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Ungendered Social Support for Cancer Patients in the Patriarchal Hegemony in Kerala

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Abstract

Although the hallmark set for the Kerala development model is an egalitarian ideology, the increasing incidence of dowry deaths and gender discrimination calls for comprehensive and intensive investigations into the prevailing social reality on gender equality in Kerala. This study explored one of the worst scenarios in life to find out whether people discriminate against women there. The study's objective was to compare the perceived social support and hope among women and men who have cancer in the Ernakulam district of Kerala. This study adopted a quantitative survey method and collected data from 240 cancer patients in 15 randomly selected panchayats in the Ernakulam district. It elicited their sociodemographic data, perceived social support and hope, using a self-structured questionnaire, the multidimensional scale of perceived social support, and the Herth Hope Index. The use of inferential statistics compared the values obtained for the perceived social support and hope for both male and female respondents. The result showed no significant difference between the dependent variables measured for men and women, which confirmed the ungendered care for cancer patients in Kerala.

Keywords

empathy, family, cancer care, awareness, social conscience

Introduction

The egalitarian ideology embraced by the Indian State of Kerala in achieving a unique social development has drawn wide attention within the country and globally (Altbach, 2013; Bowles, 2020). Although on one

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hand the Keralan model of development has been praised and emulated by other developing countries, on the other hand critics elaborate upon the fallouts (Devika, 2010; Nowfal, 2019; Thresia, 2014). An intersection of caste, gender and spatial axes of power shapes inequalities in the Kerala landscape (Devika, 2016).

While some scholars place Kerala ahead of other Indian states in the Gender Development Index, some studies underscore the gender paradox and claim that patriarchy determines the dimensions of women's well-being (George, 2011; Kodoth & Eapen, 2005; Mitra & Singh, 2006). Although Kerala has a place in global health discourses, it underappreciates the factual facets of women's health due to the ingrained gender biases in health research (Thresia & Mohindra, 2011). Pointing out the persisting health inequalities, Thresia (2018) argues that women in Kerala belong to the part of the population with forbidden freedom and lingering privations. This study was conducted amongst cancer patients in 15 panchayats in the Ernakulam district of Kerala, and aimed at identifying the gender disparity in their social support.

Cancer, a Major Public Health Issue

Cancer is a significant public health concern as it is among the top causes of death that affect millions of people globally (Przystupski et al., 2019). The dynamic increase of cancer cases around the world aggravates the pressure on researchers and clinicians. A global statistic on cancer estimated that there would be 18.1 million new cases in 2018 (Bray et al., 2018). Cancer is an illness that causes distress to people affected by it (Gibbons et al., 2016; Mitchell, 2010; Secinti et al., 2019). The diagnosis of cancer is a family experience as it brings challenging situations to the family and changes in relations and roles, imposing a stressful care giving role on family members (Ugalde et al., 2021; WoŸniak & I¿ycki, 2014).

The burden that gynaecological cancers confer on women is enormous (WoŸniak et al., 2021). One of the principal causes of cancer mortality in India is breast cancer (Sathwara et al., 2017). Cancer treatments cause severe psychological disturbances due to the disfigurement of the body and the inability to care for children and continue with sexual intimacy with the partner (Alexander et al., 2019; Sharma & Purkayastha, 2017). Daniel and others (2021) report that the patriarchal context of living aggravates the

psychological distress of women in India diagnosed with breast cancer. The gender specific core roles and role expectations are challenged by cancer (Daniel et al., 2021). As women are given caring roles in the Indian cultural context, caring for women with cancer is becoming a crisis which heightens their psychological distress. Another study found that perceived social support (PSS) enhances their positive effects and life satisfaction (Srivastava et al., 2021). Social support is vital in promoting resilience and hope in cancer patients (Somasundaram & Devamani, 2016), and it predicts their well-being (Fong et al., 2017; Schroevers et al., 2010). Therefore this study analysed the PSS of the cancer patients and their hope.

Perceived Social Support

Social support is the actual instrumental, informational and emotional support an individual receives from family, friends, the community, and other agencies in the social network (ªahin et al., 2019). In contrast, PSS is subjective, and it concerns how individuals perceive the availability of family, friends and significant others for supporting them when needed (Grey et al., 2020). Received social support (RSS) measures the actual supportive behaviours of supporting networks, but PSS measures individuals' perceptions on the availability and adequacy of supports (Eagle et al., 2019). Objective (RSS) and subjective (PSS) social supports are moderately correlated, but the association between RSS and mental health is weak (Grey et al., 2020). Therefore, this study assessed the PSS of respondents, which is positively correlated to their resilience (Ong et al., 2018).

