INTERNATIONAL JOURNAL OF
GYNECOLOGICAL CANCER

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A Pan-European ESGO-ENGAGe Survey in 1436 patients

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Perceptions, expectations and experiences of gynecological cancer patients: A Pan-European ESGO-ENGAGe Survey in 1436 patients

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Higlights

- The study established a baseline of unmet needs of gynecological cancer patients during their treatment journey.
- The article addressed key points towards a more effective cancer prevention and early detection and in Europe.
- Significant deficiencies across many levels were identified, especially in regards to supportive care.

Article Category: Cancer Therapy and Prevention

Novelty and Impact: ENGAGe is the first Pan-European group of patient advocacy groups in gynecological cancers. This survey was developed as an ESGO-ENGAGE as a first of its kind collaborative project between medical experts and non-profit gynecological cancer patient advocacy organizations to establish a baseline of unmet needs of gynecological cancer patients during their treatment journey. Responses from 1436 patients across all types of gynecological cancer from 10 European countries identified aspects of care that require quality improvement and addressed key points towards a more effective cancer prevention and early detection and in Europe. Significant deficiencies across many levels were identified, especially in regards to supportive care.

Abstract: This survey aimed to fill an important void in cross-national survey research as a collaborative effort of medical professionals with non-profit organizations, collecting data from 1436 gynecological cancer patients in ten European countries. We found that patients' knowledge about screening programs varied by type of cancer: 56.5% for cervical smear test 42.5% for HPV/DNA based cervical cytology, 41.2% for HPV vaccine, 30.7% for BRCA test for ovarian carcinoma, and 6.3% for weight control for endometrial carcinoma. Wait time for treatment still had room for improvement in many countries, and overall, we found that 68% of the patients had to wait up to 1 month for their treatment to start; 19.2% of the patients waited 1-2 months, and 12.7% of the patients longer than 2 months. An important goal was to identify areas of unmet need, especially in the area of supportive care, so that patients orientated service and care provision can be better navigated and structured. The level of complimentary support offered to patients remained at low levels in most areas across all 10 countries. Most accessible support was psychological support for 52.8% patients, while other aspects of complimentary support such as social support (13.6%), dietician input (26.3%), sexual counseling (5.1%), access to a rehabilitation program (12.8%), early access to palliative care support (5.1%) remained at critically low levels. Also only 1/3 of patient stated having offered adequate access and information to patient organizations and support groups.

Precis: This survey identified key areas of unmet need in the care of gynecological cancer patients, especially in regards to complimentary support, access to palliative care, information material, patient education and communication.

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Introduction

Gynecological cancers account for a significant amount of all cancers among women. In 2018 alone, cervical-, uterine- and ovarian- cancers accounted for 13.7% of all cancers among women worldwide[1], and it is estimated that each year gynecological cancers cause half a million deaths worldwide by an incidence of over a million new cases[2]. Furthermore, despite the fact that a significant proportion of gynecological cancer types might be preventable through lifestyle adaptations, vaccination- and screening programs[3], overall progress seems to be slow.

Attributed to the nature of their origin, gynecological cancers have a significant impact on the reproductive and sexual aspects of health of the affected patients. In addition to physical stress, loss of fertility in younger patients, along with the complex nature of surgical and systemic treatment can lead to high levels of emotional stress[4] significantly affecting patients quality of life[5]. During the treatment journey, not just medical care, but also adequate supportive care including good communication with health care professionals[6], networking with other patients and having access to valuable information in printed and video materials[7], and support by patient advocacy groups[8], all have been shown to contribute in reducing the levels of stress and anxiety experienced by patients.

In an effort to capture the overall perception and needs of gynecological cancer patients' that relate not just to their actual diagnosis but also their entire treatment journey, ESGO-Engage designed and carried out a cross-national survey in ten European countries between August and September 2017 collecting data from 1436 patients. ESGO-ENGAGe-European Network of Gynecological Cancer Advocacy Groups. Established in 2012 by ESGO- The European Society of Gynecological Oncology, ENGAGe is a network of European patient advocacy groups representing all gynecological cancers. The main goal of the research was to establish a baseline

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of unmet needs, attitudes and behavioral patterns of gynecological cancer patients during their treatment, identify areas of improvement relating to patient-doctor communication aspects but also the overall quality of care, so that we can help better navigate treatment pathways and advocate for patients needs and access to a more holistic approach in Europe, especially in the area of supportive care: an approach that goes beyond medical care, with elements of psychological and social needs, sexual counseling, access to broad information and resources, including patient support and advocacy organizations, and improving of communication with health care professionals.   Among firsts in its class in scope and outreach, it included a wide range of measures such as patient awareness of prevention, disease, treatment options, perception and evaluation of quality of communication with medical professionals, knowledge or availability of clinical trials, access to information on patient advocacy organizations and palliative care.

Materials and Methods

The survey has been developed by the ENGAGe-European Network of Gynecological Cancer Advocacy Groups. Data collection took place between August and September of 2017 in ten European countries including Czech Republic, Denmark, Germany, Great Britain, Greece, Hungary, Poland, Serbia, Spain and Turkey, collecting data from 1436 patients. Translated into patients' respective native languages, the survey was carried out as online when possible, and as paper survey in person collected at collaborating hospitals, and later manually entered into a web based database.

