

Self-reported Costs of Endometriosis Patients in Germany

Selbstberichtete Kosten von Endometriosebetroffenen in Deutschland



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ABSTRACT

Endometriosis patients face a significant economic burden. In addition to the directly attributable costs of the diagnosis and therapy of endometriosis, such as drug treatment and multimodal pain therapy, various indirect follow-up costs can be expected, e.g., due to incapacity for work and reduced work performance. As already reported in previous publications, endometriosis is associated with considerable costs for the health care system and society as well as for the affected women and their families.

In order to measure the extent of the costs associated with endometriosis patients, 250 patients with an average age of 32.80 years were recruited via social media and interviewed about their self-financed costs as part of an online survey. The assessed direct costs comprise inpatient treatments, outpatient or pain therapy, fertility treatments, hormone therapies, prescribed and privately paid medications and aids, other therapeutic procedures, and directly attributable travel costs for endometriosis treatments.

This resulted in an average cost of € 2059.55 per year. Indirect costs were calculated based on loss of income, day-to-day support, care costs, costs due to follow-up illnesses and other costs. On average, the indirect costs were € 2174.25. The average costs resulting from the survey totalled € 4233.81 per year with a standard deviation of € 8240.31.

An increase of out-of-pocket costs can be assumed. This may result from an improved range of services for alternative treatment methods and an increased awareness of the need for personal investment in health. However, further health economic studies are needed to validate the results.

ZUSAMMENFASSUNG

Endometriosebetroffenen entstehen im Laufe ihres Lebens erhebliche Kosten. Neben den direkt zurechenbaren Kosten der Diagnostik sowie der Therapieverfahren, wie medikamentöser Behandlung, multimodaler Schmerztherapie, beispielsweise in Form von psychischen und physiotherapeutischen Behandlungen, sind diverse indirekte Folgekosten z.B. durch Fehlzeiten und Leistungsminderungen zu erwarten. Wie bereits in vorangegangenen Publikationen berichtet, ist die Erkrankung Endometriose mit beträchtlichen Kosten für das Gesundheitssystem

tem, die Gesellschaft und auch für die betroffenen Personen selbst sowie Angehörige verbunden.

Um den Umfang der Kosten der Endometriosebetroffenen bemessen zu können, wurden im Rahmen eines Onlinesurveys 250 Betroffene im Alter von durchschnittlich 32,80 Jahren via Social Media rekrutiert und zu ihren selbstgetragenen Kosten befragt. Die erhobenen direkten Kosten, die über die Erstattung der Krankenkassen hinausgehen, setzen sich aus Behandlungen im stationären Bereich, dem ambulanten beziehungsweise schmerztherapeutischen Bereich, Kinderwunschbehandlungen, hormonellen Therapien, verschreibungspflichtigen und privat gezahlten Medikamenten sowie Hilfsmitteln, weiteren therapeutischen Verfahren, und direkt den Endometriosebehandlungen zurechenbaren Fahrtkosten zusammen. Daraus ergeben sich durchschnittliche jährliche selbstberichtete Selbstzahlerkosten von 2059,55 €, die direkt mit der Krankheit

einhergehen. Indirekte Kosten wurden aus den Einkommensverlusten, Alltagsunterstützungen, Pflegekosten sowie Kosten durch Folgeerkrankungen und weiteren Kosten ermittelt. Es ergeben sich durchschnittlich jährliche indirekte Kosten von 2174,25 €. Die sich aus der Umfrage ergebenden Summe der von Patient*innen selbstgetragenen Kosten umfassen im Durchschnitt jährlich 4233,81 € mit einer Standardabweichung von 8240,31 €.

Allgemein kann von einem Anstieg der Selbstkosten ausgegangen werden. Dieser kann in einer Verbesserung des Leistungsspektrums für alternative Behandlungsmethoden und einem gestiegenen Bewusstsein für die Notwendigkeit von Eigeninvestitionen in die Gesundheit begründet liegen. Zur Validierung der Ergebnisse werden jedoch weitere gesundheitsökonomische Studien benötigt.

