

# Level of Satisfaction with Nursing Care and Unmet Care Needs among Parents of Children with Cancer - An Exploratory Study

Navdeep Kaur<sup>1</sup>, Navjot Kaur<sup>2</sup>, Manprit Kaur<sup>3</sup>, Shruti Kakkar<sup>4</sup>

## Abstract

*When a child is diagnosed with cancer the situation becomes stressful for him as well as for the parents and family. During the treatment of the child in hospital, parents may or may not be satisfied with the nursing care provided to their child and they may report unmet care needs. This study was designed to assess their level of satisfaction with nursing care and to explore the unmet care needs that parents may report during their stay in hospital. A structured Likert scale and a questionnaire was used to assess the level of satisfaction and unmet care needs among the parents of children with cancer. From the sample of 50 parents, 43 (86 %) were highly satisfied while 7 (14 %) were satisfied with nursing care provided to their children. Maximum number of unmet care needs were related to information followed by needs related to nursing practice. The study concluded that maximum number of the parents were highly satisfied with the nursing care provided to their children. Maximum number of unmet care needs was related to information and nursing practice.*

Cancer is the second leading cause of death worldwide with an estimated global health burden of 193.6 million disability-adjusted life years (Alananzeh et al, 2016). In children and adolescents, cancer is biologically very different from adult (Magrath et al, 2013).

The diagnosis of cancer has a significant impact on the patients as well as their parents but still they are the primary source of social and emotional support for children (Stenberg et al, 2010). They face many stressors throughout the course of their child's illness (JM-Ch et al, 2001). They notice various care needs of their child which are to be fulfilled by the nurse and other staff. So, there is a need to assess the level of satisfaction with nursing care and unmet care needs of parents (Campbell et al, 2009; Keiza et al, 2017; Fakhoury et al 1996). Literature relating to family care needs has demonstrated that caregivers report unmet needs related to information, physical and emotional support, practical assistance and financial support but the need for information was the most cited area of concern (Arabiat & Altamimi, 2012; Kerr et al, 2004).

During the treatment of cancer, patients are greatly dependent on the quality of care provided to them. In order to maintain the standards of care, it is important to know about the level of satisfaction with the nursing care and the perceived and unmet

care needs among the parents of the children with cancer.

## Literature Review

Keiza et al, 2016 conducted a cross sectional study to assess the perception of parents about the quality of paediatric oncology inpatient care at Kenyatta National Hospital, Kenya. The data was collected from systematically selected 107 respondents (parents) by using a semi-structured questionnaire and the results revealed that 57.9 percent of respondents were satisfied with overall quality of nursing care. Arabiat & Altamimi (2012) conducted a study on unmet care needs of the parents of children with cancer in Jordan. Data was collected from 98 parents of children with cancer by using Family Inventory of Needs – Pediatric II. Results revealed that only 78 percent of the needs were met by health-care professionals. The results clearly highlighted the importance of informing parents about child's illness, treatment and outcome.

## Objectives

The study was carried out with following objectives:

- ☐ To assess the level of satisfaction with nursing care among the parents of children with cancer.
- ☐ To explore the unmet care needs among the parents of children with cancer.
- ☐ To find out the association of level of satisfaction with nursing care among the parents of children with cancer with selected socio-demographic variables.

*Authors are: 1. Nursing Tutor, 2. Assistant Professor, and 3. Nursing Tutor respectively in DMCH College of Nursing Dayanand Medical College & Hospital, Ludhiana, 4. Assistant Professor in Dayanand Medical College & Hospital, Ludhiana (Punjab).*

