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Aus der Klinik für Gynäkologie
der Medizinischen Fakultät Charité – Universitätsmedizin Berlin

DISSERTATION

**A comparative survey of German and Indian patients
with ovarian carcinoma as regards to needs and
expectations in respect of the Physician-patient
relationship and treatment management**

zur Erlangung des akademischen Grades
Doctor medicinae (Dr. med.)

vorgelegt der Medizinischen Fakultät
Charité – Universitätsmedizin Berlin

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Datum der Promotion: 09.12.2016

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ABSTRACT

In vier Zentren im Bundesstaat Odisha in Indien und in verschiedenen akademischen und nicht-akademischen Zentren in Deutschland wurde eine Querschnittstudie durchgeführt. Ein strukturierter Fragebogen mit Fragen zu Erwartungen und Wünschen der Patientinnen in Bezug auf die Arzt-Patient-Beziehung wurde verwendet. Mit diesem Fragebogen wurde jeweils ein semi-strukturiertes Interview mit 86 indischen Patientinnen mit Ovarialkarzinom durchgeführt und mit den Daten von 427 deutschen Patientinnen verglichen. Ziel dieser Umfrage war es, Gemeinsamkeiten und Unterschiede zwischen den Patientinnen aus Indien und Deutschland mit Eierstockkrebs in Bezug auf die Bedürfnisse und Erwartungen an das Therapie-Management zu identifizieren.

Die deutschen Patientinnen beurteilten die bisherigen therapeutischen Beratungen durch die Ärzte im Vergleich zu den indischen Patientinnen weder besser noch schlechter. Dies gilt auch für verschiedene Faktoren wie Therapieerfolg, Nebenwirkungen, Belastungen durch Operationen, Schmerzen, Übelkeit/Erbrechen und den Grad der Erschöpfung.

Die am häufigsten genannten Anregung der deutschen Patientinnen, um die Behandlung des Eierstockkrebs zu verbessern war: die Therapie sollte nicht zu Haarausfall führen (49%), hingegen die am häufigsten genannte Aussage der indischen Patientinnen war : die Behandlung sollte insgesamt kürzer dauern (47%).

Ein hoher Prozentsatz sowohl der deutschen (90%) als auch der indischen (79%) Patientinnen glaubten, dass ein Gespräch mit dem behandelnden Arzt die effektivste und patientenfreundlichste Informationsquelle ist, um die verschiedenen Behandlungsmöglichkeiten für Eierstockkrebs zu erfahren.

59% der deutschen und 73% der indischen Patientinnen haben auf eine vollständige Heilung ohne weitere Komplikationen gehofft. 27% der indischen Patientinnen und nur 7

% der deutschen Patientinnen haben auf einen weniger schmerzhaften Verlauf der Erkrankung gehofft.

Im Fall der indischen Patientinnen wurden im Gegensatz zu den deutschen Patientinnen Defizite in der Schmerztherapie und beim Management von Nebenwirkungen der Therapie beobachtet.

Die Studie stellt die zentrale Rolle des Arztes als wichtigste Informationsquelle für Patientinnen mit Eierstockkrebs in beiden Ländern heraus. Obwohl die Patientinnen aus zwei verschiedenen Ländern mit höchst unterschiedlichen sozio-ökonomischen Situationen stammen, waren die Erwartungen an ihre Ärzte und das klinische Management bezüglich vieler Aspekte ähnlich.

Die vorliegende Studie zeigt den Bedarf nach weiterer Forschung in diesem Bereich und könnte als Grundlage für weitere multinationale prospektive Studien hilfreich sein. Dabei könnte der Fokus auf den Bedürfnisse und Erwartungen von Patientinnen mit Ovarialkarzinom in Zusammenhang mit der Arzt-Patienten-Kommunikation und der Behandlung insgesamt liegen, wobei sozio-kulturelle und wirtschaftliche Unterschiede berücksichtigt werden, die die Behandlung in Entwicklungsländern sowie den entwickelten Ländern beeinflussen können.

SUMMARY

A cross sectional survey was conducted in the state of Odisha, India in four centres and in various academic and non-academic centres in Germany. A structured questionnaire, which contained questions regarding patient's need and expectations in respect to physician-patient relationship, was used. A questionnaire developed by a multidisciplinary team was given to 427 German patients suffering from ovarian cancer and interview was performed with the same questionnaire with 86 Indian patients and the data were compared. The objective of this survey was to identify similarities and differences between the patients from India and Germany suffering from ovarian cancer in regard to the needs and expectations from the therapy management.

The German patients did not judge better or worse than the Indian patients in regard to the previous therapeutic consultations given to them by doctors, different factors of therapy, such as, success of therapy, side effects of therapy, burdens of the surgery, pain, nausea/ vomiting, and level of exhaustion.

The most valuable suggestions made by German patients to improve the treatment of ovarian cancer was: the therapy shouldn't lead to hair loss (49%), whereas the Indian patients preferred for a treatment of shorter duration (47%).

A high percentage of German (90%) and Indian (79%) patients believed that a discussion with the treating physician is the most effective and patient-friendly information source for the various possible treatments available for ovarian carcinoma.

59% German and 73% of Indian patients hoped for a complete healing without any further complications. 27% of Indian patients and only 7 % of the German patients just hoped for a less painful course of sickness.

Unlike in the case of the German patients a lack in management of pain and side effects of the therapy were observed in the case of Indian patients.

The study underlines the key role of the physician as the most relevant source of information for patients with ovarian cancer in both countries. In spite of a significant difference in the socio-economic status between the two different countries, the expectations from their physicians found to be similar in many aspects. Further multinational prospective studies with a focus on needs and expectations of patients with ovarian carcinoma in context of physician-patient communication and treatment should be carried out and due consideration given to socio-cultural and economic factors, which could influence the treatment in developing as well as developed countries.

INTRODUCTION

Cancer of the ovary is the most malignant tumour of the female genital tract in most of the western world (55, 95). It accounts for 6% of all deaths from cancer in women with a very bad prognosis (6). Ovarian cancer takes 7th place in the incidence of cancer in Germany (78) and 5th in USA (41). It accounts also the 5th leading cause of cancer related death in females (41, 55).

According to GLOBCAN 2012 (29) ovarian cancer is the seventh most common cancer in women worldwide (18th most common cancer overall), with 239,000 new cases diagnosed in 2012. The 5-year survival rate ranges from approximately 30 to 50 per cent. The highest incidence of ovarian cancer was in Europe and Northern America; and the lowest incidence in Africa and Asia. The age standardised incidence of ovarian cancer per 100,000 was 6.1 worldwide. The Incidence was higher in more developed compared with less developed countries. The more developed countries showed an incidence of 9.1 per 100,000, whereas the less developed countries showed an incidence of 5.0.

Some other authors stated that cancer of the ovary takes 6th most common cancer in women worldwide and accounts less than 5% of all cancers in women (60, 71). Almost 80% of cervical cancer cases were diagnosed in the developing countries. Two third of the cancer of corpus uteri are diagnosed in the developed countries, where as ovarian cancer occurs with equal frequency in the developed and developing countries. The incidence rate of ovarian cancer is higher in the developed countries (around 10 per 100,000) excepting Japan (58, 57), than the developing countries (less than 5 per 100,000) (60).

In the present study, we tried to find out the difference and compare the patients with ovarian carcinoma between a developed country, with Germany taken as an example of a developed country and India as an example of a developing country.

In the present study it was expected to get a discrepancy in the results because of a difference in the life status and socio economic structure, which indirectly influence the diagnosis and management of the patients from the two countries.

2.1 Causes of ovarian cancer:

There is no certain cause of developing ovarian cancer. The risk of developing ovarian cancer seems to be affected by several factors (66). Women of older age, and those who have a first or second degree relative with ovarian cancer, have an increased risk. Hereditary forms of ovarian cancer can be caused by mutations in specific genes (most notably BRCA1 and BRCA2, but also in genes for hereditary nonpolyposis colorectal cancer). Women with infertility and suffering from endometriosis, nulliparity, and uptake of postmenopausal estrogen replacement therapy have an increased risk of ovarian cancer. Use of combined oral contraceptive pills is a protective factor (7, 91). Multiparity, early pregnancy, older age of final pregnancy and the use of low dose hormonal contraception have been shown to have a protective effect. Women who have had their fallopian tubes blocked surgically (tubal ligation) are have lower risk (7, 91).

2.2 Diagnosis of ovarian cancer:

Diagnosis of ovarian cancer starts with a physical examination (including a pelvic examination) and transvaginal ultrasound. The diagnosis must be confirmed with surgery to inspect the abdominal cavity, take biopsies and look for cancer cells in the abdominal fluid. Abdominal ultra sound, computer tomography and magnetic resonance imaging are the other possibilities to visualize the tumour in abdomen. According to the guideline published by AGO Ovar in Germany, the transvaginal ultrasound is the most promising method for routine screening for ovarian cancer. Due to its lower specificity, CA 12-5 is not recommended for routine screening for ovarian cancer (40, 90). Then, surgical exploration is the best method to judge the stage and the operability of the cancer. Because of the danger of intraperitoneal spreading, the diagnostic aspiration of the cyst or the solid mass is contraindicated.

Because of the lower specificity, CA 12 5 is not recommended for screening for the cancer, but it should be determined before the therapy begins to follow the course of the disease.

2.3 Prognosis of ovarian cancer:

Ovarian cancer usually has a poor prognosis. It is disproportionately deadly because it lacks any clear early detection or screening test, meaning that most cases are not diagnosed until they have reached advanced stages. More than 60% of women presenting with this cancer have stage III or stage IV cancer, when it has already spread beyond the ovaries.

The prognosis for patients with ovarian cancer depends on multiple factors such as tumour stadium, age of the patient, histological subtype, post-operative tumour rest. The histology of the cancer is a very important parameter in the prognosis of the ovarian cancer. Clear cell carcinoma and mucinous carcinoma have a very bad prognosis in comparison to the serous papillary type of cancer and they respond poorly to conventional platinum based chemotherapy (27, 39).

In the EURO CARE-5-a population-based study (20) it was found that European mean age-standardised 5-year survival for ovarian cancer was low (37.6%) and decreased steeply with advancing age (70.9%, at 15–44 years; 20.1% at ≥ 75 years). Geographical variation was substantial, with survival ranging from 31.0% in the UK and Ireland, to 41.1% in northern Europe. Survival did not change significantly over time in Europe overall. Significant ($p < 0.05$), although not substantial, changes occurred in all regions except southern Europe; the largest gains were in eastern Europe. Five-year age-standardised relative survival (RS, %) for ovarian cancer patients diagnosed in 2000–2007, in Germany was 43.1% with 95% confidence interval of 39.3 - 41.3 (20).

Chen et al. used a pooled German database dataset including data from 11 cancer registries covering a population of 33. Period analysis was carried out to calculate the 5-year relative survival (RS) for the years 2002–2006. Trends in survival between 2002 and 2006 were examined using model-based period analysis. Overall, the age-adjusted 5-year RS in 2002–2006 was 41%. A strong age gradient was observed, with a decrease in the 5-year RS from 67% in the age group 15–49 years to 28% in the age group 70+ years. Furthermore, the prognosis varied markedly depending on histology, laterality, and stage,

with the age-adjusted 5-year RS ranging from 25% (for carcinoma not otherwise specified) to 81% (for stromal cell carcinoma), reaching 46% for unilateral and 32% for bilateral carcinoma and reaching 82% for Federation of Gynaecology and Obstetrics (FIGO) stages I and II, 36% for FIGO stage III, and 18% for FIGO stage IV. No improvement in survival could be observed for any of the subgroups in the period between 2002 and 2006 (16).

