RESEARCH ARTICLE

Unmet psycho-social needs, coping strategies and psychological distress among people with cancer: Evidence from Pakistan

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Abstract

Objective: To explore the unmet psychosocial needs, coping styles and psychological distress among people with cancer.

Methods: The cross-sectional correlational study was conducted from May to July 2017 at Shifa International Hospital, Islamabad and Hayatabad Medical Complex, Peshawar, Pakistan which comprised of 182 patients diagnosed with cancer. Data was collected using the Supportive Care Needs Survey-Short Form-34, Mini-Mental Adjustment to Cancer Scale and the Hospital Anxiety Depression Scale. Data was analysed using SPSS 23v.

Results: It was found that all psychosocial needs were unmet among all participants (100%) who were suffering from cancer. However, health care information needs and psychological needs emerged to be strikingly unmet with 35.61% and 30.7% respectively. Moreover, maladaptive coping styles were highly endorsed than adaptive coping styles.

Conclusion: This study pointed towards gaps in delivering quality care services in health care settings, inadequate attention and serious psychological health care neglect of people fighting with life threatening disease, indicating a dire need for proper psychological interventions for effective and holistic treatment planning to improve the whole process of illness and recovery.

Keywords: Cancer, Psychosocial support system, Psychological distress, Coping skills. (JPMA 71: 1373; 2021)

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Introduction

Cancer is a dreadful disease that has become a common disease today. A recent study shows that the types of cancer responsible for highest death rates in Pakistan include breast cancer, followed by oral cavity, lungs and non-Hodgkin lymphoma.[1] During its treatment, the main focus is mainly and rightfully on chemotherapy and radiation therapy (RT) but along with it, a very serious "psychological" aspect related to this illness is often overlooked.[2]

Cancer is a disease that threatens one's various dimensions of life and therefore has strong and compelling psychological entailments.[3] Individuals diagnosed and seeking treatment for cancer are at high risk of developing mood disorders that include anxiety and depression.[4,5] The risk associated with cancer for the development of psychological issues is huge as more than half of cancer patients (62.7%) go through clinical depression, anxiety or both.[6] Over the last decennium, there has been increased interest in assessing ways of coping with stressful and traumatic situations in general, whereas coping with cancer illness in particular has pointed towards an urgent need of mental health support and services.[7] Despite progress in securing remission and possible cancer cure, it still remains a disease which is connected with hopelessness, pain, fear and death where psychological distress is reflected in the form of number of unmet needs and mental disorders.[8,9] Depression and anxiety are common in cancer patients and usually tend to co-exist.[10,11] However, it has been noted that the evidence available for Asian communities regarding their psycho-social needs is very limited.[12,13]

The current study was planned to assess unmet psychosocial needs, coping styles and the association of various factors with the degree of psychological distress among cancer patients.

Patients and Methods

The cross-sectional correlational study was conducted from May to July 2017 at Shifa International Hospital, Islamabad, and Hayatabad Medical Complex, Peshawar, Pakistan which comprised of people diagnosed with cancer. After approval from the ethics review board of the two institutions, the sample size of 182 was determined by G-power calculator using two-tailed test, effect size 'r' 0.3, alpha error probability 0.05 and power 1 - beta error probability 0.95.[14] The sample was selected from both

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inpatient and outpatient departments of afore mentioned hospitals.

Those included were patients aged 18 years and above who could read and understand urdu who were aware of their diagnosis and were seeking treatment including medication, chemotherapy, surgery or radiation therapy, for at least three months post-diagnosis with no current medical or past reported psychiatric history. The rest of the cancer patients were excluded along with those who were severely ill.

After taking informed consent, data was collected using the Supportive Care Needs Survey-Short Form-34 (SCNS-SF34), Mini-Mental Adjustment to Cancer Scale (Mini-Macs) and the Hospital Anxiety Depression Scale (HADS). Demographic data was collected using an information sheet that had questions related to age, gender, marital status, work status, locality, education, family system and monthly income. Besides, the sheet also extracted relevant clinical data like the type of cancer, duration post-diagnosis, stage of cancer and current treatment method.

