



MALLOW MIRROR

Cervical cancer and ovarian cancer patient journey survey 2019™

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Foreword

The aim of the Mallow Flower Foundation is to support the recovery of women affected by gynecological tumors and to help prevent cervical cancer. Our organization has more and more members every year and we describe ourselves 'obsessed' in the positive meaning of the word. The range of jobs we take up is very wide: patient journey management, mental support, assistance in contacting the doctor, campaigns, organizing programs, or rehabilitation support are just a few of these. It is essential that in every field of our work we closely co-operate with the professional side, in every case we ask for doctors' and health care experts' opinions, the materials we publish are always lectured by them.

In the last 6 years we have had many 'colourful and conspicuous' events, consciously trying to fight taboos related to cervical cancer (today also tumors in the ovaries, uterus, vulva and vagina), raise awareness and promote a prevention-based approach. Beside our mainly emotion-related activities, in 2019 we started a project based on rationality in order to be able to discuss the facts we hear every day and the data related to the disease in terms of concrete numbers. As a result of this, last February the Mallow Flower Foundation, the Inspira Healthcare Research market researcher and Big Data co-operated and carried out an exclusive medical survey. In the operation of the above mentioned agencies CSR has always played a major role, so they were immediately open to conducting the research. Processing a relatively big sample, this unique and also niche research thoroughly examines patients' physical and mental impressions and experiences in great detail, and this summary aims at presenting the results.¹

The aim of the Mallow Flower Foundation is to communicate the results towards the habilitator, doctors, the medical profession and the general public, and also to use them in order to improve health care, to highlight improvable points, education - thus further strengthening the responsible build-up of the Mallow Flower brand and also placing its operations on an even more scientific footing.

¹ The study summarizes emphasized statistics results relevant to analysis, but does not contain details of every question. (Which explains why in some cases the presented percentages do not make up 100%.)

Research methodology

The research was carried out using quantitative questionnaires, with online surveys, self-filling (CAWI) methods. The participants were randomly invited from two sources:

- on the one hand, ladies registered to the Mallow Flower's own Facebook community were sent individual invitation links,
- on the other hand, with the help of some Hungarian medical institutions, the ladies affected by the diseases were invited by their doctors and assistants to participate in the research.

The field work of the survey was carried out in Feb-March 2019, our questionnaire was filled by 425 cervical cancer and 96 ovarian cancer patients.

Filling the questionnaire containing 170 questions took 30-40 minutes on average, with mostly simple, closed questions. The given answers are retrospective in nature, therefore the results are based on patients' memories. Our research did not aim at comparing the recalled experiences with actual happenings (and it would also have been technically impossible).

The sample of nationwide coverage was regionally mixed, and due to the methodology, the proportion of middle or higher educated participants is somewhat overrepresented. It is therefore important to state that the sample, due to the composition, cannot be considered representative, yet it provides a deep enough scoop to draw the general conclusions regarding the target group. In addition, from the methodology point of view, the filling-in rate can be considered extraordinarily high for the following reasons:

- the affected target group is special by nature, in the classic market research framework it is extremely hard to reach, so with the lack of a supporting background (e.g. the help of a patient organization) such a high volume project would be difficult and very expensive to carry out;
- the questionnaire can be considered especially long, so it is challenging to maintain interest, given that participation was voluntary and without interaction (online),
- considering the above and the fact that data collection took less than a month, we can state that the patients' interest (and involvement) was high in the topic – also seen from the high number of participants.

Considering the possible limitations, it can nevertheless be stated that the research plugs gaps, since no such research has ever been carried out with so much detail on such a big sample regarding patients' journeys and feelings.

Composition of sample

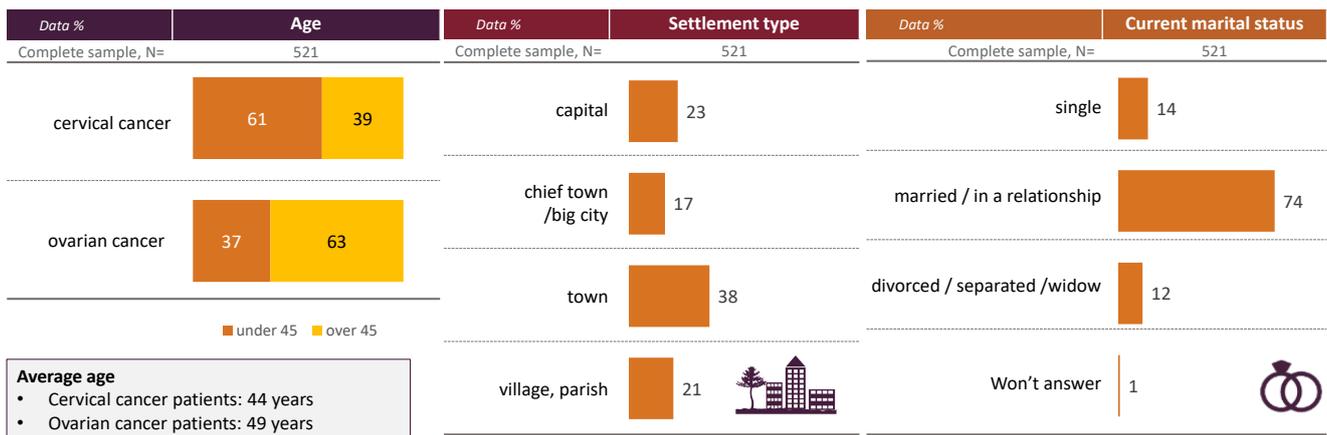
Demographic data

The average age of participating ladies affected by cervical cancer is 44 years, while that of those affected by ovarian cancer is somewhat higher, 49 years.

According to qualification, the majority of participants has higher level education (40%) or at least secondary education (40%). Regarding settlement type, the sample is mixed, the number of those living in cities is the highest (38%), 23% in Budapest, 17% in chief towns of counties. 5% of participants answered the questions from abroad (mostly from Austria and Romania).

Whether we consider cervical or ovarian cancer cases, we can state that the marital status had not changed considerably compared to before the disease, three quarters of the ladies live in relationships.

Graph 1: Composition of sample



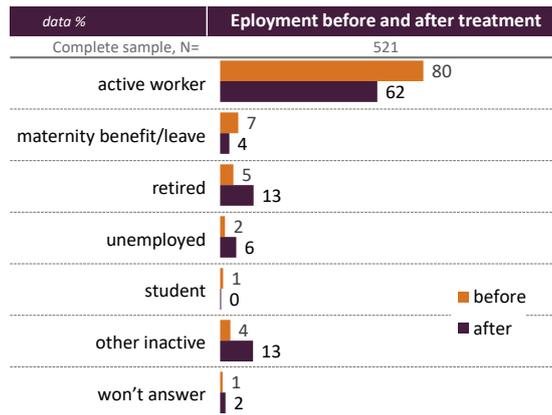
48% do not smoke at all, 25% used to smoke but not anymore, and the same is the percentage of active smokers.

All in all, 50% of participants have family history of gynecological tumors, this number is a little higher for those, who are affected by ovarian cancer, 59% (with cervical cancer 48%). The most commonly occurring cancer type is breast cancer, cervical cancer and in ovarian cancer cases it is ovarian cancer.

Employment data

The tumor had a high impact on women’s activity levels: after getting back to work, employment rates decreased by 20% among those affected, especially in ovarian cancer cases. Before the disease, on average 80% were actively working, after the illness only 62%. At the same time, the number of those in an inactive status increased from 4-5% to 13% (especially in ovarian cancer cases).

Graph 2: Employment data



After the disease 57% of participants returned to their previous workplaces within 3 months, another 28% over 3 months. About 10% of the participants were forced to change workplaces after the disease.