Hope

Hope is the most effective strategy when fighting against cancer (Li et al., 2016) since 'hope influences adaptation to illness and promotes wellness' (Herth,1992:1251). Hope is the individual's belief in their capability to achieve goals using personal strengths, and is one of the determinants of the quality of life of patients (Li et al., 2016). The trend of cancer is predicated on hope as it supports patients emotionally and physiologically to tolerate the disease (Mahdian & Ghaffari, 2016). Individuals with hope set a goal, and they find meaning in life. Hope increases with increased PSS as social support is positively connected with hope (Khodapanahi et al., 2010).

Method

The study began with ethical clearance obtained from the ethical committee at the Rajagiri College of Social Sciences, Kochi, Kerala. After drafting and piloting the questionnaire, researchers conducted a field survey to collect primary data on cancer patients in the selected geographical area. This study randomly selected 15 panchayats in the Ernakulam district of Kerala. With the help of Kudumbashree (a women's empowerment programme of Kerala) representatives, researchers identified cancer patients in the selected areas. Considering their capability and willingness to answer the questions, respondents were selected from the cancer patients identified. This research collected data from 240 respondents in the selected clusters, meeting them in person for 6 months from May 2019 to October 2019. After obtaining signed informed consent for participation and the publication of results safeguarding their privacy, we elicited data.

This study used a structured questionnaire to gather socio-demographic data of participants. It further used the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988) to subjectively assess the respondents' social support. MSPSS is a 7-point scale with 12 statements on the support of family, friends, and significant others. Another scale used was the Herth Hope Index (HHI) (Herth, 1992) to measure the three factors of hope in respondents: 'inner sense of temporality and future, inner positive readiness and expectancy, and interconnectedness with self and others' (Rustøen et al., 2018). HHI is a 4-point scale with 12 items, where #3 and #6 needed reverse coding. A bilingual expert translated all items on both the scales into the local language of Malayalam, and back translated, ensuring accuracy. Piloted the instruments and checked Cronbach's alpha which is 0.85 and 0.83 respectively for MSPSS and HHI for this study.

We analysed the data using SPSS version 25. The analysis included:

- Frequency distribution and cross-tabulation of gender, age and type of cancer using descriptive statistics.
- Cross-tabulation of levels of PSS and age group, religion and marital status.
- Cross-tabulation of levels of hope and age group, religion and marital status.
- Independent sample t-test to compare means of PSS and hope, setting gender as the grouping variable.

The results of t-tests were checked against the alternative hypotheses. H1(a) showed that there is a significant difference between the perceived social support to males and females affected with cancer, and H1(b) showed that there is a significant difference between the hope possessed by males and females affected with cancer.

Results

Gender-wise Distribution of Respondents in Age Groups

The variable age was recoded into a different variable, age group, categorising respondents into five groups, and checked cross tabulations to find out the distribution of males and females across the groups. Statistical test results showed that 65 per cent of females and 35 per cent of males constituted the study sample. The largest age group was 40–60 with a 51.25 per cent representation, followed by the 60-80 group with a 28.3 per cent contribution to the total sample. Table 1 shows the distribution of respondents based on age and gender.

Table 1: Age group and gender

Age Group	Gender		
	Male	Female	Total
Below 20	1	7	8
20-40	11	25	36
40-60	40	83	123
60-80	30	38	68
Above 80	2	3	5
Total	84	156	240

Type of Cancer among the Respondents

Among the respondents, the most prevalent type of cancer was breast cancer (31.7%), which affected only females. About 49 per cent of the women respondents had breast cancer, followed by another 14.7 per cent with uterus cancer. Lung cancer was the leading one among male respondents, followed by blood cancer. Table 2 shows the distribution of different types of cancer among the respondents.

Table 2: Type of cancer and gender

Type of cancer	Gender		
	Male	Female	Total
Breast	0	76	76
Brain tumour	1	7	8
Uterus	0	23	23
Oral	7	4	11
Neck related	5	4	9
Colon cancer	5	1	6
Lung cancer	18	2	20
Bone cancer	4	3	7
Blood cancer	12	9	21
Pituitary	0	1	1
Others	32	26	58
Total	84	156	240

Level of PSS

We trichotomised the respondents based on the average score of their PSS; 1 to 2.99 into low support, 3 to 5 into moderate support, and 5.01 to 7 into high support categories (Zimet, 2016). A noticeable 66.7 per cent belonged to the high support group, 31.3 per cent had moderate support, and 2 per cent had poor support. Table 3 illustrates the frequency of respondents in the categories of PSS.