**Table 1: Distribution of parents of children with cancer as per their socio-demographic profile**

| Socio demographic variables                                 | f (%)     |
|-------------------------------------------------------------|-----------|
| <b>Total number of parents</b>                              | 50 (100)  |
| <b>Relation with the child</b>                              |           |
| Father                                                      | 20 (40)   |
| Mother                                                      | 30 (60)   |
| <b>Age of the parent (years)*</b>                           |           |
| 21-30                                                       | 09 (18)   |
| 31-40                                                       | 29 (58)   |
| 41-50                                                       | 11 (22)   |
| >50                                                         | 01 (02)   |
| <b>Habitat</b>                                              |           |
| Urban                                                       | 19 (38)   |
| Rural                                                       | 31 (62)   |
| <b>Educational status of the parent</b>                     |           |
| Illiterate                                                  | 05 (10)   |
| Elementary                                                  | 21 (42)   |
| Secondary                                                   | 07 (14)   |
| Graduation                                                  | 17 (34)   |
| <b>Religion</b>                                             |           |
| Sikh                                                        | 24 (48)   |
| Hindu                                                       | 23 (46)   |
| Christian                                                   | 01 (02)   |
| Muslim                                                      | 02 (04)   |
| <b>Occupation of respondent</b>                             |           |
| Working                                                     | 24 (48)   |
| Non-working                                                 | 26 (52)   |
| <b>Type of work (n=24)</b>                                  |           |
| Businessman                                                 | 09 (37.5) |
| Labour                                                      | 04 (16.7) |
| Assistant professor or teacher                              | 05 (20.8) |
| Famer                                                       | 06 (25.0) |
| <b>Socio-economic status (as per Kuppuswamy scale 2017)</b> |           |
| Upper middle class                                          | 17 (34)   |
| Lower middle class                                          | 26 (52)   |
| Upper lower class                                           | 06 (12)   |
| Lower class                                                 | 01 (02)   |
| <b>Total number of children</b>                             |           |
| 1-3                                                         | 46 (92)   |
| 4-6                                                         | 03 (06)   |
| >6                                                          | 01 (02)   |

\*Mean age  $\pm$  SD of parent = 35.90  $\pm$  6.425.

## Methodology

It was an exploratory study conducted on 50 parents whose children were suffering from cancer and were receiving treatment from DMC & Hospital, Ludhiana. Sample was chosen with convenience sampling technique. Either of the parent whose child was below 18 years of age and who had completed atleast one cycle of chemotherapy was included as sample. Data was collected by using questionnaire related to socio demographic profile of parent as well as the child and clinical profile of the child, a structured Likert scale to assess the level of satisfaction with nursing care among the parents of children and a structured questionnaire to explore

the unmet care needs. Reliability of the tools was assessed before the use. Socio-demographic characteristics of the parents and the clinical profile of child was presented as frequencies and percentages for categorical variables, level of satisfaction was ascertained by calculating means, standard deviations and mean percentage, nursing care needs were explored by calculating the frequencies and association was calculated with use of t test and ANOVA with the help of SPSS software.

## Results

The findings revealed that out of total sample of 50, 30 respondents were mothers of the children. More than half of the parents (58%) were in the age group of 31-40 years. More number of the parents (62%) was from rural areas and was qualified up to elementary level (42%). Around half of them (48%) were Sikh and 24 were working out of which 9 were businessmen. More than half of the parents (52%) were from lower middle class. Maximum number of parents (92%) had 1-3 numbers of children (Table 1).

Out of 50, 40 percent children who were suffering from cancer were from age group of 01-06 years. Maximum (70%) of them were boys and none of their sibling were suffering from chronic illness (Table 2). Most of the children (80%) were suffering from acute lymphocytic leukemia. Maximum number of children (86%) of children was admitted in hospital from day one. All of the children (100%) had past history of hospitalisation and were receiving chemotherapy. Around half of the children (48%) were in the 3rd cycle of chemotherapy. All of them (100%) had complications related to their chemotherapy treatment. Most common complications were weakness, alopecia, fever and weight loss (Table 3).

This study used a structured Likert scale to assess the level of satisfaction with nursing care among the parents of children with cancer which

**Table 2: Distribution of children with cancer as per their socio-demographic profile**

| Socio demographic variables of children                 | f (%)    |
|---------------------------------------------------------|----------|
| <b>Total number of parents</b>                          | 50 (100) |
| <b>Age of child (in years)</b>                          |          |
| 01-06                                                   | 20 (40)  |
| 07-12                                                   | 17 (34)  |
| 13-18                                                   | 13 (26)  |
| <b>Gender of child</b>                                  |          |
| Male                                                    | 35 (70)  |
| Female                                                  | 15 (30)  |
| <b>Any other sibling suffering from chronic illness</b> |          |
| Yes                                                     | -        |
| No                                                      | 50 (100) |