Background

Endometriosis is characterized by the presence of endometrium-like tissue outside the uterus, resulting in chronic inflammatory processes accompanied by cyclic and acyclic pain and other symptoms. It is estimated that 10–15% of all persons of reproductive age defined according to their sex as female, which in Germany corresponds to 40 000 people annually, develop endometriosis [1, 2]. The relevance of this disease is due to its often early presentation, resulting in a long period of suffering during the productive and reproductive stages of life of persons with the disease. It is associated with high individual and social costs related to frequent sick leave and reduced productivity. Persons with endometriosis also face considerable additional disease-related costs.

Primary medical treatment consists of primary drug treatment or, depending on the findings, surgical laparoscopic procedures. The course of treatment can include the administration of GnRH analogues, dienogest-based hormone products and/or analgesics. The costs of the different medications and possible side effects also requiring treatment differ considerably. The symptoms of endometriosis may recur and new foci of disease may develop after surgery or after discontinuation of medical therapies, leading to significant follow-up costs due to absence from work and reduced productivity. In addition to drug therapies, multimodal pain therapy in the form of psychological treatment and physiotherapy is an integral part of care for affected persons.

Overall, endometriosis is associated with significant costs for the health care system, for society and for the affected persons themselves as well as their relatives. The direct self-reported costs identified for the first time in this study have only been estimated in previous studies.

The direct costs of the disease comprise the costs of outpatient and inpatient surgical treatment as well as the costs of drug therapies and possibly multimodal as well as complementary therapies. Then there are the costs of infertility treatment. But there are also

indirect costs related to endometriosis. They include both the costs of treatment as well as possible costs arising from non-treatment of disease because of the long latency period until diagnosis. Such costs can include the cost of times when the affected person was unable to work or entirely incapacitated. And then there are also the costs arising from additional childcare needs or support for activities of daily life which, in most cases, are borne by the affected persons alone. There are also indirect costs arising from possibly unachieved career prospects due to a disease-related reduction in the ability to reach the full professional potential. These costs could not be included in this study as it is not always possible to clearly identify a theoretically monetarily more lucrative professional position and quantifying such costs is even more difficult.

Politicians have begun to realize the role of endometriosis as a social and health-economic burden and understood its significance by providing funds for research.

To obtain an understanding of the personal costs currently borne by affected persons in a single calendar year, a survey was carried out among endometriosis patients which asked them about the above-listed costs. This study focuses on all costs financed personally by affected persons with endometriosis. Other costs covered by medical insurance companies, pension insurance or other social security systems were not investigated in this study.

Method

Study design

The perspective chosen for this analysis of disease-related costs was that of the patient. Indirect and direct self-reported costs related to endometriosis were determined using a bottom-up approach, i.e., starting at the level of the individual patient. This analysis includes both affected patients and their relatives. The costs reported here are those arising in just one year.

► **Table 1** Overview of self-reported costs (sum).

Parameters	Total			Statutory health insurance			Private health insurance		
	n	mean	SD	n	mean	SD	n	mean	SD
Direct costs (total) [€]	250	2059.55	3664.30	235	2073.3	3670.2	15	1844.2	3689.15
Indirect costs (total) [€]	250	2174.25	5959.22	235	2302.31	6124.42	15	168.07	310.51
Self-reported costs (total) [€]	250	4233.81	8240.31	235	4375.61	8425.98	15	2012.27	3924.94

For this study, quantitative data were collected using an online survey tool. The study used the SoSci Survey Tool to create an online questionnaire, presented in the supplementary online material (Fig. S1). Data were collected exploratively or used to generate hypotheses. The target population consisted of persons with a diagnosis of endometriosis (N80) living in Germany. In a first step, the sociodemographic data of participants was collected. Then information about their health insurance was collected, although this information does not form part of the findings reported here. Using a numeric input field, participants were then asked about endometriosis-related costs which they funded themselves. Finally, data was collected about quality of life and the emotional burden of endometriosis on the affected persons and their social environment. These findings are also not part of the results reported here.