As to employment after the disease, more than 80% of the participants did not change their working hours. According to the results of the survey we can state that ovarian cancer has a higher impact on working abilities, since in the case of ovarian cancer it is more typical that

- the side effects of recovery after treatments/surgery made work hard and
- the workplace offered more beneficial working hours and/or conditions.

9% of participants are considering the possibility of, while 16% have already opted for invalidation. Seeing the above results, it is not surprising that the proportion of applicants is considerably higher (29%) among women affected by ovarian cancer (with cervical cancer only 13% initiated it).

Invalidated women have an average age of 50 years, while that of those considering it is only 47 years.

Graph 3: Invalidation data

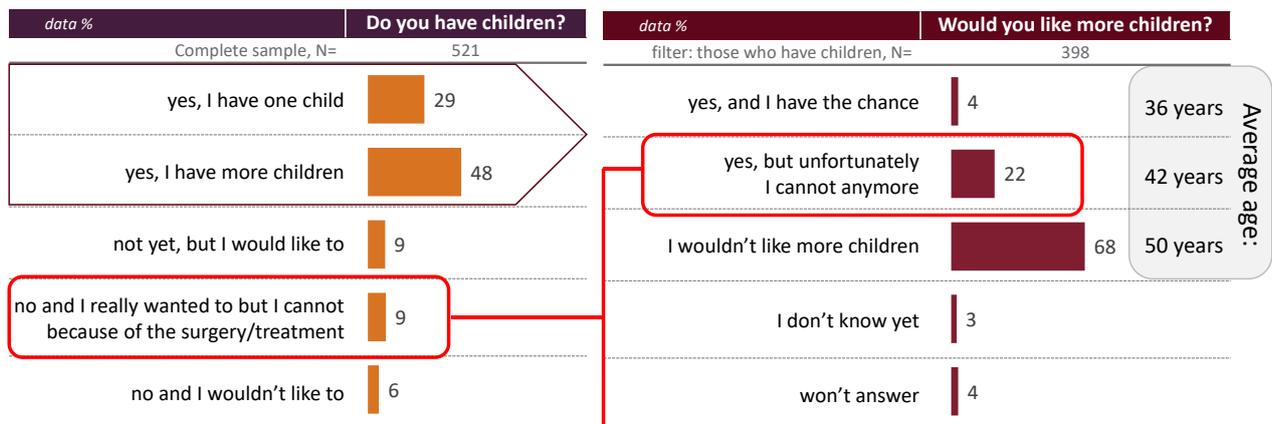
Because of your illness did you/would you apply for invalidation?			
Data %	Total	Cervical cancer	Ovarian cancer
Complete sample N=	521	425	96
yes, i am invalidated	16	13	29
no, and i am not planning it	53	55	44
not yet, but i am planning it	9	8	13
not yet, but i don't know	22	24	15

Willingness to have children

80% of the participants already have children, while 9% (mostly in ovarian cancer cases) did not have a child before the illness and cannot have children anymore due to it. One fifth of those with children (22%) wanted more children but due to the disease cannot give birth anymore, this is more common among ladies affected by cervical cancer, 25%. Very few are considering the possibility of adoption (2%).

All in all, it can be stated that 26% (!) of ladies affected although wanted to have more children, it is not possible due to the disease. The average age of ladies losing the opportunity is only 40-45 years.

Graph 4: Willingness to have children



In the full sample (n=521) 26% (!) of patients wanted to have children but it is not possible due to the illness.

With respect to contraceptive methods, the majority (44%) of participants take hormonal tablets, 27% use condoms, 23% use nothing at all. Significant differences occur in the applied methods according to age, since those under 45 mostly use hormonal tablets (53%) and condoms (33%), among those over 45 intrauterine instruments (16%) or the interruption methods (15%) are more popular.

Symptoms and diagnosis

The first symptoms and visiting the doctor

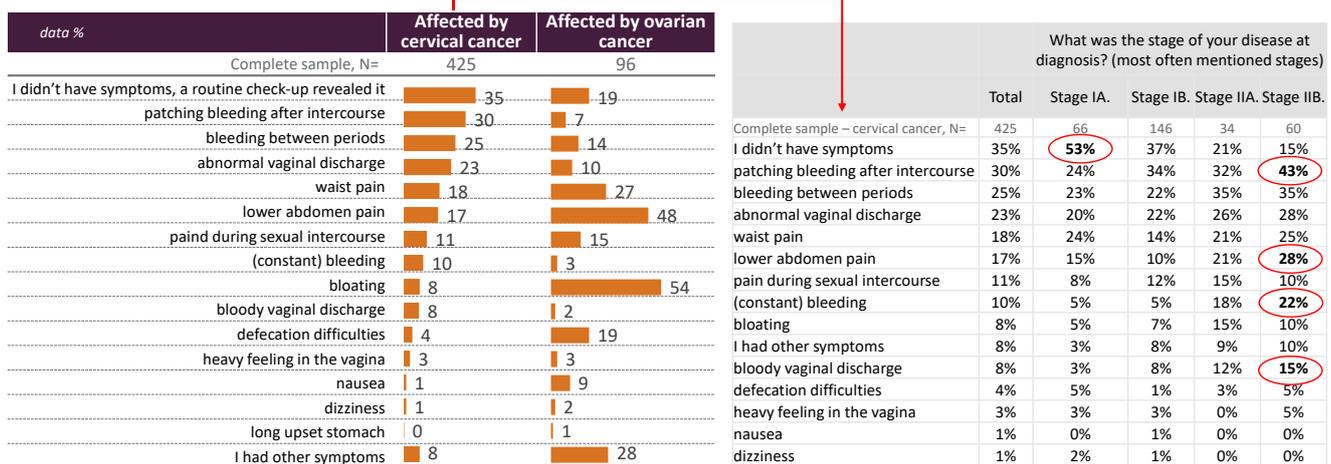
The average age at the diagnosis was 40 years in cervical cancer, while 45 years in ovarian cancer cases.

The nature of symptoms is quite different according to the two disease types. With cervical cancer it is more common (35%) that there are no symptoms at all, if there are, then patching bleeding after sexual intercourse (30%), bleeding in between monthly periods (25%) or abnormal vaginal discharge (23%) are the most common symptoms. As opposed to this, the most common symptoms of ovarian cancer patients are bloating (54%) and abdominal pain (48%).

With patients diagnosed in the early stage of cervical cancer, the proportion of ladies without any symptoms is significantly higher (53%), while for patients diagnosed in more advanced stages (IIB) typical symptoms are patching bleeding after sexual intercourse (43%), abdominal pain (28%), constant bleeding (22%) and bloody vaginal discharge (15%).

Especially in connection with the symptoms of ovarian cancer, it is very important to emphasize that the often mild or disguised (as other organ-related) symptoms contribute greatly to the fact that patients receive proper treatment too late. It is therefore essential that even as non-professionals we keep the possibility of the disease in mind.

Graph 5: The first symptoms



After the occurrence of the symptoms about half of the participants visited the doctor within a month. After visiting the expert, half of the participants had the diagnosis within a month, the number is a little higher for ovarian cancer (59%) than cervical cancer (48%).