SCNS-SF34 assess the perceived needs of people undergoing cancer. It consists of 34 items and five basic domains: health information needs 11 items, psychological 10 items, sexual 3 items, patient's care 5 items and daily living needs 5 items. It is scored on a 5-point Likert scale, and takes about 10 minutes to complete. For both long and short forms of SCNS, reliability coefficients are substantial, exceeding 0.8 in all domains.[15]

The Mini-Macs assesses coping responses in cancer patients. It has 29 items scored on a 4-point Likert scale. Higher subscale score suggests greater use of that particular coping strategy. It measure five cognitive coping styles in response to cancer: helplessness-hopelessness (e.g., 'I give up, I have lost everything), anxious preoccupation (e.g., 'I am fearful and worried'), cognitive avoidance (e.g., 'when I don't think about illness, I am able to spend my life in a better way), fatalism (e.g., 'I should accept what has happened so that I can live in every single moment'), and fighting spirit (e.g., 'My illness is a challenge for me'). These five coping responses can also be grouped into two main response categories of adaptive and maladaptive coping styles which facilitate its interpretation in research and its use in clinical setup.[16]

The HADS assesses anxiety and depression among people experiencing any medical illnesses.[17] It is a 4-point Likert scale comprises of 14 items and comprises 14 items; 7 each for the assessment of anxiety and depression, taking 2-5 minutes to be filled up. The HADS questionnaire has been validated in many languages, countries, and settings and is one of the most useful tools for initial diagnosis of psychological symptoms. In the current study, Urdu version of this scale was used for which reliability and validity has been well established.[18]

In first two phases of the study, translation and adaptation of SCNS-SF and Mini-MACS into Urdu language was done according to the World Health Organisation's (WHO) guidelines.[19]

After taking permission to translate these scales from the authors the tools were given to three mental health professionals who were bilingual. They were asked to be simple and concise, to avoid long sentences, address the common audience and to focus on the conceptual and cultural equivalence of the words and phrases.

Subsequently, another bilingual expert panel comprising two practicing psychologists, one oncologist and a doctoral candidate of psychology identified any inappropriate word, expression and other possible differences between the original and translated versions of the tools. The feedback from the panel was duly incorporated.

The translated tools were then back-translated by three independent translators into English to assess the conceptual equivalence of the translated scales with the original versions.

As a final step in this phase, cognitive interviews were administered in a pilot study comprising 30 subjects. Prior to administration, the participants were informed regarding the purpose of their participation and were debriefed systematically regarding the importance of their thoughts, understanding and suggestions by repeating the phrases in their own words eventually selecting the most appropriate options and addressing their queries with regard to comprehension and suitability of the translated instruments.

The feedback from the pilot study in the form of alternative words or expressions was integrated and the final urdu version of the tools were used for data collection which was the second phase of the study.

The collected data was analysed using SPSS 23v after screening out data entry errors. Alpha coefficient reliability of the three scales was assessed. Cronbach's alpha for all the scales and their subscales were found to be in the satisfactory range from α=0.73 to α=0.98. Skewness and kurtosis values also revealed data distribution scores. For preliminary analysis, chi-square

test of independence was used to examine the relationship between study variables. Multimodal binary logistic regression was computed to estimate the degree of change in psychological distress due to unmet psychosocial needs and maladaptive coping styles. Demographic variables taken as covariates were those with statistically significant association in the preliminary chi-square analysis. P<0.05 was considered significant.

Results

Of the 182 patients, 92(50.5%) were males and 90 (49.5%) were females with majority of age range between 18-40 years. Among the females, 81(82.2%) were unemployed compared to 19(17.8%) males. More females 36(48.9%) were undergoing chemotherapy than males 23(31.5%). There were 101(55.4%) patients with carcinoma for 6-12 months. Majority of the patients were at their early stages of cancer 86(47.3%) and hailed from urban areas 130(71.4%) (Table-1).

Table-1: Demographic and clinical data (N=182).