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The questionnaire was developed by a large team of 30 people, included a total of 35 questions: 10 demographic questions and 25 questions on general patient awareness of their disease, diagnosis, prevention models, treatment pathways, access to clinical trials and patient education (See questionnaire attached in the appendix). Hospitals as well as the patients included in the study were selected using convenience sampling, chosen to reach the maximum number of responses within the specified time frame. Patients who fit the initial selection criteria were approached and responses from those who agreed to participate were collected. No rejection or official response rate was collected. Once the data collection window is closed, all collected surveys were transferred for data entry.

Income levels were calculated using the OECD net income per country in local currency, and designating respondents below 50% of median income as lower income, between 50-150% of median income as average income, and respondents with above 150% of the median income as higher income.

All results are presented here as frequency and rate for categorical variables, compared with Pearson Chi-Square test, and ordinal variables with Kendall's tau *b*. Nominal two-sided *P* values set to *P*<0.01 significance are reported. All data were analyzed using IBM® SPSS® Statistics release 25.0 (SPSS Inc. an IBM Company, Chicago, IL).

Results

The country distribution of total respondents was as follows: Czech Republic=173, Denmark=125, Germany=119, Great Britain=231, Greece=108, Hungary=123, Poland=110, Serbia=152, Spain=113 and Turkey=182. 622 (43.3%) of the respondents had ovarian-/

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fallopian tube cancer, 378 (26.3%) breast cancer, 219 (15.3%) uterine cancer, 185 (12.9%)

cervical cancer, and 32 (2.2%) vulval or vaginal cancer. 739 (51.5%) of them had completed

initial treatment, 535 (37.3%) of them were currently under treatment, 963

Demographics: 963(67.1%) respondents were between the ages of 41-65 years, 263 (18.3%)

were 66 and older, 197 (13.7%) were between 26-40, and 13 (0.9%) were 25 or younger. 803

(55.9%) respondents had a college or higher education, 477 (33.2%) were high school graduates,

and 156 (10.9%) were primary school graduates. 471 (32.8%) respondents were considered as

low-income earners, 540 (37.6%) as average income earners, and 422 (29.4%) high income

earners. 3 out of 1436 respondents chose not to answer the income question.

Cancer and Cancer Screening/Prevention Methods Awareness: A total of 1018 patients (70.9%)

stated having heard of their cancer type before. The highest ratio of people who have never

heard of their particular type of cancer (68.8%) were vulvar and vaginal cancer patients,

followed by uterine (37.9%) and ovarian/fallopian tube cancer patients (37.9%).

56.5% of the patients indicated they are aware of cervical smear test for early diagnosis/

prevention of cervical carcinoma, yet that number dropped down to 42.5% for HPV/DNA based

cervical cytology, 41.2% for HPV vaccine, 30.7% for BRCA test for ovarian carcinoma, and

6.3% for weight control for endometrial carcinoma.

27.6% of the respondents said they had not attended any breast or cervical cancer routine

screening programs before their diagnosis. Among the reasons for not complying with screening

programs were: not knowing about them (n=194; 13.5%); not having access to them (n=48;

3.3%), not finding them relevant for themselves (n=100; 7%) and financial reasons (n=12;

0.8%).

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Diagnosis: 46.9% of patients said that they were diagnosed as a result of continuous health problems, 30.4% with self-exam, 24.7% at regular checkup/screening, and 4% with routine bloodwork. There were significant variations on the diagnosis method by cancer type. The majority of cervical (89.7%) and ovarian and fallopian tube cancer patients (85.6%) were diagnosed by routine checkup and/or checkups after continuing health problems. On the other hand, 64.3% of breast cancer patients stated to have palpated a suspicious mass at self-examination that then subsequently led to their diagnosis.

Treatment Timelines: 977 (68%) patients stated to have waited up to 1 month for their treatment; 276 (19.2%) patients waited 1-2 months and 183 (12.7%) patients indicated having to wait longer than 2 months. Waiting times were independent of cancer type, and more related to country specific infrastructures and health care systems. While in Germany, Denmark and Greece over 80% of the patients had access to treatment within 1 month after being diagnosed, that ratio dropped to 40.9% in Poland. 21-25% of patients in Poland, Serbia and Hungary indicated waiting times exceeding 2 months for treatment.

Communications with Doctors: The majority of patients indicated they were confident with their doctor of choice (69.4%), were well-informed about the disease and available treatment options as offered by their doctor and nurses at the hospital (70.9%), that they felt like their doctor was empathetic to them and the difficulties they were going through (66.2%), that they were satisfied with the doctor-patient communication (64.1%), that they felt like all their questions and concerns were addressed (60.4%), and that their doctor explained adequately potential early- and long term side effects of the disease and any related treatment (59.7%). 48.9% of the patients stated that their doctor discussed with them possible relapse of the disease and symptoms.

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Levels of support for cancer patients: Most accessible support seems to be the psychological support (52.8%), with significantly lower levels of: social support (13.6%), dietician input (26.3%), sexual counseling (5.1%), access to a rehabilitation programs (12.8%), palliative care (5.1%). Furthermore, access to information on patient organizations and support groups was at 33.2%.

There is significant variation by country across all categories of cancer support services: In regards to psychological support, Germany, Spain and Turkey exceed 60%, while Denmark with 38.1% and Hungary with 26.3% rank last. Dietary support numbers remain relatively low across ranging from 12.5% in Denmark to 39.6% in Germany. Rehabilitation programs also show a wide range: while Germany stands out as an outlier with 58.6% oncological rehabilitation support, Denmark, Czech Republic, Hungary, Poland, Serbia provide such services to just over 20% of their cancer patients. 11.3% of the Greek patients stated to have access to oncological rehabilitation, whereas that was the case in only 4.3% of patients in Great Britain, Spain and Turkey. Early access to palliative care was low across all countries, with a range of 9.6% in Spain to 0.7% in Turkey. Sexual counseling also ranges from 20% in Denmark as an outlier, to 0% in Czech Republic and Turkey. Providing information on support groups and patient organizations is most prevalent on Great Britain (68.7%), followed by Denmark (52.4%), Hungary (47.5%), and Greece (39.4%). Patients in Czech Republic (12.1%), Turkey (8.4%) and Poland (5.4%) had the lowest access and information to patient support groups.