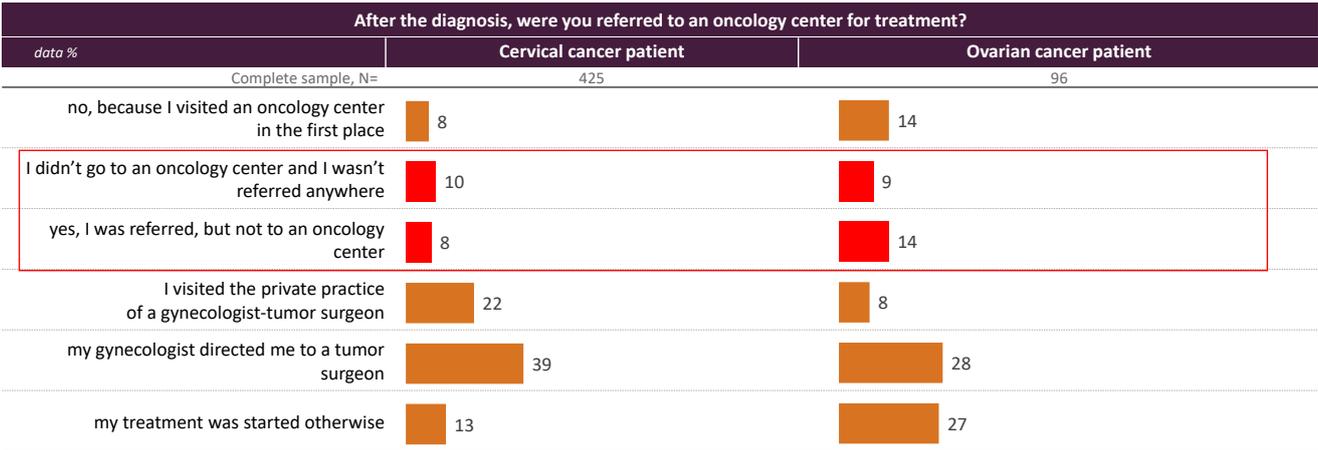
After cross factoring data analysis it can be stated that among those visiting the doctor within 1-3 months, it was significantly more common that bleeding between monthly periods, patching bleeding after intercourse and abnormal vaginal discharge occurred.

Whichever disease type we look at, the most featureless symptoms that women visited the doctor with, sometimes even 6 months later, were abdominal and waist pain.

After the diagnosis, the common practice is that the gynecologist refers the patient to the oncological surgeon. In cervical cancer cases the diagnosis is more often reached in private practice (27%), in ovarian cancer other ways (27%).

All in all, 20% of ladies were not referred to an oncology center after the diagnosis.

Graph 6: Referral after diagnosis



Cervical cancer diagnosis

After the examination by the doctor, 25% of the women affected by cervical cancer got the diagnosis in a few days, 54% within one month.

Two thirds of cervical cancer patients' diagnosis was given by the gynecologist, and this practice is significantly higher (above 80%) among patients not treated in oncology centers. The proportion of a diagnosis given by a gynecologist-tumor surgeon is 23%, mostly reached in private practice, while in oncology centers usually the oncologist gave a diagnosis.

To reach a diagnosis, in two thirds of the cases citology was carried out (61%) and conisation (59%), while one third had a CT or MRI. The type of tests done significantly varies according to the geographical position of patients.

- **MRI: significantly rarer in the capital (24%), while more common in cities (45%)**
- **colposcopy²: its occurrence decreases by city size (most common in Budapest (28%), least common in villages (18%))**
- **HPV test: more typical in chief towns (33%), rarer in villages (12%)**

Graph 7: Tests done to reach diagnosis (cervical cancer)

data %	Tests
Complete sample – cervical cancer, N=	425
citology	61
other sample-taking (conization)	59
MRI	36
CT	35
colposcopy	22
HPV Test	22
tumor marker test	10
punch biopsy	5
biomarker test	1
other test/tests	10
I don't now/don't remember	1

34% of patients were in stage IB when the diagnosis was given, 16% were in stage IA, 14% were in stage IIB. Most stages (55%) did not change later, while 10% got worse, 17% got better.

² We did not examine patients' understanding of test types during this research.

For 55% of cervical cancer patients the biopsy showed epithelioma, for 20% adenocarcinoma, another 5% had both. 8 out of 10 participants could not recall the exact diagnosis results.

The type of biopsy result shows a connection with the disease stage at the diagnosis: 60% of patients diagnosed with IA-IB stages had epithelioma, while adenocarcinoma was more common among patients diagnosed in stages IIA-IIB.

61% of the ladies felt that they were able to discuss every detail with their doctor, 25% of them felt that the information was only partial, 7% had no information at all (even though it would have been welcome).

Ovarian cancer diagnosis

The ladies got the ovarian cancer diagnosis somewhat faster, 42% got it in a few days, another 35% within one month (the soonest in the countryside, the latest in the capital)³.

In most cases the diagnosis was given by the gynecologist (47%), but in this respect the gynecologist-oncological surgeon (28%) and oncologist (17%) have an important role. According to age, the mention of the gynecologist is more common under 45 (57% compared to the 42% among women over 45) , whereas among elder patients the same holds for the oncologist (under 45 only 6%, over that age 22% mention them).

Most patients had tumor marker tests (73%), CT (65%) and complete bloodcount (50%). The type of tests done shows significant differences according to geographical position in this case as well.

- **CT: lower in chief towns, 46%, while at other places (capital, other cities) higher (63-77%)**
- **MRI: significantly more common in chief towns (31%), other places more rarely done (18-25%).**

Graph 8: Tests done to reach diagnosis (ovarian cancer)

data %	Tests
Complete sample – ovarian cancer, N=	96
tumor marker test	73
CT	65
complete bloodcount	50
laparoscopy sample-taking	25
MRI	23
other test/s	42
I don't know/don't remember	1

³It would be an extremely important question how much time passes between the occurrence of symptoms and the diagnosis, but because the symptoms are featureless it is impossible to estimate. The stage definition allows some conclusions as to the time frame.

Treatment practice for cervical cancer

Cervical cancer and HPV screening

It is a further problem to be emphasized that a lot of women still do not have regular cervical screening. According to the patients' answers, for this purpose only about 50% of participants visit the doctor every year, and the proportion of those who go to regular screening is significantly higher (56%) among those under 45 (above 45 only 41%!).

14% of those screened had a positive last test result.

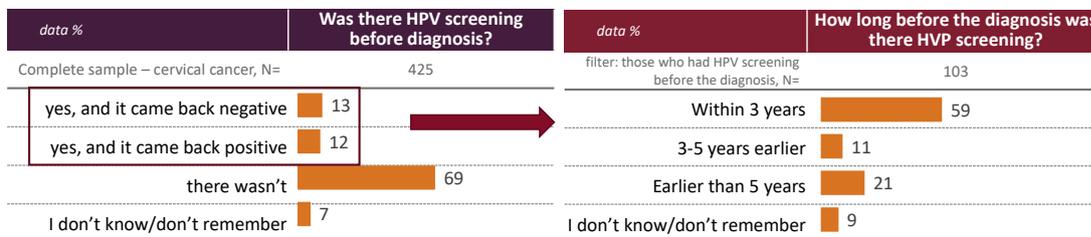
73% of those who had a cervical screening within one year of the diagnosis never had a positive result (that is, the cytology came back negative)!

Graph 9: Cervical screening practice (cervical cancer)



Before the diagnosis 25% of cervical cancer patients had HPV screening, most of them (59%) within 3 years. Almost half had a positive result, and among those whose test came back positive, the proportion of those who had the HPV screening at least 5 years earlier was significantly higher (31%).

Graph 10: HPV testing practice (cervical cancer)



The most commonly identified types with screening are 16 (47%) and 18 (24%), but 39% of HPV-infected participants could not name the type that had caused the disease. Few got HPV vaccination (4%) (on average at the age of 30, and the mention of the available vaccines was mixed).

Only 2% of ladies had a biomarker test.

Major surgery type and place

81% of those affected by cervical cancer had surgery and expectedly will not need further operations. Around 6% will need further surgery.

71% of ladies undergoing surgery chose their operating doctors. Most ladies who had an operation (43%) chose the tumor surgeon by the treating doctor's recommendation or by the recommendation of acquaintances (29%) (the latter is significantly more common in Budapest, 40%). Smaller is the proportion of those who chose the operating doctor according to information found online (7%) or with the help of the Mallow Flower (4%)⁴.