Variables	Categories	F	(%)
Gender	Male	92	50.5
	Female	90	49.5
Age	18- 40 years	110	60.4
	41 - 60 years	64	35.2
	61 years& Above	08	4.4
Marital Status	Unmarried	35	19.2
	Married	147	80.8
Residence	Rural	52	28.1
	Urban	130	71.4
Family System	Nuclear	130	71.4
	Joint	52	28.6
Education	Intermediate & Below	80	44.0
	Graduation &Above	102	56.0
Work Status	Employed	83	45.6
	Unemployed	99	54.4
Monthly Income	None	92	50.5
	Below 40,000	22	12.1
	41,000- 80,000	41	22.5
	81,000& Above	27	14.8
Type of Cancer	Sarcoma	81	44.5
	Carcinoma	101	55.4
Duration	6 months & Below	14	7.7
	6 - 12 months	72	39.6
	12- 18 months	54	29.7
	18 - 24 months	13	7.1
	24 - 36 months	13	7.1
	36 months & Above	16	8.8
Stage of Illness	Early stage	86	47.3
	Advanced stage	23	12.6
	Don't Know	73	40.1
Treatment Method	Chemotherapy	73	40.1
	Medication	56	30.8
	Radiation therapy	53	29.1

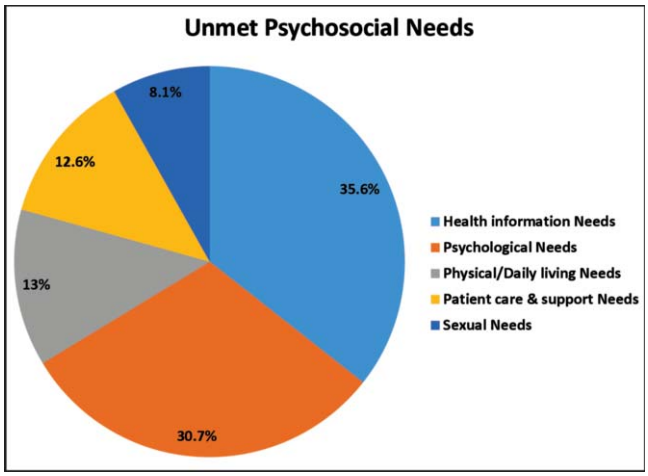

Figure-1: Unmet psycho-social needs.

The relationship was significant for gender, work status, family system, education and treatment method (p<0.05). Females were more prone to experience elevated psychological distress than males (p<0.05). The difference was also significant between family system and level of education (p<0.05). A significant interaction was also found between treatment method and psychological distress (Table-2).

The need of health information emerged as the most frequent followed by psychological need (Figure-1). Anxious preoccupation and hopelessness/helplessness coping strategies were commonly used maladaptive coping styles among patients (Figure-2).

Significant relationship existed for psychological, daily living and sexual need components of psychosocial needs with psychological distress (p<0.05). The other domains

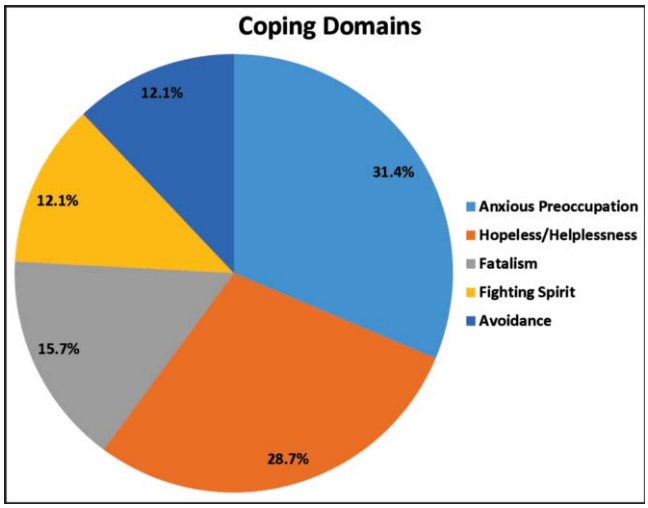

Figure-2: Cognitive coping styles in response to diagnosis of cancer.

