Comparison of mental burden across different types of cancer patients in Nepal: a special focus on cervical cancer patients

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Abstract

Purpose – The purpose of the study is to assess the differential impact of gender and cancer sites on mental burden across different types of cancer and control patients.

Design/methodology/approach – The paper is based on a primary survey undertaken in 2015–2016 of 600 cancer and 200 control patients across five hospitals of Nepal. The data was analyzed using propensity score matching methods and treatment effect weighting estimators.

Findings – The authors find that of all the types of patients covered under this study, cervical cancer patients suffered from a greater intensity of anxiety and lack of functional wellbeing. On an average, all other female, male cancer patients, and control patients experience significantly lower intensity of mental burden in the range of 1.83, 2.63 and 3.31, respectively when compared to patients of cervical cancer. The results are robust across all the four treatment effect estimators and through all the measures of mental burden. The implications of suffering from cervical cancer, as a unique gynecological cancer was studied in-depth. An effect size analysis pointed out to the dysfunctional familial relationship as additional causes of concern for cervical cancer patients.

Originality/value – An important finding that emerged is that female cancer patients especially those who have cervical cancer should be given special attention because they appear to be the most vulnerable group. Further work is needed to delineate the reasons behind a cervical cancer patient facing higher amount of stress.

Keywords Cancer, Mental burden, Propensity score matching, Cervical, Nepal

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Introduction

A cancer diagnosis is a life-changing phenomenon which can lead to a considerable amount of psychological and emotional stress in any individual. Cancer affects the overall functional well-being of patients. Following diagnosis, patients experience disruptions in their personal lives through unmet physical challenges and in their social lives through isolation from friends and family [1]. Inability to take care of one's personal needs, financial distress from higher treatment expenses, and associated societal stigma take an emotional toll on their lives. We approached the issue of mental burden from the point of these functional disabilities at different domains of life. It is not only the cancer incidence, but types of cancer, age and various disease stage leave heterogeneous impacts on the magnitude of their mental burden.

Previous literature has shown that gynecological symptoms and mental burden share a positive association. Psychosomatic symptoms and psychosocial stress are common in women who also face reproductive health issues [2]. Taking this stream of thought forward, in our paper, we focus on a particular group of individuals, the cancer patients, and within that, we specifically discussed the role of gynecological cancer in giving rise to mental burden.

The magnitude of depression or anxiety among cancer patients varies considerably. Depression among patients differ by gender, age, stage of cancer, cancer sites [3, 4] and also by socioeconomic characteristics of patients [5, 6]. For example, cervical cancer involves treatment of reproductive organs, sometimes this leads to female infertility, changes in sexual or hormonal functions, or bring in stigma to the patients [7]. All these contribute to increased psychiatric symptoms among the patients [3, 8]. Cervical cancer, transmitted through sexually transmitted infection, brings in an underlying stigma and fear of social exclusion. This also adds to their sense of depression and anxiety [9]. To the best of our knowledge this is the first paper that did a comparative analysis of cervical cancer with other cancer and control patients in the context of Nepal. It econometrically estimated the mental burden of cancer patients in general and cervical patients in particular. We applied propensity score matching techniques to find that cervical cancer patients face the highest intensity of mental burden in relation to all other categories of patients. The results are robust across different measures of burden and estimation techniques.

The contribution of the paper not only lies in the econometric analysis of the extent of burden a cancer patient face, but in the identification of a group of cancer patients that appears to be the most vulnerable one. In addition to the physical pain and treatment side effects that a typical cancer patient face, patients with cervical cancer also endure infertility and reproductive issues and family level distress leading to higher mental burden. Identification of this gynecological problem as an additional source of burden is a contribution to this stream of literature.