Before major surgery, about three quarters of the ladies underwent minor surgery, 53% had cold knife conisation, 20% underwent Leep/Loop operation. Minor surgery before major surgery is significantly more common among patients diagnosed in stages IA and IB. Leep/Loop operation done before major surgery is rare among patients diagnosed in stage IIB.

Cervical cancer patients' major surgery lasted 4 hours on average, the most common type is Wertheim-operation (62%), especially at a higher age (under 45 53%, above this 76%). Wertheim-ART is more often mentioned by younger patients (20% under 45, over this only 7%.)

⁴ With regards to our work, this justifies that more patients find us when they already have the specific diagnosis. Another important, also practical, experience is that many ladies who turn to us often hear about patient support opportunities by the recommendation of friends, acquaintances. Considering the high recommendation number in Budapest, we consider there is a high chance of our Foundation being mentioned more often in the capital.

Cross factoring data about the major surgery type and disease stage at diagnosis, we can conclude that in stage IIA Wertheim is significantly more common, while in stage IB a quarter of patients undergo Wertheim-ART.

Graph 11: Type of major surgery (cervical cancer)

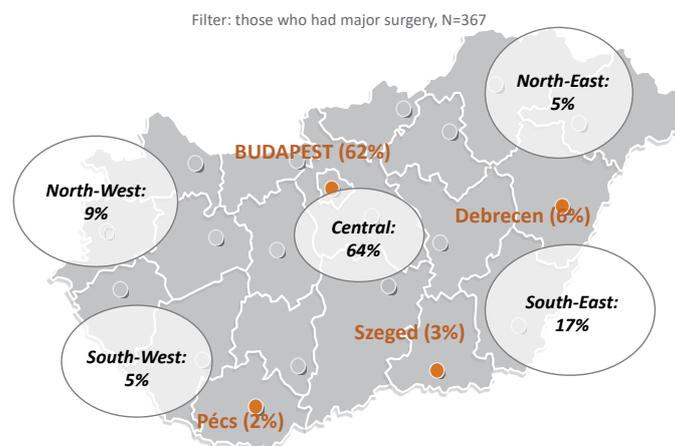
Type of major surgery:	Total	What was the stage of your disease at diagnosis? (most often mentioned stages)			
		stage IA.	Stage IB.	Stage IIA.	Stage IIB.
filter: those who had major surgery, N=	369	62	144	30	36
Wertheim (radical hysterectomy)	62%	52%	67%	93%	75%
Wertheim-ART (radikal abdominalis trachelectomia)	15%	16%	24%	0%	14%
simple uterus removal	8%	10%	3%	3%	6%
laparoscopy trachelectomia	4%	6%	4%	0%	0%
exenteration	0%	0%	0%	0%	0%
other	6%	10%	2%	3%	6%
I don't know/don't remember	5%	6%	1%	0%	0%

After major surgery 12% of patients had some kind of infection, 5% in the hospital, 7% later. Embolism or thrombosis during/after surgery is very rare (around 1-3%).

Major surgery was performed in city hospital in most cases (63%), every fifth lady (21%) underwent it at a university hospital. Operations performed at oncology centers was 11%. Rarely (5% of cases) the surgery was done at a private hospital in the city. The latter was mentioned more often in Budapest (7%) and chief towns (9%), while the oncology centers were more often indicated by patients living in the capital (16%).

Apart from a few exceptions, surgery was always performed (94%) in a state hospital publicly-funded.

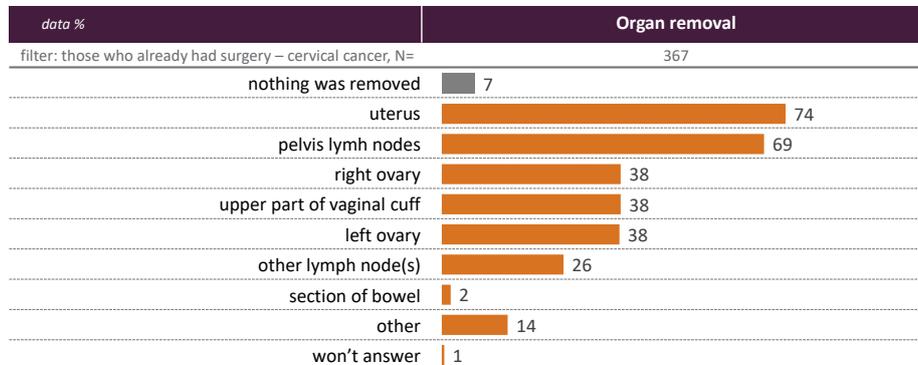
Graph 12: Place of major surgery (cervical cancer)



9 out of 10 patients had an organ removed, most often the womb (74%) and lesser pelvis lymph nodes (69%), but equally mentioned (38%) were the right or left ovaries, and the upper part of the vaginal cuff. The number of removed organs was 3 on average.

74% of women undergoing surgery lost their fertility, their proportion is higher over 45, 89% (at younger patients 66%).

Graph 13: Organs removed during major surgery (cervical cancer)



Repeated surgery, most often within one year, was necessary for 14% of patients undergoing major surgery, and occurred the least often in the case of women living in Budapest (7%).

17% of women with cervical cancer had metastasis, typically in the lymph node(s) (82%), rarely in the lungs (7%).

Treatment practice for ovarian cancer

Type of disease

Among patients affected by ovarian cancer the most commonly occurring (mentioned) disease type is epithelial (serosus) ovarian cancer (18%), but quite a few participants (21%) were unable to recall the exact histology.

During the consultation with the doctor 41% of patients felt that they could discuss every detail with the doctor, while 35% considered the information superficial. 16% had the specific demand to discuss the histology result in detail, but it did not take place.

Graph 14: Type of ovarian cancer

data %	Type of ovarian cancer
Complete sample – ovarian cancer, N= 96	
18	epithelialis (serosus) ovarian cancer – type: high grade
14	epithelialis (serosus) ovarian cancer – type: I don't know the type
12	endometrioid ovarian cancer
7	epithelialis (serosus) ovarian cancer – type: low grade
4	Granulosa tumor
4	Borderline tumor
2	epithelialis pure cell ovarian cancer
2	egg cell ovarian cancer
1	epithelialis ovarian cancer (undefineable)
1	mucinous ovarian cancer
1	primarily peritoneum origin
1	tube tumor
1	teratoma
12	other
21	I don't know

48% of ovarian cancer patients had genetic testing, equally during or after treatment. According to nature, it was 69% BRCAI., 56% BRCA II. (both were present in some cases), a complete genetic map was done in 22% of the cases. Among those who had genetic testing, 42% had some genetic mutation.

Most of the tests carried out (86%) were publicly-funded, but every tenth (11%) was privately financed.

Major surgery type and place

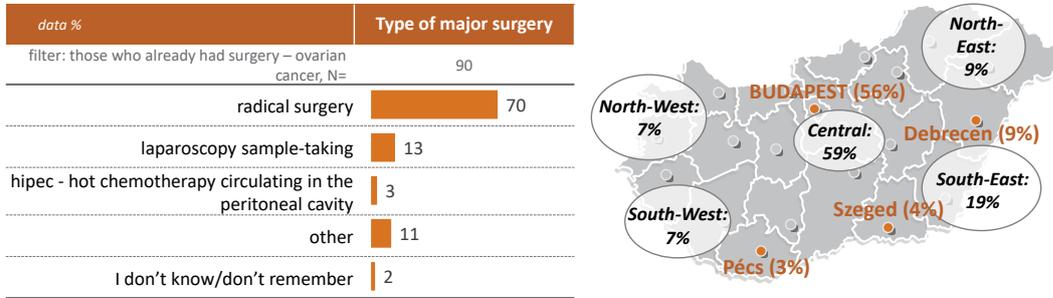
Most ladies affected by ovarian cancer (55%) had one or two (34%) major surgeries, and it can be observed that 'more surgeries' was more common under 45 (51%), while over 45 maximum one operation was performed (67%).

