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Original Research Article

Awareness and experiences of side effects and infections during chemotherapy treatment: a cross sectional survey among family caregivers of cancer patients in India

Sayan Roy, Gopika M. G., Jissa Vinoda Thulaseedharan*

Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum, Kerala, India

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***Correspondence:**
Dr. Jissa Vinoda Thulaseedharan,
E-mail: jissa@sctimst.ac.in

ABSTRACT

Background: Adequate understanding of side effects and infections is essential for family caregivers to ensure proper management for cancer patients during chemotherapy. The present paper describes the family caregivers' awareness of the symptoms of possible side effects and infections during chemotherapy treatment.
Methods: Family caregivers were identified through the lodging facilities near the cancer treatment centres in Thiruvananthapuram and Mumbai. The cross-sectional survey was conducted using a structured interview schedule formulated in the Kobo-collect toolbox and analyzed using IBM-SPSS-Statistics-25.
Results: Among the 217 family caregivers aged between 19 to 76 years, 83% were close relatives of the patients. The majority of the family caregivers were able to identify conditions such as hair loss (95%), appetite change (88%), and nausea/vomiting (88%) as side effects of chemotherapy. At the same time, participants recognized the symptoms of infections were less. Unusual vaginal discharge/irritation (57%) and burning/pain with urination (55%) were the commonly recognized symptoms of infections. From the list of symptoms, more than six out of the thirteen side effects and more than three out of seven infections were correctly identified by 82% and 42% of family caregivers, respectively.
Conclusions: The family caregivers were largely aware of side effects but not much about infections. Since chemotherapy is an immune suppressive treatment, infection awareness among family caregivers is essential to avoid any serious complications during the treatment period. Communication with family caregivers on 'the symptoms and management' of 'side effects and infections' and when to seek treatment is crucial for cancer treatment success.

Keywords: Awareness, Chemotherapy, Family caregiver, Infections, Side effects

INTRODUCTION

According to Globocan 2020, the incidence of cancer, excluding non-melanomatous skin cancers, is projected to rise from 19.3 million to 28.9 million between 2020 and 2040.[1] The estimated number of patients requiring the first course of chemotherapy as part of cancer treatment was 9.8 million in 2018. It is expected to rise by 53% between 2018 and 2040 if evidence-based recommendations are fully followed. In addition, 75% of the additional 5·2 million people anticipated to benefit from chemotherapy by 2040 will be from low-and middle-income countries.[2]

Chemotherapy prevents tumour invasion and metastasis by inhibiting cell proliferation and tumour multiplication. However, the drugs used in chemotherapy not only destroy tumour cells but also affect and kill normal

healthy cells, causing side effects. The rapidly dividing cells, such as those in blood-forming bone marrow, hair follicles, oral cells, digestive tract, and reproductive system cells, are more likely to be affected by chemotherapy drugs. Fatigue, hair loss, easy bruising and bleeding, anaemia, nausea, vomiting, appetite change, constipation, diarrhoea, sore throat, skin and nail changes, weight loss, and mood swings are some of the common side effects during the treatment period. Moreover, the side effects and severity vary from person to person.[3-5]

In addition to the side effects, the cancer patients' natural body immunity is compromised due to the disease and treatment. Neutrophil counts typically begin to decline about 7 to 14 days after each course of chemotherapy.[6] The degree and duration of neutropenia, the type of underlying malignancy and exposure to microorganisms, put the patient at risk of infection. The common signs and symptoms of infections are fever, chills or sweating, sore throat, burning sensation when urinating, infectious diarrhoea, cough or shortness of breath, and unusual vaginal discharge or itching.[7,8] Infections could be of bacterial, viral, fungal, or parasitic origin. It may be possible to acquire such infectious agents during the hospital visit, travel between the hospital and stay, or from the home environment. Hence a protected sterile environment is suggested for cancer patients during the treatment period.[9]