Printed Materials: The average ratio of patients who received any printed informational materials from their health care providers is 31.1%. Out of those who received any printed materials, 91.1% think that the materials they received was helpful. Denmark (62.4%) and Great Britain

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(52.8%) rank highest in printed information distribution, Serbia (16.4%), Hungary (13.8%) and Greece (4.6%) rank last.

Discussion

This survey identified key areas of unmet need in the care of gynecological cancer patients, especially in regards to complimentary support, access to palliative care, information material, patient education and communication between medical personnel, patients and patients advocates. We could demonstrate a very broad variation across European countries in regards to the different levels of care, with most deficiencies relating to complimentary support, access to palliative care and patient support and advocacy groups. Patients' knowledge about screening programs show at 56.5% for cervical smear test 42.5% for HPV/DNA based cervical cytology, 41.2% for HPV vaccine, 30.7% for BRCA test for ovarian carcinoma, and 6.3% for weight control for endometrial carcinoma. In terms of treatment wait times, 68% of the patients had to wait up to 1 month for their treatment to start; 19.2% of the patients waited 1-2 months, and 12.7% of the patients longer than 2 months. The level of complimentary support offered to patients remained at low levels in most areas across all 10 countries. Most accessible support was psychological support for 52.8% patients, while other aspects of complimentary support such as social support (13.6%), dietician input (26.3%), sexual counseling (5.1%), access to a rehabilitation program (12.8%), early access to palliative care support (5.1%) remained at critically low levels. Also only 1/3 of patient stated having offered adequate access and information to patient organizations and support groups.

There are not many cross-national surveys designed to collect data from all gynecological cancer patients, if any, which include the components of this survey: screening knowledge and

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behavior, treatment time information, perceptions and needs of quality of care under the same

study. Although there are a significant number of published single country based survey studies,

they mostly focus on cancer risk factors[9], one aspect of cancer treatment or patient perspective or

behavior[10]. A number of published cross-national research also focus on a specific type of

cancer. Two most recent and comprehensive studies in this area, The "Every Woman" study

supported by the World Ovarian Cancer Coalition completed a study in 2018 by surveying 1531

women in 44 countries, and incorporated attitudes and practices in its scope[11]; Expression III:

patients' expectations and preferences regarding physician–patient relationship and clinical

management[6] also reports data from 1830 patients in European countries, and both look at

ovarian cancer patients. Therefore, even though they provide important comparison for ovarian

cancer patient data, the scope of this survey extends beyond their focus covering all

gynecological cancer types. Many other studies conduct meta-analysis of existing publications

or reports from centers and organizations[12]. There have been significant achievements with this

study such as the extensive collaboration between multiple number of patient organizations

working under the umbrella of ENGAGe and oncologists on site, number of countries covered in

the survey, the total number of patients reached, and the breadth of the questionnaire. However,

the data was collected in a relatively short amount of time and at a limited number of hospitals,

and there was some variation in data collection methods. These factors led to some important

limitations, such as not being able to conduct statistical analyses that are significant at country

level, and less than ideal conditions for the generalizability of the findings. Hospitals as well as

the patients included in the study were selected using convenience sampling, and cohort size at

each site was not monitored nor standardized at any point. Nevertheless, the authors believe that

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the study provides very important insights on gynecological patient care and patient expectations in Europe, and allow new directions for supportive care in Europe.

One of the most important findings of this European survey is that the level of complimentary help offered to patients remain at well below desired levels in most areas across all 10 countries.

Early detection plays a crucial role in the fight against cancer[13] and it requires population based screening programs and greater awareness of the early signs and symptoms of cancer. The findings of this study show that the percent of the patients diagnosed as a result of routine screening is still low (24.7%) identifying and confirming an area of unmet need that requires improvement to encourage women to understand the importance of routine checkups in diagnosing gynecologic cancers.

Longer wait for treatments in cancer patients is known to cause a series of detrimental effects for patients, including tumor progression, deterioration of patients overall performance status, increased levels of anxiety for the patient, lower levels of patient satisfaction with their medical center, and possibly on a longer term reduced oncologic outcome[14] A broadly accepted timeline from diagnosis to treatment, as published in international literature ranges from 30 days to 8 weeks[15,16]. Our study indicates that on average 12.7% of patients in Europe still have to wait longer than 2 months, and 21-25% of patients in Poland, Serbia and Hungary have waiting times exceeding 2 months for treatment, leaving much room for improvement.

Coping with cancer and its treatment is a complicated process, and it requires the patient and its caregivers to be well educated about multiple aspects and stages of the process[17]. Patient-caregiver education not only impacts the effectiveness of the medical treatment, it also helps

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reduce strain and anxiety for both patients and their caregivers[18]. A small yet crucial medium of increasing patient education is the use of printed materials: It is shown that patients who receive printed information fare better in their disease management[19]. Yet this study shows that only an average of 31.1% of patients received any printed materials from their healthcare providers.