Regarding the type of major surgery, 70% of patients underwent radical major surgery, occurring more commonly at an older age (77%).

Laparoscopy sample-taking was mostly mentioned by younger patients (21%).

Every second major surgery took place in city hospitals, 30% at university hospitals, 14% in oncology centers, mainly publicly-funded (99%).

Graph 15: Type and place of major surgery (ovarian cancer)



The average surgery time was 3 hours, and in almost all cases some organ was taken out, most commonly the left (92%) or the right (90%) ovary had to be removed. For 93% of the women undergoing surgery fertility could not be saved, more commonly over 45 (100%).

Repeated surgery was necessary for 42% of patients, mainly among those under 45.

68% of ovarian cancer patients undergoing major surgery said that their tumor had been completely removed during the operation, for 18% only partially. In 14% of the cases the patients thought the removal was optimal but it turned out later that it was not, the latter was significantly more common among younger patients (24%, while with older patients 9%).

About the significance of suboptimal (partial) surgery 24% of patients did not receive any information, while a fully detailed explanation was given to only 53% of the ladies.

In this patient group 49% of the women had some kind of metastasis.

Oncoteam

Participation in the sessions

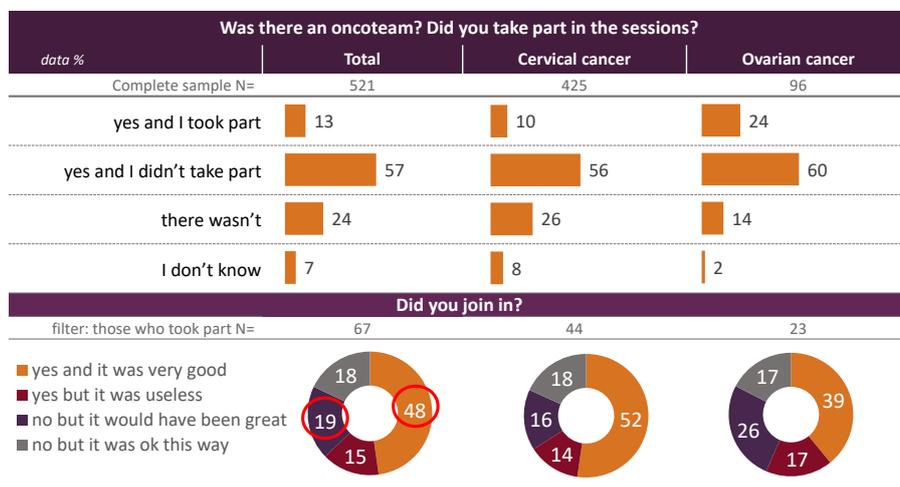
70% of participants were aware that an oncoteam was established regarding the therapy, but in the majority of cases the patients did not take part in the sessions of the team. Altogether 10% of cervical cancer patients were present, while in ovarian cancer cases somewhat more, 24% took part.

Among those taking part, two thirds also joined the conversations, and from this respect the younger patients proved to be more active: under 45 74%, over this age only 46%.

It is important to point out that the ladies taking part in the sessions had a positive experience, and every second lady present in the meetings (48%) considered this a very good opportunity!

In most cases (88%) the team’s decision was accepted by the patient, rarely not at all (8%) or only partially (4%).

Graph 16: Oncoteam practice



The ladies not taking part in the oncoteam meetings were informed by the board draws decisions by the oncologist (39%), the gynecologist (35%), rarely by the surgeon (16%).

Further treatment

Chemo-, radiation and Brachy-therapy

49% of the participants did not receive any treatment after surgery, and their proportion is significantly higher in cervical cancer cases, 58%, compared to ovarian cancer cases where this number is only 9%.

Most of those receiving post-operation treatment (76% on average) received chemotherapy, mainly after surgery (48%). Among cervical cancer patients the number of those who did not get any treatment is much higher (29%), whereas it was common (23%) that there was no surgery, but chemotherapy was given (23%). Among ovarian cancer patients there was pre-operation (22%), but mainly post-operation treatment (70%).

71% of patients finished their appointed number of chemotherapy occasions, while 11% missed some because of the side effects.

Radiation and Brachy-therapy was given to cervical cancer patients and apart from a few exceptions, everyone finished and completely went through with the prescribed medication treatment.

Graph 17: Applied treatments

data %	Chemotherapy		Radiation therapy		Brachy-therapy	
	Cervical cancer	Ovarian cancer	Cervical cancer	Ovarian cancer	Cervical cancer	Ovarian cancer
filter: those who received treatment, N=	180	87	180	87	180	87
yes, I also had it before the surgery	6	22	7	1	6	1
yes, I had it after the surgery	37	70	51	5	42	3
I had it, but no surgery	23	2	25	1	17	0
I didn't get it	29	5	12	91	28	92
it was recommended, but I refused	2	1	1	0	2	0
other	2	0	4	2	5	1

Biological therapy

Biological therapy was more common for ovarian cancer patients (27%), in cervical cancer cases it was rarely applied (3%).

All in all, it can be concluded about those receiving the therapy that:

- for most of them (55%) the therapy was available fully publicly-funded, while for 24% with equity funding,
- 86% received the medication in Hungary,
- to 93% the oncologist recommended the biological therapy, and
- most of them (76%) received it in infusion
- **from applying for biological therapy to the start of the therapy 38% had to wait 2 weeks-1 month, 31% waited 1-3 months.**

Graph 18: Biological therapy

Were you recommended biological therapy?		
data %	Cervical cancer	Ovarian cancer
filter: those who received treatment, N=	180	87
yes, only biological	1	5
yes, with chemotherapy	2	22
no	74	61
I don't know what biological therapy is	22	10
I don't remember	1	2

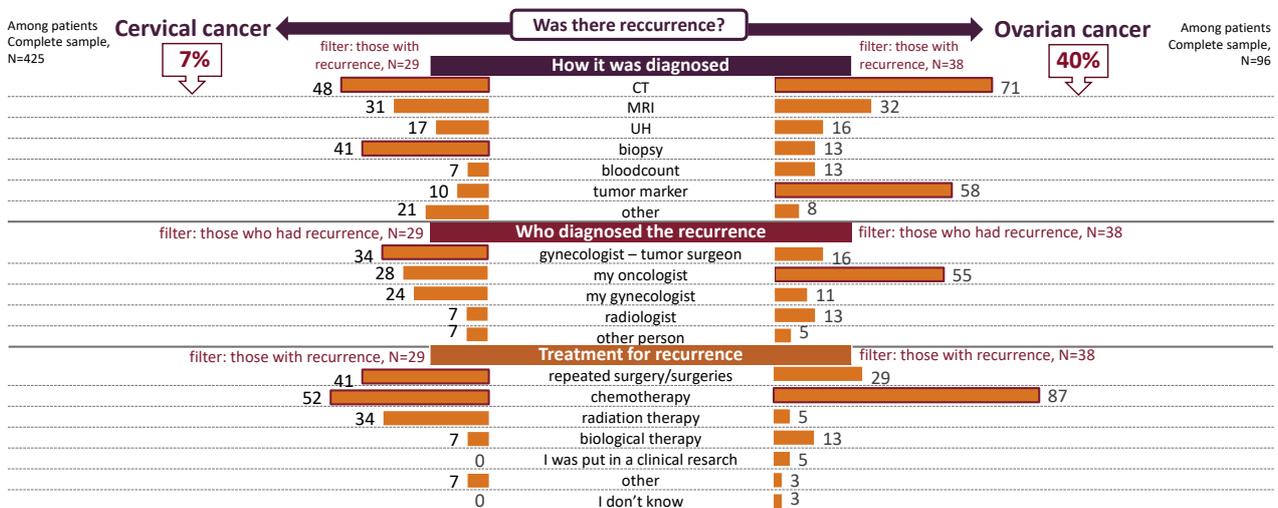
All treatments, detailed above, were provided mostly (44%) in oncology centers, 31% in city hospitals, and 23% in university hospitals. Regarding the geographic position of the treatment, the number of patients treated in Budapest was higher (56%) in ovarian cancer cases, while for cervical cancer it was lower (20%).