Table 3: Distribution of children as per their clinical profile

| Variable                                             | f (%)    |
|------------------------------------------------------|----------|
| <b>Diagnosis of child</b>                            |          |
| Acute lymphocytic leukemia                           | 40 (80)  |
| Acute myeloid leukemia                               | 02 (04)  |
| Rhabdomyo sarcoma                                    | 03 (06)  |
| Langerhans cell histiocytosis                        | 01 (02)  |
| Ewing's sarcoma                                      | 01 (02)  |
| Medulloblastoma                                      | 01 (02)  |
| Wilm's tumour                                        | 01 (02)  |
| Germ cell tumour (Ovary)                             | 01 (02)  |
| <b>Duration of present hospitalisation (in days)</b> |          |
| One                                                  | 43 (86)  |
| Two                                                  | 07 (14)  |
| <b>History of hospitalisation</b>                    |          |
| Yes                                                  | 50 (100) |
| No                                                   | -        |
| <b>Treatment modalities received for cancer*</b>     |          |
| Chemotherapy                                         | 50       |
| Cycle (n = 50)                                       |          |
| 2nd                                                  | 19 (38)  |
| 3rd                                                  | 24 (48)  |
| 4th                                                  | 07 (14)  |
| Radiation therapy                                    | 06       |
| <b>Complications related to chemotherapy</b>         |          |
| No                                                   | -        |
| Yes                                                  | 50 (100) |
| Various complications*                               |          |
| - Fever                                              | 49       |
| - Ulcers                                             | 17       |
| - Vomiting                                           | 31       |
| - Weakness                                           | 50       |
| - Alopecia                                           | 50       |
| - CNS symptoms                                       | 05       |
| - Weight loss                                        | 48       |
| - Pain                                               | 04       |
| - Diarrhoea                                          | 05       |
| - Constipation                                       | 04       |
| - Gum bleed                                          | 01       |
| - Loss of appetite                                   | 31       |
| - Rash                                               | 07       |
| - Infection                                          | 07       |

\*Multiple response table.

depicted that maximum number of the parents (86%) were highly satisfied with the nursing care provided to their children while rest of the parent (14%) were satisfied with the nursing care provided to their children and no parent was dissatisfied with nursing care (Table 4).

Table 4: Distribution of level of satisfaction among the parents of children with cancer

| Level of satisfaction | Score   | f (%)  | Mean $\pm$ S.D     | Mean % |
|-----------------------|---------|--------|--------------------|--------|
| Highly satisfied      | 153-190 | 43(86) | 171.09 $\pm$ 9.661 | 90.05  |
| Satisfied             | 115-152 | 07(14) | 146.67 $\pm$ 4.179 | 77.19  |

Maximum score = 190 Mean  $\pm$  S.D = 168.26  $\pm$  12.340  
Minimum score = 38 Mean % = 88.56

Table 5: Distribution of parents of the children with cancer as per the unmet care needs

| S. No.                              | Unmet Care Needs                          | f (%)  |
|-------------------------------------|-------------------------------------------|--------|
| <b>Informational need regarding</b> |                                           |        |
| 1                                   | Rights of the child                       | 4 (8)  |
| 2                                   | Prognosis of the child                    | 2 (4)  |
| 3                                   | Tests being performed on the child        | 2 (4)  |
| 4                                   | Side effects of treatment                 | 2 (4)  |
| 5                                   | Management of symptoms                    | 1 (2)  |
| 6                                   | Discharge procedure and follow up         | 1 (2)  |
| <b>Needs related to practice</b>    |                                           |        |
| 1.                                  | Comfort and safety                        |        |
| 2.                                  | Provision of comfort devices              | 5 (10) |
| 3.                                  | Promotion of rest and sleep for the child | 1 (2)  |
| 4.                                  | Environment                               |        |
| 5.                                  | Cleanliness of unit                       | 1 (2)  |
| 6.                                  | Collection of specimen                    |        |
| 7.                                  | Collection of reports on time             | 1 (2)  |

A structured questionnaire was used to explore the unmet care needs. The results depicted that in maximum number of parents' informational needs were unmet. The maximum number of parents reported that most of nursing care needs of their children were completely met but some of the parents reported that their informational needs were unmet and out of informational needs the informational need regarding right of the child was unmet (8%). Other needs regarding the provision of comfort devices was also unmet (10%) (Table 5).

Association of level of satisfaction with nursing care among the parents of children with cancer with selected socio demographic variables depicts that parents from urban area had more mean score of satisfaction with nursing care i.e. 172.74 $\pm$ 10.289 than the parents from rural area (165.52  $\pm$  12.835) and the difference was found to be statistically significant ( $p=0.043$ ). All other demographic variables i.e. relation with child, age of the parent, educational status of the parent, religion, occupation, socio economic status, total number of children, age of child suffering from cancer, gender of child suffering from cancer, any other child suffering from cancer were found to be statistically non-significant at  $p>0.05$ .