Methodology

Sample

Nepal is a landlocked country in South Asia with approximately 28 million population in 2020. Of the 77 districts of Nepal, Kathmandu, Bhaktapur and Chitwan feature in the top 10 most cancer affected districts of Nepal. We randomly selected 538 cancer patients from two hospitals of Kathmandu district and one each from Bhaktapur and Chitwan districts. Additionally, 62 cancer patients were also surveyed from Kavrepalanchok district. A total of 600 adult cancer patients (>18 years) were randomly enumerated during the three months of survey from December 2015 to February 2016. Female cancer patients constituted 55% of the participants; of which 29% were breast and 19% cervical cancer patients. Among males, lung at 19% and stomach cancer at 16% are the most common cancers. We also randomly interviewed 200 adult control patients (>18 years) from the same hospitals with no current or

past history of cancer diagnosis. They were chronic inpatients who have stayed overnight in a medical facility for at least 3 or more days and had undergone more than two diagnostic testings. The control patients had varied ailments such as kidney ailments, liver disease, diabetes, cardiovascular problems among others.

Measures

Our primary dependent variable of interest is *Mental Burden-Disease 1*. This index was created from a set of variables such as concerns over their financial status, stigma over appearances, family level distress, and their physical disabilities following diagnosis with cancer. Using the responses to the above set of variables, a continuous index, *Mental Burden-Disease 1* is created with higher values representing higher intensity of mental burden faced by the patients. Manifestation of mental burden can also be assessed through patients' feelings of depression, their displeasure in doing things or their feeling of self-harm; all of which are additional variables that are coded into *Mental Burden-Disease 2. Mental Burden-Disease 3* assessed questions on their physical discomforts such as pounding heart beats, feeling of chest pain, or vomiting. Individuals who faced all these conditions on everyday basis suffered from the highest intensity of burden. Finally, we also tried to capture the self-assessed health status of individuals. *Self- Assessed health* index is composed of two variables measuring patients' quality of life.

Primary independent variables of interest included interpersonal social support through better social networks or familial ties of individuals. Having support also meant that patients did not feel the need to hide their disease from others or that they did not feel lonely in their fight against the disease. Three binary variables *(Higher support, Moderate support, Low support)* indicating varying levels of societal ties were also included in the model.

Additionally, we also use the medical expenses incurred by the patients, lifestyle variables such as alcohol intake or routine exercising habits, and socioeconomic indicators.

Empirical strategy: propensity score matching

For studies that use observational data (non-randomized experiments), direct comparisons of treated and untreated groups may be misleading because the baseline characteristics of these groups can differ systematically [10]. Therefore, we must account for these differences before determining the effect of treatment on outcome through Propensity Score Matching techniques (PSM) as explained below:

$$Y_i = Y_{0i} + T_i(Y_{1i} - Y_{0i})$$
$$p(X) = \Pr(T_i = M|X_i) = E(T_i|X) \tag{1}$$

Y_{1i} = The potential outcome of unit "i" if exposed to the treatment;

Y_{0i} = the potential outcome of unit "i" if not exposed to treatment;

$T_i \in 1, 2, M$ = Multivalued treatment received by unit "i".

X_i = the set of pre-treatment characteristics.

The effects of being in the treatment and control groups were measured through average treatment effects (ATE) and average effect of treatment on the treated (ATT) using four weighting estimators such as Regression Adjustments (RA), Inverse Probability Weighting estimators (IPW), Augmented Inverse Probability weight (AIPW), and Inverse-probability-weighted regression-adjustment (IPWRA). ATE is the difference between potential outcome means (POM) for the treated and control groups whereas ATT is the average effect of

treatment on those subjects who ultimately received treatment (POM refers to the means of the potential outcomes for a specific treatment level).

Ethics statement
Three separate ethics committee had individually evaluated the study protocol. The Institutional Review Board Requirement (IRB) of the University of New Mexico-USA [Reference Number: 02815 of Project ID 724145-2], The Kathmandu University School of Medical Sciences Institutional Review Committee, Nepal and the Nepal Health Research Council had provided the approval for this study.

Results
Descriptive statistics
Table 1 gives the descriptive statistics of the variables used in the analysis. The groups differ in their experience of mental burden as well as on various other factors such as age, index of social isolation, education, and income. Therefore, before attempting to establish a relationship between cancer and their intensity of burden, it is important to establish a balance in the distribution of covariates between the two groups. Mean intensity of burden ranges from 12.13 units to 20.54 units for cancer patients which is statistically and significantly different from control group of patients.