The problems in determining the vital status of registered patients of specified intervals after diagnosis are manifold in developing countries due to inadequate death registration system, lack of national and regional population registries and of routine linkage mechanisms and inadequately developed clinical follow-up systems in hospitals. In a study conducted by Yeole in Mumbai, India it was observed that the overall five year relative survival from ovarian cancer was 25.4%. Higher survival was observed for those younger than 35 years (97).

In a report published by International Agency for Research on cancer it was mentioned that five-year survival of ovarian cancer patients was less than 30% in India (80).

In a study conducted by Rastogi et al., the data was collected from Indians residing in different geographic regions around the world. Ovarian cancer rates varied little among Indians in Singapore, the UK and USA. The rate for India as a whole was notably lower, although within India, the rates vary considerably, with a strong urban/rural gradient. In fact, rates in the urban areas were similar to those among Indians in Singapore, the UK and the USA. The patterns suggest possible under-diagnosis as well as a potential role of behavioural or environmental factors (76).

2.4 Management of ovarian cancer:

Ovarian cancer is usually treated with surgery and chemotherapy, and sometimes radiotherapy (18). Surgical treatment may be sufficient for malignant tumours that are well-differentiated and confined to the ovary. Addition of chemotherapy may be required for more aggressive tumours that are confined to the ovary. For patients with advanced disease, a combination of surgical reduction with a combination chemotherapy regimen is standard. Borderline tumours, even following spread outside of the ovary, are managed well with surgery, and chemotherapy is not seen to be useful. Surgery is the preferred treatment and it is frequently necessary to obtain a tissue specimen for differential diagnosis through histology. Surgery performed by a specialist in gynaecological oncology usually results in an improved result (8, 44, 45). The type of surgery depends upon how widespread the cancer is when diagnosed (the cancer stage), as well as the presumed type and grade of cancer. The surgeon may remove one (unilateral oophorectomy) or both ovaries (bilateral oophorectomy), the fallopian tubes (salpingectomy), and the uterus (hysterectomy). For some very early tumours (stage 1, low grade or low-risk disease), only the involved ovary and fallopian tube will be removed (called a "unilateral salpingo-oophorectomy," USO), especially in young females who wish to preserve their fertility.

Chemotherapy:

In a review published by McGuire (54), it was mentioned that taxane–platinum combinations is the standard of care for women with advanced ovarian cancer, and these are now generally recommended for first-line treatment. Chemotherapy has been a general standard of care for ovarian cancer for decades, although with highly variable protocols (54). It is used after surgery to treat any residual disease, if appropriate. The selection of the chemotherapy depends on the histology of the tumour; some kinds of tumour (particularly teratoma) are not sensitive to chemotherapy. In certain cases neoadjuvant chemotherapy is the preferred option, followed by surgery.

A clinical trial conducted by Armstrong in patients with stage IIIC epithelial ovarian adenocarcinomas, who have undergone successful optimal debulking, in which intravenous paclitaxel plus cisplatin was compared with intravenous paclitaxel plus intra-

peritoneal cisplatin and paclitaxel. He demonstrated that median survival time is significantly longer for patients receiving intra peritoneal (IP) chemotherapy, in spite of a significantly worse quality of life of patients who received peritoneal chemotherapy (5). Although intra peritoneal chemotherapy has been recommended as a standard of care for the first-line treatment of ovarian cancer, the basis for this recommendation has been challenged, and it has not yet become standard treatment for stage III or IV ovarian cancer (88).

In a double-blind, placebo controlled, phase 3 trial conducted in the USA (12), it was found that the use of Bevacizumab during and up to 10 months after carboplatin and paclitaxel chemotherapy prolongs the median progression-free survival by about 4 months in patients with newly diagnosed stage III (incompletely resectable) or stage IV epithelial ovarian cancer who had undergone debulking surgery.

Radiation therapy is not typically used in ovarian cancer. This is because radiation would need to be given to the entire abdomen and pelvis, increasing its toxicity. Radiation is sometimes useful to treat isolated areas of tumour that are causing pain and are no longer responsive to chemotherapy, and to kill cancer cells that still remain after other treatments.

2.5 Ovarian carcinoma in India:

In India, the ICMR (Indian council of medical research) registry reports the crude incidence rate of ovarian cancer as 4.2 per 100,000 women, making it the fourth most common malignancy in women in India (58). According to Globocan (33), International Agency for Research on Cancer (IARC), ovarian cancer has the third in incidence and mortality in India. According to various Indian registries, cancer of the ovary is one of the most common cancers amongst females, ranking a third/fourth in frequency among cancers occurring in women in 2004-05. During the period 2004-2005, Age-standardized Incidence rates of ovarian cancer in India ranges from 1.7% to 8.7% of all female cancers in various urban and rural populations based upon registries operating within the framework of the National Cancer Registry program (NCRP) of the Indian Council of Medical Research (57). It was observed that there is a steady increase in the age-standardized incidence rate of

ovarian cancer ranging from 0.26% to 2.44% per year in different registries in India during the period 2001-06 . Murthy concluded that the possibility of environmental and /or life-style factors affecting the change had an influence on all the age groups. (57). India is rapidly becoming industrialized and urbanization is progressing, which leads to changes in life style factors, particularly in an increase in the age of marriage, delay in age of first birth, reduction in parity and improved socio-economic conditions etc. These factors possibly might have contributed to gradual increase in the incidence of ovarian cancer in India. Based on the trends, there is every reason to believe that the burden of ovarian cancer will continue to grow not only in terms of the absolute number of cases but also in terms of incidence. That is why it may be concluded that, ovarian cancer has emerged as one of the most common malignancies affecting women in India.

2.5.1 Management guidelines for ovarian cancer in India:

There has been an increase in the incidence of ovarian cancer in recent years reported in India. Being a vast developing sub-continent with great cultural diversity and varying socioeconomic conditions availability of medical facilities and infrastructure and medical expertise across the country, it was necessary to generate appropriate evidence-based management guidelines in India. In 2006, a team of leading clinicians, with the help of regional cancer centers and institutions of excellence, developed management guidelines for treating patients with ovarian carcinoma. It was expected to manage patients with ovarian carcinoma according to the guidelines (28).

It was decided that it would be practical to first categorise treating hospitals and institutions into groups depending upon the facilities, infrastructure as well as medical expertise as follows:

- a) Regional cancer centers, teaching institutes of academic excellence
- b) Large well-equipped private or centrally funded hospitals
- c) Small hospitals and nursing homes

The management guidelines had made a little variable suggestion in regards to diagnosis, management of the suspicious adnexal mass according to availability of trained

professionals, infrastructure and the facilities. In the interest of patients' safety, it was suggested to refer the patients to the larger centers if there is no availability of infrastructure and the professionals (28).

The therapy and management of patients with ovarian cancers in India is usually conducted in accordance with the above guidelines. Because of unavailability of the medical facilities in rural areas, most patients with ovarian cancers or adnexal masses are referred to specialized centers and large private hospitals, which are generally located in large cities.

2.6 Ovarian carcinoma in Germany:

From 1980 up to the mid 1990s the incidence of ovarian cancer in Germany has increased and afterwards, a tendency of decreasing in the incidence was observed. During the period of 1980 and 2006, 10% increase in incidence and 40% increase of prevalence was observed in case of ovarian carcinoma in Germany. The mortality rate has decreased up to 30%, especially in women younger than 60 years (79). A slight improvement in life expectancy could be the reason of increase of incidence.

The survival rate of the patients with ovarian cancer is very bad in comparison to the patients with other diseases and malignancies of sexual organs. The survival rate was found to be around 35% during the period of 1978-1989 in Europe which was worse in comparison to the other gynaecological cancers such as endometrial (75%) and cervical cancers (62%) during the same period (31). From the different cancer registers in Germany during 2005/2006 it was observed that the five year survival rate for ovarian cancer was between 35% and 49%. In the year of 2006 there were a total of 26000 women in whom ovarian cancer was diagnosed in the course of the previous five years (79). In the year 2006, the number of new diagnosed cases in Germany was 9670 and the incidence was projected to 9960 in 2010 (79). The life-time risk of developing ovarian cancer in Germany was 1.8 % in the year of 2006 (79).

The slight increase in survival rate of patients with ovarian carcinoma could be because of the early diagnosis, improved health care and application of more effective chemotherapy. It shows that in spite of the development of the therapy procedures and early diagnosis, the 5 year survival rate of ovarian cancer patients has not changed significantly (31). The 5-year relative survival rate decreased markedly with age. The decrease was especially evident for ovarian cancer, which declined from 65% to 18% from the youngest to the oldest age group. For patients aged 75 years and above, the relative risk of dying compared with the youngest patients (15- 45 years) was 6 for ovarian cancer (31).

2.7 Studies conducted to compare cancer patients in developed with those in developing countries:

Although, a large number of studies have been conducted to compare the incidence, prevalence and the situation of cancer patients among the countries in Europe or Western World (9, 31, 43), there have been very few studies conducted to compare cancer patients from the developed and developing countries (56,73). For example there is a study which compares a developed country (Scotland) and a developing country (Kenya) in respect of the experiences of illness and needs and use of services (56). There was a large discrepancy between the two groups observed in that study. The emotional pain of facing death was the prime concern of Scottish patients and their caretakers, while physical pain and financial worries dominated the lives of Kenyan patients and their caretakers. Psychological help was the most keenly felt need of patients of the developed country, whereas the physical needs often went unattended to in developing countries (56).

A multinational study was conducted in Asia which compared the demographic, clinical, pathological and outcome data in breast cancer patients treated at participating breast cancer centers in India, Malaysia and Hong Kong. The results showed significant differences in clinical pictures and outcomes between developed, newly developed, and developing countries (1). It showed that better socioeconomic conditions, health awareness, and availability of breast cancer screening in developed Asian countries seem to be the major causes of favourable clinical pictures and outcomes in these countries.

To date there is no study available, which compares the life quality of patients with ovarian carcinoma of developed and developing countries. In the present study, Germany represented the developed country and India represented the developing country. The objective of the study was to find out how the patients in Germany differ from the patients in India suffering from ovarian cancer in regard to their expectations from the treating physician and from the clinical/ therapy management. Although India is currently emerging as a newly industrialized country, there is much room for improvement in the health situation. Up till now the government is providing an incomplete and largely under-funded primary health service in rural areas with a backlog in remote areas. (86)

2.8 Comparison of health care situation between India and Germany:

Germany and India differ a lot in their culture, socio economic status, and education.

Germany is one of the countries with a modern infrastructure. It has the world's fourth largest economy by nominal gross domestic product and the fifth largest by purchasing power parity (PPP). It is the most populous member state and the largest economy in the European Union. It is one of the major political powers of the European continent and a technological leader in many fields. The country has developed a very high standard of living and a comprehensive system of social security (93).