Recurrence and follow-up

Recurrence of the tumor is a lot more common among ladies affected by ovarian cancer (40%), in cervical cancer cases it is significantly rarer (7%). In the latter case, there is a wider range of therapy options, chemotherapy, radiation therapy or repeated operation(s) are all applicable, whereas for recurring ovarian cancer the main therapy option is chemotherapy.

The diagnostics and treatment of recurring disease show a different pattern in the examined patient groups, summarized in the graph below.

Graph 19: Recurrence of the disease

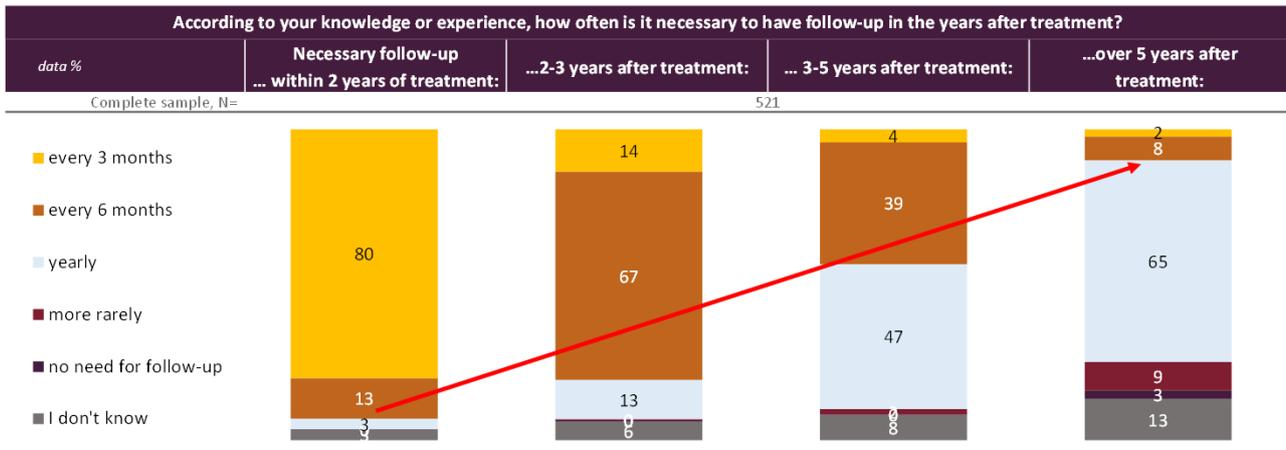


Follow-up tests

94% of patients mentioned that they have follow-up, in a similar proportion according to disease and settlement type. It can be observed that ovarian cancer patients mention significantly more often the need for follow-up tests at least every three months from the second year after treatment – but they just as often give the answer 'I don't know'.

83% of the ladies received proper information concerning the necessary frequency of follow-up visits, while 10% was not informed at all (in their case the proportion of those who could not answer the question regarding the required frequency of follow-up was higher).

Graph 20: Necessary follow-up



For ladies affected by cervical cancer in the first two years follow-up tests included citology (73%), vaginal ultrasound (57%), bloodcount (48%), and abdominal ultrasound (47%).

With ovarian cancer the most important tests were tumor marker (75%), bloodcount (69%) and CT (68%).

The tests were mostly publicly-funded, but in some cases the number of patients visiting private practices for follow-up is specifically high, among these are vaginal ultrasound (64%), citology (50%), colposcopy (48%), abdominal ultrasound (43%) and breast ultrasound (34%). The tests financed by the patients were mostly concentrated in Budapest.

Graph 21: Follow-up tests

data %	Total	Cervical cancer	Ovarian cancer
complete sample, N=	521	425	96
citology	64	73	24
vaginal ultrasound	53	57	38
bloodcount	52	48	69
CT	47	42	68
abdominal ultrasound	46	47	44
MRI	40	41	34
tumor marker testing	33	23	75
colposcopy	24	28	6
mammogram	23	23	26
breast ultrasound	14	14	17
HPV test	13	15	3
surgery	2	1	7
Other	3	2	6
I don't know/don't remember	8	7	10

Change in life quality, patient support⁵

Physiological changes – ‘Triple function loss’

In our research we paid special attention to examining the possible function changes as a result of surgery and other treatments that (can) have a great impact on the patients’ life quality. Therefore we asked them in detail if the applied therapies influenced their urinating, defecation and sexual habits and if yes, to what extent.

The disease had a great impact on the ladies’ urinating habits. 70% of participants indicated that due to the disease their urinating technique changed, and 54% do not feel the need to urinate or in a different way.

By looking at the differences between the two patient groups we can conclude that urinating habits mainly triggered significant changes for cervical cancer patients.

Graph 22: Feeling of the need to urinate

Do you feel when you need to urinate?			
data %	Total	Cervical cancer	Ovarian cancer
Complete sample, N=	521	425	96
I don't feel the need to urinate	21	25	4
I feel the need to urinate in a different way	33	34	27
it is the same as before, nothing changed	41	36	67
other	3	3	2
won't answer	1	1	0

Most can only urinate doing a crunch (28%), another 17% supplement the spontaneous urination process with this technique. Among cervical cancer patients the number of patients who urinate with a crunch is a lot higher (33%).

21% of participants developed stress incontinence due to the disease, while incontinence due to urgent need to urinate is significantly rarer, 5%. Both incontinence problems mostly concern cervical cancer patients. Not often, but sometimes the use of a catheter is needed for urination.

⁵ The Mallow Flower Foundation Recovery Support Program supports patients’ life quality improvement.

Graph 23: Changes in the urinating habits

data %	Nature of urinating technique
Complete sample, N= 521	
I pee like before	43
I pee while doing crunches	28
I developed stress incontinence (sudden movement, coughing)	21
I pee while doing crunches and spontaneously	17
I developed incontinence with sudden peeing urges (regular)	5
I always self-catheter	1
sometimes I use self-catheter	1
I pee with crunches besides self-catheter	1
I have a subpubic catheter	1
other	7
won't answer	2

54% of participants had not had urinary tract problems since the treatments, the number for ovarian cancer patients is higher (65%). Infections are not typical (27%), but for 13% of patients they occur more frequently.

Due to the disease, almost two thirds of patients' defecation habits changed, for 38% the change is major, for 23% minor, and this phenomenon is significantly more common among cervical cancer patients, 66% (ovarian cancer 45%). A typical problem is more or less severe constipation, but painful defecation, occasional diarrhoea and the lack of stimulus also cause problems in the ladies' everyday life.

Almost 60% of the patients who reported defecation changes use some form of help, most use laxatives (40%), but relatively many (14%) use their hands to help the process or self-clyster (8%).