Table 3: Participants with different levels of PSS

Level	Frequency
Low	5
Moderate	75
High	160
Total	240

A cross-tabulation of the level of PSS and age groups illustrated that the 20–40 age group had the lowest representation (55.6%) in the high-level social support category while 60–75 per cent of respondents in the other age groups perceive it. Sixty-nine per cent of the cancer patients studied in the largest age group of 40–60, have high PSS. The extreme age groups, below 20 and above 80, had no representation in the low-level

category. Table 4 provides details on the age group-wise classification of PSS.

Table 4: Age group and the level of PSS

	Level of PSS			
Age group	Low	Moderate	High	Total
Below 20	0	2	6	8
20–40	2	14	20	36
40–60	2	36	85	123
60–80	1	21	46	68
Above 80	0	2	3	5
Total	5	75	160	240

Cross-tabulation of marital status and PSS showed that 70 per cent of married people received high social support, whereas separated ones had no representation in this category. On the contrary, the divorced group had moderate and high categories of social support. Table 5 gives details on the variations in social support according to marital status.

Table 5: Marital status and the level of PSS

	Level of PSS			
Marital status	Low	Moderate	High	Total
Single	1	8	11	20
Married	2	54	132	188
Widowed	1	8	14	23
Divorced	0	2	3	5
Separated	1	3	0	4
Total	5	75	160	240

The sample had a more or less an equal representation from the Hindu (46.3 %) and Christian (42.1 %) religions, and a comparatively lesser number of respondents in the Muslim (11.7 %) category. However, 75 per cent of them enjoyed high PSS, and the remaining 25 per cent had moderate PSS. Among Christians, 71.3 per cent received high PSS, whereas in the Hindu category, high PSS was reduced to 60.4 per cent of the total Hindu respondents. Low PSS was distributed between Hindu and Christian

categories with 80 per cent and 20 per cent respectively. Table 6 provides information on the distribution of PSS among respondents from different religions.

Table 6: Religion and the level of PSS

Religion	Level of PSS			Total
	Low	Moderate	High	
Hindu	4	40	67	111
Christian	1	28	72	101
Muslim	0	7	21	28
Total	5	75	160	240

Level of Hope among the Respondents

After computing the variable 'Hope' for each respondent, it was recoded into a different variable named 'Hope Level' with three categories: 12 through 24=1=Low, 25 through 36=2=Medium, 37 through 48=3=High and further calculated the frequency of the levels of hope among the respondents. While 37.1 per cent possessed a high level of hope, 61.7 per cent had a medium level of hope, and an insignificant 1.3 per cent had low hope. Table 7 shows the frequency of the level of hope among the respondents.

Table 7: The level of hope

Level	Frequency
Low	3
Medium	148
High	89
Total	240

Cross tabulation of the level of hope and age group illustrated that 41.5 per cent of the 40–60 age group have a high level of hope while 57.7 per cent possess medium hope. Low hope was absent from the below 20 and above 80 age groups when other groups equally shared the number of respondents with low hope. All respondents in the above 80 age group showed medium hope, while around 60 per cent of patients from all other

age groups held the same. Table 8 shows the details of cross tabulation of the level of hope and age group.

Table 8: Age group and level of hope

	Level of Hope			
Age group	Low	Medium	High	Total
Below 20	0	5	3	8
20–40	1	23	12	36
40–60	1	71	51	123
60–80	1	44	23	68
Above 80	0	5	0	5
Total	3	148	89	240

All the respondents in the separated and divorced categories of marital status had a medium level of hope, whereas 39 per cent of those who were widowed, 38 per cent of those who were married, and 40 per cent of those who were single possessed a high level of hope. Respondents with low hope were from the married and single categories, although their representation is trivial in the sample. Table 9 shows the result of cross tabulation of the level of hope and marital status.

