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Effect of perceived barriers to symptom management on Quality Of Life (QOL) and the effectiveness of a multicomponent intervention among cancer patients in selected cancer hospitals of Karnataka State.

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ABSTRACT (DR. Malathi G Nayak)

A research study titled "A quantitative study to assess the perceived barriers to symptom management on quality of life among cancer patients and their caregivers and to find the effectiveness of a multicomponent intervention among cancer patients in selected cancer hospitals of Karnataka State" was carried out by Ms. Malathi G Nayak as a requirement for the award of PhD degree from Manipal University. The objectives of the study were to: Assess the self-reported symptoms among cancer patients, identify the perceived barriers to symptom management among cancer patients and family caregivers, assess the QOL among cancer patients and their caregivers and to evaluate the effectiveness of a multicomponent intervention in terms of reduction in self-reported symptoms and improvement in QOL of cancer patients.

The study was conducted in two phases. The first phase included identifying the barriers to symptom management and quality of life among cancer patients and their caregivers. In the second phase of the study a multicomponent intervention was developed based on the findings from phase I and evaluated the effectiveness of it in reducing the symptoms and improving the quality of life of cancer patients. In order to achieve the objectives, a quantitative research approach was adopted for the research study. Phase I research design was exploratory survey and phase II research design was evaluative research. For generating necessary data following tools were used: Demographic proforma, self-reported symptom assessment tool, perceived barriers to symptom management, and Quality of Life (QOL) questionnaire. The tools developed by the researcher were validated, pretested and reliability were established. Multicomponent intervention was developed and validated.

The exploratory survey research was conducted among 768 cancer patients aged 30 years and above, diagnosed to be in 3rd or 4th stage of cancers of breast/cervix/head and

neck/GIT/lung region & have undergone radiotherapy/chemotherapy/surgery or combination of them in the selected cancer hospitals of Karnataka. Patients unable to perform activities and with psychiatric problems were excluded from the study. Seven reputed cancer hospitals all over Karnataka were selected by purposive sampling. Convenient sampling with sample size proportion to the patients' enrolment in the seven hospitals was used to enrol patients for the study. Data were collected from cancer patients from the seven hospitals after obtaining permission from the respective hospital administrators. Based on the result of pilot study of both phases, sample size was calculated and was found that 768 cancer patients and their caregivers are required for phase I and 27 cancer patients required for phase II. Data were collected by interview technique from 768 cancer patients and their caregivers who fulfilled the inclusion criteria from the selected hospitals. For phase II, researcher identified the patients with cancer of cervix/breast/head & neck cancer and who were in the 3rd or 4th stage of cancer. Addresses of these patients were taken from the health records and the cancer patients were communicated about the study and its purpose. Those who agreed only were included in this phase of the research. After consent from the cancer patients, they were informed about the multicomponent intervention and follow up at home for first, third and sixth month intervals. At the first visit pre-test was conducted followed by multicomponent intervention. Separate room was identified in the hospital for teaching pranayama, relaxation technique and education. It was conducted three times in a week when they were in the hospital and were followed up every week up to four weeks. Post-test was conducted at first, third and sixth month interval. The data were coded, tabulated and analysed using SPSS package version 16.

The result shows that in phase I, out of 768 cancer patients, 232 (30.2%) of the participants were in the age group 51 to 60 years and the mean age was 52 ± 11.21 years. More than fifty percent of the participants (57.2%) were females. Three hundred and eight

(40.1%) of the participants were suffering from head and neck cancer. Majority of the participants i.e. 596 (77.6%) were suffering from the illness for less than one year and 443 (57.7%) were suffering from stage III of cancer and remaining 325 (42.3%) were in stage IV.

With regard to self-reported symptoms the majority of the cancer patients i.e. 591 (77%) reported of having pain, 741 (96.5%) had tiredness, 740 (96.4%) had disturbed sleep, 658 (85.7%) had irritability, 742 (96.5%) were feeling sad and 726 (94.5%) were worried after diagnosis.

Concerning the perceived barriers, most of the participants i.e. 548 (71.4%) were worried about side effects of the medication and 696 (90.6%) had fear of consequences to the treatment and 752 (96.9%) had fear about disease progression and 712 (92.7%) perceived that increasing pain signifies disease progression. Majority i.e. 686 (89.3%) of them had lack of resources in the family and 760 (99%) perceived that the treatment was very expensive and 638 (82.6%) had lack of financial resources to pay for health care services. With regard to the quality of life, out of 768 cancer patients, 632 (82.3%) were in the category of below average QOL score. Very few i.e. four (0.5%) had high QOL score and none of them had very high category of QOL score. Most of the participants' physical wellbeing was affected by pain for 560 (72.9%). Sleep problem was experienced by 551 (71.7%), and fatigue by 705 (91.8%). Six hundred and thirty two (82.3%) were in the category of below average QOL score.

One way ANOVA test was computed to find the association between the perceived barriers and QOL of cancer patients. The findings showed that there is statistically association between perceived barriers and QOL (F= 96.99, p = .001). It is inferred that as the perceived barrier increases the QOL of cancer patients decrease. The perceived barriers were statistically associated with education F = 13.556, (p = .001) and income F = 16.338,

(p = .001) respectively. Thus, it is interpreted that the cancer patients who have high educational status and income, perceive less barriers for symptom management and vice versa. Study also found that the cancer patients with high income have better QOL (F = 3.612, p = .006).

With regard to caregivers, their mean age was 41.63 ± 11.24 years and the spouses were the care providers i.e. 350 (45.6%) to the cancer patients. The majority i.e. 654 (85.1%) had financial problems in the family, 750 (97.7%) had lack of knowledge about the disease to provide care. Most of the caregivers i.e. 606 (78.9%) had reported that due to hospitalization of the patient, the caregivers could not continue their job/education, 696 (90.6%) were unable to carry out their routine work and 725 (94.4%) had stress due to financial worries. There is statistically significant negative correlation between the perceived barriers to symptom management and the quality of life of caregivers (r = -.419, p < .001). There is significant association between the perceived barriers to symptom management with education and income level of caregivers (F = 4.982, p < .001 and F = 9.101, p < . 001 respectively). A statistically significant positive correlation between the perceived barriers to symptoms management reported by the cancer patients and their caregivers was observed (r = .669, p = .001). The mean pre and post-test scores of self-reported symptoms was significantly different (F = 207, p = .001) from baseline to six months interval. Statistically significant difference in the mean pre and post-test scores of quality of life (F = 63, p = .001) from baseline to six months interval also was found. Thus, it is concluded that the multicomponent intervention was effective in reducing the self-reported symptoms and improving the QOL.

This study revealed that many symptoms are experienced by cancer patients because of their illness which affect their quality of life. The family caregivers provide care to their beloved one with cancer throughout their life. Hence caregivers also experience burden and

it affect their quality of life. There is a need to develop measures for effective management of symptoms and to improve the quality of life of cancer patients and their caregivers. Future research in this area may help further management of symptoms and formulate a more integrated approach to improve the status of the cancer patients and their caregivers. Thus study generates scope to develop nursing interventions built on patients' own needs.