Family caregivers are those persons who are family members or a friend who has chosen to support and give care to the loved one without any compensation.[10] They spend most of their time with the patient and manage the caregiving process. It is a common practice or social norm that the lady of the household will be the caregiver for the sick.[11,12] Family caregivers are essential to the patient's recovery, irrespective of whether the patient is in a day-care centre, in an inpatient hospital, or critically ill. Family caregivers communicate with the patient and the medical team, are sensitive to the patient's feelings, and motivate the patient to overcome the critical illness.[13]

Furthermore, the family caregiver is responsible for maintaining a healthy environment for the patient to avoid infections.[5] Caregivers with higher levels of education often communicate better with healthcare providers, and they can meet patients' needs better than less educated caregivers.[12] It is also likely that the family caregivers are often unaware of the patient's stage of disease and the goal of chemotherapy.[14]

A recent systematic review based on 50 studies from different parts of the world to identify unmet care needs among cancer patients and informal caregivers documented that the most common unmet need for family caregivers was getting appropriate information related to illness, treatment, and care during cancer treatment. The need for information related to illness and treatment was reported as 26% to 100%, and the need for care-related information was reported as 21% to 100% by the participants of various studies documented in the review.[15]

Lack of information regarding the patient's health status, possible side effects and infections during chemotherapy may result in critical situations and physical and emotional burdens to the caregiver and the patient. Caregivers' knowledge and understanding of the side effects or infections play a crucial role in focusing on better health care and meeting the priority needs of the patients. This paper presents the family caregivers' awareness regarding the disease status, chemotherapy treatment and symptoms of possible side effects or infections during chemotherapy. This paper also describes the side effects experienced by the patients during chemotherapy.

METHODS

Study setting

The present paper is based on a cross-sectional survey conducted in Thiruvananthapuram, Kerala, and Mumbai, Maharashtra, from mid-March to mid-May 2022, locating the two major cancer centres in both the cities, namely the Regional Cancer Centre (RCC), Thiruvananthapuram and the Tata Memorial Hospital, Parel, Mumbai. Family caregivers of cancer patients receiving chemotherapy treatment were the study participants. The participants were identified through the lodging facilities near the cancer centres, where the patients and caregivers stayed for shorter durations during cancer treatment.

Sample size and sampling

Assuming at least half of the family caregivers have adequate knowledge regarding side effects of chemotherapy treatment (p=0.5), with an absolute precision of 7% (D=0.07) for the 95% confidence interval, the estimated sample size was 196, using the formula, $n = \frac{Z^2 P(1-P)}{D^2}$, where Z= 1.96 for alpha at 5%. Further, assuming a 10% nonresponse rate, the final sample size was rounded to 220, and we decided to take 110 family caregivers from each location of the centres.

Since it was difficult to find the sampling frame for the study participants, we used convenient sampling. The official websites of both hospitals were the primary sources to identify the lodging facilities available near the hospitals in both centres. The investigators contacted the management of the lodging centres through personal meetings or telephone calls and submitted the necessary documents to get permission to contact the cancer patients or caregivers in their lodging facility. After receiving approval, the investigators went to the lodging facilities and identified the eligible individuals based on the inclusion criteria. In addition to lodging centres identified through the websites, we also identified a few centres through the family caregivers. In total, we

approached 15 centres in both study locations and got permission from 11 and 10 centres in Trivandrum and Mumbai, respectively, to collect phone numbers of patients or caregivers or to conduct in-person interviews with family caregivers of cancer patients at the facilities themselves (Figure 1).

