**The social and ethical issues faced by chronically ill female cancer patients**

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**A statement of competing interests and funding support:** The authors affirm no conflict of interest. There is no financial support related to the resources of this study

**A statement of any submission of very similar work, with references to the previous submission if applicable:** Not applicable

**Abstract**: This study examines and explains the impact of chronic illness on the social fabric and related ethical issues in female cancer patients. Sixty female patients from the medical oncology department from private medical college Hospital participated in this study. The data was collected from responses to a self-administered validated questionnaire comprising of 5 domains. The 5 domains used were (1) Dependency (2) Communication (3) Issues with gender (4) Hesitancy regarding personal acts and, (5) Emotional components. The domains were used and social and ethical issues were dissected out. The response to most of the domains consisting queries regarding autonomy and dignity in this study was moderate. A significant proportion of the participants however, showed concern in emotional domain with 70% being forced to spend time in bed during episodes of pain and 73.3% fearing to lose hope if left alone during their illness. This study emphasized the importance of social and ethical issues arising from chronic illness like cancer.

**Key words:** Chronic illness, female cancer, autonomy, dignity, social and ethical issues

**Background:**

Chronic illness like cancer, leukaemia arthritis etc has been looked upon as biographical or continual disruption of a person’s ongoing life, touching the individual’s sense of self or even causing a loss of self(1).12.5% of deaths worldwide are attributed to cancer in an estimate given by World Health Organization (WHO). Cancer in itself and various multimodal treatments involved lead to physical, mental and numerous social issues. It can affect relationship with family members and society. Both the patients and their families face many social and ethical issues arising as a result of disease progression and long treatment regimens (2, 3, 4, 5, 6).

**Introduction:**

Pain and/or restriction in mobility and the dependence on others for day to day activities have a disproportionate impact on such chronically ill patients. Women cancer patients suffer more because traditionally they are considered as caregivers and a number of people(e.g., family members) have been seen to be heavily dependent on them(7).It has been illustrated that chronically ill women patients struggled for self-esteem or dignity(8). Several studies have indicated that chronic illness is experienced as a moral event, concerning shame and blame, responsibility and stigmatisation. The patients strive to legitimize their chronic illness and to achieve a sick role (9). Autonomy, literally “self-rule,” is a bedrock principle of biomedical ethics. It emphasizes the respect for a person to make self-directed, independent personal choices. Although some authors contend that concerns about autonomy have come to override all other ethical considerations (10), respect for autonomy or self-determination is certainly a critical aspect ethically (11). The impact of chronic illness on autonomy retains the patient’s capacity to make decisions regarding their care, inability to enact decisions seriously (12).The physical aspects of the condition limit one’s capacity to work; the cosmetic features of the condition compromise the interactions with others, assault self-image, and weaken confidence. The anxiety and secondary depression faced by such patients may further undermine the capacity to exercise autonomy. The notion of “loss of self” is a stark feature of the above clinical scenario (13).Because of increased longevity and delayed childbearing age, women often provide care both for their children and their aging parents(14). These taken-for-granted traditional roles put severe strains on women’s lives and their well-being. Frequently, people with chronic diseases require assistance that goes beyond the patients’ medical needs and includes arranging for functions such as cleaning, cooking, shopping, help with dressing, toileting, and the provision of transportation. As a result of such responsibilities, hardships of an emotional, psychological, and financial nature may be incurred and, due to their chronicity, may become overwhelming for the caregivers, straining the solidarity and cohesion of the family unit (15).

Takashi Takeuchi *et al.,*(2017) in an internet –based cross sectional study, aimed to locate the grading of social snags in palliative care in Japan. The data collected on 1) trouble in daily activities 2) trouble in looking for guidance from the expert 3) Conflict over family/ spouse relations and with society 4) trouble in solving workplace issues 5) trouble in adjusting to variations in the society. This study reported various limitations and findings were exaggerated by measurement bias as data was from internet- based survey. This study recommended future questionnaire or interview surveys in amalgamation with assessment of truthful medical records at medical institutions (21). Thus, the present study is aimed to explore the social and ethical issues in association with autonomy and dignity from the perspectives of female cancer patients at medical institution with the help of medical records and by self-administered questionnaire.

**METHODS:**

**Participants and setting**

This cross-sectional study was carried out in the medical oncology ward at a Tertiary Private Medical College Hospital. The sample size was determined based on convenience and on experience in the last 3-monthsMedical Record Department (MRD) where 121 female patients suffering from cancer for more than 6 months were enrolled during this period. We presumed that at least 75% similar patients will attend medical oncology Out Patient Department (OPD) in the study period and further presuming that based on their mental and physical willingness 60% will agree to take part in this study. The final sample size was conveniently determined as 60.