Table-2: Relationship of demographic and clinical variables with psychological distress.

Variables	Categories	Psychological Distress		χ^2	P	Phi/Cramer V
		Case	No case			
Gender	Male	71(47.0)	21(67.7)	4.41	.034	0.16
	Female	80(53.0)	10(32.3)			
Age	18-40 years	97(64.2)	13(41.9)	5.35	NIL	0.17
	41- 60 years	48(31.8)	16(51.6)			
	61 & Above	06(4.0)	02(6.5)			
Marital Status	Unmarried	125(82.8)	22(71.0)	2.31	NIL	-0.11
	Married	26(17.2)	09(29.0)			
Family System	Nuclear	113(74.8)	17(54.8)	5.04	.031	0.16
	Joint	38(25.2)	14(45.2)			
Education	Inter & Below	79(52.3)	23(25.8)	4.99	.023	0.16
	Grad &Above	72(47.7)	08(74.2)			
Work Status	Employed	64(42.4)	19(61.3)	3.71	.026	0.14
	Unemployed	87(57.6)	12(38.7)			
Income	None	82(54.3)	10(32.3)	6.18	NIL	0.18
	Below 40k	17(11.3)	05(16.1)			
	41k - 80k	33(21.9)	08(25.8)			
	81k & Above	19(12.6)	08(25.8)			
Duration	6m & Below	12(7.9)	02(6.5)	9.28	NIL	0.23
	6 - 12 months	60(39.7)	12(38.3)			
	12- 18 months	48(31.8)	06(19.4)			
	18 - 24 months	07(4.6)	06(19.4)			
	24 - 36 months	11(7.3)	02(6.5)			
	36 & Above	13(8.6)	03(9.7)			
Stage of Illness	Early stage	71(47.0)	15(48.4)	3.26	NIL	0.13
	Advanced	22(14.6)	01(3.2)			
	Don't Know	58(38.4)	15(48.4)			
Treatment	Chemotherapy	69(45.7)	04(12.9)	15.9	.001	0.29
	Medication	38(25.2)	18(58.0)			
	Radiotherapy	44(29.1)	09(29.0)			

χ^2: Chi Square; p< .05*, p<0.01** p<0.001***

Table-3: Relationship of unmet psychosocial needs and coping styles with psychological distress.

Variables	Categories	Psych Distress		χ^2	P	Phi/CramerV
Psycho-social Needs		Cases	No cases			
Daily living Needs	Met	07(4.6)	05(16.1)	5.52	.022	0.17
	Unmet	144(95.4)	26(83.9)			
Psychological Needs	Met	01(0.7)	05(16.1)	19.34	.001	0.38
	Unmet	150(99.3)	26(83.9)			
Sexual Needs	Met	11(7.3)	10(32.3)	15.72	.001	0.29
	Unmet	140(92.7)	21(67.7)			
Patient care/support Needs	Met	10(6.6)	04(12.9)	1.43	NIL	0.09
	Unmet	141(93.4)	27(87.1)			
Coping styles						
Maladaptive Coping	Using	136(90.1)	01(3.2)	104.21	.001	0.75
	Not using	15(9.9)	30(96.8)			
Adaptive Coping	Using	28(18.5)	31(100)	77.89	.001	-0.65
	Not using	123(81.5)	0(0.0)			
Hopeless/Helplessness	Using	131(86.8)	0(0.0)	95.97	.033	0.73
	Not using	20(13.2)	31(100)			
Anxious Pre-occupation	Using	140(92.7)	02(6.5)	111.61	.001	0.78
	Not using	11(7.3)	29(93.5)			
Fighting Spirit	Using	21(13.9)	31(100)	93.41	.001	-0.72
	Not using	130(86.0)	0(0.0)			
Cognitive Avoidance	Using	28(18.5)	27(87.1)	57.32	.001	-0.56
	Not using	123(81.5)	04(12.9)			
Fatalism	Using	36(23.8)	31(100)	64.13	.001	-0.59
	Not using	115(76.2)	0(0.0)			

χ^2: Chi Square; p<0.05*, p<0.01**, p<0.001***

Table-4: Binary logistic regression analysis of unmet psycho-social needs, coping styles and their components as predictor of psychological distress.