On the other hand, India is the seventh-largest country by geographical area, the second-most populous country with over 1.2 billion people, and the most populous democracy in the world. The Indian economy is the world's eleventh-largest by nominal GDP and third-largest by purchasing power parity. Following market-based economic reforms in 1991, India became one of the fastest-growing major economies; it is considered a newly industrialized country. However, it continues to face the challenges of poverty, illiteracy, corruption, and inadequate public healthcare (94).

Before considering comparing the needs and expectations of patients with ovarian carcinoma we should have a look at the health care situation of the two countries.

Table 1 shows an overview of the two countries in respect of their health situation (93, 94).

Table 1: Comparison of health Status between India and Germany:

| Data | India | Germany |
|---|-----------------------|----------------|
| Population (in thousands) total | 1198003 in 2009 | 82167 in 2009 |
| Population median age (in years) | 25 in 2009 | 44 in 2009 |
| Population proportion under 15 (in %) | 31 in 2009 | 14 in 2009 |
| Life expectancy at birth (years) | 65 | 80 in 2009 |
| Infant mortality rate (probability of dying between birth and age 1 per 1000 live births) | 50 in 2009 | 3 in 2009 |
| Maternal mortality ratio (per 100 000 live births) - Interagency estimates | 230 [150-350] in 2008 | 6 in 2006 |
| Physicians density (per 10 000 population) | 5.99 in 2005 | 35.31 in 2008 |
| Hospital beds (per 10 000 population) | 9 in 2005 | 82 in 2008 |
| Radiotherapy units (per 1000000 population) | 0.4 in 2010 | 6.5 in 2010 |
| Private expenditure on health as a percentage of total expenditure on health | 67.2 in 2009 | 21.2 in 2009 |
| General government expenditure on health as a percentage of total expenditure on health | 32.8 in 2009 | 75.7 in 2009 |
| Per capita government expenditure on health at average exchange rate (US\$) | 15 in 2009 | 3502 in 2009 |
| Total expenditure on health as a percentage of gross domestic product | 4.2 in 2009 | 11.3 in 2009 |
| Social security expenditure on health as a percentage of general government expenditure on health | 15.9 in 2009 | 90.8 in 2009 |

Although free service is provided in government hospitals in India, there have been many serious problems observed in respect to accessibility, efficiency and quality of the health delivery system (26). Poor medical facilities and shortage of doctors as well as medicines is a feature of government hospitals. The worst affected are cancer patients from rural areas where they have to depend on rural private practitioners (RPP) and doctors practicing some form of alternative medicine (69). So to get better treatment, patients have to go to private hospitals. As there is no health insurance provided from the government

and the poor patients cannot afford to go to privately owned hospitals, they have to depend on government hospitals, where the service is not up to the requirements.

Health insurance is becoming an important supplementary instrument to health care financing in many countries. In earlier times, as in Bismarckian Germany or UK/NHS (National Health Service), the health care system was under government control and financed from general taxation and designed to provide comprehensive cover (86). But in a country like India, such a system does not exist. Private health insurance is most likely not going to include lower income classes, mainly because of their inability to pay premium. Earlier it was discussed to establish a health-insurance scheme for India that was modeled on systems used in developed countries (83). But this system is still to be planned and implemented in India. In contrast, the largest part (85%) of the population of Germany is covered by a basic health insurance plan provided for by statute. The plan is formally laid down by law in the Sozialgesetzbuch V (SGB V), which provides a standard level of coverage.

According to Pal et al. (70), the biggest challenge before the clinicians now is the management of the rising incidence of cancer in developing countries, with little prospect of more resources becoming available to fight the disease. The death rate from cancer in the developing countries is set to rise at least 3-fold by the year 2025 largely due to the increased life expectancy, containment of infectious diseases and changing lifestyles.

It is estimated that about 50% of cancers are curable if they are detected early and treated appropriately (15). Screening has a major role in early diagnosis. However, in the developing world, around 80% of cancer patients have late stage incurable disease when they are diagnosed. Moreover, in a developing country like India, about 70% of the population obtain medical help from private practitioners. Nearly half of those who seek medical help utilise alternative and traditional systems of medicine. Appalling poverty, poor hygiene and complex social dynamics pose major hurdles in this regard (68). Many persons in the private sector who call themselves doctors have no medical degree. Cancer

awareness and screening programmes for early detection thus should continue to be given utmost attention.

All the above factors are to be considered in comparing Indian and German patients in regard to their needs and requirements. A wide difference between the two groups of patients is also expected.

2.9 Factors affecting outcome of patients with ovarian carcinoma:

Many factors such as strong family history of breast cancer, ovarian cancer or both and nulliparity influence the course of the disease in case of ovarian carcinoma (14). The only factor which is not defined biologically and can be modified is the quality of the therapy. This quality of therapy of ovarian cancer is also dependent on some factors such as health insurance status, implementation and maintenance of the standard of the therapy, participation of hospitals and patients in a clinical study, the surgeons and also the selection of doctor as the primary physician, such as gynaecologist vs. non-gynaecologist (23, 24, 25, 35, 44, 45).

The role of physician, who is a specialist in gynaecological oncology is a very important factor for a positive therapy outcome (25, 35, 45). In a review paper (35) it was mentioned that in cases of patients with ovarian cancer who were managed by specialized clinicians or in specialized centers have a significant reduction of five years mortality in comparison to other patients. Another American study (25) tried to investigate the difference in outcome of the patients with ovarian carcinoma while being treated by gynaecological oncologists and other physicians. From the analysis it was concluded that patients with ovarian cancer as suggested by physical examination and laboratory findings as well as the patients with advanced age and massive intra abdominal disease should be operated on exclusively by physicians with training in gynaecological oncology; and they should be treated with the most efficacious adjuvant therapy available or placed on study protocols. These above mentioned strategies could maximise the possibility of cure or long term survival of patients with ovarian cancer.

METHODS

3.1 Study concept:

After the successful implementation of the 'Expression I study', which was conducted in Germany to define the expectation with regard to the physician-patient communication and treatment management of the patients suffering from breast cancer, the present study was conducted to evaluate the same in patients suffering from ovarian cancer.

To find out the difference between patients from different cultures and socioeconomic status, patients from Germany and India were included in the survey.

In Germany, the survey was conducted using a questionnaire which was sent to the study centers and handed over to the patients. After being filled in by the patients, the questionnaires were sent back to the study center.

In India, interviews were conducted to collect the data with the help of the same questionnaire, which was translated into English. In a country like India, where awareness regarding the disease is itself abysmal (2, 75), it was decided to conduct the interviews. Illiteracy was another key factor to be considered in opting for interviews instead of self-completed questionnaires. As most of the patients did not understand English, the interview was conducted in Odia, the regional language spoken in the state of Odisha. As a lot of patients were not aware of the disease or the therapy, the patient files were consulted to find out the answers to some questions.

3.2 Goals of the Study:

The primary goal of the survey was to characterise the expectations of patients suffering from ovarian cancer with regard to the physician-patient communication and treatment management. A trial was conducted to find out the differences and the similarities in respect of needs and expectations between patients from India and Germany who were suffering from ovarian cancer.

3.3 Study Design:

The questionnaire which was used successfully in the study conducted to find out the expectations of breast cancer patients in Germany in respect to the physician-patient relationship and treatment (61) was also used to conduct the present survey. An interdisciplinary workshop with gynaecologists (n= 5) and medical oncologists (n=3), statisticians (n= 2) and representatives of a selfhelp organization (n=2) was carried out to define various topics. Different studies on the topic were used as the basis of discussion (17, 21, 30, 38). All the relevant items for the proposed questionnaire were described in a written statement, discussed in the workshop and subjected to consensus voting. The questions emerging from the workshop were used to structure the questionnaire which contains a total of 62 items.

These questions were then tested for comprehensibility in a monocentric pilot study (at Charité University Hospital of Berlin/ Campus Virchow Clinic) involving 20 patients with metastatic breast cancer. The test was conducted on the basis of semistructured interviews and feedback questionnaires under the supervision (GO) of a physician trained in interview technique. No tape recorder or video recorder was used. The interviewer was not involved in the patients' medical care. The average duration of an interview was around 40 minutes; patients were assured at the start of the interview that their replies would be in no way detrimental to their care or clinical management. No interview item had been misunderstood or excluded from the questionnaire in the pilot study.

The questionnaire was sent to the 87 participating academic and non-academic centers in Germany. The patients were requested to send back the completed questionnaire to the study center. To minimise the amount of work the patients were asked to do, the numbers of questions were deliberately limited. Participation of the survey was completely anonymous and the participants were not asked to mention their personal details such as name, address or date of birth. The data was collected in the year of 2008 in Germany.

During the period of February to March 2008, simultaneously the data was collected in the State Odisha, in east India in four centers. For getting a balanced result, the survey was

conducted in a government regional cancer center, in a private medical university and in two private hospitals. In this way, the data could be collected from the patients from every social class, so that the result could be generalized. Most of the patients, who were treated in the government regional cancer center, belonged to the lower socio economic status and the majority of the patients treated in the private university and the private hospitals were of a higher socio-economic status. A semi-structured interview was conducted to collect the data. The participation was also completely anonymous. The patients were informed that the participation in the survey would not affect their care or clinical management. The interviewer was also not involved in the patients' medical care. All participants gave fully informed consent. 86 patients suffering from ovarian cancer participated in the survey during that period.

In the survey, a trial was conducted to find out the difference/ similarities between the two groups of patients in the following aspects:

- The initial tumour stage at diagnosis.
- Type of therapy they received.
- Side effects of the therapy.
- Satisfaction with the therapeutic consultation and therapy.
- Patient's rating of the physician's competence.
- Wishes/ suggestions of patients to improve the treatment of ovarian cancer.
- Support during the course of therapy.
- Source of information.
- Seeking second opinion about adequate therapy and treatment options.
- How honest is the physician while providing the details of therapy and disease?
- Most important information, which the patients want to get.
- Hopes from the therapy.
- The efficacy and tolerability of the therapy.
- Aftercare.

3.4 Patients Selection:

Participation in the survey was open to all patients with a diagnosis of ovarian cancer irrespective of the FIGO staging of the disease, whether metastatic or non-metastatic in Germany. The minimum age of 18 years was defined as a criterion for inclusion.

In India, the minimum age of 18 years was also defined as a criterion for inclusion. All the patients suffering from ovarian cancer irrespective of FIGO stages, pre operative, post-operative, metastatic and non-metastatic were included in the survey. There were some patients from whom the diagnosis of cancer was hidden by the physician and the family members. In the case of those patients, no interview was conducted.

3.5 Structure of the questionnaire:

The questionnaire was developed into two broad parts. The first part, the so called 'Basic sheet', contained the questions regarding information such as age, accessibility to internet, tumour stage, whether metastasis occurred during the first diagnosis, whether the patient was operated on, whether the patient received chemotherapy, radiotherapy, hormone therapy, whether there were any reoccurrence of tumour, the current therapy received, and participation in any study. With the help of the above questions, the investigator tried to find out the demographic data of the patients and the basic information about their illness.

The second part of the questionnaire, which was called 'Progress sheet', contained questions regarding the following points:

- Side effects of the therapy.
- Judgment of various factors regarding the previous therapeutic consultations and therapy effects.
- Suggestions of the patients, which could improve the treatment of ovarian cancer.
- Who supported most towards overcoming the sickness?
- How do they rate the success of the therapy?
- What would the respondents do to know whether the therapy they are getting is the right one?

