Knowledge regarding Home Care Management of Patients Undergoing Chemotherapy Among Primary Caretaker

Sameer Sanjay[1], Eram Ansari[2], Richa Gautam[3], Sarita Verma[4], Alwin Issac[5]

Abstract:

Chemotherapy occupies a pivotal role in the recovery process of cancerous patient. A descriptive study was undertaken to assess the knowledge regarding home care management of patients undergoing chemotherapy among primary caretaker in a tertiary hospital, Lucknow. A total of 100 primary caretakers were selected by purposive sampling. The level of knowledge was assessed in areas of medication management at home and side effects, dietary management, neutropenic precautions to be followed at home, when to seek medical help and complications of chemotherapy. The findings of the study brought out that there was a lack of family caregiver's knowledge regarding chemotherapy and it is necessary to have a tailored health education programme for family caregivers of patients undergoing chemotherapy to prepare them with required knowledge and skills.

Diagnosis of cancer in a family is a devastating blow to the patient, parents, children, siblings, and others who love the family. Cancer creates an instant crisis in the lives of the whole family. Care of patients with cancer is a complex, challenging and lengthy process.

Programmes of care directed only towards the patient are seldom sufficient to meet patient's needs because so much of the patients care depends on family caregivers. The ability of the family caregiver to provide quality care, vital resource, contributes to the management of chronic disease. The capacity of family caregivers to take on the care of the person with cancer may have a significant influence on both health outcomes and cost in terms of readmission rates and the use of in-patient facilities (Northhouse et al, 2010).

The preparation of family caregivers must begin in the hospital and should only be concluded when the family caregiver demonstrates cognitive and instrumental skills to provide care. Using these skills caregivers administer medications, plan and provide meals, and provide direct care such as meeting the hygienic needs and lifting and turning them. Studies have also indicated that enhancement of the caregivers' knowledge about chemotherapy and the problems associated with it had a significant effect on family support, leading to a perceptible increase in the quality of life of these patients.

The authors are: 1-4. BSc Nursing 4th year students, College of Nursing, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow (UP); 5. Tutor, College of Nursing, AIIMS, Bhubaneswar (Odisha).

Demands on caregivers escalate as treatment plans shift, the disease progresses, and the patient's functional capacity deteriorates. The complexity of care giving is influenced by the quantity of required tasks, many of which are not predictable. These tasks may require insights and abilities that caretakers do not possess, adding to caretakers' anxiety and frustration. Information thus becomes a key resource for caretakers.

So this study aimed at assessing the chemotherapeutic regimen knowledge of caregivers whose dependents were undergoing chemotherapeutic treatment in SGPGIMS hospital, Lucknow.

Objective

The objective of the study was to assess the level of knowledge regarding home care management of patients undergoing chemotherapy among primary caretakers whose dependents were undergoing chemotherapy.

Review of Literature

Chitra & Vishnu Priya (2013) studied the level of awareness regarding adverse effect of chemotherapy among parents of children attending Oncology units of Amrita Institute of Medical Sciences, Kochi. They concluded that of the 60 parents interviewed 6.7 percent (4) had very poor knowledge, 68.3 percent (41) parents had inadequate knowledge and 25 percent (15) parents had adequate knowledge regarding chemotherapy and its side effects.

In their study on assessment of home care management for caregivers having leukemic adolescent

patients in Erbil city, Hasan et al (2011) found that the majority of caregivers had deficit knowledge regarding cause of leukemia and nutrition to reduce fatigue for adolescent leukemic, the majority of caregivers had poor practices regarding preparing meals, with poor practice regarding oral hygiene. The study revealed that of the 80 caretakers interviewed, 90 percent of caregivers had deficient knowledge regarding causes and symptoms of the disease and 80 percent had deficient knowledge regarding importance of nutrients and 85 percent had deficient knowledge regarding psychosocial support to child.

Methodology

A descriptive survey design was used for the present study and a tertiary hospital in Lucknow was selected on the basis of approachability and convenience.

Selection of sample: The sample consisted of primary caretaker, whose dependents were undergoing chemotherapy in selected wards of SGPGIMS hospital and a purposive sampling technique was adopted.

Sampling criteria: Primary Caretakers of patients, whose dependents were undergoing chemotherapy in SGPGIMS Hospital; Primary Caretakers, who were above 18 years of age; Primary Caretakers of patients, whose dependents had received at-least one cycle of chemotherapy were included.

Data collection technique: The following data collection instruments were used to obtain the data.

Tool 1: Demographic Proforma: The demographic proforma was developed to acquire the background data of the patients. The tool consisted of 5 items. Experts' opinion and suggestions were taken in determining the areas to be included. The subjects were asked to answer using tick mark (✓) in the appropriate space provided on the right side of each item.

Tool 2: Knowledge questionnaire about chemotherapy: This was a multiple choice questionnaire developed by the researchers to assess knowledge level of primary caretaker whose wards were undergoing chemotherapy. The items of the tool contain areas of medication management at home and side effects, dietary management, neutropenic precautions to be followed at home, when to seek medical help and complications of chemotherapy.

The tool consisted of 27 items. The samples were asked to place tick mark (✓) in the column of their choice. Each correct answer was awarded 1 mark. The knowledge questionnaire score was arbitrarily classified as good (19-27), average (10-18), and poor (0-9). To ensure the content validity, the tool along with the blue print, objectives and validity criteria checklist was submitted to seven experts. The tool was translated into Hindi by language expert. The language validity was determined by giving translated Hindi tool to another language expert to retranslate tool to English and translation was found to be valid. The reliability of the tool was determined using Cronbach's alpha test by administering the tool to 20 primary caretakers whose wards were undergoing chemotherapy in SGPGIMS, Lucknow. Reliability coefficient of the tool was 0.92.