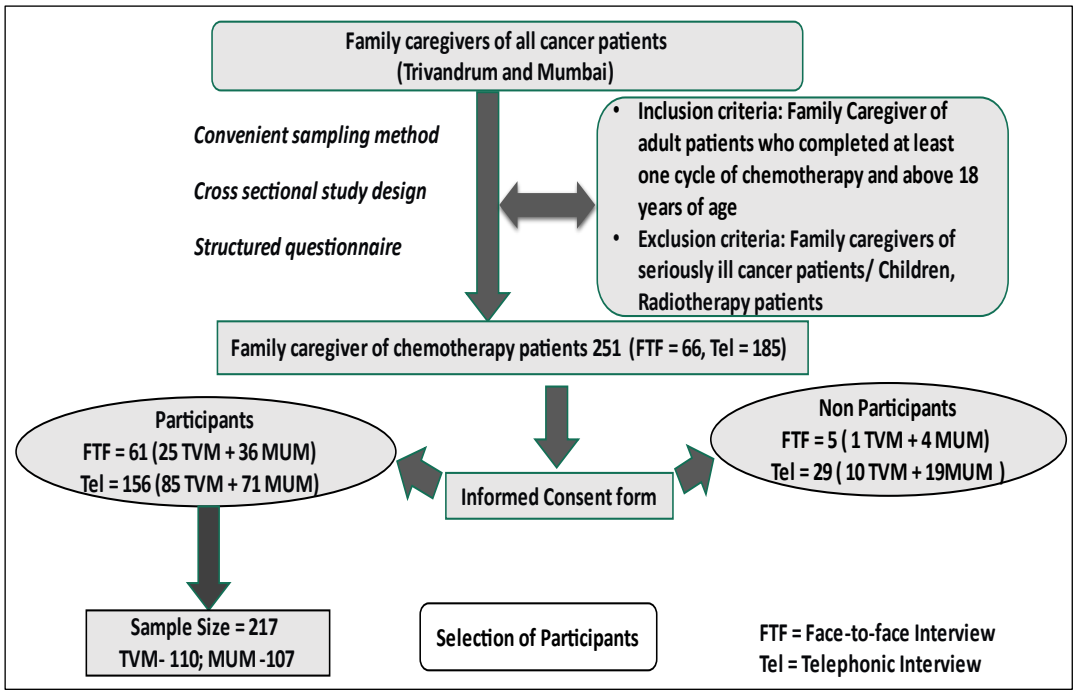


Figure 1: Sample selection process.

Inclusion criteria

For this study, we defined the family caregiver as a person who is a family member or a friend who has chosen to support and give care to the loved one who has cancer, without any compensation. If there was more than one family caregiver, those who spent more time staying with and caring for the patient were selected. If any paid caregiver was present, the person who recruited or dictated the caregiver to do the job was considered the family caregiver. Family caregivers of adult cancer patients who completed at least one cycle of chemotherapy, and were above 18 years of age were included in the study after getting their consent.

Exclusion criteria

Family caregivers of seriously ill cancer patients and children, and patients who were receiving radiotherapy along with chemotherapy, were excluded from the study.

Data collection process

Since the study was conducted in two locations with differences in the native languages, the second author, a native speaker of Malayalam, accompanied the primary investigator to contact the management of lodging facilities in Trivandrum and also take part in data collection from Trivandrum. The primary investigator himself contacted the lodging facilities in Mumbai and conducted the interviews. After receiving permission from the lodging centres, the investigators communicated with the caregivers of the patients and identified whether they were the primary caregivers or not. If they were not the primary caregivers, investigators requested them to give the contact details of the patient's family caregiver at home, and later they contacted them over the phone. Those family caregivers who found no time for a personal meeting at the lodging facility were also requested for a telephonic interview at their convenience. The investigator provided the study details and obtained a signature or thumb impression in the informed consent form from the eligible participants who agreed to a face-to-face interview at the lodging centres. The investigator read the informed consent and recorded the willingness with the permission of those who participated via telephonic interviews.

Study tool

A structured interview schedule was developed in English and translated into Malayalam and Hindi for the two study locations. The first section of questions was to capture the socio-demographic details of the family caregiver, awareness regarding the disease condition and chemotherapy received by the patients. A pool of 20 symptoms which are the possible side effects or infections were provided in the next section. The investigator read the items one by one, and the participants had the option to answer whether the items could be a possible side effect or infection of chemotherapy or both. In the next section the investigator

asked the family caregiver whether the cancer patient had experienced any side effects listed in the questionnaire. If a patient experienced the symptom, then the investigator proceeded to the sub-question of when the side effect was first experienced.