			95% CI of odd ratio	
	B(SE)	Odds Ratio	LL	UL
Psychological Needs	3.33(1.16)	0.49	0.01	0.35
Daily living Needs	1.08(0.71)	0.34	0.08	1.36
Sexual Needs	1.65(0.53)	0.29	0.07	0.54
Coping Overall	-4.20(0.63)	0.01	0.01	0.05
Adaptive Coping	21.30(36.08)	0.00	0.00	0.00
Fighting Spirit	-4.59(1.15)	1.0	0.00	0.00
Cognitive Avoidance	3.39(0.57)	26.65	9.60	91.55
Fatalism	-21.05(37.14)	1.0	0.00	0.00
Maladaptive Coping	5.61(1.50)	0.01	0.00	0.03
Helpless/Hopeless	3.64(35.11)	0.03	0.01	0.05
Anxious-Preoccupation	5.22(0.79)	0.01	0.01	0.03

B: Beta; SE: Standard error; CI: Confidence Interval; $p<0.05$*, $p<0.01$**, $p<0.001$***

although highly unmet, did not have significant association with psychological distress ($p>0.05$). The difference was significant ($p<0.001$) among participants who adopted maladaptive coping styles compared to those opting for adaptive coping (Table-3).

Binary logistic regression indicated strong predictive value for elevated psychological distress in response to both unmet psychosocial needs and maladaptive coping styles among those suffering from cancer (Table-4).

Discussion

The study found significant relationship for gender, work status, family system, education and treatment method. Females, living in a nuclear family system with less formal education and participants undergoing chemotherapy tended to experience more psychological distress. These findings are in accordance with earlier studies.[5,6]

Among other things, the study indicated a significant association of various domains of unmet psychosocial needs with psychological distress, including psychological, daily living and sexual needs. Earlier studies also reported sexual needs as a matter of great concern.[6] Unmet physical care needs was the only sub-domain that showed no association with psychological distress. This information might suggest patients improved "physical support services" by the hospitals which is also validated by earlier findings.[20]

In the current study, the association of degree of distress in response to unmet psychosocial needs was higher than other countries around the globe. This can be explained by the fact that there is limited number of studies done in Asian countries in this regard.[21,22] Also, patients' psychological and emotional needs often get neglected due to predominant focus on high technological biomedical interventions.[6] This is indicative of disintegrated treatment plans in cases of chronic medical illnesses like cancer.[6,20]

A statistically significant difference was observed among participants who adopted maladaptive coping style than adaptive coping style indicated our findings to be well supported by a number of studies.[7,12,13,23-25]

Multimodal binary logistic regression showed that even if covariates are controlled and kept constant, unmet psychosocial needs and its domains would still remain strong predictors for elevated degree of psychological distress. These findings are supported by previous studies.[23-25] Similarly, maladaptive coping also predicted high psychological distress among people with cancer. These results pointed towards much needed psychosocial assessment to gauge individual's mental state during the entire phase of illness. Moreover, it was observed that number of patients often had more reservations and sense of embarrassment in expressing their psychological and sexual concerns. These issues, if left unaddressed, can contribute to mental health impairment among the already vulnerable individuals. Therefore, clinicians need be cautious about the pivotal role of psychological assessment for quality care provision and better mental health among those fighting with life-threatening diseases like cancer.[23-26]

The current study has several limitations including the use of objective measures alone, exclusion of patients with severe mental illnesses due to cancer, variance in duration and mode of treatment. Also, due to cross-sectional design, conclusions could not be drawn related to cause-and-effect relationship among the variables.

Conclusion

There was serious psychological healthcare neglect of cancer patients psychological interventions and holistic treatment planning for patients suffering from cancer.

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