- What is the most effective and patient friendly information source with regard to information about the various possibilities of therapy available?
- Which measure do the respondents think is most effective for adequately providing patient information and ensuring patient participation in a therapy?
- What would help the respondents to follow the success of the therapy?
- What are the hopes from the therapy?
- How honestly has the treating physician informed the patients about the sickness and therapy?
- What is the most important information with regard to the sickness and therapy?
- What are they doing to influence the course of illness favourably?
- What are they doing to pursue the course of their illness and treatment?
- What do they think is the cause of their illness?
- Which aspect of the illness and previous therapy they experienced as the most difficult?
- How important, in the respondent's view are the efficacy and tolerability of the therapy?
- Which after-care measures are offered regularly?

The statements of judgment of various factors regarding the previous therapeutic consultations were scaled with a Likert Scale of 1 -10, in which 1 was regarded as very poor and 10 was regarded as very good. The statements regarding the therapy effects were scaled with a Likert scale of 1 -10, in which 1 was regarded as worse than expected and 10 was regarded as better than expected. Also the importance of the efficacy and tolerability of the therapy were scaled with a Likert scale of 1 -10, in which 1 was regarded as not at all important and 10 was regarded as very important. Regarding the other questions, the patients had to select the most correct statements from a number of given suggestions or they could give their own opinion.

3.6 Data processing and data entry:

After collection of data in Germany and India, the questionnaires were sent to the documentation center. The data were entered in a Microsoft Excel Data sheet for

evaluation. First of all a list of codes was generated to be used in the main spreadsheet. The codes correspond to the numbering of the questions in the questionnaire. In the main spreadsheet, the codes were entered in the row and the data was entered in two separate spreadsheets, one for Indian patients and another for German patients.

3.7 Statistical Analysis:

SPSS (release 10) and Microsoft Excel (2007) were used for statistical analyses and data processing. For some questions patients were asked to rate their answers from 1 to 10 on the Likert scale. The statistical analysis of the given answers focused primarily on a descriptive analysis. Median and ranges were calculated for ordinal scale variables.

Mann-Whitney rank sum test was used to find out the significance of the difference between median ages of the two groups.

Chi-Square test was used to find out the significance of difference in respect of the stages of the tumour of the two groups.

For some questions, patients were asked to rate their answers from 1 to 10 on a Likert scale. The Kendall's tau b rank correlation coefficient was used to measure the association between the two groups for those answers.

RESULTS

4.1 Basic data:

The basic data of the two patient groups are listed below in Table 2.

Table: 2 Basic Data

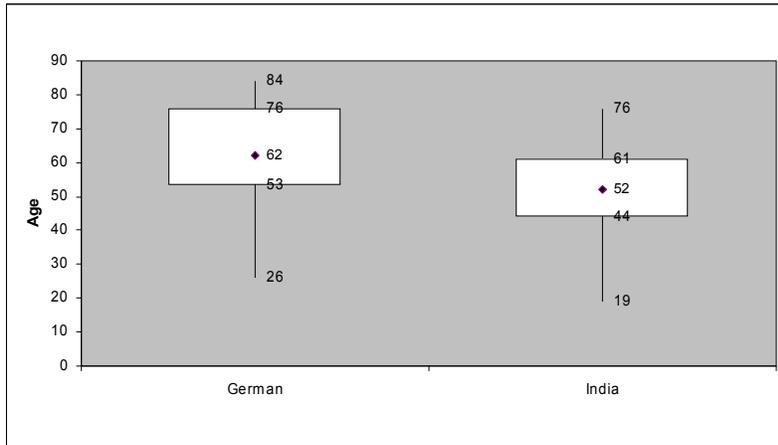
| Parameter | Germany | India |
|--|-----------|-----------|
| No. of participants | 427 | 86 |
| Median age in years | 62(26-84) | 52(19-76) |
| Internet access in % | 49 | 8 |
| Tumour stage at first diagnosis in % | FIGO I | 0 |
| | FIGO II | 7 |
| | FIGO III | 33 |
| | FIGO IV | 6 |
| | Not known | 45 |
| Metastasis during first diagnosis in % | 29 | 21 |
| Chemotherapy received in % | 86 | 98 |
| Primary operation in % | 94 | 68 |
| Recurrence of tumour in % | 41 | 43 |
| Operation after recurrence in % | 54 | 3 |
| Chemotherapy after recurrence in % | 95 | 100 |

4.1.1. Age structure of the patient collectives:

The median age of the Indian patients was 52, the youngest was 19, and the oldest was 76 year. The median age of the German patients was 62 (26-84), 10 years older than the Indian patients. On the basis of Mann-Whitney Rank Sum Test, the differences in the median values among the two groups are greater than would be expected. The difference was statistically significant with a p value of <0.001.

One fourth of German patients were younger than 53 (1st quartile) and 25% were older than 68 (3rd quartile). In contrary 25 % Indian patients were younger than 44 (1st quartile) and older than 61 (3rd quartile).

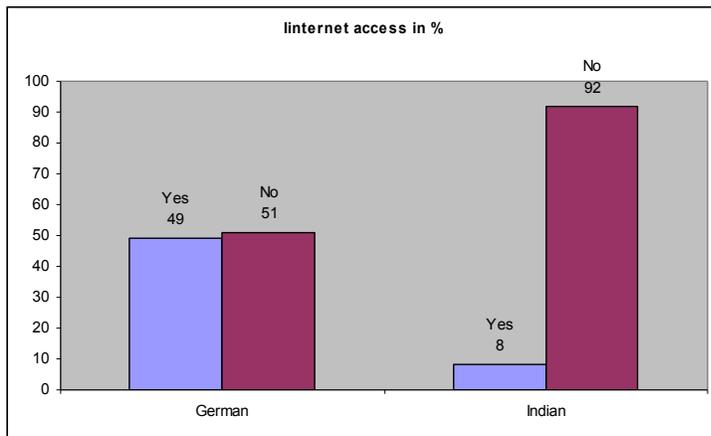
Figure 1: Age of the patients during the survey



4.1.2. Internet Access:

49% of German patients had internet access during the survey compared with only 8% of Indian patients.

Figure 2: Internet Access



4.1.3. Participation in the survey alone or with someone's help?

69 % German patients took part in the survey alone, and in contrast, in the case of 71% Indian patients another person was present during the survey.

4.1.4. Initial tumour stage during the first diagnosis:

At the time of first diagnosis, the Indian patients were at an advanced stage in comparison to the German patients. For example, not a single Indian patient was diagnosed in the FIGO I stage, whereas in the case of 9 % of German patients, the disease was detected at FIGO I stage. On the basis of Chi-Square Test, the two groups showed a significant difference in respect to the stage of the tumour with a p-Value < 0.001.

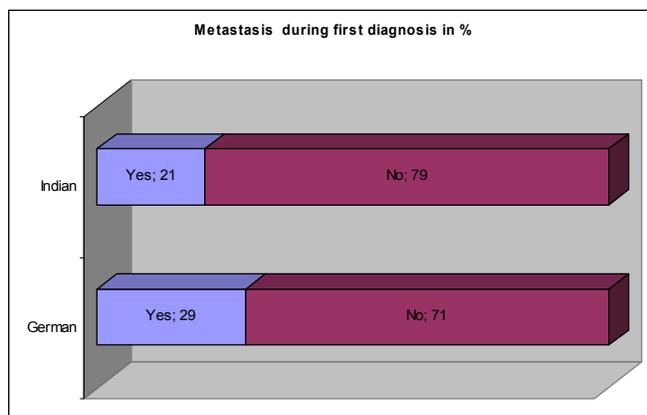
Table 3: Stage of the Tumour at the first diagnosis in %

| Tumour Stage | FIGO I | FIGO II | FIGO III | FIGO IV | Not known |
|--------------|--------|---------|----------|---------|-----------|
| India | 0 | 12 | 42 | 17 | 29 |
| Germany | 9 | 7 | 33 | 6 | 45 |

4.1.5. Metastasis at first diagnosis:

At the time of the first diagnosis, 29 % of German patients and 21 % of Indian patients had metastasis.

Figure 3: Metastasis at the time of first diagnosis in %



4.1.6. Type of therapy

Of the 427 German patients who took part in the survey, 401 (94%) underwent some kind of surgery because of ovarian carcinoma; whereas only 58 (68%) of the Indian patients got a surgical treatment. 86% of the German patients received chemotherapy and nearly all the Indian patients (98%) were treated with chemotherapy.

Table 4: Which type of therapy received?

| | Surgery | Chemotherapy | Radiotherapy | Hormonal therapy |
|---------|---------|--------------|--------------|------------------|
| Germany | 94 | 86 | 5 | 4 |
| India | 68 | 98 | 0 | 1 |

Radiotherapy and hormonal therapy were a rare therapy option in both German and Indian patients. Only 5% and 4 % of German patients received radiotherapy and hormone therapy, respectively, whereas not a single Indian patient received radiotherapy and only 1 % of Indian patients were treated with hormone therapy.

4.1.7. Type of chemotherapy

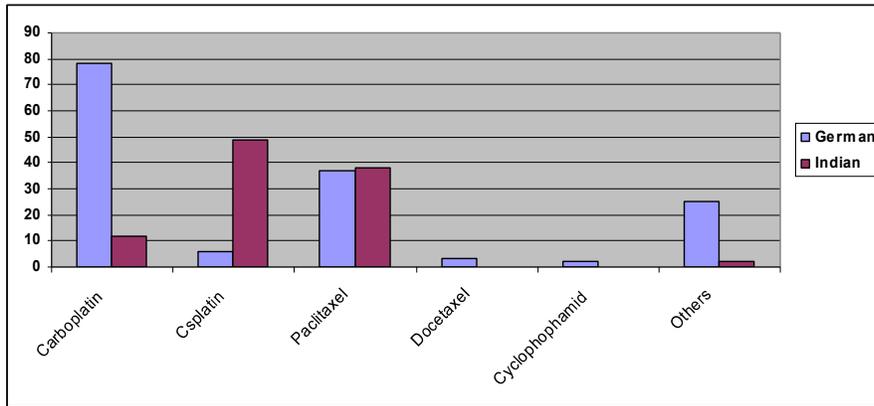
A total of 84 % of the German patients received chemotherapy, which contains platinum (78 % received carboplatin and 6% received cisplatin). 61% of Indian patients were treated with platinum-based chemotherapy (12% received carboplatin and 49% received cisplatin).

Table 5: Chemotherapy received (in %)

| | German | Indian |
|------------------|--------|--------|
| Carboplatin | 78 | 12 |
| Cisplatin | 6 | 49 |
| Paclitaxel | 37 | 38 |
| Docetaxel | 3 | 00 |
| Cyclophosphamide | 2 | 00 |
| Others | 25 | 2 |

40 % of German patients were treated with taxol and 38 % of Indian patients received the chemotherapy containing taxol.

Figure 4: Chemotherapy



4.1.8. Recurrence of the tumour:

Of the total German patients who took part in the survey, 41% had a recurrence of the tumour. Out of the recurrence cases, 22% recurrence occurred within 6 months of the treatment, 27% had a recurrence within 6-12 months and in 49% of the cases the tumour recurred after 12 months.