## Discussion

The objective of the study was to assess the level of satisfaction with nursing care and to explore the unmet care needs among the parents of children with cancer. The data was collected by conducting interview from 50 parents. The results of the study revealed that 86 percent of the parents were highly satisfied while 14 percent were satisfied with nurs-

ing care provided to their children during hospital stay whereas in previous study conducted by Keiza, et al (2016) on 107 parents revealed that only 57.9 percent of respondents were satisfied with overall quality of nursing care.

The current study reveals that maximum number of unmet care needs were related to information followed by needs related to practice of nurses while a study by Monterosso et al (2009) on 134 parents revealed that parents indicated the need of clear information about the patient, financial and practical assistance, more practical resources and information to assist with the management of their child's nutrition, pain and other care at home.

This study also revealed that parents from urban area had higher mean score of satisfaction with nursing care i.e.  $172.74 \pm 10.289$  than the parents from rural area ( $165.52 \pm 12.835$ ) and this difference was found to be statistically significant ( $p=0.043$ ). All other demographic variables were found to be statistically non-significant at  $p>0.05$ .

## Implications

### Nursing practice

- As maximum number of the parents were fully satisfied with nursing care provided to their children so the nursing care provided to children should be continued as it is already being given, improvement should be done as per the requirement.
- As per the needs, most of the care needs of the children were met but the informational needs and needs related nursing practice were not met properly so they should be focused.

### Nursing education

- Nursing personnel should organise teaching programme related to various types of cancer present in the children, their symptoms, treatment modalities, side effects of treatment etc.

### Nursing research

- The finding of the study can be used to further justify the need for improvement in the deficit areas of nursing care.

### Nursing administration

- Nurse administrators should make policies for nursing care of the cancer patients.
- Parents as well as the children should be provided counselling.
- Nursing administrator should organise programmes to educate the parents as well as children for cancer, its management and side effects.

## Recommendations

- A similar study can be conducted (a) on large number of sample, (b) in different settings and

different places.

- A study can be conducted on the adolescents to assess their level of satisfaction with nursing care and unmet care needs.
- A study can be conducted to assess the whole general care provided to pediatric patients in different paediatric wards of the hospital.

## Conclusion

The study concluded that majority of the parents were highly satisfied with nursing care provided to their children suffering from cancer. In case of unmet care needs, maximum number of unmet care needs were related to informational needs followed by needs related to nursing practice. The association of level of satisfaction was statistically significant with the habitat of the parent, all other socio-demographic variables had no significant association with level of satisfaction.

## References

1. Alananzeh I, Levesque J, Kwok C, et al. Integrative review of the supportive care needs of Arab people affected by cancer. *Asia Pac J Oncol Nurs* 2016; 3(2): 148-56
2. Magrath I, Steliarova-Foucher E, Epelman S, et al. Paediatric cancer in low-income and middle-income countries. *Lancet Oncol* 2013; published online Feb 20. Available from: [http://dx.doi.org/10.1016/S1470-2045\(13\)70008-1](http://dx.doi.org/10.1016/S1470-2045(13)70008-1). Accessed September 21, 2013
3. Stenberg Una, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology* 2010; 19: 1013-25
4. Yiu JM-Ch, Twinn S. Determining the needs of Chinese parents during the hospitalisation of their child diagnosed with cancer: An exploratory study. *Cancer Nursing* 2001; 24: 483-89
5. Campbell HS, Sanson-Fisher R, Taylor-Brown MSW, et al. The cancer support person's unmet needs survey: Psychometric properties. *Cancer* 2009; 115: 3351-59
6. Keiza EM, Chege MN, Omuga BO. Assessment of parents' perception of quality of pediatric oncology inpatient care at Kenyatta National Hospital. *Asia Pac J Oncol Nurs* 2017; 4: 29-37
7. Fakhoury WKH, McCarthy M, Addington-Hall JM. Determinants of informal caregivers' satisfaction with services for dying cancer patients. *Soc Sci Med* 1996; 42: 721-31
8. Arabiat HD, Altamimi A. Unmet care needs of parents of children with cancer in Jordan: Implications for bed-side practice. *Journal of Clinical Nursing* 2012; 1-8
9. Kerr LM, Harrison MB, Medves J, Tranmer J. Supportive care needs of parents of children with cancer: Transition from diagnosis to treatment. *Oncology Nursing Forum* 2004; 31: 116-26
10. Monterosso L, Kristjanson LJ, Phillips MB. The supportive and palliative care needs of Australian families of children who die from cancer. *Palliative Medicine* 2009; 23: 526-36