It is also shown that cancer patients have high levels of unmet needs and prefer receiving more information and support for their disease[6,20,21]. They have a strong preference in being involved in the decision making process of their treatments[22–24], an involvement that can only increase in efficiency by a matching increase in support and educational services.

The levels of support services available to patients in our study show that with the exception of psychological support (52.8%), most other levels of support that can help improve the quality of life of cancer patients[25,26], such as access to social services, dietician input, sexual counseling, palliative care, and information on patient advocacy groups remain at critically low levels. Nutrition has been shown to be of paramount importance in oncologic outcomes, whereas extensive surgery in advanced stages often affects gastrointestinal absorption, function and nutritional patterns, so that dietician input and support is crucially important on a long term basis to help patients cope not only with their actual cancer diagnosis but also the long term effects of their treatment[27]. Our study demonstrated low numbers of dietary input and support with an average of only 26.3%.

Similar low levels of support apply to sexual health. Female cancer patients have been repeatedly shown to "receive insufficient counseling, support, or treatment to preserve or regain sexual function after cancer treatment"[28,29]. Our study confirmed these experiences with sexual counseling being offered in an average of 5.1% and hence flagging up a further area urgently requiring improvement.

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In 2014, the World Health Assembly Resolution on Palliative Care called for all countries to develop, strengthen and implement, where appropriate, palliative care policies[30]. For comparison, in the US, one of the pioneers in palliative care, sixty-seven percent of hospitals with 50 or more total facility beds are reported to have a palliative care program[31]. The ratio of patients who had access to palliative care in this study remained at a very low 5.1%.

The initial findings showed that there were significant areas that could use improvement, particularly in palliative care, including the areas of psychological support, social support, diet/nutrition support, and sexual counseling. We also identified that there was need for more information on patient support groups and increased connection between hospital staff/patients/patient support groups, and production and distribution of a series of printed information leaflets for patient education and reference.

Our interdisciplinary and inter-professional designed European study is an ideal example that a collaborative effort of medical professionals with non-profit organizations, administered to all types of gynecological cancer patients in ten European countries is the best approach to perform such a study with high number of patients in a very limited recruiting time. This is also the best approach to start immediately a subsequent discussion to translate these findings into the clinical day and to discuss further prospective studies.

The research team of this study strongly believes that even small adjustments in the hospital environment and practices can increase existing support, provide better tools to help raise patient awareness, and increase patients' access to palliative care, making a significant effect on gynecological cancer patients' overall wellbeing.

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Acknowledgements

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Table 1 Treatment Wait Time by Country (p<0.01)

			Treatment Wait Time			
			Up to a Month	1-2 Months	More than 2 Months	
Country	Czech Republic	Count	133	28	12	173
		% within Country	76.9%	16.2%	6.9%	100.0%
	Denmark	Count	106	14	5	125
		% within Country	84.8%	11.2%	4.0%	100.0%
	Germany	Count	104	10	5	119
		% within Country	87.4%	8.4%	4.2%	100.0%
	Great Britain	Count	131	63	37	231
		% within Country	56.7%	27.3%	16.0%	100.0%
	Greece	Count	88	8	12	108
		% within Country	81.5%	7.4%	11.1%	100.0%
	Hungary	Count	66	31	26	123
		% within Country	53.7%	25.2%	21.1%	100.0%
	Poland	Count	45	37	28	110
		% within Country	40.9%	33.6%	25.5%	100.0%
	Serbia	Count	93	26	33	152
		% within Country	61.2%	17.1%	21.7%	100.0%
	Spain	Count	90	13	10	113
		% within Country	79.6%	11.5%	8.8%	100.0%
	Turkey	Count	121	46	15	182
		% within Country	66.5%	25.3%	8.2%	100.0%
Total		Count	977	276	183	1436
		% within Country	68.0%	19.2%	12.7%	100.0%

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Table 2 Level of Support by Country

Level of Support by Country

			Level of Support for Cancer Patients[a]							
			Psychological support	Social support	Diet rec/ dietitian help	Sexual counselling program	Rehabilitation program	Palliative care	Info on patient org or support groups	Total
Country	Czech Republic	Count	28	3	13	0	15	5	7	58
		%	48.3%	5.2%	22.4%	0.0%	25.9%	8.6%	12.1%	
	Denmark	Count	32	7	13	17	30	1	44	84
		%	38.1%	8.3%	15.5%	20.2%	35.7%	1.2%	52.4%	
	Germany	Count	77	48	44	6	65	10	31	111
		%	69.4%	43.2%	39.6%	5.4%	58.6%	9.0%	27.9%	
	Great Britain	Count	73	22	29	8	4	9	103	150
		%	48.7%	14.7%	19.3%	5.3%	2.7%	6.0%	68.7%	
	Greece	Count	36	8	24	2	8	5	28	71
		%	50.7%	11.3%	33.8%	2.8%	11.3%	7.0%	39.4%	
	Hungary	Count	21	1	10	2	19	2	38	80
		%	26.3%	1.3%	12.5%	2.5%	23.8%	2.5%	47.5%	
	Poland	Count	46	10	26	8	25	6	5	93
		%	49.5%	10.8%	28.0%	8.6%	26.9%	6.5%	5.4%	
	Serbia	Count	43	4	27	2	16	1	23	80
		%	53.8%	5.0%	33.8%	2.5%	20.0%	1.3%	28.8%	
	Spain	Count	57	2	19	3	2	8	24	83
		%	68.7%	2.4%	22.9%	3.6%	2.4%	9.6%	28.9%	
	Turkey	Count	88	24	45	0	6	1	12	139
		%	63.3%	17.3%	32.4%	0.0%	4.3%	0.7%	8.6%	
Total		Count	501	129	250	48	190	48	315	949