Data evaluation was carried out using Excel and SPSS.

Recruitment

Recruitment into the study was done exclusively online from 1 August 2023 to 12 August 2023. A total of 266 responses were registered via the online questionnaire. The survey was carried out entirely digitally to allow patients from every region in Germany to participate. The sample population was recruited via different social media. All participating persons were informed in advance about the study objectives, assured that their data would be anonymized and provided with the contact data of the study administrators in case of any questions.

Sample

Persons of legal age with endometriosis and statutory or private health insurance living in Germany who agreed to participate in the study were eligible for inclusion in the study. Persons who did not meet these criteria were excluded from the study.

Results

A total of 250 persons met the inclusion criteria and were included in the study. Of these, 94% (n = 235) had statutory health insurance and 6% (n = 15) were privately insured (see ► **Table 1**). Sixteen of the original 266 recorded responses were ultimately not included: 12 were excluded because no answers were given, two were not included because they were civil servants which made it impossible to classify them as having private or statutory health insurance, and two responses were not evaluated because the persons lived in Austria and Switzerland, respectively.

Sociodemographic data

The mean age of the included participants was 32.84 years (SD: 6.55). The maximum age was 53 years. The youngest participant was 21 years old. All of the participants in the study characterized themselves as female.

At the time of the survey, 86.4% (n = 216) of the study participants were in paid employment; 8.4% (n = 21) still went to school or were attending university, and only 5.2% (n = 13) of the participants were seeking work at the time of the survey.

The annual net household income varied considerably. 53 participants had a net household income of less than €20000. The majority (n = 101) had a net household income of between €20000 and €40000. 56 persons were in the income group between €40000 and €60000, 18 had an annual net household income of between €60000 and €80000. Only 12 persons had a net annual household income of between €80000 and €100000. Ten participants in the study had a net household income of over €100000. The mean reported annual net household income was slightly over €40000.

Participants were also asked about their current marital or family status. 48 participants were single; 22 were in a permanent relationship but did not live with their partner; 177 were in a permanent relationship and lived together with their partner; two participants were divorced, and one participant was a widow.

45 of the persons taking part in the study were mothers with one (n = 22), two (n = 17), three or more children (n = 6) (mean: 1.87; SD: 1.83).

Costs

For reasons of clarity, all reported costs are shown ► **Table 1**, ► **Table 2**, and ► **Table 3**. More detailed tables about individual cost blocks are available in the online supplementary material (Tables S1–S9). Unless stated otherwise, the mean values presented here are based on the number of patients who provided particulars about the respective cost category.

The majority of self-reported costs were incurred in an inpatient medical setting (n = 104) and only n = 42 occurred in an outpatient medical setting. The mean self-financed cost per capita not covered by health insurance incurred in an outpatient medical setting amounted annually to €263.50 (SD: €524.18); in the same period, the per capita cost in an inpatient setting was €245.78 (SD: €996.22) annually. 41.2% (n = 103) of the study participants did not incur these costs.

►Table 2 Overview of self-reported direct costs.