Patients irrespective of being in cancer or control groups demonstrated better connection with their family; smoking and alcohol-use were prevalent in both of them. Not surprisingly, they differ in their treatment expenses. Cancer patients incurred a significantly higher amount of economic burden (the logged value of treatment cost is 10.70 vs. 8.97 for control patients). The patients belong to the lower strata of society with low educational attainment and income level.

Multivalued treatment effects
To look into the differences of mental burden from a gender perspective, we extended the current state of the literature by comparing female specific cancers to male cancer patients and control patients. Through this, we were not only distinguishing female from male cancer patients, but also comparing mental burden within female patients. Cervical and breast cancers are the most predominant ones among female patients and been increasing over the last 10 years [11]. We hypothesized that cervical cancer is even more invasive in the life of a female patient because it gives rise to sensitive gynecological issues potentially affecting interpersonal relationships. Therefore, we studied this group closely under multivalued treatment effect indicators. The effect estimates of the multivalued categories calculated under RA, IPW, IPWRA and AIPW were given in Table 2. The treatment effect captured the deviation of potential outcome means (POM) between respective groups of patients. The results were uniformly negative for all other categories of patients across different measures of burden. According to the doubly robust IPWRA estimator, all other female cancer patients, male cancer patients, and control patients experience significantly lower intensity of mental burden in the range of 1.83, 2.63 and 3.31 when compared to the cervical cancer groups (See ATET values for IPWRA for *Mental Burden Disease-2*).

Our findings suggested avenues for future research. It would be important to delineate the relationship further in future to see what unique characteristics of cervical cancer led to such a higher magnitude and heterogeneity of burden within them. With our cross-sectional data, we did not have sufficient information to validate any causal relationship. Hence, we resorted to two approaches: (1) Item level analysis to see which component of the mental burden mattered most for cervical cancer patients (2) Validating the findings with the help of existing literature.

Variables	Cancer	Control	*p*-value
Dependent variables			
Mental burden – disease 1	12.13 (0.14)	9.62 (0.22)	0.00
Mental burden – disease 2	18.38 (0.20)	15.11 (0.32)	0.00
Mental burden – disease 3	20.54 (0.20)	17.82 (0.35)	0.00
Self-assessed health	3.90 (0.07)	5.03 (0.13)	0.00
Social support			
High support	0.50 (0.02)	0.59 (0.04)	0.03
Moderate support	0.38 (0.02)	0.32 (0.03)	0.11
Low support	0.10 (0.01)	0.08 (0.02)	0.36
Lifestyle/habits			
Alcohol	0.25 (0.01)	0.35 (0.03)	0.01
Smoke	0.30 (0.01)	0.33 (0.03)	0.38
Exercise	0.34 (0.01)	0.48 (0.03)	0.00
Kitchen-inside	0.75 (0.01)	0.80 (0.02)	0.15
Wooden fuel	0.62 (0.01)	0.62 (0.03)	0.96
Live_mainroad	0.40 (0.02)	0.33 (0.03)	0.10
Screening for cancer	0.17 (0.01)	0.01 (0.007)	0.00
Economic expenses			
Ln(expenses)	10.70 (0.08)	8.97 (0.23)	0.00
Ethnicity			
Brahmin	0.24 (0.01)	0.26 (0.03)	0.53
Chhetri	0.17 (0.01)	0.22 (0.02)	0.11
Newar	0.17 (0.01)	0.16 (0.02)	0.85
Janajati	0.24 (0.01)	0.18 (0.02)	0.08
Dalit	0.15 (0.01)	0.15 (0.02)	0.92
Income level			
Income_<10k	0.65 (0.02)	0.52 (0.04)	0.002
Income_10–20k	0.20 (0.01)	0.20 (0.02)	0.93
Income 20–30k	0.10 (0.01)	0.21 (0.03)	0.0003
Income >30k	0.05 (0.008)	0.07 (0.02)	0.18
Educational level			
No education	0.59 (0.02)	0.43 (0.03)	0.0001
Education class 1–8	0.20 (0.02)	0.21 (0.02)	0.8
Education class 9–12	0.16 (0.01)	0.29 (0.03)	0.0001
Education class >12	0.03 (0.007)	0.065 (0.01)	0.13
Occupation			
Unemployed	0.36 (0.02)	0.37 (0.03)	0.75
Agriculture	0.24 (0.02)	0.12 (0.02)	0.0002
Self-employed	0.09 (0.01)	0.11 (0.02)	0.46
Ad_ExJobs	0.04 (0.008)	0.14 (0.02)	0
Laborers	0.07 (0.10)	0.11 (0.02)	0.07
Housewife	0.16 (0.02)	0.14 (0.02)	0.32
Other socioeconomic			
Married	0.94 (0.009)	0.85 (0.02)	0
Age	52.18 (0.58)	44.79 (1.29)	0
Family history of cancer	0.12 (0.01)	0.08 (0.01)	0.16