Data entry and analysis

The data was entered using Kobo collect toolbox and analysed using IBM SPSS Statistics-25. The list of side effects (n=13) and infections (n=7) from the pool of 20 conditions included in the questionnaire was separated, and the frequency distribution of participants correctly identifying each condition as a side effect or infection was evaluated. Later, we created a variable to define the awareness regarding side effects by combining the results of 13 side effects. The variable was assigned the value '1' if more than six side effects were correctly identified and '0' otherwise. Similarly, another variable was created to define the awareness regarding infections by combining the results of seven infections by assigning the code '1' if more than three infections were correctly identified and '0' otherwise. The above two variables were cross tabulated with the characteristics of family caregivers to explore the factors related to awareness. The statistical significance was tested using the Chi-square test for associations.

RESULTS

In Thiruvananthapuram, 25 face-to-face and 85 telephonic interviews were conducted (n=110). There were no refusals in Thiruvananthapuram, except for the termination of one face-to-face interview due to the inconvenience to the participant. In Mumbai, 36 face-to-face and 71 telephonic interviews were conducted (n=107). There were some refusals in Mumbai due to the reluctance to sign the consent form, being occupied with patient care or other matters, and lack of monetary assistance.

The lowest age of the study participants was 19 years, and the highest age was 76 years, with a mean and standard deviation of 41.65 years and 12.1 years, respectively. The socio-demographic details of family caregivers (n=217) are provided in Table 1. Almost 83% of the study participants were close relatives of the cancer patients, and two third of the family caregivers were less than 50 years old. In Trivandrum, nearly 60% of the participants were females, but 67% were males in Mumbai. Half of the participants in both places had an education of graduation or above. Nearly 60% of family caregivers were self-employed/homemakers, and 10% of participants were students (Table 1).

Table 1: Socio-demographic-details of family caregivers of cancer patients undergoing chemotherapy.

Variables	Overall (n=217)		Trivandrum (n=110)		Mumbai (n=107)	
	N	%	N	%	N	%
Relationship with the patient						
Husband/wife	82	37.8	31	28.2	51	47.7
Father/mother	46	21.2	35	31.8	11	10.3
Son/daughter	52	24	18	16.4	34	31.8
Other	37	17.1	26	23.6	11	10.3
Age category (years)						
<30	39	18	17	15.5	22	20.6
30-39	69	31.8	41	37.3	28	26.2
40-49	51	23.5	27	24.5	24	22.4
50-59	36	16.6	19	17.3	17	15.9
>=60	22	10.1	6	5.5	16	15
Sex of the respondent						
Male	117	53.9	45	40.9	72	67.3
Female	100	46.1	65	59.1	35	32.7
Highest level of education						
No formal education	7	3.2	0	0	7	6.5
Primary school level (1-7th STD*)	8	3.7	2	1.8	6	5.6
High school level (8-10th STD)	52	24	34	30.9	18	16.8
Higher secondary and diploma level	38	17.5	20	18.2	18	16.8
Graduate and above	112	51.6	54	49.1	58	54.2
Working status						
Working in government sector	14	6.5	12	10.9	2	1.9
Working in private sector	50	23	28	25.5	22	20.6
Student	23	10.6	10	9.1	13	12.2
Other(self-employed/home maker)	130	59.9	60	54.6	70	65.4

*Standard.

Table 2: Details of patients, disease condition and chemotherapy-responses from family caregivers.

Variables	Overall (n=217)		Trivandrum (n=110)		Mumbai (n=107)	
	N	%	N	%	N	%
Patient's age category						
<30	21	9.7	13	11.8	8	7.5
30-39	37	17.1	19	17.3	18	16.8
40-49	50	23	23	20.9	27	25.2
50-59	64	29.5	32	29.1	32	29.9
>=60	45	20.7	23	20.9	22	20.6
Sex of the patient						
Male	120	55.3	61	55.5	59	55.1
Female	97	44.7	49	44.5	48	44.9
Types of cancer						
Gastro intestinal	59	27.1	23	20.9	36	33.6
Breast	40	18.4	15	13.6	25	23.4
Lungs	34	15.6	19	17.3	15	14
Blood cancer	30	13.8	26	23.6	4	3.7
Sarcoma	17	7.8	9	8.2	8	7.5
Head and neck	13	5.9	5	4.5	8	7.5
Lymphoma	9	4.1	7	6.4	2	1.9
Others /not known	15	6.7	6	5.4	9	8.4
Mode of chemotherapy						
Intravenous	194	89.4	102	92.7	92	86
Injection	16	7.4	2	1.8	14	13.1
Oral	12	5.5	6	5.5	6	5.6
Don't Know	2	0.9	0	0	2	1.9
FCG* knew the stage of cancer	96	44.2	43	39.1	53	49.5
FCG* knew the cycles of chemotherapy received by the patient	209	96.28	106	96.4	103	96.2
Responses regarding why the patient is advised to receive chemotherapy**						
To shrink the tumour size	64	29.5	20	18.2	44	41.1
To reduce the spread of cancer cells	77	35.5	20	18.2	57	53.3
To destroy the remaining cancer cells	146	67.3	83	75.5	63	58.9
Others	5	2.3	4	3.6	1	0.9
Don't know	18	8.3	10	9.1	8	7.5