Article Category: Cancer Therapy and Prevention

Novelty and Impact: ENGAGe is the first Pan-European group of patient advocacy groups in gynecological cancers. This survey was developed as an ESGO-ENGAGE as a first of its kind collaborative project between medical experts and non-profit gynecological cancer patient advocacy organizations to establish a baseline of unmet needs of gynecological cancer patients during their treatment journey. Responses from 1436 patients across all types of gynecological cancer from 10 European countries identified aspects of care that require quality improvement and addressed key points towards a more effective cancer prevention and early detection and in Europe. Significant deficiencies across many levels were identified, especially in regards to supportive care.

Abstract: This survey aimed to fill an important void in cross-national survey research as a collaborative effort of medical professionals with non-profit organizations, collecting data from 1436 gynecological cancer patients in ten European countries. We found that patients' knowledge about screening programs varied by type of cancer: 56.5% for cervical smear test 42.5% for HPV/DNA based cervical cytology, 41.2% for HPV vaccine, 30.7% for BRCA test for ovarian carcinoma, and 6.3% for weight control for endometrial carcinoma. Wait time for treatment still had room for improvement in many countries, and overall, we found that 68% of the patients had to wait up to 1 month for their treatment to start; 19.2% of the patients waited 1-2 months, and 12.7% of the patients longer than 2 months. An important goal was to identify areas of unmet need, especially in the area of supportive care, so that patients orientated service and care provision can be better navigated and structured. The level of complimentary support offered to patients remained at low levels in most areas across all 10 countries. Most accessible support was psychological support for 52.8% patients, while other aspects of complimentary support such as social support (13.6%), dietician input (26.3%), sexual counseling (5.1%), access to a rehabilitation program (12.8%), early access to palliative care support (5.1%) remained at critically low levels. Also only 1/3 of patient stated having offered adequate access and information to patient organizations and support groups.

Precis: This survey identified key areas of unmet need in the care of gynecological cancer patients, especially in regards to complimentary support, access to palliative care, information material, patient education and communication between medical personnel, patients and patients advocates.

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Introduction

Gynecological cancers account for a significant amount of all cancers among women. In 2018 alone, cervical-, uterine- and ovarian- cancers accounted for 13.7% of all cancers among women worldwide[1], and it is estimated that each year gynecological cancers cause half a million deaths worldwide by an incidence of over a million new cases[2]. Furthermore, despite the fact that a significant proportion of gynecological cancer types might be preventable through lifestyle adaptations, vaccination- and screening programs[3], overall progress seems to be slow.

Attributed to the nature of their origin, gynecological cancers have a significant impact on the reproductive and sexual aspects of health of the affected patients. In addition to physical stress, loss of fertility in younger patients, along with the complex nature of surgical and systemic treatment can lead to high levels of emotional stress[4] significantly affecting patients quality of life[5]. During the treatment journey, not just medical care, but also adequate supportive care including good communication with health care professionals[6], networking with other patients and having access to valuable information in printed and video materials[7], and support by patient advocacy groups[8], all have been shown to contribute in reducing the levels of stress and anxiety experienced by patients.

In an effort to capture the overall perception and needs of gynecological cancer patients' that relate not just to their actual diagnosis but also their entire treatment journey, ESGO-Engage designed and carried out a cross-national survey in ten European countries between August and September 2017 collecting data from 1436 patients. ESGO-ENGAGe-European Network of Gynecological Cancer Advocacy Groups. Established in 2012 by ESGO- The European Society of Gynecological Oncology, ENGAGe is a network of European patient advocacy groups representing all gynecological cancers. The main goal of the research was to establish a baseline

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of unmet needs, attitudes and behavioral patterns of gynecological cancer patients during their

treatment, identify areas of improvement relating to patient-doctor communication aspects but

also the overall quality of care, <mark>so that we can help better navigate treatment pathways and

advocate for patients needs and access to a more holistic approach in Europe, especially in the

area of supportive care: an approach that goes beyond medical care, with elements of

psychological and social needs, sexual counseling, access to broad information and resources,

including patient support and advocacy organizations, and improving of communication with

health care professionals.</mark>   Among firsts in its class in scope and outreach, it included a wide

range of measures such as patient awareness of prevention, disease, treatment options, perception

and evaluation of quality of communication with medical professionals, knowledge or

availability of clinical trials, access to information on patient advocacy organizations and

palliative care.

Materials and Methods

The survey has been developed by the ENGAGe-European Network of Gynecological

Cancer Advocacy Groups. Data collection took place between August and September of 2017 in

ten European countries including Czech Republic, Denmark, Germany, Great Britain, Greece,

Hungary, Poland, Serbia, Spain and Turkey, collecting data from 1436 patients. Translated into

patients' respective native languages, the survey was carried out as online when possible, and as

paper survey in person collected at collaborating hospitals, and later manually entered into a web

based database.

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The questionnaire was developed by a large team of 30 people, included a total of 35 questions: 10 demographic questions and 25 questions on general patient awareness of their disease, diagnosis, prevention models, treatment pathways, access to clinical trials and patient education (See questionnaire attached in the appendix). Hospitals as well as the patients included in the study were selected using convenience sampling, chosen to reach the maximum number of responses within the specified time frame. Patients who fit the initial selection criteria were approached and responses from those who agreed to participate were collected. No rejection or official response rate was collected. Once the data collection window is closed, all collected surveys were transferred for data entry.