Graph 24: Changes in the defecating habits

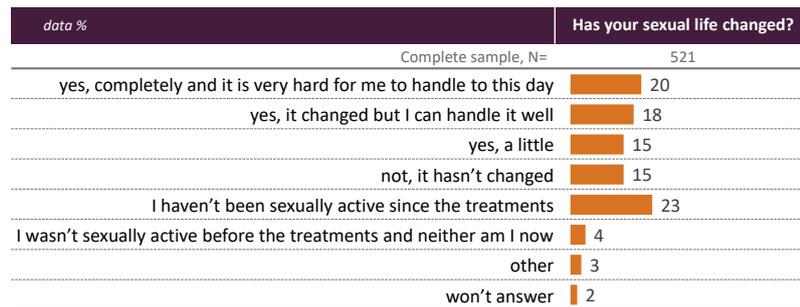
data %	Total	Cervical cancer	Ovarian cancer
filter: for whom it changed , N=	323	280	43
it is difficult for it to pass	40	43	23
sometimes I have constipation	27	26	30
I always have constipation	25	28	12
I rather have droppings	25	28	12
once I have constipation, once diarrhoea	17	16	23
defecation is painful	10	11	2
sometimes I have diarrhoea	9	7	21
I don't feel the need on time	8	9	2
sometimes there is blood in my defecation	7	7	5
I have little defecation	5	5	2
I have diarrhoea all the time	3	3	2
other	8	8	7
won't answer	0	0	2

Almost 50% of patients have experienced changes in sexual life, and for many (20%) the situation is very difficult to handle.

A significant proportion of patients, 23% (!) had not had sexual life since the treatments, and while there are only minor differences according to disease type, with respect to age, more patients over 45 are sexually inactive (in their case it is 31%, among younger patients 17%).

Almost 40% use some kind of helping tool, most of them (31%) lubricant.

Graph 25: Changes in sexual life



Relatively few sought professional help to improve altered functions. Although 32% of patients do not exclude the possibility of asking for help in the future, 37% completely reject it. It is mostly ladies under 45 who are definitely planning to seek expert help, while the older patients try to cope with the situation alone.

All in all, 26% of patients visited a specialist, most of them (12%) a urologist or gastroenterologist (5%).

Graph 26: Seeing a specialist



During the analysis it is worth looking at the number of patients visiting an expert based on whether they had function change, since the probability of visiting a specialist can significantly decrease if a patient did not have to change previous routines or only to a small extent.

From this respect it can be concluded that among those who experienced changes the number of those who had visited or might visit a specialist is higher. At the same time, the need to visit a specialist is not influenced by which function changed, therefore all forms of function changes have the same disturbing and negative effect on life quality.

Menopause symptoms

Due to the disease 45% of women developed menopause, with a lot higher occurrence rate among ovarian cancer patients (59%). Within disease groups some differences occur according to age, because in case of cervical cancer menopause symptoms appear after treatment rather over 45 (54% vs. under 45: 34%), whereas with ovarian cancer rather under 45 (80% vs. over 45: 48%).

Relatively few patients (30% of those who have symptoms) treat menopause, but quite a few (19%) feel they would need some solution. Natural supplements are the most commonly used (17%), but the number of those taking prescribed hormone medication is not much lower (13%). The mention of the latter is twice more common (16%) by patients under 45 than over (9%).

Graph 27: Menopause treatment

data %	Treating menopause
filter: those who developed menopause, N=	232
yes, hormone medication prescribed by the doctor	13
yes, natural products	17
all of the above	1
no, because I don't consider it necessary	36
I don't treat it because I mustn't due to the disease	15
I don't treat it but I think I would need to	19

Lymphedema problems

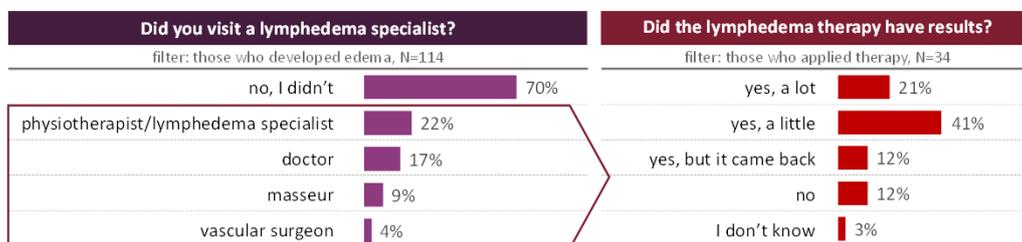
As a result of tumors 2 out of 10 women developed lymphedema (22%), mainly among cervical cancer patients (25% vs. 7%). Lymphedema cases are typically mild (57%) or moderately severe (36%) and mostly occurred in the lower body (twist, thigh, ankle, lower legs).

59% of lymphedema patients do not use compression stockings, and those who do, with mixed frequency: 18% occasionally, 13% often but not every day, while almost 10% on an everyday basis.

Surgery is not common for lymphedema, although a high number of patients (17%) feel the need for surgical treatment. From this respect there is a significant difference based on age, as under 45 10% would require it, over 45 27%!

30% of those who have symptoms visited a lymphedema specialist, most of them (22%) a physiotherapist/lymphedema expert or doctor (17%), but every tenth patient visited a masseur. 21% of those who had therapy said it helped a lot, 41% said it helped only a little. 12% experienced considerable improvement but it was only temporary, and about the same number of patients said the therapy did not bring improvement.

Graph 28: Lymphedema treatment



Fistula only developed for 5% of the ladies maximum once, and in more than half of the cases (56%) between the bladder and the vagina, for one third of patients between the rectum and the vagina.

Getting support, mental help

Beside the treatments one fifth of patients received some kind of support, in most cases from a psychologist (70%), dietician (48%), but many visited a physiotherapist (30%) or pshychiatrist (18%) as well. Whichever form of support, the number of those seeking help is higher among ovarian cancer patients.

There are, however, many cases (4 out of 10 women) when the patient felt the need for help but did not receive any at all. It is more common in the capital and in chief towns.

57% organized the support for themselves, 20% were aided by the oncologist, while 10-10% were directed to the contacts by the oncologist or a patient organization, respectively.

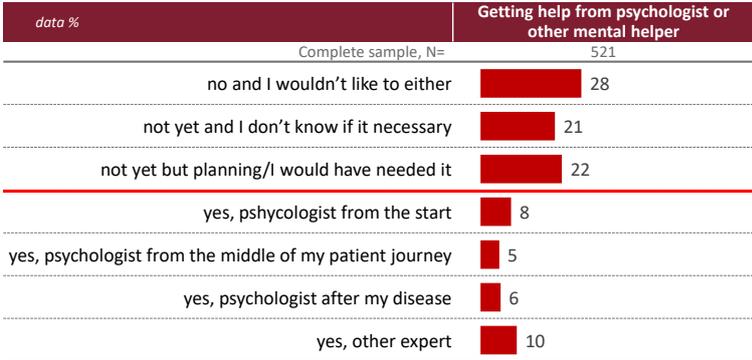
Graph 29: Getting help, support

Did you get other help apart from the treatment (psychologist, dietician...etc)?			
data %	Total	Cervical cancer	Ovarian cancer
Complete sample, N=	521	425	96
no, I didn't although I needed it	37	36	41
no, I didn't but I didn't need it	42	44	33
yes, I did and it helped	19	18	26
yes, I did but it was useless	1	2	0
What specialist did you visit?			
filter: those who got help N=	107	82	25
psychologist	70	65	88
dietician	48	45	56
physiotherapist	30	30	28
psychiatrist	18	15	28
social worker	5	4	8
sexual psychologist	4	5	0
other	14	15	12
I don't know	2	2	0

In a separate question we examined the practice of visiting mental supporters. All in all, regarding the whole sample, 30% of women turned to a psychologist or other mental helper, and their number is higher among ovarian cancer patients, 42% (cervical cancer 26%). The first visit to the psychologist took place almost equally at the beginning (8%), in the middle of the journey (5%) and after the disease (6%).

Almost one third (28%) of patients definitely feel that they do not wish to seek mental support, while 22% are planning to visit a pshychologist, psychiatrist or sexual psychologist. Every fifth woman (21%) is hesitant in this question.