Table 1.
Descriptive statistics of
cancer and control
patients

Item level analysis
We estimated a standardized mean difference of different components of *Mental Burden Disease-1* between cervical and non-cervical cancer patients using Cohen's d statistic (The effect size is a sub-sample analysis of only the cancer patients. It is the difference in the mean

Outcome variables	RA		IPW		IPWRA		AIPW
	ATE	ATET	ATE	ATET	ATE	ATET	ATE
Mental burden disease-1							
Cervical cancer [base]							
All females	−1.01**	−1.50***	−1.26**	−1.56***	−1.05***	−1.69***	−0.93*
All males	−1.05**	−1.86**	−1.50**	−1.64***	−1.40***	−2.19***	−1.11**
Control	−2.67***	−3.31***	−3.18***	−3.30***	−2.72***	−3.05***	−2.50***
Mental burden disease-2							
All females	−0.95	−1.56***	−1.32**	−1.66**	−0.93	−1.83***	−0.8
All males	−1.19*	−2.29***	−1.90***	−1.91**	−1.62***	−2.63***	−1.29*
Control	−2.97***	−3.62***	−3.84***	−3.73***	−3.04***	−3.31***	−2.74***
Mental burden disease-3							
All females	−0.23	−0.99	−0.62	−0.96	−0.06	−1.21**	−0.03
All males	−0.64	−1.92***	−1.30*	−1.44*	−0.9	−2.34***	−0.66
Control	−2.05***	−2.87***	−2.83***	−2.89***	−1.85***	−2.41***	−1.70**
Self-assessed health							
All females	−0.25	−0.18	0.04	−0.009	−0.26	−0.07	−0.19
All males	−0.11	−0.43	0.04	−0.3	−0.17	−0.44*	−0.09
Control	0.95***	0.70**	1.29***	1.03***	1.01***	0.83***	1.06***
[Cervical cancer]	12.7	13.61	13.29	13.63	12.97	13.8	12.73
[Mental burden disease-2]	18.82	19.97	19.78	20.01	19.16	20.23	18.88
[Mental burden disease-3]	22.59	23.84	23.52	23.8	22.71	24.06	22.54
[Self-assessed health]	3.94	4.12	3.7	3.95	3.93	4	3.89

Note(s): RA = regression adjustments, IPW = inverse probability weights, AIPW = augmented inverse probability weights, IPWRA = inverse probability weighting regression adjustment
Significance levels are indicated as $p < $ * 0.1, $p < $ ** 0.05, $p < $ *** 0.01

Table 2.
Average treatment effect across different measures of mental burden (multiple treatment categories)

mental burden of the two groups divided by the pooled standard deviation (SD) for the entire group).

Most of the items showed higher mean scores for the cervical cancer group (see Table 3). The greatest difference between the two groups was found for *Family distress (d = −0.47)*

Items	Cervical cancers	Other cancers	Cohen's *d*
Worried finance	3.3	2.95	−0.35
Family distress	3.25	2.76	−0.47
Awkward appearances	2.2	2	−0.17
Lose hope against illness	2.3	1.97	−0.29
Unable to personal care	2.37	2.22	−0.12
Little interest in things	2.37	2.24	−0.11
Depressed	2.47	2.19	−0.28
Feeling like hurting self	1.78	1.74	−0.04
Heart pounding fast	1.3	1.43	0.18
Vomiting	1.33	1.47	0.18
Chest pain	1.37	1.56	0.22
Content with QOL	1.97	1.98	0.01
General life is good	1.97	1.94	−0.03

Table 3.
Item level analysis of mental burden (cervical vs. all other cancer patients)

and *Worried about finance (d = −0.35)*. This indicated that non-cervical cancer patient face 0.47 SD lower familial distress than their counterparts. The value is 0.35 SD lower for finance related worries.

