Patient reported symptoms of cancer treatment and patient satisfaction in BNGO practices – a German survey including the NCCN distress thermometer

Jörg Schilling, Alexandra Hansen, Petra Ortner, Mascha Pömmnerl

For the German Professional Association of Gynaeco-Oncology in Practices (BNGO)

Background and objectives

Providing high-quality treatment for patients with gynaecologic malignancies on an outpatient basis and maintaining patients' quality of life are pivotal objectives of the German Professional Association of Gynaeco-Oncology in Practices (BNGO). Therefore, Gynaeco-oncologists associated in the BNGO perform biannual quality assurance surveys on patient satisfaction with treatment and care and on the burden of disease and cancer treatment.¹ In 2015, questions about the frequency of adverse effects of cancer treatment and patient reported burden of side effects and symptoms were added to the questionnaire. In 2017, questions of the NCCN distress thermometer² were additionally included. The survey took place in the period September–December 2017.

Methods

In August 2017, 11,900 printed questionnaires were distributed to 113 practices. Documentation period was 3 months. 1,116 patients treated in 32 practices completed the 8-page-questionnaire including questions on the distress they were experiencing, on tumor- and treatment-related symptoms, and on their satisfaction with the practice and the physician. Patients used pictograms to assess their satisfaction with practice, physician and medical staff. In order to assess the distress caused by their cancer treatment in the past weeks, patients used the NCCN distress thermometer.

All patients reported the frequency of the symptoms and side effects they experienced using the categories never, seldom, sometimes, often and always/all the time. Patients also reported the burden of the symptoms and side effects using a Visual Analog Scale (VAS) from 1 (least) – 5 (most) or 10 (most). Chemotherapy patients reported the frequency of side effects of chemotherapy and rated the most distressing symptoms on a scale of 1 (least) to 10 (most).

Am meisten belastet haben mich:										
	AM WENIGSTEN						AM MEISTEN			
Hitzewallungen	☐	☐	☐	☐	☐		☐	☐	☐	☐
Übelkeit am Tag der CT	☐	☐	☐	☐	☐		☐	☐	☐	☐
Erbrechen am Tag der CT	☐	☐	☐	☐	☐		☐	☐	☐	☐
Übelkeit an den Tagen nach der CT	☐	☐	☐	☐	☐		☐	☐	☐	☐
Erbrechen an den Tagen nach der CT	☐	☐	☐	☐	☐		☐	☐	☐	☐
Haarausfall	☐	☐	☐	☐	☐		☐	☐	☐	☐
Lockere Zähne	☐	☐	☐	☐	☐		☐	☐	☐	☐
Hautausschlag	☐	☐	☐	☐	☐		☐	☐	☐	☐
Rötungen, Druckstellen oder Blasen an Händen, Füßen oder anderen Stellen z.B. Achselhöhlen	☐	☐	☐	☐	☐		☐	☐	☐	☐
Nagelveränderungen z.B. Verfärbungen oder Rillen	☐	☐	☐	☐	☐		☐	☐	☐	☐
Taubheit oder Kribbeln in Händen oder Füßen, so dass Sie z.B. keine Knöpfe mehr schließen können (Polyneuropathie)	☐	☐	☐	☐	☐		☐	☐	☐	☐

At the end of the questionnaire, patients were asked for a final overall assessment of their cancer treatment and were asked for suggestions for improvements.

Results

Age and treatment

The majority of patients were aged 50–59 years (30.5 %), 25.6 % of the 1,116 patients were aged 60–69 years. At the time of the survey, almost 69 % of patients received chemotherapy and 32 % received a drug-based treatment other than chemotherapy. 39 % received radiation therapy and 55 % had undergone surgery.

Satisfaction with practice and physician

Equipment and organisation of the practice were assessed as “very good” or “good” by more than 90 % of women and the practice staff and physicians were rated “very good” or “good” by 99 % of patients. 67 % of patients said they would choose outpatient treatment again, 31.7 % did not specify. Of all patients who gave an overall assessment of their cancer treatment, 100 % said they would seek treatment in the same practice again.

Overall distress

How much distress have you been experiencing in the past weeks? (n=936)

Daily problems, n=1 000

In the week prior to the survey, almost half of the patients experienced fears (45 %), worries (43 %), sadness (34 %), and nervousness (31 %). The most common physical symptoms included fatigue, problems sleeping, pain and paraesthesia:

Side effects and symptoms – all patients

Most common disease symptoms, n=938		Most distressing disease symptoms, n=938	
Always or often, %		Very or most distressing	
Tiredness	41 %	Fatigue	34 %
Fatigue	39 %	Problems sleeping	33 %
Problems sleeping	36 %	Tiredness	30 %
Hot flushes	35 %	Bone pain	27 %
Loss of sexual desire	31 %	Hot flushes	27 %

Side effects and symptoms – chemotherapy patients

Most common side effects of chemotherapy, n=648		Least common side effects of chemotherapy, n=648	
Always or often		Never or rare	
Alopecia	83 %	Fevers	92 %
Tiredness and fatigue	54 %	Loose teeth	90 %
Numbness/tingling in hand/feet	40 %	Vomiting, day 1	87 %
Sleeping disorders	39 %	Vomiting, day 2	84 %
Nail changes	36 %	Bruises	83 %

Most distressing side effects of chemotherapy, n=626		Least distressing side effects of chemotherapy, n=626	
Very or most distressing		Less or least distressing	
Bone pain	47 %	Fever	88 %
Alopecia	44 %	Loose teeth	83 %
Numbness/tingling in hand/feet	25 %	Vomiting, day 1	80 %
Fatigue	23 %	Vomiting, day 2	77 %
Tiredness	23 %	Bruises	81 %

Problems after the end of chemotherapy

Problems persisting after the end of chemotherapy, n=425	
Always or often	
Tiredness and fatigue	36 %
Numbness and tingling in hands/feet	34 %
Bone pain	32 %
Hot flushes	32 %
Sleeping disorders	31 %

Complementary therapies

19 % of patients used complementary medication during their cancer treatment, 37 % of patients did not specify. In 51 % of patients, complementary drugs were recommended by their oncologist and in 31 % by another physician.

Conclusion

According to the NCCN distress thermometer included in the survey, 66 % of patients described the distress they experienced due to their cancer or cancer treatment using the categories 0–6 (no distress at all – moderate distress). Side effects of chemotherapy that can be prevented by supportive care such as nausea and

emesis are among the least common side effects. Alopecia is the most common side effect of chemotherapy and is also the second most distressing symptom after bone pain. After the end of chemotherapy, fatigue persisted in 36 % of patients. 40 % of patients had paraesthesia (always or very often) during chemotherapy that persisted in 34 % of patients even after they had finished chemotherapy.

1 Schilling J, et al. Geburtshilfe Frauenheilkd 2016; 76 – P129 DOI: 10.1055/s-0036-1593016
2 https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf. Last accessed 5.2.2018