Data collection : The investigator explained the purpose of the study and obtained their willingness to participate. Demographic proforma and knowledge questionnaire about chemotherapy was given to the samples who were asked to place a tick mark (✓) from the choices against each question, which they think as most accurate.

Results and Discussion

Description of sample characteristics: Demographic data analysis of the samples (100) revealed that majority of the caretakers (35%; n=35) belonged to the age group of 28-37 years and majority (27%; n=27) of them had only primary education. Majority (32%; n=32) were unemployed and majority (92%; n=92) said that their major source of information regarding chemotherapy were health personnel. Majority of the patients (23%; n=23) were undergoing 5th cycle of chemotherapy or more.

Knowledge regarding home care management of patients undergoing chemotherapy: Analysis of the knowledge data of the caretakers revealed that majority 58 samples (58%) had average knowledge, one (1%) had poor knowledge and 41 samples (41%) had good knowledge.

The findings of the study are supported by a study by Gunawan et al (201 4) in Indonesia on parents and health care providers perspectives on side-effect of childhood cancer, among parents and health care providers, whose children were being treated with cancer drugs found that of the 40 samples interviewed, 98 percent parents expressed a desire to receive more information about side-effects of chemotherapy.

An evaluation study of the home visits by community nurses for cancer patients after discharge from hospital by Van Harteveld et al (1997) found that among 337 patients who were offered a continuity visit, 93 percent experienced one or more physical, psychological or social problems, 70 percent mentioned a need for information and 47 percent needed emotional support within 2 weeks of their discharge. The findings of the study also suggested that continuation of the continuity visit could be useful.

Implications

Nursing education: The nursing personnel should be given in-service education to update their knowledge

Table 1: Frequency and percentage distribution of demographic characteristics

Parameters	Frequency (n=100)	Percentage (%)
Age in years		
18-27	20	20
28-37	35	35
38-47	15	15
48-57	18	18
58 and above	12	12
Education level of primary caregiver		
Illiterate	14	14
Primary school	27	27
High school	13	13
Inter College	21	21
Graduation	20	20
Post-graduation and above	5	5
Occupation of caretaker		
Farmer	27	27
Business	21	21
Government service	11	11
Private firm	9	9
Unemployed	32	32
Source of information about chemotherapy		
Health professional	92	92
Neighbourhood	2	2
Internet	1	1
Other patients	5	5
Cycles of completed chemotherapy		
One	19	19
Two	18	18
Three	24	24
Four	16	16
Five and more	23	23

Table 2: Knowledge level among primary caretaker

Category	Score Range	Percentage / Frequency
Poor	0-9	1% / (1)
Average	10 – 18	58% / (58)
Good	19 - 27	41% / (41)

and abilities to identify the learning needs and impart education to those who care for terminally ill cancer patients, thereby improving their quality of life.

Nursing practice: The oncology nurse should be able to use the acquired knowledge to give health education to the care takers in the clinical area and supervise the symptomatic care measures adopted by the care takers while providing care to their wards. Different AV aids can be used in imparting knowledge. This facilitates a dignified death for the patient and to make the end days better.

Nursing administration: Having thorough knowledge regarding non-curative care of terminally ill cancer patients can prevent suffering of terminally ill cancer patient. Nurse administrator should arrange continuing educational programme for nursing personnel regarding non-curative care. They should prepare adequate learning material on health education, emphasise the need for implementing planned educational strategies for improving the knowledge of the care takers. Association of care takers who can then carry out periodic meetings and programmes can be encouraged for the new care takers.

Nursing research: Study reveals that there is a need for extended Nursing research into different aspects of terminal stage of cancer. Nursing research will emphasise to increase the knowledge regarding non-curative care in terminal stage of cancer.

Recommendations

1. Tailored health education programme for family caregivers of patients undergoing chemotherapy to prepare them with the required knowledge and skills so they can provide appropriate care for their wards.
2. A protocol of home care for patients undergoing chemotherapy to help caregivers to provide appropriate care.

Conclusion

Since there was a lack of family caregiver's knowledge regarding home care management of patients undergoing chemotherapy, the nursing personnel should update their knowledge and abilities to identify the learning needs of those who care for terminally ill cancer patients, thereby improving the quality of such patients. The administrator should emphasise the need for implementing planned educational strategies for improving the knowledge of the care takers. Specific association of care takers who can then carry out periodic meetings and programmes can be helpful for the new care takers.

References

1. Northhouse LL, Katapodi M, Song L, Mood DW. Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. *CA Cancer Journal for Clinicians* 2010; 60: 317-39
2. Chitra P, Vishnu Priya MB. Awareness regarding adverse effects of chemotherapy among parents of children attending oncology units of aims. *International Journal of Nursing Care* 2014; 2(2): 20-26
3. Hasan SS, Hussain KA, Al-ani MH. Assessment of home care management for caregivers having leukemic adolescent patients in erbil city. *Kufa Journal for Nursing Sciences* 2011; 2(1): 1-2
4. Gunawan S, Wolters E, Van dongen J, Van de ven P, Sitaresmi M, Veerman A, et al. Parents and health care providers perspective on side effects of childhood cancer treatment in Indonesia. *Asian Pacific Journal of Cancer Prevention* 2014; 15(8): 3593-99
5. Van harteveld JT, Mistiaen PJ, Dukkers van emden DM. Home visits by community nurses for cancer patients after discharge from hospital: An evaluation study of the continuity visit. *Cancer Nursing* 1997; 20(2): 105-14