Table 9: Marital status and the level of hope

	Level of Hope			
Marital status	Low	Medium	High	Total
Single	1	11	8	20
Married	2	114	72	188
Widowed	0	14	9	23
Divorced	0	5	0	5
Separated	0	4	0	4
Total	3	148	89	240

Cross tabulation of religion and hope revealed that 40.6 per cent of Christians, 35.1 per cent of Hindus, and 32.1 per cent of Muslims affected with cancer had a high level of hope. Low-level hope was absent among Muslims, while the other two categories have an insignificant presence at this level. However, a medium level of hope was dominant in the sample

studied. Table 10 provides the result of cross tabulation of the level of hope and religion.

Table 10: Religion and the level of hope

Religion	Level of Hope			Total
	Low	Medium	High	
Hindu	1	71	39	111
Christian	2	58	41	101
Muslim	0	19	9	28
Total	3	148	89	240

Hypothesis testing (T-Test)

By performing the independent samples t-test, this study compared the means of PSS and hope by setting gender as the grouping variable. Table 11 shows the group statistics.

Table 11: Group statistics for T-Test

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
						Lower	Upper
PSS	-0.374	238	0.708	-0.05266	0.14066	-0.32976	0.22444
	-0.375	170.398	0.708	-0.05266	0.14056	-0.33012	0.22481
Hope	-1.301	238	0.195	-0.80220	0.61660	-2.01689	0.41250
	-1.248	151.015	0.214	-0.80220	0.64286	-2.07236	0.46797

Table 12: Independent Samples t-test

	Gender	N	Mean	Std. Deviation	Std. Error Mean
Perceived Social Support (PSS)	Male	84	5.3859	1.03776	0.11323
	Female	156	5.4386	1.04024	0.08329
Hope	Male	84	34.5119	4.96614	0.54185
	Female	156	35.3141	4.32070	0.34593

Independent samples t-test for equality of means of PSS and hope were performed with gender as the grouping variable and 95 per cent confidence interval. Table 12 shows the test results obtained when running the test assuming equal variances and not assuming equal variances.

Table 12 shows that $p>0.05$ in all the cases. Therefore, this study rejected both the alternative hypotheses and confirmed that H0(a): there is no significant difference between PSS of males and females who have cancer, and H0(b): there is no significant difference between hope of males and females who have cancer.

Discussion

Corresponding to the 19.3 million new cancer cases in 2020, GLOBOCAN (Bray et al., 2018) projected an incidence of 28.4 million cases in 2040, assuming the rate of increase remains constant (Sung et al., 2021). The National Cancer Registry Programme, India, projected 1,392,179 cancer patients for the year 2020, and breast, lung, mouth, cervix, uterus and tongue as the common leading sites (Mathur et al., 2020). With a well-established cancer care system and cancer registry, Kerala reported the highest rate of cancer incidence in India (Dhillon et al., 2018). This study result resonates with the findings that the type of cancer with the highest contribution to cancer DALYs (disability-adjusted life years) is breast cancer among women, and lung cancer among men (Dhillon et al., 2018).

This study results show the same trend as projected by GLOBOCAN 2020 that the most common type of cancer is breast cancer among women (Sung et al., 2021). A study that analysed population-based cancer registries (PBCRs) across India found the highest breast cancer crude rate (CR) was in the Thiruvananthapuram (Kerala) registry, and the disease peaks at around 40–50 years of age in Indian women (Malvia et al., 2017). The frequency analysis of the respondents of this study positioned the middle quintile of age groups (40-60) at the top.

A staggering sense of shame and social taboo is attached to gender-related cancers in India, which remains a barrier to early diagnosis and treatment for women (Nyblade et al., 2017). India's socially ingrained gender disparities keep women's health way down the list of priorities (Shukla, 2020). Although largely patriarchal, the family as a dominant social unit in Indian culture provides crucial support to women with cancer (Alexander et al., 2019). A positive perception of social support helps women to cope better with the impacts of cancer (Spatuzzi et al., 2016).

Social support and hope are positively correlated with the quality of life of individuals diagnosed with cancer (Shen et al., 2020). The perception of individuals that they are receiving adequate and quality support from their support networks instils hope in them and strengthens them in their fight against the disease. Two-thirds of the respondents of this study perceived a high-level social support, where the second quintile (20–40) age group had the lowest representation in this category. Trindade and others (2018) drew a negative link between PSS and the fear of receiving compassion. Lack of connectedness in social relationships and a sense of insecurity can contribute to the fear of receiving compassion and empathy from others (Trindade et al., 2018). Moreover, dealing with cancer at a stage of life where individuals make close relationships, create a financial base, and raise children can lead to specific challenges in navigating family life, parenting, and career change (Inhestern et al., 2017; Semple & McCance, 2010).