*Family care giver **Multiple answers possible

Table 3: Family caregivers' awareness regarding possible side effects and infections during chemotherapy.

Side effects	Overall (n=217)		Trivandrum (n=110)		Mumbai (n=107)	
	N		N		N	
	Yes	%	Yes	%	Yes	%
Hair loss	206	94.9	103	93.6	103	96.3
Appetite changes	191	88	92	83.6	99	92.5
Nausea/vomiting	191	88	95	86.4	96	89.7
Anaemia or decreased blood cell count	181	83.4	87	79.1	94	87.9
Burning, peeling, or swelling tongue and change in taste	179	82.5	95	86.4	84	78.5
Skin and nail changes	167	77	87	79.1	80	74.8
Emotional issues	165	76	89	80.9	76	71
Constipation	162	74.7	85	77.3	77	72
Dry mouth	133	61.3	85	77.3	48	44.9
Diarrhoea	118	54.6	82	74.5	36	34
Sore mouth/sore throat and trouble swallowing	113	52.3	59	53.6	54	50.9

Continued.

Side effects	Overall (n=217)		Trivandrum (n=110)		Mumbai (n=107)	
	N		N		N	
	Yes	%	Yes	%	Yes	%
Chills and sweats	108	49.8	55	50	53	49.5
Flu-like symptoms	90	41.7	53	48.2	37	34.9
Infections						
Unusual vaginal discharge / irritation	123	56.7	42	38.2	81	75.7
Burning/ pain with urination	119	54.8	47	42.7	72	67.3
Fever: more than 100 F	116	53.5	53	48.2	63	58.9
Redness, soreness, or swelling in any area, including surgical wounds.	115	53	51	46.4	64	59.8
Pain or tenderness	39	18	33	30	6	5.6
Bleeding gum	32	14.7	27	24.5	5	4.7
Puffy face or leg	22	10.1	22	20	0	0

As per the response of the family caregivers, nearly three-fourths of cancer patients (73%) were over 40 years old, and a higher number of gastrointestinal cancers (27.1%), followed by breast (18.4%) and lungs (15.6%) reported in this survey. Family caregivers of gastrointestinal and breast cancer patients participated more in Mumbai than in Trivandrum, but family caregivers of blood cancer patients were more in Trivandrum. Among the family caregivers, 44.2% knew about the patient's stage of cancer, and only 3.7% of family caregivers had no idea how many cycles of chemotherapy their patient had received. About 10% of patients had received chemotherapy either through injections or oral drugs, and others received it intravenously. Chemotherapy was identified as a destroyer of cancer cells in the body by 67.3 % of respondents. Nearly 8% of caregivers were unaware of the reason for the chemotherapy (Table 2).

Almost all family caregivers correctly identified hair loss (94.9%) as a side effect of chemotherapy, followed by appetite change (88%) and nausea/vomiting (88%). The least identified side effect was flu-like symptoms. Most participants in Trivandrum identified dry mouth (77%) and diarrhoea (74.5%) as side effects of chemotherapy. In contrast, less than half of the participants in Mumbai identified the above symptoms (45% and 34%, respectively) as side effects.