43% of Indian patients suffered from a reoccurrence of the tumour. Out of the recurrence cases, 3% got it within 6 months, 46% had the recurrence within 6-12 months and 51% had a late recurrence after a period of 12 months.

Table 6: Recurrence of Tumour in %

| | | | |
|--------|----|-----------------|----|
| German | 41 | within 6 months | 22 |
| | | 6-12 months | 27 |
| | | After 12 months | 49 |
| Indian | 43 | within 6 months | 3 |
| | | 6-12 months | 46 |
| | | After 12 months | 51 |

4.1.9. Type of therapy during the survey:

Of the 46% of German patients on therapy at the time of survey, 74% received chemotherapy, 7% got surgery, 5% got hormone therapy and around 2% received radiotherapy. Of the 65% of Indian patients on therapy at the time of survey, 96 % received chemotherapy and remaining 4% got surgery.

4.1.10. Participation in a study:

Not a single patient from India had participated in any study regarding their treatment or in any clinical study. In Germany 46% of the patients have participated in a study regarding their treatment and 31% have participated in clinical studies.

4.2. Side effects of the treatment:

Hair loss (81%) followed by numbness/ tingling in toes and/ or fingers (65%), and fatigue/ exhaustion (58%) were the most frequent side effects in German patients. In Indian patients nausea/ vomiting (78%) followed by hair loss (77%) and pain (48%) were the side effects of the therapy. 34 % of Indian patients mentioned fatigue/ exhaustion as a most frequent side effects. 48% of German patients had stated changes in blood as a side effect of the therapy, where as only 7% of Indian patients mentioned the changes of blood as a side effect of the therapy. Only 9% of Indian patients mentioned the numbness/ tingling in toes and/ or fingers as a side effect of the therapy.

Table 7: Side effects from treatment in %:

| Side effects | German | Indian |
|--|--------|--------|
| Heart damage | 06 | 00 |
| Changes in blood | 48 | 07 |
| Hair loss | 81 | 77 |
| Fatigue/ exhaustion | 58 | 34 |
| Pain | 36 | 48 |
| Nausea/ vomiting | 40 | 78 |
| Numbness/ tingling in toes and/ or fingers | 65 | 09 |

4.3. Judgment of previous therapeutic consultations

The German and Indian patients were asked to judge the previous therapeutic consultations given to them by doctors with regard to completeness, understanding, response to their questions, competence of doctors, their participation in therapy decisions and involvement of their relatives in the course of their therapy. Kendall's Tau rank correlation was used to determine the relationship between the German and Indian patients with regard to the factors noted above.

Completeness of the therapeutic consultation:

When asked to judge the 'Completeness' of the therapeutic consultations given to them by the treating physician, Indian patients' judgement was neither better nor worse than that of the German patients. The correlation coefficient was -0.02 and p-Value was 0.796.

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|---|---|---|----|----|----|----|
| Germany | 1 | 2 | 1 | 2 | 8 | 5 | 8 | 18 | 17 | 29 |
| India | 1 | 1 | 0 | 1 | 1 | 7 | 16 | 20 | 27 | 27 |

Understanding:

To the statement, 'Understanding' regarding the previous therapeutic consultations given by the consulting physician, Indian patients' judgement was neither better nor worse than that of German patients with the correlation coefficient value of -0.10 and p-Value of 0.272.

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|---|---|----|----|----|----|----|
| Germany | 1 | 1 | 2 | 2 | 6 | 6 | 8 | 19 | 17 | 27 |
| India | 1 | 1 | 0 | 0 | 5 | 10 | 14 | 17 | 23 | 28 |

Response to my questions:

When asked to judge the 'Response to their questions' by the physician, a significant difference was found between the Indian and German patients. The correlation coefficient was -0.22 and p-Value was 0.018. This may be interpreted to mean that the Indian patients had a less negative view of the responses given by the doctors to their questions regarding the disease and therapy, whereas the German patients had a more negative view about the responses of the doctors.

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|---|---|---|---|----|----|----|
| Germany | 1 | 1 | 1 | 1 | 8 | 4 | 7 | 12 | 20 | 36 |
| India | 0 | 0 | 0 | 1 | 2 | 9 | 7 | 15 | 29 | 36 |

Competence of doctors:

With a correlation coefficient 0.02 and p-Value of 0.799, the Indian patients' judgement was neither better nor worse than that of German patients of the 'Competence of doctors'.

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|---|---|---|---|----|----|----|
| Germany | 1 | 1 | 1 | 1 | 2 | 3 | 6 | 8 | 19 | 46 |
| India | 1 | 1 | 0 | 0 | 1 | 3 | 7 | 13 | 28 | 45 |

My participation in therapy decisions:

Regarding to their 'Participation in therapy decisions', the Indian patients' judgement was neither better nor worse than German patients, with the correlation coefficient -0.16 and p-Value of 0.082.

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|---|---|----|----|----|----|----|
| Germany | 2 | 1 | 2 | 2 | 8 | 5 | 6 | 12 | 17 | 28 |
| India | 2 | 2 | 0 | 6 | 9 | 15 | 21 | 20 | 7 | 17 |

The involvement of my relatives in the course of my therapy:

To the question, 'Involvement of my relatives' in the course of the treatment, the Indian patients' judgement was also neither better nor worse in comparison to the German patients. The correlations coefficient was -0.01 and the p-value was 0.926.

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|---|---|---|---|----|----|----|
| Germany | 6 | 3 | 2 | 1 | 6 | 5 | 4 | 11 | 14 | 30 |
| India | 0 | 1 | 0 | 0 | 0 | 1 | 2 | 3 | 21 | 71 |

4.4. Judgment regarding different therapy factors

The German and Indian patients were asked to judge various factors of therapy, such as, success of therapy, side effects of therapy, burdens of the surgery, pain, nausea/ vomiting, and level of exhaustion. Kendall's Tau rank correlation was used to determine the relationship between the German and Indian patients with regard to the factors noted above.

Success of therapy

When asked to judge the 'Success of therapy', the Indian patients judged it as being neither better nor worse than the German patients. The correlation coefficient was 0.01 and the p-Value was 0.874.

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|---|---|----|----|----|----|----|
| Germany | 3 | 1 | 3 | 3 | 5 | 4 | 7 | 11 | 11 | 30 |
| India | 2 | 0 | 0 | 0 | 5 | 12 | 21 | 26 | 26 | 9 |

Side effects of the therapy

The Indian patients judge the 'Side effects of the therapy' as being neither better nor worse in comparison to the German patients, with a correlation coefficient of 0.04 and p-Value of 0.874.

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|---|----|----|----|----|----|----|
| Germany | 5 | 3 | 3 | 7 | 11 | 7 | 9 | 13 | 10 | 16 |
| India | 1 | 2 | 2 | 1 | 12 | 19 | 24 | 23 | 12 | 3 |

The burdens of the Surgery

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|---|----|----|----|----|---|----|
| Germany | 6 | 2 | 7 | 4 | 11 | 10 | 12 | 12 | 8 | 13 |
| India | 2 | 1 | 1 | 3 | 13 | 16 | 17 | 12 | 3 | 30 |

When asked to judge the 'Burdens of the Surgery', the Indian patients also judged them as being neither better nor worse in comparison to the German patients. The correlation coefficient was 0.004 and p-Value was 0.967.

Pain

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|----|----|----|----|----|----|----|
| Germany | 5 | 3 | 4 | 3 | 9 | 8 | 11 | 13 | 13 | 17 |
| India | 2 | 0 | 5 | 14 | 19 | 15 | 20 | 13 | 9 | 3 |

When asked to judge the 'Pain', the Indian patients gave neither a better nor a worse opinion in comparison to the German patients. The correlation coefficient was 0.05 and the p-Value was 0.509.

The nausea / vomiting

Also with regard to 'Nausea/ vomiting', the Indian patients judged it as being neither better nor worse in comparison to the German patients. The correlation coefficient was 0.06 and the p-Value was 0.454.

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|----|----|----|----|----|----|----|
| Germany | 5 | 3 | 4 | 5 | 7 | 6 | 7 | 11 | 12 | 26 |
| India | 1 | 2 | 6 | 15 | 23 | 19 | 15 | 13 | 3 | 2 |

The level of exhaustion

To the question 'The level of exhaustion', also there was no statistically significant relationship found between the Indian and German patients. With a correlation coefficient of -0.01 and a p-Value 0.844 neither group of patients differed in their judgment.

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|----|----|----|---|----|---|----|
| Germany | 6 | 4 | 8 | 8 | 13 | 11 | 8 | 12 | 7 | 8 |
| India | 5 | 6 | 9 | 15 | 21 | 14 | 9 | 12 | 7 | 2 |

4.5. Which three important suggestions could improve the treatment of ovarian cancer?

When asked to choose three important aspects/ suggestions from 10 given suggestions, 47% of Indian patients suggested that the 'treatment should be of shorter in duration'. For 45% of the Indian patients, the 'therapy should not lead to hair loss and 38 % suggested that 'therapy should reduce the pain' as the most important opinion to improve the treatment.

In the case of German patients, the opinion was that 'therapy should not lead to hair loss' (49%), 'doctors should have more time for explanations' (44%) and the 'therapy should be made more effective' (27%).

It may be noted that the suggestion 'therapy should not lead to hair loss' was a common suggestion of German and Indian patients as the most important opinion to improve the treatment, whereas the German and Indian patients have given two different suggestions each, which reflects their concerns regarding the therapy.

4.6. Who supported most towards overcoming the sickness?

When asked who supported them most towards overcoming their sickness, 81% Indian patients said that 'family member/ friend' supported most, 19 % named the 'treating physician' as the supporting person. 73% of German patients stated that 'family member/ friend' played an important role in supporting them in overcoming their sickness. 33% of German patients named 'treating physician', 6% named 'nurse', 2% named 'self help group', and 2% named 'other patients' as those supporting them in overcoming the sickness.

4.7. How do you measure the success of the therapy?

57% of Indian patients measured the success of their therapy based on their 'current well-being', followed by 'based on the feedback received from the doctor' (36%) and 'progress of the tumour marker (CA 125)' (17%).

In the case of the German patients, the 'current well-being' (55%) was also the most often chosen measure of the success of the therapy. 42% of German patients measured their success of therapy by following the 'Progress of the tumour marker (CA 125)' and 36% measured the success based on the 'feedback received from the treating physician'.

4.8. Whom should you consult to make sure that your therapy is right?

When asked whom they should consult to make sure that the therapy they were receiving was the right one, 72% of Indian patients would ask for a second opinion from another specialist/ doctor, and 17% would ask their family doctor.

To find out whether the therapy they were receiving was the right one for them, 48% of the German patients would ask their Family doctors and 39% would ask for a second opinion from another specialist. 20% of German patients said that they would seek information from the internet to check whether they are getting the right therapy, whereas not a single Indian patient mentioned that they would seek information from the internet.

4.9. Do you wish that there should be an independent place where you could inform yourself whether you are receiving the optimal therapy or not?

47% of Indian patients wished that there should be an independent place where they could inform themselves whether they are receiving the optimal therapy or not. Of the German patients who took part in the survey, 65% wished that there should be an independent place where they could inform themselves whether they are receiving the optimal therapy or not.

4.10. What do you believe is the most effective and patient-friendly information source for you about the various therapies available?