Income levels were calculated using the OECD net income per country in local currency, and designating respondents below 50% of median income as lower income, between 50-150% of median income as average income, and respondents with above 150% of the median income as higher income.

All results are presented here as frequency and rate for categorical variables, compared with Pearson Chi-Square test, and ordinal variables with Kendall's tau *b*. Nominal two-sided *P* values set to *P*<0.01 significance are reported. All data were analyzed using IBM® SPSS® Statistics release 25.0 (SPSS Inc. an IBM Company, Chicago, IL).

Results

The country distribution of total respondents was as follows: Czech Republic=173, Denmark=125, Germany=119, Great Britain=231, Greece=108, Hungary=123, Poland=110, Serbia=152, Spain=113 and Turkey=182. 622 (43.3%) of the respondents had ovarian-/

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fallopian tube cancer, 378 (26.3%) breast cancer, 219 (15.3%) uterine cancer, 185 (12.9%)

cervical cancer, and 32 (2.2%) vulval or vaginal cancer. 739 (51.5%) of them had completed

initial treatment, 535 (37.3%) of them were currently under treatment, 963

Demographics: 963(67.1%) respondents were between the ages of 41-65 years, 263 (18.3%)

were 66 and older, 197 (13.7%) were between 26-40, and 13 (0.9%) were 25 or younger. 803

(55.9%) respondents had a college or higher education, 477 (33.2%) were high school graduates,

and 156 (10.9%) were primary school graduates. 471 (32.8%) respondents were considered as

low-income earners, 540 (37.6%) as average income earners, and 422 (29.4%) high income

earners. 3 out of 1436 respondents chose not to answer the income question.

Cancer and Cancer Screening/Prevention Methods Awareness: A total of 1018 patients (70.9%)

stated having heard of their cancer type before. The highest ratio of people who have never

heard of their particular type of cancer (68.8%) were vulvar and vaginal cancer patients,

followed by uterine (37.9%) and ovarian/fallopian tube cancer patients (37.9%).

56.5% of the patients indicated they are aware of cervical smear test for early diagnosis/

prevention of cervical carcinoma, yet that number dropped down to 42.5% for HPV/DNA based

cervical cytology, 41.2% for HPV vaccine, 30.7% for BRCA test for ovarian carcinoma, and

6.3% for weight control for endometrial carcinoma.

27.6% of the respondents said they had not attended any breast or cervical cancer routine

screening programs before their diagnosis. Among the reasons for not complying with screening

programs were: not knowing about them (n=194; 13.5%); not having access to them (n=48;

3.3%), not finding them relevant for themselves (n=100; 7%) and financial reasons (n=12;

0.8%).

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Diagnosis: 46.9% of patients said that they were diagnosed as a result of continuous health

problems, 30.4% with self-exam, 24.7% at regular checkup/screening, and 4% with routine

bloodwork. There were significant variations on the diagnosis method by cancer type. The

majority of cervical (89.7%) and ovarian and fallopian tube cancer patients (85.6%) were

diagnosed by routine checkup and/or checkups after continuing health problems. On the other

hand, 64.3% of breast cancer patients stated to have palpated a suspicious mass at self-

examination that then subsequently led to their diagnosis.

Treatment Timelines: 977 (68%) patients stated to have waited up to 1 month for their

treatment; 276 (19.2%) patients waited 1-2 months and 183 (12.7%) patients indicated having to

wait longer than 2 months. Waiting times were independent of cancer type, and more related to

country specific infrastructures and health care systems. While in Germany, Denmark and

Greece over 80% of the patients had access to treatment within 1 month after being diagnosed,

that ratio dropped to 40.9% in Poland. 21-25% of patients in Poland, Serbia and Hungary

indicated waiting times exceeding 2 months for treatment.

Communications with Doctors: The majority of patients indicated they were confident with their

doctor of choice (69.4%), were well-informed about the disease and available treatment options

as offered by their doctor and nurses at the hospital (70.9%), that they felt like their doctor was

empathetic to them and the difficulties they were going through (66.2%), that they were satisfied

with the doctor-patient communication (64.1%), that they felt like all their questions and

concerns were addressed (60.4%), and that their doctor explained adequately potential early- and

long term side effects of the disease and any related treatment (59.7%). 48.9% of the patients

stated that their doctor discussed with them possible relapse of the disease and symptoms.

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Levels of support for cancer patients: Most accessible support seems to be the psychological

support (52.8%), with significantly lower levels of: social support (13.6%), dietician input

(26.3%), sexual counseling (5.1%), access to a rehabilitation programs (12.8%), palliative care

(5.1%). Furthermore, access to information on patient organizations and support groups was at

33.2%.

There is significant variation by country across all categories of cancer support services: In

regards to psychological support, Germany, Spain and Turkey exceed 60%, while Denmark with

38.1% and Hungary with 26.3% rank last. Dietary support numbers remain relatively low across

ranging from 12.5% in Denmark to 39.6% in Germany. Rehabilitation programs also show a

wide range: while Germany stands out as an outlier with 58.6% oncological rehabilitation

support, Denmark, Czech Republic, Hungary, Poland, Serbia provide such services to just over

20% of their cancer patients. 11.3% of the Greek patients stated to have access to oncological

rehabilitation, whereas that was the case in only 4.3% of patients in Great Britain, Spain and

Turkey. Early access to palliative care was low across all countries, with a range of 9.6% in

Spain to 0.7% in Turkey. Sexual counseling also ranges from 20% in Denmark as an outlier, to

0% in Czech Republic and Turkey. Providing information on support groups and patient

organizations is most prevalent on Great Britain (68.7%), followed by Denmark (52.4%),

Hungary (47.5%), and Greece (39.4%). Patients in Czech Republic (12.1%), Turkey (8.4%) and

Poland (5.4%) had the lowest access and information to patient support groups.

