family adjustments			
6	There have been changes in personal plans			
7	There have been other demands on my time			
8	There have been emotional adjustments			
9	There have been work adjustments			
10	I feel completely overwhelmed			