Parameters		Total			Statutory health care			Private health care		
		n	mean	SD	n	mean	SD	n	mean	SD
Non-pharmacological therapy	Outpatient medical care [€]	42	262.50	524.18	40	199.13	302.54	2	1530.00	2078.89
	Inpatient medical care [€] HOSPITAL	104	245.78	996.22	101	137.14	192.76	3	3903.33	5347.06
	Pain therapy (outpt./inpt.) [€]	21	198.57	272.93	21	198.57	272.93	0	–	–
	Fertility treatment [€]	35	4227.14	5697.91	33	4446.97	5797.69	2	600.00	565.69
Drug therapy	Hormone therapy [€]	114	134.55	172.89	107	130.17	169.82	7	201.43	218.97
	Prescription drugs [€]	147	99.80	148.45	140	100.43	151.56	7	87.14	62.64
	Private drug prescriptions [€]	109	240.28	374.77	103	249.18	383.68	6	87.50	31.58
Aids	Medical devices [€]	125	119.18	111.90	119	121.07	114.03	6	81.67	43.55
	Books and specialist lectures [€]	111	78.27	83.18	103	79.54	85.79	8	61.88	34.01
Therapeutic products and complementary therapies	Physiotherapy [€]	84	201.96	249.28	80	192.31	228.59	4	395.00	539.54
	Ergotherapy [€]	5	222.00	274.44	5	222.00	274.44	0	–	–
	Osteopathy [€]	107	362.57	324.13	103	367.43	328.83	4	237.50	118.43
	Relaxation techniques [€]	50	260.40	218.94	47	266.60	223.03	3	163.33	123.42
	Psychological techniques [€]	13	361.15	573.43	13	361.15	573.43	0	–	–
	TCM [€]	28	1699.29	4872.46	26	1799.23	5048.91	2	400.00	282.84
	Homeopathy [€]	29	283.45	258.99	29	283.45	258.99	0	–	–
	Other therapies [€]	30	353.67	556.31	29	363.28	563.61	1	75.00	–
Nutritional therapy	Nutritional counselling [€]	13	226.92	209.26	13	226.92	209.26	0	–	–
	Food supplements [€]	157	293.46	321.43	149	300.42	327.06	8	163.75	143.32
	Other nutritional costs [€]	127	376.24	333.07	119	379.79	330.79	8	323.50	385.70
Non-medical direct costs	Travel expenses [€]	191	222.63	289.51	178	230.90	297.39	13	109.38	87.30
Sum of direct costs (total) [€]		250	2059.55	3664.30	235	2073.30	3670.20	15	1844.20	3689.15

►Table 3 Overview of self-reported indirect costs.

Parameters		Total			Statutory health insurance			Private health insurance		
		n	mean	SD	n	mean	SD	n	Mean	SD
Loss of income	Inability to work [€]	49	3019.03	5278.53	48	3063.18	5325.24	1	900.00	–
	Reduced workload [€]	43	4090.47	6027.74	43	4090.47	6027.74	0	–	–
	Reduction in earning capacity [€]	7	6885.71	8824.10	7	6885.71	8824.10	0	–	–
	Termination of employment or unemployment [€]	16	6231.58	11062.62	16	6231.58	11062.62	0	–	–
Other indirect costs	Support in activities of daily life [€]	15	1207.27	1181.51	14	1293.43	1176.19	1	1.00	–
	Nursing costs [€]	3	80.00	10.00	3	80.00	10.00	0	–	–
	Costs of secondary disease [€]	105	433.10	877.50	100	440.46	896.74	5	286.00	298.71
	Other costs [€]	19	421.58	381.67	16	488.75	379.51	3	63.33	47.26
Sum of indirect costs (total) [€]		250	2174.25	5959.22	235	2302.31	6124.42	15	168.07	310.51

The average annual per capita cost of pain therapy (outpatient and inpatient) was € 198.57 (n = 21; SD: € 272.93). A total of 14% (n = 35) of cases funded the cost of their own fertility treatments as they were not covered by their health insurance. The average annual cost of this amounted to € 4227.14 (SD: € 5697.91).

45.6% (n = 114) of cases paid for hormone therapy. On average, the self-financed costs over the past 12 months amounted to € 134.54 (SD: € 172.89) per person. 59.2% of study participants (n = 148) financed the costs of other prescription medicines themselves. The mean annual sum amounted to € 99.80 (SD: € 148.45) per year. Irrespective of whether they had statutory or private healthcare, 43.6% (n = 110) of respondents also bore the costs of private prescriptions for non-prescription medications which were not reimbursed by health insurance companies, amounting on average to € 240.28 (SD: € 374.77) annually. Conversely, 15.2% (n = 38) of study participants had no additional costs for medications.