Printed Materials: The average ratio of patients who received any printed informational materials

from their health care providers is 31.1%. Out of those who received any printed materials,

91.1% think that the materials they received was helpful. Denmark (62.4%) and Great Britain

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(52.8%) rank highest in printed information distribution, Serbia (16.4%), Hungary (13.8%) and Greece (4.6%) rank last.

Discussion

This survey identified key areas of unmet need in the care of gynecological cancer patients, especially in regards to complimentary support, access to palliative care, information material, patient education and communication between medical personnel, patients and patients advocates. We could demonstrate a very broad variation across European countries in regards to the different levels of care, with most deficiencies relating to complimentary support, access to palliative care and patient support and advocacy groups. Patients' knowledge about screening programs show at 56.5% for cervical smear test 42.5% for HPV/DNA based cervical cytology, 41.2% for HPV vaccine, 30.7% for BRCA test for ovarian carcinoma, and 6.3% for weight control for endometrial carcinoma. In terms of treatment wait times, 68% of the patients had to wait up to 1 month for their treatment to start; 19.2% of the patients waited 1-2 months, and 12.7% of the patients longer than 2 months. The level of complimentary support offered to patients remained at low levels in most areas across all 10 countries. Most accessible support was psychological support for 52.8% patients, while other aspects of complimentary support such as social support (13.6%), dietician input (26.3%), sexual counseling (5.1%), access to a rehabilitation program (12.8%), early access to palliative care support (5.1%) remained at critically low levels. Also only 1/3 of patient stated having offered adequate access and information to patient organizations and support groups.

There are not many cross-national surveys designed to collect data from all gynecological cancer patients, if any, which include the components of this survey: screening knowledge and

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behavior, treatment time information, perceptions and needs of quality of care under the same study. Although there are a significant number of published single country based survey studies, they mostly focus on cancer risk factors[9], one aspect of cancer treatment or patient perspective or behavior[10]. A number of published cross-national research also focus on a specific type of cancer. Two most recent and comprehensive studies in this area, The "Every Woman" study supported by the World Ovarian Cancer Coalition completed a study in 2018 by surveying 1531 women in 44 countries, and incorporated attitudes and practices in its scope[11]; Expression III: patients' expectations and preferences regarding physician–patient relationship and clinical management[6] also reports data from 1830 patients in European countries, and both look at ovarian cancer patients. Therefore, even though they provide important comparison for ovarian cancer patient data, the scope of this survey extends beyond their focus covering all gynecological cancer types. Many other studies conduct meta-analysis of existing publications or reports from centers and organizations[12]. There have been significant achievements with this study such as the extensive collaboration between multiple number of patient organizations working under the umbrella of ENGAGe and oncologists on site, number of countries covered in the survey, the total number of patients reached, and the breadth of the questionnaire. However, the data was collected in a relatively short amount of time and at a limited number of hospitals, and there was some variation in data collection methods. These factors led to some important limitations, such as not being able to conduct statistical analyses that are significant at country level, and less than ideal conditions for the generalizability of the findings. Hospitals as well as the patients included in the study were selected using convenience sampling, and cohort size at each site was not monitored nor standardized at any point. Nevertheless, the authors believe that

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the study provides very important insights on gynecological patient care and patient expectations in Europe, and allow new directions for supportive care in Europe.

One of the most important findings of this European survey is that the level of complimentary help offered to patients remain at well below desired levels in most areas across all 10 countries.

Early detection plays a crucial role in the fight against cancer[13] and it requires population based screening programs and greater awareness of the early signs and symptoms of cancer. The findings of this study show that the percent of the patients diagnosed as a result of routine screening is still low (24.7%) identifying and confirming an area of unmet need that requires improvement to encourage women to understand the importance of routine checkups in diagnosing gynecologic cancers.

Longer wait for treatments in cancer patients is known to cause a series of detrimental effects for patients, including tumor progression, deterioration of patients overall performance status, increased levels of anxiety for the patient, lower levels of patient satisfaction with their medical center, and possibly on a longer term reduced oncologic outcome[14] A broadly accepted timeline from diagnosis to treatment, as published in international literature ranges from 30 days to 8 weeks[15,16]. Our study indicates that on average 12.7% of patients in Europe still have to wait longer than 2 months, and 21-25% of patients in Poland, Serbia and Hungary have waiting times exceeding 2 months for treatment, leaving much room for improvement.

Coping with cancer and its treatment is a complicated process, and it requires the patient and its caregivers to be well educated about multiple aspects and stages of the process[17]. Patient-caregiver education not only impacts the effectiveness of the medical treatment, it also helps

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reduce strain and anxiety for both patients and their caregivers[18]. A small yet crucial medium of increasing patient education is the use of printed materials: It is shown that patients who receive printed information fare better in their disease management[19]. Yet this study shows that only an average of 31.1% of patients received any printed materials from their healthcare providers.

It is also shown that cancer patients have high levels of unmet needs and prefer receiving more information and support for their disease[6,20,21]. They have a strong preference in being involved in the decision making process of their treatments[22–24], an involvement that can only increase in efficiency by a matching increase in support and educational services.