79% of Indian patients believed that 'a talk with the treating doctor' is the most effective and patient-friendly information source about the various therapies available. 'A Talk with the treating doctor' was believed by 90% of German patients to be the most effective and patient-friendly information source.

10% of Indian and 7% of German patients believed that a patient's brochure would be the most effective and patient-friendly information source. Whereas, 6% of Indian and 3% German patients believed that a television program would be the most effective and patient friendly information source.

4.11. Which measure do you think is most effective for an adequate patient information and patient participation in a therapy?

When asked which measure did they think to be most effective for providing adequate patient information and patient participation in a therapy, 50% of Indian patients stated that a competent doctor who is ready to answer their concerns should be available to them,

followed by 24 % of patients, who thought that informative video material explaining the various stages of the therapy should be available.

60% of German patients thought, that patients should have someone with them whom they know and trust whenever a consultation takes place (Relatives, family or friends) and 31% held the opinion that before a consultation, patients should be informed about what type of questions they can ask and why they might want to do so.

4.12 Which of the following options would you use to help you follow the success of the therapy?

49% of Indian patients wished regular letters that would keep them informed about the results and the next steps to be followed in their therapy. 40% of the Indian patients who took part in the survey wished a patient's diary in which they could enter their entire lab test results, appointments and find the explanations for the lab values and therapy.

51% of German patients wished a patient's diary in which they could enter their entire lab test results, appointments and find the explanations for the lab values and therapy. 28% of the German patients wished a form which is maintained by their doctor and that both the doctor and the patient can make entries in it.

4.13. Have you ever had personal contact with a self-help group?

Not a single Indian patient had contact with a self-help group during the survey and only 18% of German patients had contact to any self-help group.

4.14. What are your hopes from the therapy?

When asked about the hopes from the therapy, 73% of Indian patients hoped for a complete healing without any further complications and 27% of Indian patients hoped for just a less painful course of sickness.

59% of German patients hoped for no recurrence of tumour-related symptoms and also 59% hoped for complete healing without any further complications.

4.15. Do you believe that your doctor had informed you honestly about your therapy?

84% Indian and 86 % German patients thought that their doctor had informed them honestly about the therapy they have received.

4.16. Have you been offered and informed about other therapy options during your previous therapy?

72% of Indian patients and 58% of German patients stated that they had not been offered or informed about other therapy options during the previous therapy.

4.17. The way of functioning of the required medications

When asked about their wish to know about the functioning of the required medications, 57% of the Indian patients said they wanted to know their side effects and how to avoid them. 29% of Indian patients said that they were not interested to know about the functioning of the required medicines. 14% of Indian patients mentioned that the function should be made clear to them so that they could understand it.

61% of German patients wished that the functioning of the required medicines should be made clear to them, so that they could understand it. 21% of them wanted to know the side effects of the medicines and how to avoid them, 2% of German patients mentioned that they did not have any interest in knowing about the functioning of the required medication.

4.18. What is the most important information for you regarding your sickness and therapy?

According to 47% of the Indian patients, the most important information for them regarding their sickness and therapy was whether they were getting the right therapy. The second most important information for the Indian patients (40%) regarding their sickness and therapy was how long they would live.

According to 69% of the German patients, the most important information regarding their sickness and therapy was whether they were getting the right therapy, whereas, for 28% of

the German patients, the most important information required was how long they would live.

4.19. What are you doing to influence the course of your illness favourably?

When asked what they were doing to influence the course of their illness favourably, 85% of Indian patients said that they followed strictly the instructions of their doctors. 13% of the Indian patients said that took care about a healthy diet than before to influence the course of their illness favourably.

69% of German patients said that they fought against the disease and not let themselves go , 65% said that they thought positive to influence the course of their illness favourably.

4.20. What do you think is the cause of your illness?

According to 24% Indian patients, nutrition was the cause of their illness, 12% thought the environmental factors and 10% thought that stress in the family were the cause of their illness.

28% of the German patients said that environmental factors were the cause of the illness. According to 26% of German patients, stress at work was the cause of the illness and according to 24% of German patients, stress in the family was thought to be the cause of their illness.

4.21. Which aspect of your illness and previous therapy have you experienced as the most difficult?

Fear of the future was the most difficult aspect of their illness as stated by Indian (43%) and German (55%) patients.

4.22. In your view how important are the efficacy and tolerability of therapy?

Effectiveness:

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|---|---|---|---|---|----|----|
| Germany | 1 | 0 | 0 | 1 | 1 | 1 | 1 | 2 | 6 | 80 |
| India | 0 | 1 | 2 | 0 | 2 | 5 | 7 | 9 | 22 | 51 |

When asked how important are the efficacy of the therapy was, the Indian patients neither answer better nor worse than the German patients. On the basis of Kendall's Tau rank correlation, no significant difference was found between Indian and German patients, with a correlation coefficient of -0.16 and p-Value of 0.117.

Tolerability:

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------|---|---|---|---|---|---|---|----|----|----|
| Germany | 1 | 1 | 1 | 1 | 5 | 5 | 6 | 10 | 7 | 54 |
| India | 0 | 1 | 2 | 0 | 1 | 8 | 6 | 6 | 16 | 59 |

When asked how important the tolerability of the therapy was, the Indian patients neither answer better nor worse than the German patients. On the basis of Kendall's Tau rank correlation, no significant difference was found between Indian and German patients, with a correlation coefficient of -0.01 and p-Value of 0.915.

4.23. Which after-care measures are offered to you regularly?

36% of Indian patients had abdominal ultrasound and 29% of them underwent tests such as MRI, CT, PET, X- ray chest etc., which were regularly offered as after-care measures. 16 % of the Indian patients mentioned that they did not receive any after care.

69 % of German patients had regular vaginal ultrasound, 60 % of them had abdominal ultrasound, 54% had physical examination and 48% of them underwent tests such as MRI, CT, PET, X- ray chest etc., which were offered regularly as after-care measures.

DISCUSSION

In the present survey, it was found that the Indian patients had an advanced stage in comparison to the German patients at the time of first diagnosis of cancer. The difference was found to be significant ($p < .001$) (Table 3).

A number of studies conducted in India support the findings of the present study. In India, more than 70% of cancer patients report for diagnosis and treatment when the disease is already at any advanced stage, which has led to a poor survival and high mortality rate (22). According to govt. of India in the year 2006, 75% to 80% of cancer patients were found in advanced stages of the disease (34).

Another study was conducted in the USA on the cultural aspects of cancer patients. Culture reflects lifestyle differences, such as practices that determine diet, exercise patterns, weight norms, work environments, birth rates, and age at first birth. Cultural factors like health-seeking patterns also play a major role in health promotion and maintenance. Cultural beliefs affect both the risk factors for cancer as well as the meaning of the disease by establishing norms of behaviour and providing guidance for its members to respond emotionally, cognitively, and socially to this disease. These beliefs mostly lead to delay in seeking medical treatment, thereby prolonging the interval between the first appearance of symptoms and the first visit to doctor. Thus, cultural beliefs and practices affect cancer care along the entire disease continuum: from prevention and early detection, treatment choices and compliance, management of side effects such as pain and its control, to appropriate psychosocial support, rehabilitation efforts, survivorship issues, hospice and effective end of life care (46).

In a survey conducted by Broom (11) in India, a statistically significant relationship between the use of TCAM (traditional, complementary and alternative medicine) and delay in seeking help from orthodox medicine was observed. In a survey conducted by Malik et al (52) in Pakistan it was found that the use of unconventional methods by cancer patients in Pakistan is widespread. Unlike western countries, these methods are often employed

before receiving any conventional therapy. This probably results in a significant delay which can be expected to adversely influence the subsequent disease management and survival.

In a study conducted by Kishore (47) in New Delhi, it was found that, 75.8% of the patients, who were aware of the diagnosis, had not undergone any sort of counselling, either by a professional counsellor or a doctor. In the same study, it was observed that there was a substantial delay of around 2 years in seeking medical treatment for cancer. Mandal et al. (53) reported that nearly 97% of cancer patients in their study presented at a hospital after several months, contributing to a moderate to advanced stage of the disease at first contact. Late reporting by the patients was attributed to lack of awareness about the symptoms of cancer.

The present investigator also observed the same trend while collecting data in India. During the interviews, it was observed that many patients did not know about their illness or they did not want to discuss about the disease. Ignorance and illiteracy was an important factor regarding the lack of awareness about the ailment. Although they were in a cancer hospital, some patients said that ascites was the cause of admission to the hospital. A lot of patients were not aware of their cancer.

There is a difference in recurrence of the disease within 6 months of first treatment between German and Indian patients. It was found that only 3% of the recurrences occur in Indian patients, whereas 22% recurrences occur in German patients. During the survey in India, the present investigator observed that many patients have to travel long distances to specialized hospitals, for which they might have reported to the hospital at a later stage. This may explain the low percentage of recurrence of the disease within 6 months of first treatment in Indian patients.

In the present survey, 32 % of the Indian patients and 6% of the German patients did not have an operation. (Table 4) Studies have found that optimal treatment of ovarian cancer begins with optimal cytoreductive surgery followed by combination chemotherapy (3, 8, 18). An operation of the ovarian carcinoma in India means a major intervention with a long

stay in hospital, which would be very expensive in India. The present investigator discussed with Indian doctors, patients and their relatives the issue of lack of surgical treatment in the case of a large number of Indian patients. It was revealed that it may be due to poverty and the long distances patients have to travel to appropriate hospital facilities.

In the underlying survey, 49% of Indian patients received cisplatin as the platinum-based chemotherapy. Only 12% of the Indian patients received carboplatin, which is the internationally preferred platinum based chemotherapy (Table 5, Figure 4).

The findings of Basu et al (8) are consistent with the results of the present study. Basu et al. found that due to the prohibitively high cost of the medicines, most of the patients cannot afford the treatment of first choice (Carboplatin/Paclitaxel) and settle for the cisplatin/ cyclophosphamide combination. Even though this combination is cheaper, many patients find it hard to bear the expenses. As most of the patients came from far-off places, chemotherapy cannot be administered on day-care basis. Due to inadequate numbers of beds in hospitals, the cycles of chemotherapy cannot be maintained properly for most of the patients. Many patients drop out as they find it difficult to visit the hospital repeatedly.

Du Bois (23) conducted a study on the treatment of advanced ovarian cancer in Germany. It was found that only about 60% of patients received treatment adhering to current standard recommendations. There was considerable heterogeneity with respect to type of institution. Patients treated in a university or a central hospital had a significantly higher chance of receiving optimal treatment compared to patients treated in smaller hospitals. In the same study, it was found that less than 40% patients in the hospitals with basic care received the standard combination chemotherapy, i.e., cisplatin and paclitaxel. The current survey shows similar results regarding the application of chemotherapy in the case of German patients.

In the current survey, there was a significant difference between the two groups of patients regarding their participation in a study. It was found that 46% of German patients participated in a study whereas not a single Indian patient had this experience.

In a study conducted by 'AGO Organkommission OVAR' to evaluate the relationship between hospital characteristics and quality of care and outcome in ovarian cancer in Germany, it was found that patients treated in study-centres received more frequently standard care and showed better survival. It was concluded that participation in clinical studies was the only transparent hospital characteristic with significant impact on prognosis of ovarian cancer. It was proposed that participation in a study should be a criterion for quality of care in counselling ovarian cancer patients and should help in selecting hospitals for primary therapy (24). The current study explains the difference in the standard of therapy received by the German and Indian patients. As no Indian patient had the opportunity to participate in a study, it is not possible to compare the standard of therapy given to Indian patients in this regard.