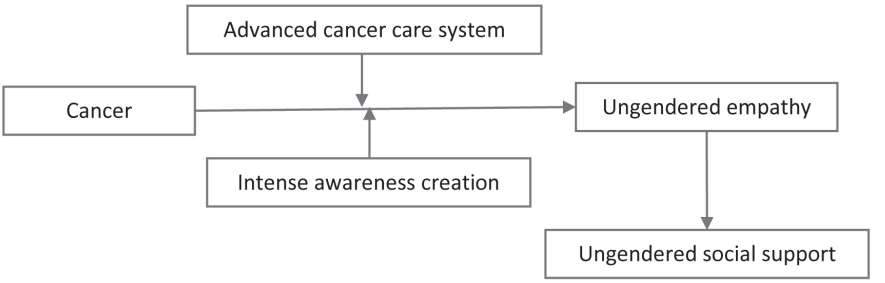
Although the role of religion is limited in modern medicine, it plays a protective role in facilitating social support during critical life events (Sohail et al., 2020). Rituals or religious practices positively affect chronically ill patients by employing spirituality to cope with their illness through faith and prayer (Roger & Hatala, 2018). Since religion provides hope to patients fighting against the disease, they adopt it as a coping strategy (Sohail et al., 2020). However, PSS is directly associated with hope in cancer patients (Somasundaram & Devamani, 2016).

The social fabric of Kerala is highly patriarchal, which juxtaposes gender equality and female subservience. However, the results of this study proved that there was no gender difference in PSS and hope among cancer patients in Kerala. Robyn Bluhm (2017), who reviewed several studies on gender and empathy, including affective empathy, cognitive empathy, and the neurophysiology of empathy, observed no consistent gender differences in empathy. The review further postulated that the possible gender difference in empathy stays in the eyes of the beholder, who is more influenced by gender stereotypes than feelings (Bluhm, 2017). 'Empathy is a potential psychological motivator for helping others in distress' (McDonald & Messinger, 2011, p. 333). Cancer is a distressing condition that triggers empathy regardless of the gender of the person affected. Therefore, family, friends, and significant others empathise with patients, disregard their gender and provide them with the needed support.

Therefore, this paper proposes a conceptual framework (Figure 1) for

an ungendered social support for cancer patients in Kerala, in which the distressing illness triggers empathy that draws social support. We assume that the creation of an intense awareness of cancer and well-developed cancer care centres in Kerala have created a public consciousness which empathises with cancer patients. However, these areas need further qualitative studies to confirm the assumption. The gender equality in PSS of cancer patients, which this study proved, does not mask the prevalent gender disparities and atrocities against women in the Keralan landscape.

Figure 1: A conceptual framework for an ungendered social support for cancer patients



Conclusion

Despite the egalitarian model for social development, patriarchy and gender disparity are undeniable in Kerala. In this context, probing for a space where society celebrates gender equity can create insights for people to unlearn the unhealthy behaviours rooted in stereotypes. This paper stresses the unbiased social buffer for cancer patients in Kerala developed through a series of awareness programmes on cancer by government and non-government agencies.

In spite of the State-sponsored women empowerment initiatives, women in Kerala are perceived to be subordinate to men, and this second sex status acts as a barrier to decision-making and accessing medical care. Moreover, the stigma attached to revealing reproductive health issues poses challenges to women's early detection and treatment of gynaecologic cancers. However, the people of Kerala demonstrate a social conscience regarding individuals diagnosed with cancer. The social background of Kerala, which is rooted in religions, motivates people to help chronic patients.

As the Keralan society considers family as the primary social unit where the members are closely interlinked, it acts as a buffer to reduce cancer-induced stress in patients. Studies proved that the immediate family is the primary source of social support for cancer patients in Kerala, where family bonding facilitates understanding among members (Alexander et al., 2019).

Moreover, Kerala has a well-established cancer care system that provides clinical and palliative care to patients. Apart from central government schemes, Kerala has Cancer Suraksha schemes for poor children affected with cancer, and another scheme, Ashwasakiranam, which covers bed-ridden cancer patients. The role of NGOs in providing support to cancer patients is significant in Kerala. Government-sponsored services, NGOs, and religious organisations in Kerala developed a public consciousness that empathises with cancer patients. This ungendered empathy ensures equal social support to both male and female cancer patients in Kerala.

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