The awareness regarding signs of infections was low among family caregivers. Compared to family caregivers in Mumbai, a large proportion of caregivers in Thiruvananthapuram correctly identified the symptoms such as bleeding gum, puffy face/leg, and pain/tenderness. In contrast, burning urination, vaginal discharge, and redness/soreness were correctly identified by family caregivers in Mumbai than in Thiruvananthapuram (Table 3).

Nearly 82% of participants identified more than six out of 13 side effects from the list. But only 40% of participants correctly identified more than three out of seven infections (Figure 2). Identifying the side effects and infections was associated with participants' education levels. A higher proportion of participants with graduation or above level of education correctly identified more than six side effects and three infections compared to participants in other educational strata (Figure 3).

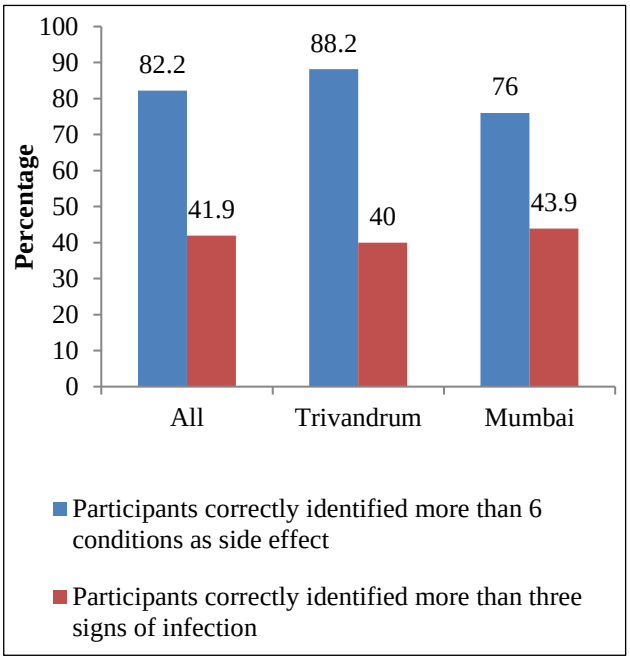
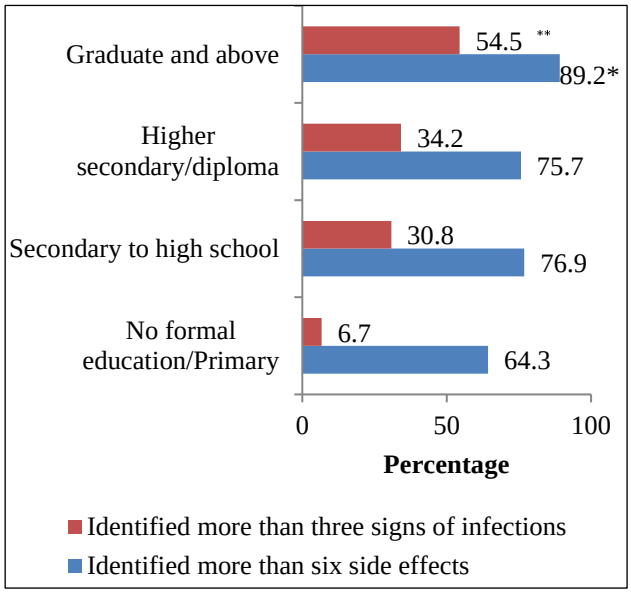


Figure 2: Proportion of participants correctly identified more than half of the side effects and infections from the list.

Based on the observations of 217 family caregivers, the most experienced side effects were taste or smell change (n=161, 74.2%) and appetite loss (n= 160, 73.7%), followed by hair loss (n= 153, 70%), and nausea (n=138, 63.6 %) respectively. Half of the family caregivers reported that their patients experienced emotional issues and constipation, and 47% reported they experienced skin and nail changes in their patients. Gum bleeding was the least experienced side effect. According to the observations of family caregivers, most side effects started manifesting within three days following chemotherapy. However, the side effects such as hair

loss, and skin and nail changes were mainly observed after seven days of chemotherapy (Figure 4).



*p value=0.031, **p value<0.001

Figure 3: Proportion of participants correctly identified more than half of the side effects and infections from the list with respect to education level.