78% of the Indian patients stated 'Nausea/ vomiting' as the most frequent side effects. 40% of German patients stated 'Nausea/ vomiting' as the frequent side effects of the therapy. This shows that a lot more Indian patients experienced 'Nausea/ vomiting' compared to the German patients. Though there is no specific information regarding the management of 'Nausea/ vomiting' available in the present study, it may be assumed that the German patients had a better management of nausea/ vomiting compared to the Indian patients. It may also be assumed that the access to medical care is less widely available to Indian patients compared to the German patients. Sun CC et al. (87) found that chemotherapy-induced nausea and vomiting is one of the most dreaded side effects of chemotherapy, which is consistent with the results of the present study. Oskay-Özcelik (61) found that 19 % of German patients suffering from breast cancer experienced nausea and vomiting as side effects of therapy. Unlike breast cancer patients, patients with ovarian cancer often receive chemotherapy. It may be stated that, due to chemotherapy, the ovarian cancer patients experience more 'Nausea/ Vomiting' compared to the breast cancer patients.

58% of the German and 34 % of the Indian patients experienced fatigue/ exhaustion as the most frequent side effect. In the study conducted by Oskay-Özcelik (61) in 62% patients the most frequent symptom was physical weakness. The result of the present study regarding fatigue/ exhaustion of the German patients was similar to the finding of Oskay-Özcelik. Regarding the low percentage of 'fatigue/ exhaustion' in Indian patients, it may be stated that they considered 'fatigue/ exhaustion' as the natural symptom of the disease and did not consider mentioning it as a side effect.

48 % of the Indian and 36 % of the German patients mentioned 'pain' as the most frequent side effect of the therapy. According to Oskay-Özcelik (61), 51 % of German patients suffering from breast cancer reported pain as the most frequent side effect of therapy. It may be stated that the difference in the opinion of the patients regarding experiencing pain is due to different types of cancer and their management.

According to Pal et al. (69), cancer pain relief still remains the cornerstone of optimal palliative care in Indian patients. Though access to morphine is much easier now, yet it has not achieved a helpful atmosphere because of the geographic and economic disparities. Therefore, palliative and pain care of Indian cancer patients continues to be suboptimal and more steps should be taken to lessen the pain during the therapy. Experience of pain in 48% of Indian patients may be due to suboptimal pain management as stated by Pal et al. (69).

The change in blood values was mentioned only by 7% of Indian patients in comparison to 48% of the German patients. It was reported by the Indian patients that regular blood tests were not performed during the therapy. Even if a blood test was performed, the patients were not interested to know the result, which explains the lack of awareness and ignorance regarding the therapy and the disease.

In spite of vast difference between the two groups of patients regarding the therapy management, there was no significant difference observed regarding many aspects such as judgment of the completeness of the therapeutic consultation, understanding of the

previous therapeutic consultations given by the consulting physician, competence of doctors, participation in therapy decision and involvement of patients' relatives in the course of the treatment.

A significant difference was observed between the Indian and German patients in the case of the statement 'judgement of the response of the physician to my questions'. The correlation coefficient was -0.22 and p-Value was .018. It was found that only 3 % of the Indian patients had a negative opinion regarding the answers given by the doctor to their questions (on a ten point Likert scale), whereas 12 % of the German patients had a negative opinion. It may be stated that the German patients were more interested to know about their disease and therapy, which was not properly answered by the doctors. The Indian patients were not more critical about the disease and therapy.

The German and Indian patients were asked to judge on a Likert scale of 1 (worse than expected) to 10 (better than expected) factors such as therapy success, side effects of the therapy, burden of the operation, the pain, nausea/ vomiting and the level of exhaustion. The Indian patients' judgement of the above factors was neither better nor worse in comparison to the German patients.

Before the beginning of the survey, it was assumed that the two collectives of patients from the two different countries with a huge difference in sociocultural status would vary in their views regarding the therapy consultations given by the treating physician and the therapy management. But the results of the present study proved at variance with our expectations.

49% of the Indian patients in the present study wished that the duration of the therapy should be shorter. Sharma (84) mentioned that the global cancer burden and its financial impact has shown a distinct shift in the past two decades, even among patients living in high resource countries, with comprehensive health insurance policies. He mentioned that in the developing countries, where there are often no insurance policies, cost becomes the greatest barrier in providing cancer treatment. It is recognized that these costs include the

direct cost of treatment and care of cancer patients, indirect costs accrued by the patient and the family, and economic losses to the society as a whole. The result of the present study correlates with the assumption of Sharma. One hospital stay can consume a sizeable share of a poor household's resources, often leading to financial crisis. That was the explanation given by most patients who wished a shorter duration of the therapy.

38 % of the Indian patients stated that there should be more effective therapy to lessen the pain, where as the lessening of the pain was not one of the three important wishes of the German patients. Only 8% of German patients wished for an effective therapy to lessen the pain. The findings of the current study correlates with the findings of Pal et al. (69), as 38% of the Indian patients wished a better and optimised management of pain.

The therapy should not proceed until hair loss was the only important common wish of both the Indian and German patients. 49 % of German patients and 45% of Indian patients mentioned that the therapy should not be continued until hair loss, as the most important opinion to improve the treatment. In a review paper published by Lemieux (49), it was mentioned that chemotherapy-induced hair loss is considered to be the most important side effect of chemotherapy, frequently ranking among the first three effects for breast cancer patients and can lead to refusal of chemotherapy and cause distress and traumatization. The results of the current study reveal that the chemotherapy induced hair loss remains to be one of the important side effects causing distress among patients.

In the present study, it was found that 81% OF THE Indian patients were supported by family members and friends in their efforts to overcome their sickness. Also a vast number of German patients (73%) mentioned that their family members and friends supported them a lot in their efforts to overcome their sickness. In the study conducted by Oskay-Özcelik (61), it was found that 86 % of the patients said a family member/ friend supported them most in coping with the illness. In a review paper published by Kotkamp-Mothes et al.(48), it was mentioned that the relatives and family members were increasingly seen as a source of social support for patients with potential influence on coping, morbidity and mortality. Family members carry financial, professional and social burdens; they may be able to

support patients emotionally, to provide nursing tasks and to help patients in making treatment decisions. They could therefore act as a “guaranty of stability” in times of change. The current study shows similar result as regards to support by the family members towards overcoming the illness. From the findings it could be concluded that the family members play a major role in coping with cancer in Indian as well as German patients.

Kishore et al (47) observed that the majority (87%) of the patients in India suffering from cancer were discriminated in one way or the other. In 60% of the cases, the patients were isolated completely. It has also been noted that considerable stigma is attached to this disease. In a pilot study conducted in the state of west Bengal in east India by Ray et. Al (77), it was found that 21.33% of cancer patients have the vague idea that cancer is an infectious disease, which creates the problem of isolation from the family/ society to some of the unfortunate cancer patients. In the current study, a difference to the above authors was observed regarding support from the family members in helping to overcome the sickness in ovarian cancer patients in India.

19 % of Indian patients and 33% of German patients named the ‘treating physician’ as the supporting person to overcome the sickness. In the study conducted by Oskay-Özcelik (61), it was observed that 29 % of the patients got support from the family members in helping the patients to overcome the sickness. The current study came up with nearly the same information regarding the support of the physician in overcoming the sickness.

In the present study, 10% of Indian and 7% of German patients believed that a patient’s brochure would be the most effective and patient friendly information source. Whereas, 6% of the Indian and 3% German patients believed that a television programme would be the most effective and patient friendly information source.

In a pilot study conducted in a West Bengal in east India by Ray & Mandal (77), it was found that only 8.33% have faced any cancer awareness programme conducted by govt. Organisation/ NGOs/ other organizations. 37.33 % of the patients have listened to any

cancer awareness programme conducted by the All India Radio and nearly the same number (36.33 %) have seen any programme shown by any television channel, 34% of them have read any cancer awareness articles in the newspapers/ magazines. These facts showed that cancer awareness programme in this region is woefully inadequate. Also the Indian patients in the present study did not mention television and information materials as an effective source. As there is a lack of an adequate awareness programme, it is understandable that the patients did not mention television and information materials as an effective source.

79% of the Indian patients and 90% of the German patients named the doctor as most effective and patient friendly information source. The study conducted by Oskay-Özcelik (61) showed that 84% of respondents regarded consultations with their doctor as the most effective and patient-friendly source of information about treatment options. A study by Jenkins et al. (42) showed that 87% of the patients suffering from cancer wanted as much information as possible from their physicians. The results of the current study correlates to the results of Oskay-Özcelik and Jenkins.

40% of the Indian patients and 51 % of German patients who took part in the survey wished a patient's diary in which they could enter their entire lab test results, appointments, and find the explanations for the lab values and therapy. Fifty-six per cent of respondents in the Germany-wide study conducted by Oskay-Özcelik (61) stated that a patient diary allowing them to enter all laboratory values and appointments and find explanations of test results and treatments would be their most important aid for keeping track of their response to treatment. The result of the current survey is similar to the observation of Oskay-Özcelik in this regard.

In an observational study conducted by Giese-Davis (32) for a period 3–6 months to measure the outcomes for both newly diagnosed women with breast cancer and peer counsellors, a significant decrease in trauma symptoms and increases in emotional well-being and self-efficacy in breast cancer patients. Also, no decreases in depression and no increases in social well-being were observed.

In a study conducted by Taleghani (89) in two cities in Iran on patients with breast cancer it was observed that patients supported by a peer group enjoyed a higher quality of life compared to others.

In a review paper published by Liebermann (50) an attempt was made to compare self help groups with professionally led groups. Definitive conclusions regarding the effectiveness of self-help groups compared with other forms of intervention could not be made because of the problem of self selection of participants. It was assumed that overall, both self-help and professionally led groups would be productive and that each specific situation would require analysis to determine which would be most effective for a particular patient. Such factors as the availability of leadership skills and the attitudes toward treatment modalities probably play an important role in determining which format is most appropriate. From a cost-effectiveness perspective, however, self-help groups are certainly desirable compared to the other form of interventions. Self-help groups offer an important service to troubled individuals.

In the current study it was observed that only 18 % of the German patients and not a single Indian patient was in contact with a self help group during the data collection. Contact with a self-help group could be helpful to the patients of both the collectives to enable them better to cope up up with the disease and to have a better quality of life.

84 % of Indian and 86% of German patients believed that the doctor informed them honestly during the therapy. If we analyze the two groups, it can be concluded that the treating physician could be assumed to be the most important person in regard to the therapy.

In a survey conducted in India by Broom (11), it was observed that 34.3% of the participating patients used alternative medicine, representing a significant proportion of the population. Cassileth et al. (13) stated that Patients appear increasingly willing to discuss the use of alternative medicines, especially when asked by their oncologists. In order to

encourage open communication of CAM use by their patients, oncologists should be knowledgeable about the most commonly used remedies, or at least be able to direct patients to reliable sources of information. On the other hand, complementary therapies that help manage pain, nausea, fatigue, anxiety, and other symptoms should be integrated into the patient's overall care. In some cases, patients feel that problems they perceive as important fail to receive sufficient attention. Complementary therapies improve patients' quality of life, patient satisfaction, and the physician-patient relationship.