Other self-funded costs incurred by 50% (n = 125) of persons were for special medical devices and amounted to € 119.18 (SD: € 111.90). An average annual sum of € 78.27 (SD: € 83.18, n = 111) was spent on books or specialist lectures. The answers to the question about the costs of digital health applications were ambiguous. It was not clear whether participants were referring to reimbursable digital health applications or to general health apps, and these data were therefore not included in the analysis.

On average, participants tried 1.7 additional therapies over the course of one year, which they paid for themselves. Additional therapies included physiotherapy (33.6%, n = 84) amounting annually to € 201.96 (SD: € 249.28), ergotherapy (n = 5, € 222.00, SD: € 274.44), osteopathy (n = 107, € 362.57, SD: € 324.13), relaxation techniques (n = 50, € 260.40, SD: € 218.94), psychotherapy (n = 13, € 361.15, SD: € 573.43), traditional Chinese medicine (n = 28, € 1699.29, SD: € 4872.46), homeopathy (n = 29, € 283.45, SD: € 258.99) and other therapies (n = 30, € 353.67, SD: € 556.31). The average cost for the entire study population amounted to € 522.66 (SD: € 1856.32) of self-funded costs for further therapeutic procedures excluding nutritional services and therapies.

When we looked at nutritional costs in the widest sense of the word, 5.2% of persons participating in the study had nutritional counselling in the past 12 months, for which they paid an average of € 226.92 (SD: € 209.26). An average of € 293.45 (SD: € 321.43) per person per year was spent on food supplements by 62.8% (n = 157) of the participants. Other costs for adapting their nutrition and diet were incurred by 50.8% (n = 127) of cases. The average cost of this over 12 months was € 376.18 (SD: € 333.07). Calculated for the entire study population, an average of € 387.19 was spent on nutrition-related services and goods (SD: € 492.75) per capita per year.

Self-funded travel costs related to endometriosis treatments were incurred by 76.4% (n = 192) of the study participants in the past year, which amounted to approximately € 222.63 (SD: € 289.51).

In total, based on the entire study population, this amounts to a mean of € 2059.55 (SD: € 3664.30) of directly attributable self-funded costs per person and year.

19.6% (n = 49) of persons participating in the study reported a loss of income due to an incapacity for work. The mean loss of in-

come over the past 12 months amounted to € 3019.03, with a standard deviation of € 5278.53. The mean annual cost of disease-related reduced working hours for 17.2% (n = 43) of the study participants amounted to € 4090.47 (SD: € 6027.74). Seven of the persons participating in the study (2.8%) reported a reduced earning capacity; 16 persons (6.4%) had received notice of termination or were unemployed. The costs of being terminated from their job or being unemployed as estimated by affected participants amounted on average to € 6231.58 over the past 12 months (SD: € 8824.10). When the sum of all self-reported losses of income was calculated, it amounted on average to € 1886.91 per year and person (SD: € 5580.63) for the entire study population.

Other costs asked about in the survey included the cost of support for activities of daily life (n = 15, € 1207.27, SD: € 1181.51), nursing care (n = 3, € 80.00, SD: € 10.00), the cost of follow-up diseases (n = 105, € 433.11, SD: € 877.50), and other costs (n = 19, € 421.58, SD: € 381.67). All figures refer to one year and one person.

For the indirect results, this resulted in a mean of € 2174.25 (SD: € 5959.22) for the entire study population per person and year.

Participants were also asked whether they failed to use required services because of a lack of funds and to rate their statement on a scale from 1 to 5, from not applicable to applicable. The mean result was 3.1 with a standard deviation of 1.35.

There were six cases (2.4%) where health insurance companies did not reimburse any services in the past year, compared to 35.6% (n = 89) of insured persons whose health insurance companies funded all requested services.

In detail, for this sample of 250 patients obtained via an online survey, reimbursement of physiotherapy was rejected in 12.8% of cases, fertility treatments in 9.6%, relaxation techniques in 19.2%, prescriptions for medical cannabis in 11.2%, hormone therapies in 26.8%, digital health applications in 6%, rehabilitation measures or follow-up treatment in 7.6%, and nutritional counselling in 11.2% of cases. With regards to medical devices and services, prescriptions were rejected in 7.2% of cases, pain therapy in 6% of cases, sonography in 7.2%, modern therapeutic procedures in 10.8%, and alternative medicine prescriptions in 34.4% of cases. There was no case where endometriosis surgery was rejected.