Inclusion criteria were:

1. Hospitalised female patients with chronic illness 6months or more due to cancer and day care patients.
2. Patients who know to read Kannada and English language.
3. Age range 19 to 80 years.

Exclusion criteria were:

1. Patients who couldn’t read informed consent and participant information sheet.

**Measurement tools:** The self-administered questionnaire comprised of five domains on

Dependency.

Communication.

Issues with gender

Hesitancy regarding personal acts

Emotional components.

It contained 25 items of questions and used score ranged from not at all to very much. The total score measured the frequency and percentage whether the chronic illness due to cancer affects the autonomy and dignity of the female cancer patients. In this study we considered not at all score to indicate no frequency and percentage of ethical issues in regards to autonomy and dignity; score indicated moderate frequency and percentage of ethical issues in regards to autonomy and dignity; very much score indicated severe frequency and percentage of ethical issues in regards to autonomy and dignity. The validity of this self-administered questionnaire was confirmed by three faculty members.

**Ethical considerations**

Prior to data collection, the aim and method of the study were explained to the participating cancer female patients and informed consent was given by them. The ethics committee of the Yenepoya (deemed to be) University approved the study, dated July 23, 2018. Participation was on voluntary basis, and the participants were secured that no identifying data would be collected from them.

**Data collection and analysis**

From August 2018 to October 2018, the self-administered questionnaire was given to the female cancer patients in female medical oncology ward and they were asked to fill them out by means of self-report mode. All concluded self-administered questionnaires were coded and data entry was done in Microsoft excel 2013. Data analysis was performed using the SPSS 22 software. Demographic data, dependency, communication, Issues with gender, hesitancy regarding personal acts, emotional components were analysed through descriptive statistics (frequency, percentage, mean, and standard deviation).

**Results:**

60 circulated self-administered questionnaires responses were collected. The age range of the participants was 19-80 years (mean 47.70, SD 13.427). All of them were married, 6 patients being widows. Out of 60 cancer patients, 11 consisted of Breast cancer, 6 comprised of that of stomach cancer. Carcinoma of cervix, oesophagus and ovary consisted of 5 cases each. Uterus and colon cancer cases were 3 each in number, Thyroid, Chronic Myelogenic Leukaemia, Inguinal Lymphadenopathy, Blood cancer, Buccal Carcinoma and acute Myelogenic Leukaemia consisted of 2 cases each. 1 each case was from Carcinoma Rectum, Lung, Glioblastoma, Thymoma, Soft Tissue Sarcoma, Chondrosarcoma Hip, Anal, Squamous Cell Carcinoma Gluteal Region, Hodgkin’s Lymphoma and that of the Gall bladder.

Results are obtainable as per the different domains**.**

**Table 1: Demographic characteristics of female cancer patients (n=60)**

|  |  |  |  |
| --- | --- | --- | --- |
| **Demographic Characteristics** | |  | |
| Age (years) | 19 to 80 | Mean | Standard deviation |
| 47.70 | 13.427 |
| Marital Status | Single  Married | Frequency | Percentage |
| 6  54 | 10.0  90.0 |

*\*Data presented mean, standard deviation and percentage.*

**Table: 2 Social and ethical issues on dependency rate**

|  |  |  |  |
| --- | --- | --- | --- |
| **Dependency rate study variables (n=60)** | | | |
| **Predictors** | **Variables in frequency and percentage** | | |
| not at all | Somewhat | very much |
| Do you feel fatigue to the extent that you have to depend on some other family member for your daily life activities? | 3(5.0%) | 35(58.3%) | 22(36.7%) |
| Do you feel devalued for not meeting the needs of your family due to your physical condition? | 10 (16.7%) | 37 (61.7%) | 13 (21.7%) |
| Do you feel your family members have accepted your illness and have not changed their approach towards you? | 15(25.0%) | 32(53.3%) | 13(21.7%) |
| Can you dress yourself without assistance? | 4(6.7%) | 14(23.3%) | 42(70.0%) |
| Do you feel your dependency is a burden for your family? | 28(46.7%) | 23(38.3%) | 9(15.0%) |

*\*Data presented 53.3% participants felt change in family approach towards them*