The levels of support services available to patients in our study show that with the exception of psychological support (52.8%), most other levels of support that can help improve the quality of life of cancer patients[25,26], such as access to social services, dietician input, sexual counseling, palliative care, and information on patient advocacy groups remain at critically low levels. Nutrition has been shown to be of paramount importance in oncologic outcomes, whereas extensive surgery in advanced stages often affects gastrointestinal absorption, function and nutritional patterns, so that dietician input and support is crucially important on a long term basis to help patients cope not only with their actual cancer diagnosis but also the long term effects of their treatment[27]. Our study demonstrated low numbers of dietary input and support with an average of only 26.3%.

Similar low levels of support apply to sexual health. Female cancer patients have been repeatedly shown to "receive insufficient counseling, support, or treatment to preserve or regain sexual function after cancer treatment"[28,29]. Our study confirmed these experiences with sexual counseling being offered in an average of 5.1% and hence flagging up a further area urgently requiring improvement.

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In 2014, the World Health Assembly Resolution on Palliative Care called for all countries to develop, strengthen and implement, where appropriate, palliative care policies[30]. For comparison, in the US, one of the pioneers in palliative care, sixty-seven percent of hospitals with 50 or more total facility beds are reported to have a palliative care program[31]. The ratio of patients who had access to palliative care in this study remained at a very low 5.1%.

The initial findings showed that there were significant areas that could use improvement, particularly in palliative care, including the areas of psychological support, social support, diet/nutrition support, and sexual counseling. We also identified that there was need for more information on patient support groups and increased connection between hospital staff/patients/patient support groups, and production and distribution of a series of printed information leaflets for patient education and reference.

Our interdisciplinary and inter-professional designed European study is an ideal example that a collaborative effort of medical professionals with non-profit organizations, administered to all types of gynecological cancer patients in ten European countries is the best approach to perform such a study with high number of patients in a very limited recruiting time. This is also the best approach to start immediately a subsequent discussion to translate these findings into the clinical day and to discuss further prospective studies.

The research team of this study strongly believes that even small adjustments in the hospital environment and practices can increase existing support, provide better tools to help raise patient awareness, and increase patients' access to palliative care, making a significant effect on gynecological cancer patients' overall wellbeing.

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Table 1 Treatment Wait Time by Country (p<0.01)

			Treatment Wait Time			
			Up to a Month	1-2 Months	More than 2 Months	
Country	Czech Republic	Count	133	28	12	173
		% within Country	76.9%	16.2%	6.9%	100.0%
	Denmark	Count	106	14	5	125
		% within Country	84.8%	11.2%	4.0%	100.0%
	Germany	Count	104	10	5	119
		% within Country	87.4%	8.4%	4.2%	100.0%
	Great Britain	Count	131	63	37	231
		% within Country	56.7%	27.3%	16.0%	100.0%
	Greece	Count	88	8	12	108
		% within Country	81.5%	7.4%	11.1%	100.0%
	Hungary	Count	66	31	26	123
		% within Country	53.7%	25.2%	21.1%	100.0%
	Poland	Count	45	37	28	110
		% within Country	40.9%	33.6%	25.5%	100.0%
	Serbia	Count	93	26	33	152
		% within Country	61.2%	17.1%	21.7%	100.0%
	Spain	Count	90	13	10	113
		% within Country	79.6%	11.5%	8.8%	100.0%
	Turkey	Count	121	46	15	182
		% within Country	66.5%	25.3%	8.2%	100.0%
Total		Count	977	276	183	1436
		% within Country	68.0%	19.2%	12.7%	100.0%

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Table 2 Level of Support by Country

Level of Support by Country

			Level of Support for Cancer Patients[a]							
			Psychological support	Social support	Diet rec/ dietitian help	Sexual counselling program	Rehabilitation program	Palliative care	Info on patient org or support groups	Total
Country	Czech Republic	Count	28	3	13	0	15	5	7	58
		%	48.3%	5.2%	22.4%	0.0%	25.9%	8.6%	12.1%	
	Denmark	Count	32	7	13	17	30	1	44	84
		%	38.1%	8.3%	15.5%	20.2%	35.7%	1.2%	52.4%	
	Germany	Count	77	48	44	6	65	10	31	111
		%	69.4%	43.2%	39.6%	5.4%	58.6%	9.0%	27.9%	
	Great Britain	Count	73	22	29	8	4	9	103	150
		%	48.7%	14.7%	19.3%	5.3%	2.7%	6.0%	68.7%	
	Greece	Count	36	8	24	2	8	5	28	71
		%	50.7%	11.3%	33.8%	2.8%	11.3%	7.0%	39.4%	
	Hungary	Count	21	1	10	2	19	2	38	80
		%	26.3%	1.3%	12.5%	2.5%	23.8%	2.5%	47.5%	
	Poland	Count	46	10	26	8	25	6	5	93
		%	49.5%	10.8%	28.0%	8.6%	26.9%	6.5%	5.4%	
	Serbia	Count	43	4	27	2	16	1	23	80
		%	53.8%	5.0%	33.8%	2.5%	20.0%	1.3%	28.8%	
	Spain	Count	57	2	19	3	2	8	24	83
		%	68.7%	2.4%	22.9%	3.6%	2.4%	9.6%	28.9%	
	Turkey	Count	88	24	45	0	6	1	12	139
		%	63.3%	17.3%	32.4%	0.0%	4.3%	0.7%	8.6%	
Total		Count	501	129	250	48	190	48	315	949

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