The self-funded costs of endometriosis patients in a single calendar year based on all the items reviewed in this survey amounted to an average of € 4233.81 with a standard deviation of € 8240.31 (n = 250).

Discussion

Method

The risk of carrying out a survey with an online tool is that it is not possible to exclude persons from other countries or persons without a confirmed diagnosis of endometriosis from participating. Moreover, a digital survey where participants are recruited via social media excludes persons with no internet access or no access to social media, which can also lead to bias in terms of the study population. The short recruitment period during the summer holidays of almost all federal states in Germany may have led to a further selection bias. The format of the questions also did not

permit a clear distinction of surveyed costs subsequently. In terms of health economics, pain therapy costs are part of outpatient and inpatient settings. But which sector included self-reported costs of pain therapy could not be deduced from the answer format, meaning that the overall costs incurred could be skewed by the sum of pain therapy costs. The question about the self-reported costs of digital health applications was also too unspecific, as it was not clear whether the answers referred to reimbursable digital health applications or to general health apps. There is also a risk with this survey that affected patients overestimate or underestimate costs, due to a lack of insight into the cost structures of the health care system, especially with regards to statutory health insurance, where invoicing is primarily done by the respective health insurance company.

As the overall format of questions was relatively open, this could have led to distorted responses.

It is not possible to exclude the possibility that the reported loss of income also included income losses which were settled or not settled by health insurance companies or pension insurance schemes. Similarly, support for activities of daily life could include other types of support in addition to the suggested examples of home help and childcare, which the participants subjectively assigned to this category.

The example given for modern procedures not reimbursed by health insurance companies only included magnetic resonance imaging-guided focused ultrasound therapy, which leaves a lot of scope for interpretation on the part of the respondents answering the question.

As this represented an initial collection of patient data, more clearly defined question formats could validate the data in subsequent publications.

This study also did not investigate in detail whether services for which reimbursement was refused were considered medically useful by treating physicians or whether the physicians doubted the value of the proposed treatments. This could be the subject of further surveys among affected persons.

It should be noted that the authors are employees or paid consultants of Endo Health GmbH. A conflict of interest can therefore not be objectively excluded, even though good scientific practice was complied with at all times.

Study population

The study population corresponds in many aspects to the average German population defined as female. Compared to the general female population in Germany, the unemployment rate of the study participants was slightly lower (5.2% compared to 5.8%) [3]. There was also a slight difference with regards to the mean net household income of €43 932 [4]. The mean value for the group was 2.46, which corresponds to an average net household income of €49 200 (1: <€20 000, 2: €20 000–€40 000, 3: €40 000–€60 000, 4: €60 000–€80 000, 5: €80 000–€100 000, 6: >€100 000). When the age of the study population was compared with that reported in previous endometriosis cost studies such as the EndoCost study [3], it was found that the population in our study had a mean age of 32.80 years (SD: 6.554), which was almost three years younger than the population of the EndoCost

study (mean: 36.80 years, SD: 6.8). This difference in age could be a consequence of recruiting participants only via social media.

Costs

When the costs identified in this study are placed in the context of other reported costs for endometriosis patients incurred by the health care system and macroeconomically (cf. [5]), endometriosis clearly results in high costs for the health care system, the overall economy, and affected persons themselves. The studies which Brandes looked at also used a bottom-up approach but from the perspective of the health care system. In contrast to the self-reported costs of patients discussed here, the studies in the Brandes publication, which also used a bottom-up approach, primarily looked at the utilization of services and then multiplied the figures by the current cost datasets to calculate the annual costs per head. This approach has the advantage that affected persons cannot overestimate or underestimate the costs they incur as they are not informed about costs for the health care system. There is no information bias with regards to incurred costs, although both retrospective data collection methods may have a recollection bias.