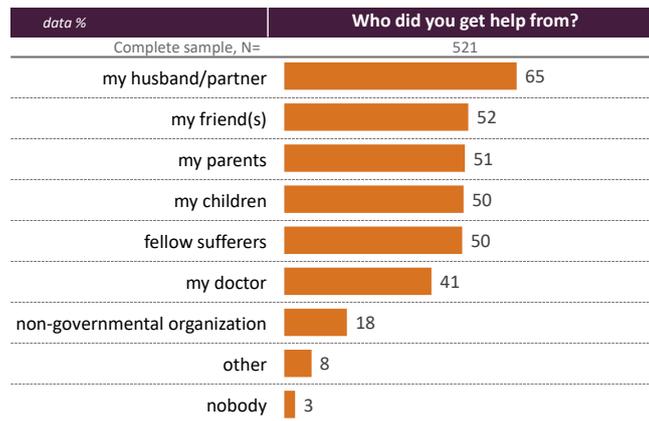
Graph 30: Seeking help from a psychologist or other mental specialist



The highy mental involvement of the disease is also indicated by the fact that beside traditional medicine, a high number of women, 55% tried some alternative complementary therapy: 34% some dietary supplement, 17% mental healing, 16% some other solution. There are no significant differences according to age or disease type.

It is typical in both disease groups that the ladies received a lot of support from the closer family and friends, under 45 rather the parents, over 45 rather the children provided considerable support. Every second patient (50%) had fellow sufferer helpers, and 4 out of 10 received compassion from the treating doctor. One fifth of patients (18%) got help from a NGO, more commonly in Budapest and chief towns.

Graph 31: Patients' helpers

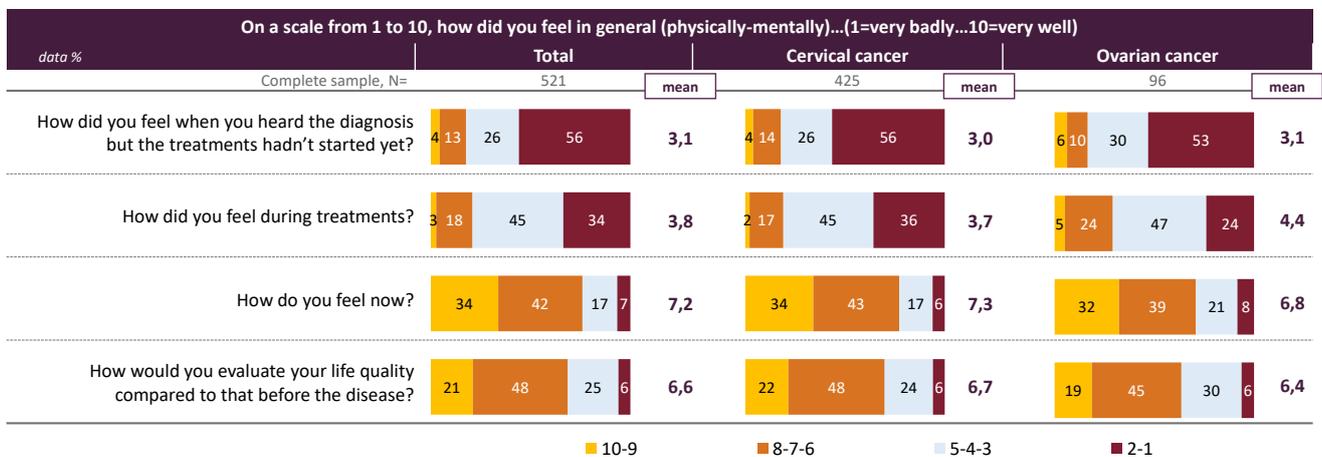


From among the forms of support options, almost exclusively personal meetings were preferred (75%), but keeping contact was 54% in online communities, 39% on Internet forums and to a lesser extent via email (12%). There are no significant differences according to geography or age.

Patients' mental status after the disease

'Living' the disease, whichever phase we look at, is similar in the two disease types. As can be seen on graph 32, evaluating the impact of the disease on physical and mental condition on a 1-10 scale, it keeps increasing from the diagnosis until the current condition. At the diagnosis the average was 3.1, during treatments a little higher, 3.7 on average, while the current condition is evaluated at 7.2. The current life quality index of patients on the scale of 10 is somewhat lower, 6.6 on average. (During the research we did not evaluate patients' interpretation of the average scaling levels, but the above detailed physical changes and the need for mental support suggest the reasons.)

Graph 32: Life quality scores

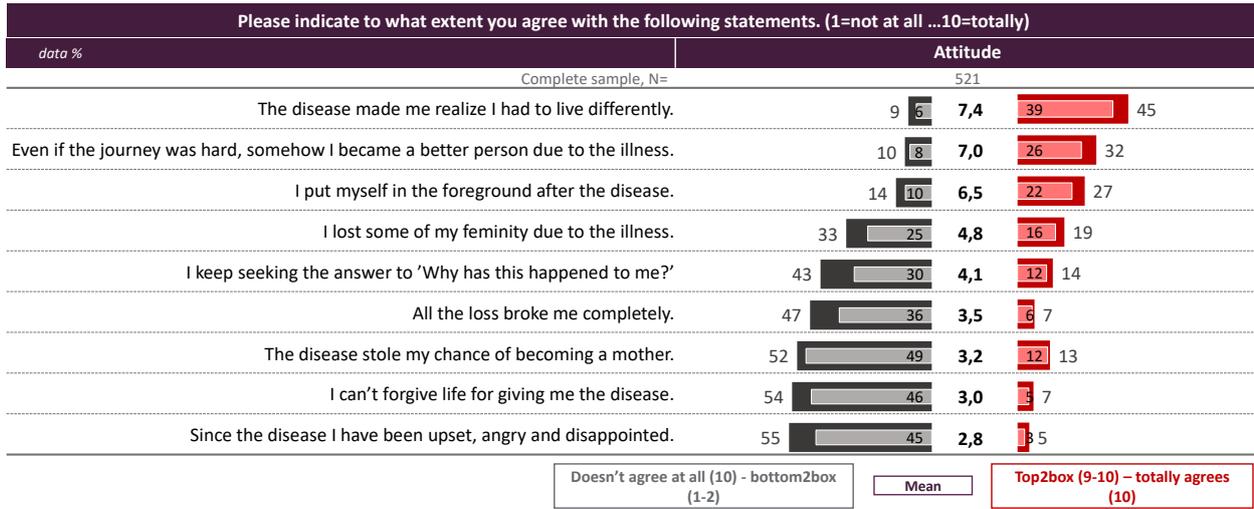


The disease, in most cases, triggered a change in patients' attitude towards life: 45% definitely agree with the statement that they started living differently due to cancer, about one third feel that by putting themselves in the foreground they were also able to become better persons.

Regarding the impact on femininity, almost 70% of patients feel that cancer influenced their lives in this respect as well, and every fifth (19%) definitely agrees that they lost a great deal of their femininity.

Based on disease type the answers to the attitude statements showed a similar result.

Graph 33: Attitude test



Summary

One important thing the study reveals is that both cervical and ovarian cancer have a huge impact on patients' life quality. The diseases influence the ladies both physically and mentally: their roles as mothers, employees or women, their femininity.

The results of the study also indicate, but also in the everyday work of the Mallow Flower Foundation we often face the experience, that women find it hard to talk about changed physiological functions or sexual problems, these are taboos, however, many patients feel the need for support!

Altogether it can be concluded and it also to the credit of the current health care system that most women 'overstep' the disease with a positive attitude and approach to life, and have positive expectations for the following chapters of their lives.

Regarding the symptoms, it is extremely important to point out that the often mild symptoms or those disguised (as related to other organs) contribute greatly to patients getting proper treatment too late. Education therefore has an essential role and it is important that even as non-professionals we should keep the possibility of the diseases in mind.

The improvable points that our study identified clearly highlight that the victory against cervical or ovarian cancer does not exclusively depend on the patient or the doctor, but in the long term, on the co-operation of the peer professions, the health care specialists, the direct family and social-workplace environment in a wider sense.