In a survey conducted by Coss (19) in California, seventy-five percent of respondents reported that they would prefer to receive a referral from their doctors. Two thirds of patients felt that alternative care providers should be encouraged by the medical profession, and 85% indicated that alternative care should be offered at the cancer center as part of oncology treatment.

Some authors (15, 68) found that the use of alternative or traditional medicine is widespread among Indian patients. The inaccessibility (long travel distance, high costs) of standard medical care may have the biggest influence in developing countries on the use of unconventional medicine (81). In developing countries, ignorance, socioeconomics and inadequate access to mainstream medical facilities are major factors that play an important role for patients opting for alternative therapies rather than mainstream treatment, whereas in developed countries, a significant proportion of cancer patients try complementary therapies as adjuncts to mainstream care for management of symptoms and to improve quality of life (85).

78% of Indian patients and 58% of German patients from the current study stated that they had not been offered and informed about the other therapy options during the previous therapy. If we analyse the above mentioned findings and the results of the current survey, it could be concluded that in India as well as in Germany the treating physicians should offer and explain other therapy options available in addition to the current treatment.

27% of Indian patients just hoped for a less painful course of sickness. In contrast only 7% of German patients hoped for a less painful course of sickness. This observation indicates that the management of pain is poor in India compared to Germany and a lot must be done to improve the pain management of the patients suffering from cancer.

In an anonymous survey (10) conducted in USA to evaluate the attitudes, knowledge, and practices of US medical oncologists related to the management of cancer pain, it was found that a focus on cancer pain has not adequately addressed the perception of treatment barriers or limitations in pain-related knowledge and practice within the oncologist community. It was concluded that additional efforts were needed to achieve meaningful progress.

Another survey was conducted by the Eastern Cooperative Oncology Group (ECOG) (92) to determine the amount of knowledge about cancer pain and its treatment among physicians practicing in ECOG-affiliated institutions and to determine the methods of pain control being used by these physicians. It was concluded that professional education needs to focus on the proper assessment of pain, on the management of side effects, and on the use of adjuvant medications. A better understanding of the pharmacology of opioid analgesics is also needed. Physicians also need to educate patients to report pain and to effectively use the medications that are prescribed for pain management. In a similar survey conducted in Thailand (59) to evaluate the knowledge and attitudes of interns regarding cancer pain and its management, it was found that the interns demonstrated positive attitudes toward cancer pain and its management, based principally on opioid usage. However, a significant number of them had misconceptions about prescribing opioids. To provide better cancer pain management, attention must be given to improving the curriculum and integrating it into clinical practice.

If we analyse the above publications and the results of the current survey regarding pain as a side effect and concern of the patients, especially in the case of Indian patients, it could be concluded that should be done more towards better pain management. Oncologists

should get more professional training regarding the proper assessment of pain and use of pain medications.

When asked about the hopes from the therapy, 73% of Indian patients and 59 % of the German patients hoped for a complete healing without any further complications. Oskay-Özcelik (61) observed that 81% of patients in an adjuvant setting and 34% of patients in a palliative setting hoped for a full recovery with no more symptoms. It should be mentioned that the participants of the current study are suffering from ovarian cancer and there are more palliative patients compared to the study conducted by Oskay-Özcelik, which included the patients with breast cancer. This could be the reason for the difference in the results of the two studies. No such observation in cancer patients of India was found in the literature.

57% of the Indian patients of the current study wanted to know the side effects of the medication and how to avoid them, where as 21% of the German patients wanted to know their side effects and how to avoid them. It was found before that the Indian patients in the present study suffered more side effects in terms of pain and nausea. It could be the reason for the difference in the opinion regarding the functioning of the required medication in respect of side effects and their avoidance.

29% of Indian patients and 2% of the German patients said that they were not interested to know about the functioning of the required medicines. 14% of Indian patients and 61% of the German patients mentioned that it should be explained to them so that they could understand it. The illiteracy and the ignorance about the disease of the Indian patients could explain the difference in the opinion in regard to the above factors between the two groups of patients.

According to 47% of Indian patients in the present study, the most important information for them regarding their sickness and therapy was whether they were getting the right therapy. According to 69% of German patients the most important information regarding their sickness and therapy was whether they were getting the right therapy. In the study conducted by Oskay-Özcelik (61) it was found that in the case of 89 % patients, the most

important information regarding their sickness and therapy was whether they were getting the right therapy. A difference was observed in case of the two studies in the above aspect.

According to 24% Indian patients of the present study, nutrition was the cause of their illness; 12% thought environmental factors and 10% thought that stress in the family was the cause of their illness. In a study conducted by Kishore (47) in India, the causes of cancer cited by patients were frequently curses, evil eye, spirits and past sin. In another study conducted among cancer patients in New Delhi, it was reported by Pahwa et al. (67) that many patients viewed their disease to be due to bad 'karma' (action). More than half of the respondents in the study conducted by Pahwa believed that cancer is contagious. This belief was also highlighted in the study conducted in West Bengal, India, by Ray and Mandal (77) where it was reported that about 21% of people thought that cancer was an infectious disease. The outcome of the present study differs from the studies conducted in India in regard to beliefs of the patients about the cause of cancer.

In the present study, very few Indian patients compared to German patients thought stress as a cause of their illness. Instead, more Indian patients thought nutrition was a cause of cancer. In a meta-analysis, Petticrew (72) tried to find out the relationship between adverse life events and breast cancer. Random effects meta-analysis of the studies found no significant relationship between breast cancer and either bereavement or other adverse life-events. In a study conducted by Protheroe (74), no association between adverse life events or difficulties and onset of breast cancer was found.

28% of German patients of the present study mentioned that environmental factors were the cause of illness. According to 26% of German patients, stress at work is the cause of the illness, and according to 24% of German patients, stress in the family was thought to be the cause of their illness. The results of the present study differ somewhat from the observation made by Oskay-Özcelik (61). 42% of the patients stated stress in the family, 39% of the patients stated stress at work and 33 % of the patients stated environmental factors as the cause of their illness.

16 % of Indian patients mentioned that they do not receive any aftercare. After the completion of treatment, it is necessary to come for a regular check-up/ follow-up at certain intervals as advised by the Oncologists even in a disease-free condition. Ray et al. (77) observed that only 13.33% of the respondents who suffer from cancer in their survey know this fact. This ignorance leads to a large number of dropout (lost to follow-up) cases. The above factor and the financial burden associated with a visit to hospital could be considered as the cause of the findings of the present study.

5.1 Conclusion from the survey:

If we analyse the results of our survey, we find that there is a large discrepancy between the Indian and German patients regarding the diagnosis, therapy and aftercare management. In spite of that the patients of both countries did not differ much in regard to the satisfaction with the therapy management and the treating physician. In one study conducted in India by Alexander et al. (4), it was found that psychiatric morbidity was significantly lower in those who were 'unaware' of the diagnosis of cancer and had a more hopeful outlook for the outcome of treatment. Maybe this is the cause of better satisfaction with the therapy management of Indian patients even though there was a lack of health personnel and the facilities available to the patients were inadequate.

After analysing the results of the current survey it could be concluded that there are a lot of things to be done to improve the management of patients with ovarian cancer. The treating physicians should get regular training and attend regular courses on the management of pain, vomiting, latest therapy options etc.

The survey also shows that there is a need for self-help groups in India and Germany. Self-help group networks could be a good option for the patients to inform themselves regarding the illness and treatment from the patients and peer counsellors from other region of the country and also from the other country.

An international working group of physicians could also be a good option for optimising the therapy management of the patients suffering from ovarian cancer. This could provide a

common platform for the treating physicians, where they could discuss the problems of the treatment, exchange ideas and get information for a better management of ovarian cancer.

Quality control in ovarian cancer surgery is another point, which could improve therapy management. In a literature review of papers (37) it was found that investigators from Hesse, Germany were the first to document the quality of surgery performed on patients with ovarian cancer. Subsequently, investigators in the United States and European countries have demonstrated that patients treated by gynaecological oncologists in large-volume tertiary institutions had the best outcomes. The Gynaecological Cancer Group of the European Organisation for Research and Treatment of Cancer (EORTC) has developed a series of process quality indicators for ovarian cancer surgery that could be used by surgeons or units to audit and improve their practice. That's why quality control in ovarian cancer surgery would be a very important factor in Germany as well as in India for a better outcome of the treatment which can lead improved satisfaction of patients suffering from ovarian cancer.

The current survey makes a comparison of patients suffering from ovarian cancer in Germany and India. From the data from patients in Germany suffering from ovarian cancer, it was concluded that there is a great need for ovarian cancer patients to discuss all details about treatment options and clinical management. Ovarian cancer patients need more information about side effects, studies, supportive care and additional opinions. The physician is the most relevant source of information for patients. No impact of age, profession or tumor stage was observed on the results (62, 64). To find out the needs of the patients further international studies are needed.

On the basis of these results, another survey (Expression III) was performed from December 2009 to October 2012 with patients with ovarian cancer from 8 countries in Europe (Austria, Belgium, France, Germany, Italy, Poland, Rumania, Spain). The Expression III survey underlines the great need of ovarian cancer patients to discuss all details concerning treatment options and clinical management with only minor difference

between the countries. Patients also need more information about side effects of cancer therapies and second opinion opportunities (82, 63).

On the basis of the results of the above three surveys, currently another survey Expression IV Ovar, a European survey (10-12 countries) is continuing to identify information needs and preferences regarding maintenance therapy among patients with ovarian cancer (82).

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Eidesstattliche Versicherung

„Ich, Soumya Prasad Kar, versichere an Eidesstatt durch meine eigenhändige Unterschrift, dass ich die vorgelegte Dissertation mit dem Thema: “A comparative survey of German and Indian patients with ovarian carcinoma as regards to needs and expectations in respect of the Physician-patient relationship and treatment management” selbstständig und ohne nicht offengelegte Hilfe Dritter verfasst und keine anderen als die angegebenen Quellen und Hilfsmittel genutzt habe.

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Datum

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LEBENS LAUF

ACKNOWLEDGEMENT

First of all I would like to thank my family members in India, who supported throughout my study. Without their support and good wishes it would not be possible to finish the study in medicine and to complete the thesis.

My special appreciation goes to my wife Ranjita Pati-Kar who supported throughout my study. I would thank her for the support during the interviews conducted in India and writing the thesis.

I would like to thank all the patients with ovarian cancer who took part in the survey and provided their data. This survey has only been possible through their commitment. A special thank also go to the institutions in India (Acharya Harihar Regional cancer Institute in Cuttack , Kalinga Institute of Medical Sciences in Bhubaneswar, Sparsh Hospitals in Bhubaneswar, Ayush Hospital in Bhubaneswar) for giving permission and supporting me to perform the interviews.

I would like to express my special appreciation and thanks to Professor Dr. med. Jalid Sehouli for his support and guidance throughout the survey and correction of thesis. I would also like to thank Dr. med. Gülten Oskay-Özcelik for her support and advices during the complete period of time.

Special thanks also go to Dr. Rolf Richter for his advices and support in statistical analysis of the data.

Special thanks to the North- Eastern German Society of Gynaecologic Oncology (NOGGO) for their great support and to Alcedis GmbH, Giessen for helping in documentation of the data from the survey.