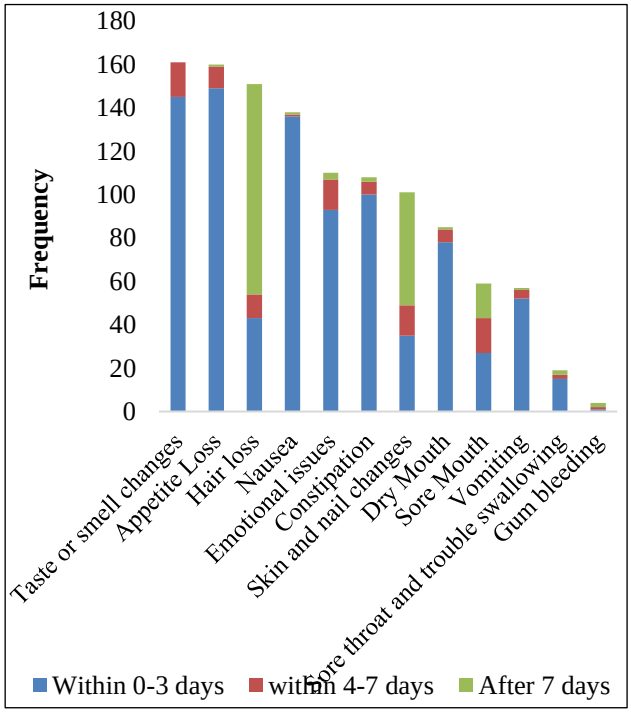


Figure 4: Side effects experienced by the patients-responses from the family caregivers (n=217).

Based on the observations of 217 family caregivers, the most experienced side effects were taste or smell change (n=161, 74.2%) and appetite loss (n= 160, 73.7%), followed by hair loss (n= 153, 70%), and nausea (n=138, 63.6 %) respectively. Half of the family caregivers reported that their patients experienced emotional issues and constipation, and 47% reported they experienced skin and nail changes in their patients. Gum bleeding was the least experienced side effect. According to the observations of family caregivers, most side effects started manifesting within three days following chemotherapy. However, the side effects such as hair loss, and skin and nail changes were mainly observed after seven days of chemotherapy (Figure 4).

DISCUSSION

In the present study, we mainly assessed the family caregivers' understanding of possible side effects and infections when patients receive chemotherapy, along with the awareness of disease and treatment status. The majority of participants correctly identified the symptoms such as hair loss, appetite change, and nausea/vomiting as side effects of chemotherapy. We found that the family caregivers are generally aware of chemotherapy side effects compared to symptoms of infections during chemotherapy. Also, the awareness of side effects and infections is associated with higher education levels. As per the observations of the family caregivers, the patients mainly experienced the side effects such as taste or smell change, appetite loss, hair loss, and nausea.

Educating the patients and family caregivers about potential chemotherapy side effects and post-chemotherapy symptom management are critical components to ensure proper care for the patient during the chemotherapy process.[16] In the present study, most respondents identified chemotherapy as a destroyer of cancer cells. Less than 10% of participants reported they did not know why the patient receives chemotherapy. A similar perception of the need to fight the disease and maintain hope, coupled with feelings of fear, was reported in another study conducted in a hospital setting in Ireland.[17]

However, less than half of the family caregivers in the present study were aware of the stage of cancer patient. The family caregivers' education level may influence the understanding of the details, such as the cancer stage. Often caregivers never think about it or consciously do not want to know about the severity of the disease. Sometimes, the person accompanying a cancer patient to the hospital will be another family member, and that person will do the disease-related communications with the healthcare provider. Perhaps to lessen the emotional burden to the caregiver, especially when the caregiver is a woman, this person may not reveal the cancer stage information to the family caregiver. The disagreement in the disease stage was reported in studies where a study on cancer patients' experience in South Korea showed that the agreement rates between patient-doctor and caregiver-doctor regarding the cancer stage were 63.0% and 65.9%, with corresponding weighted kappa values of 0.46 and 0.52, respectively.[18]

Before starting chemotherapy, the healthcare provider usually informs the patient or family caregiver about the potential side effects or infections. In this study, we assumed that the family caregivers were informed about the side effects or infections in general, and we assessed whether they were aware of the common symptoms. Also, in the present study, we separately analysed the knowledge related to side effects and infections. About 80% of family caregivers accurately identified more than six of the 13 conditions as possible chemotherapy side effects, and approximately 40% were able to recognise more than three of the seven signs of infections. Overall, the family caregivers more frequently identified chemotherapy side effects than signs of infections.