The highest value for family level distress gave an indication that cervical cancer can be intrusive to familial relationships. For example, the nature or characteristics of cervical cancer are such that it disrupts the intimacy among couples [12]. In the absence of household data on the dynamics of domestic relationships in our survey, we resorted back to literature to see what variables might explain their mental burden. At the outset, we acknowledged that this is only a discussion for future research and with the present data limitations, we are unable to test them empirically.

There is a growing literature linking domestic and sexual abuse with an increased risk of developing cervical cancer. According to Hindin *et al.* [13], three pathways through which IPV increases the risk for cervical cancer are as follows. The first is increased exposure to cervical cancer risk factors among IPV victims, including smoking, psychosocial stress, risky sexual behaviors, and sexually transmitted infections (STDs/STIs), particularly human papillomavirus infection. The second pathway is poor compliance with cervical cancer screening. The third is delay/discontinuation in treatment for cervical dysplasia and neoplasia. Control imposed by an abusive partner, competing life priorities, and limited access to financial/support resources restrict a woman's ability to seek cancer services [14, 15]. Higher rates, severity, and duration of IPV among low-income, Black, and Hispanic women explain the pervasive cervical cancer disparities.

We also find instances where women with cervical cancer do experience increased abuse and violence because of their disease. Literature suggests that women with cervical cancer face sexual violence twice that of women who never had cancer [16]. The side effects of cervical cancer treatment can lead to anatomic and physiological changes to one's genital organs giving rise to dysfunctions in an intimate relationship. Women of childbearing age reports moderate or much distress because of the infertility that resulted from treatment of the disease. These negative effects on their sexual functioning ultimately is a source of higher levels of distress for patients. Even, among cervical cancer survivors, sexual worry and dysfunctions are evident, which impacts their quality of life [17, 18]. Sexual distress between partners and their relational dissatisfaction was also studied in Refs. [18, 19], and they found that half of the cervical cancer survivors reported professional healthcare needs for their sexual concerns. This lack of sexual satisfaction between partners can therefore give rise to increased violence. Finally, Hysterectomy is a surgical procedure for cervical cancer patients where the uterus is removed from the women's body as a process of treatment. For a young cervical cancer survivor, this sudden and unexpected event results in infertility. Hysterectomy is found to complicate mental health illness and can lead to post traumatic stress disorder among some patients [20].

Conclusion

Using our primary survey data of 600 cancer patients, we had attempted to measure the intensity of mental burden faced by different types of cancer patients. Especially, we compared cervical cancer patients with other female, male, and a group of control patients using propensity score methodology. By application of various treatment effect indicators such as RA, IPW, IPWRA and AIPW, cervical cancer patients in relation to all other patients faced significantly higher intensity of mental burden. Attempts have been made to explain these findings with the support of previous literature and item level responses. Empirical estimates pointed to the fact that cervical cancer patients face higher magnitude of familial distress.

Limitations

First, mental or emotional distress can be transitory or persistent. Therefore, we should be cautious in interpreting the results. Due to the lack of longitudinal data, it is only possible for us to reflect on their current state of health. We do not have information on their pre-cancer stress levels or late-term survivor effects to study long-term individual outcomes as has been pointed out in earlier literature [21]. Second, due to the unavailability of relevant information, we could not explore the different channels impacting a cervical cancer patient. A comprehensive household survey with a module on domestic violence is needed to rigorously delineate such relationships. These shortcomings suggest avenues for future research.

Practice implications

The present study identified specific cancers whose side-effects are not limited to physical disabilities but may lead to dysfunctional relationships yielding to even higher mental burden. Female patients especially those who have cervical cancer should be given special attention because they appear to be the most vulnerable group. Cervical cancer is highly linked to family related challenges. Therefore, authorities should make concerted efforts to hold discussions with both husband and wife explaining them about the common side effects of cervical cancer. It is important that men are also made aware of HPV especially about the needs of early screening and treatments.

Conflicts of Interest: None

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