**Table: 3 Social and ethical issues with communication**

|  |  |  |  |
| --- | --- | --- | --- |
| **Communication rate study variables (n=60)** | | | |
| **Predictors** | **Variables in frequency and percentage** | | |
| not at all | Somewhat | very much |
| After your friends have come to know of your condition. Do you feel that they have grown distant from you? E.g. they don’t meet you as frequently as before | 35(58.3%) | 21(35.0%) | 4(6.7%) |
| Has your condition limited your social activities like attending any marriage functions? | 22(36.7%) | 20(33.3%) | 18(30.0%) |
| Does your condition compromise the interaction with family and friends? E.g. Guilt in their eyes | 32(53.3%) | 25(41.7%) | 3(5.0%) |
| Do you feel your condition has affected your confidence? | 16(26.7) | 34(56.7%) | 10(16.7%) |
| After your illness has become known, do you have freedom of making family decisions? | 16(26.7%) | 38(63.3%) | 6(10.0%) |

**\**Data presented that 63.3% of the participants were not the part of family decisions****.*

**Table: 4 Issues with gender**

|  |  |  |  |
| --- | --- | --- | --- |
| **Issues with gender study variables (n=60)** | | | |
| **Predictors** | **Variables in frequency and percentage** | | |
| not at all | Somewhat | very much |
| After your illness, do you feel any change in the relationship with your partner? | 32(53.3%) | 19(31.7%) | 3(5.0%) |
| Do you feel hesitant due to cultural restriction to seek help from medical/family members of the opposite gender? | 37(61.7%) | 21(35.0%) | 2(3.3%) |
| Due to your condition, how do you like the appearance of your body as a woman? | 29(48.3%) | 30(50.0%) | 1(1.7%) |
| From the time of diagnosis of your condition till today, do you feel that your family has kept you out of decision-making process? | 5(8.3%) | 48(80.0%) | 7(11.7%) |
| Do you think your role as mother/ grandmother / wife has been affected due to your condition? | 18(30.0%) | 34(56.7%) | 8(13.3%) |

**\****Data presented moderate issues with the appearance of body as women and in family decision makings.10% of the females were widow were some questions were not applicable to those participants.*

**Table: 5 Hesitancy regarding personal care**

|  |  |  |
| --- | --- | --- |
| **Hesitancy regarding personal acts study variables in percentage %(n=60)** | | |
| Are you unable to take care of your personal hygiene during menstruation and does it bother you? | attained menopause | 46.7 |
| sometimes | 46.7 |
| always | 6.7 |
| Do you feel being forced into accepting you physiological practices i.e. birth control, segregation during menstruation etc? | not at all | 61.7 |
| completed family | 21.7 |
| Always | 8.3 |
| NA | 8.3 |
| How do you feel about your family having to take extra efforts for your care? | family responsibility | 30.0 |
| stressed and burden | 58.3 |
| comfortable | 11.7 |
| How satisfied are you with your quality of life (QOL) right now? | not at all | 18.3 |
| Sometimes | 65.0 |
| Always | 16.7 |
| Are you satisfied with your sex life? | not at all | 3.3 |
| not bothered | 60.0 |
| very much | 21.7 |
| NA | 15.0 |

*\*8.3% of the participants mentioned that question no: 2 is not applicable to them, whereas 15% of the participants didn’t wish to answer question no: 5*

**Table: 6 Emotional components**

|  |  |  |  |
| --- | --- | --- | --- |
| **Emotion component study variables (n=60)** | | | |
| **Predictors** | **Variables in frequency and percentage** | | |
| not at all | Somewhat | very much |
| Due to your illness do you feel ill and sad? | 18.3 | 56.7 | 25.0 |
| Due to your illness, are you being forced to spend most of your time in bed? | 15.0 | 70.0 | 15.0 |
| After the diagnosis of your illness have you noticed the change in emotional support from spouse/son/daughter/mother in law/ parents/ siblings (Tick the appropriate one) if applicable**?** | 33.3 | 55.0 | 11.7 |
| Are you losing hope in the fight against your illness? | 23.3 | 73.3 | 3.3 |
| Do you worry that your condition is going to worsen? | 28.3 | 33.3 | 38.3 |

\**Data presented 73.3% participants were feeling alone when left alone by family members.*

**DISCUSSION:**

The results of this study posed primary outline of autonomy and dignity by chronically ill female cancer patients. The findings of this study are in conformity with those in the study by EP Wright *et al.,*(2002)and Monika Keller and Gerhard Henrich *et al.,*(1999)which showed anguish in emotional domain. Restraining the autonomy of chronically ill female cancer patients narrowed their capacity on family relationship, self-care, and family significant decisions and increased their emotional grief showed similarity in the findings reported by EP Wright *et al.,*(2002) in their study reported total mean frequency of 26% concerns about body image and sexual activity, this is in line with our study,with50% of the patients being nervous about their body image and 60% not bothered about sexual activity. The present study showed similarity with the study conducted by Kathryn J *et al.,* (2013) in which women unveiled their supported relationship with the partners after their illness. However, patients with breast cancer reported worried emotional and sexual connections associated with communication rifts.