A recollection bias with regards to incurred costs and the associated overestimation or underestimation of self-funded costs could be the reason why the sum of the self-incurred costs reported in our study were, on average, around €500 lower than the average costs of endometriosis patients reported by Brandes (€4786.20) (cf. [5]).

The variability of self-reported outcomes is reflected in the wide standard deviations. This inconsistency of outcomes could be result of information bias or recollection bias on the part of affected persons about the costs for the health care system. The lack of information about which costs should be assigned to a specific area could also lead to bias in the individual results.

The increase in health-care costs and the rise in inflation since the publication of the comparative studies needs to be considered. If the inflation figures since the publication of the respective studies (cf. [5]) are added to the total costs, the costs amount to €6245.99 per capita and year.

The increase in reported self-funded costs could be explained by the increased information available about therapy methods and the greater general knowledge of the disease. It can also be assumed that the range of services has increased since the studies came out in 2005–2009. This increase in services, possibly also of alternative treatment methods, could result in a further rise in the costs self-funded by endometriosis patients. Higher indirect costs could be due to an increased awareness on the part of affected persons that menstrual pain no longer needs to be considered as normal and that “no menstruation” and working arrangements adapted to the disease have become more common.

As endometriosis is a topic which predominantly affects the population defined by sex as female, an economic view of the gender pay gap should also be included. The current gender pay gap in Germany is about 7%; if additional factors such as the number of paid working hours per month (gender hours gap) and the employment rate (gender employment gap) are included alongside average gross hourly earnings, the gender gap is as high as 39% [4].

Based on a prevalence of disease of 10% and a female population of 42866224 women [6], we can assume that at least 4286662 women cannot adequately provide for their retirement as they are affected by days where they are incapable of working, illness-related reduction in their working hours, or unemployment. Persons with endometriosis are affected by the increased costs associated with this chronic disease, which additionally reinforces the economic imbalance between persons with endometriosis and healthy persons of the same age and gender in Germany.

Summary

These results show how high the costs incurred by women with endometriosis are. It is imperative to curb these costs and reduce the burden on affected persons and their relatives, and not just for health-economic and macroeconomic reasons. Further national surveys will be needed to be able to gauge the full extent of the health-care and macroeconomic costs.

The solidarity principle which underpins the health care system in Germany requires the system to provide affected persons with the support they need to be able to actively participate in society and to sustainably improve the quality of life of endometriosis patients.

This will not just need further health-economic studies. Information and education provided by high-quality scientific media and further research into the disease are essential to increase the general awareness of this disease and provide affected persons with adequate support.

Supplementary Material

- Table S1: Overview of self-reported direct costs for the cost block: non-pharmacological therapies.
- Table S2: Overview of self-reported direct costs for the cost block: drug therapies.
- Table S3: Overview of self-reported direct costs for the cost block: aids.
- Table S4: Overview of self-reported direct costs for the cost block: therapeutic products and complementary therapies.
- Table S5: Overview of self-reported direct costs for the cost block: non-medical direct costs.
- Table S6: Overview of self-reported direct costs for the cost block: nutritional therapy.
- Table S7: Overview of self-reported indirect costs for the cost block: loss of income.
- Table S8: Overview of self-reported indirect costs for the cost block: other indirect costs.
- Table S9: Overview of self-reported direct and indirect costs for all blocks of costs.
- Fig. S1: Online questionnaire.

Conflict of Interest

All authors declare the following: Payment/services info: The Endo Health GmbH (formerly UG) received funding from the European Regional Development Fund (ERDF) from the state of Saxony, Germany. Financial relationships: Nadine Rohloff declares employment and stock/stock options from Endo Health GmbH. CEO, Shareholder. Nadine Rohloff and Nicole R Heinze declare personal fees from DGE (German Nutrition Society). Nicole R Heinze and Teres Götz declare employment from Endo Health GmbH. Consulting fees. Intellectual property info: The Endo-App is a medical device and a registered trademark. Other relationships: All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

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