However, there were studies where chemotherapy side effects and infections were not distinguished and considered infections as a side effect of chemotherapy. One such study in the US found impaired function and side effects such as infection and other conditions associated with unplanned hospital admissions during the active treatment phase. However, that study did not find family caregiver knowledge as a moderating factor in unplanned hospital admissions.[19]

In the present study, we also recorded family caregivers' observations of the symptoms the patients actually experienced. More than half of the participants reported that their patients experienced appetite loss, nausea, changes in taste or smell, hair loss, and emotional issues. A study conducted in Malaysia also reported similar observations regarding side effects, and they found nausea and vomiting as the most worrisome side effects experienced by the patients.[20]

Cancer communication with patients and family caregivers is crucial in cancer treatment. However, consultation with a doctor in a time constraint situation is very tough, and doctors often prefer additional supplementary information sources apart from their advice. A Korean study showed that 82% to 87% of patients want to be told about any side effects (mild or severe) of cancer drugs. However, oncologists are reluctant to share information about mild side effects with patients and family caregivers.[11] The same study describes that an oncologist preferred an oncology nurse, booklet or video, or the pharmacist as a reliable source of drug side effects information. However, the patients and family caregivers did not find it helpful and depended on the oncologist or other physicians.[11]

A study on the experiences of family caregivers of patients receiving chemotherapy observed that the family caregivers expect to receive more information about their patient's condition and the course of the disease from the oncologists who treat the patient and also expect to get psychological support to both the patients and the family caregiver.[21] Family members face many difficulties during the treatment and trying to adopt different strategies to cope with the situation. Poor communication between healthcare providers and patients or family caregivers affects their ability to cope with the adverse emotional situation of cancer, decisions after the cancer diagnosis, therapeutic procedures, and adherence to the treatment.[22,23]

The limited scope of generalisability of the findings due to convenience sampling is a major limitation of the present study. We identified the family caregivers through the nearby lodging centres where they stay for cancer treatment. However, this was a feasible way of identifying family caregivers since finding cancer patients undergoing chemotherapy from the community was not ideal in the study area. Also, due to the time restraints within the academic calendar, formal approval to approach the patients and caregivers through the cancer hospitals was hard to obtain. However, the study explored the awareness of family caregivers regarding the possible side effects and infections during chemotherapy treatment and provided factual data on the topic, where literature from the study locations is scarce. We used the study tool in Hindi and Malayalam, and the first and second authors conducted the interviews in Mumbai and Thiruvananthapuram, respectively. Before moving to data collection, a clear consensus on the mode of questions and operation of the study tool was made between the investigators to avoid information bias.

CONCLUSION

The present study reveals that the family caregivers were aware of common side effects of chemotherapy but not much about infections, and the family caregiver's knowledge of side effects and signs of infection was associated with their level of education. Communication about cancer and its caregiving process between healthcare professionals and caregivers is crucial in cancer care. Generally, family caregivers assume that all patients follow the same care plan, and the healthcare provider will also give general instructions to the patients and family caregivers. The patient's age, sex, and nature of the disease should be considered while providing homecare instructions to the patients and family caregivers. It will help to lessen patients' and family caregivers' physical, emotional, social, and financial burdens during the treatment phase. The caregiver should be aware of side effects, symptoms of infections, how to manage side effects, and when to seek health care. Disease-related information and homecare management should be communicated effectively and properly at different treatment periods by integrating patient care plans through the health facility. It helps the family caregiver to decide on appropriate care for the patient. It promotes trust among family caregivers, patients, and healthcare providers, which is crucial during disease treatment.

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Ethical approval: The study was approved by the Institutional Ethics Committee of Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum

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