The variety and complexity of societal and ethical difficulties described by the patients undoubtedly establishes that these problems are common and of importance. All types of social problems were felt and experienced by all participants although there were variances between the age groups, treatment stages experienced in the comprehensiveness and occurrence of reported social problems.

The participants under the age of 50 years in this study reported the greatest number of social and ethical problems. This tendency of younger age group facing more issues than the older counterparts is in concomitant with studies done by Mor*et al.,*(1994) and Harrison and Maguire, (1995) who investigated unmet needs and psycho-social concerns respectively. Younger females are usually burdened with increasing demands of generating revenue and have the duty of taking care of the children. This could be because of women of more advanced age may show adaptability to the ill effects of chronic illnesses like cancer.

The response to most of the domain questions consisting queries regarding autonomy and dignity in this study was moderate. The reasons could be that all the patients involved in this study were ambulatory and not dependent much for routine activities. Different social and ethical dimensions may contribute to bigger levels of psychological and autonomy suffering. Alternatively, autonomy and dignity distress may make social problems tougher to manage with. Both views support the need for wide-ranging calculation of social and ethical problems as part of patient centred care in all oncology practice.

The social problems encountered by cancer patients may apply likewise to diseases of other types. The epicentre of a patient-oriented health care needs to take care of social, ethical and psychological facets of patient care. The social and ethical problems of cancer patients have been highlighted in this study. This study recommends the need for valuation of social and ethical problems along with assessment in oncology departments, thereby enhancing a multidisciplinary approach for the care of cancer patients.

The National Institute of Health Revitalization Act, mandate that Office Research into Women’s Health(ORWH) USA, create a registry focused solely on women's health owing to lack of any such data in the health registries(15).The gender literature from low/middle-income, country contexts suggests an uneven background in socially attributed roles associated with narrowing gaps in gender inequity (16,17,18).A cross sectional self-administered questionnaire study conducted by Monika Keller *et al.,* 1999 in which cancer patient’s ailment was evaluated to each of the following category: emotional component, relationship and communication with the partner, social care using evidenced reliable Likert scale ranging from 1 & 5 (not at all to very much) respectively. This study reported score ‘very much degree of anxiety’ and ‘emotive grade' in cancer patients (19) Ruddy *et al.,* (2013) with respect to 3 key difficulties namely relationship with husband regards to age, menopausal issues and challenges in anticipated care, concluded that young women with breast cancer stated multiple and more difficulties in relationship issues and anticipated care(20).EP Wright *et al.,*(2001) showed in their study range and depth of social problems faced by cancer patients. The various social problem chosen for discussion with patients were grouped in several categories namely 1) home 2) health and welfare schemes 3) financial issues 4) employment 5) legal issues 6) employment 7) sexuality and 8) recreation. The most extensive and frequently coded social problems were those concerning relationships and communication with those close to the patient (11).

The difficulties encountered in patient’s relations are high on their agenda, as was revealed in the conveyed occurrences, but they are multifaceted, show vast differences and cannot be grouped in a simple way. Women’s groups disclosed more social problems than the men’s groups EP Wright *et al.,*(2002). Therefore, the current study employed female cancer patients only. The change in the gender role in the recent times could be the reason for the discrepancy in autonomy and ethical issues between the two genders. Women are continuously delving into the traditionally male dominated employment sector. Despite such changes women have not given up their traditional role of principal homemaker and as a result may be loaded with a broader range of responsibilities than men. To establish these gender differences regarding autonomy and dignity perspectives associated with chronic illness patients’ further studies involving both the genders and a larger sample size can be carried out.

**CONCLUSION:**

In conclusion there were multiple social issues towards autonomy and dignity faced by female cancer patients in this study. The psychological stress showed anguish in feeling burden on family members, not being a part of family discussions which in turn may create hardships in dealing with social difficulties. The breast cancer patients were overburdened psychologically, suffering from lack of attention by their spouses. We recommend a comprehensive appraisal of psychological distress and social problems in patient care in all oncology practices, thereby enhancing a multidisciplinary approach for the care of cancer patients

**ACKNOWLEDGMENTS:**

This article was the result of the Post graduate diploma in bioethics and medical ethics thesis in physiotherapy of Mudasir Rashid Baba, by centre of ethics Yenepoya (deemed to be) university. We acknowledge all the participants from medical oncology ward who participated in this study. Also, we appreciate and sincerely thank medical oncology ward nurses for their support.

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