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ORIGINAL PAPER

Economic burden of blindness and visual impairment in Germany from a societal perspective: a cost-of-illness study

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Abstract

Background Visual impairment and blindness cause a considerable and increasing economic burden affecting not only persons with vision loss and their families, but also societies. For the majority of countries, there is no solid database that would allow a comprehensive assessment of costs from a societal perspective. The present study was conducted to fill this gap.
Objectives To investigate resource utilization of blind or visually impaired people and to assess the economic burden of blindness and visual impairment in Germany.
Methods This cross-sectional cost-of-illness study measures the economic burden of blindness and visual impairment bottom-up and from a societal perspective. Therefore, blind and visually impaired persons were recruited via national self-help organizations (prevalence-based approach) and interviewed regarding their utilized resources using various survey modes (mixed-mode approach). The observation period was 6 months retrospectively. Utilized resources were valued applying standardized unit costs (macro-costing). Calculations for the study population provided direct and indirect costs per person for a period of 6 months. Further cost per category was extrapolated to 1 year for the general population of Germany. Uncertainty of results was addressed applying univariate deterministic sensitivity analyses.
Results Complete data were collected from 683 participants (54.84% women; average age: 60.28 ± 17.02 years). Decreasing vision was associated with increasing costs ($p < 0.001$). Most costs were incurred by informal support from relatives, which was the most important resource for coping with everyday life for people with visual loss. Together with assistive/medical devices and loss of productivity due to disability, informal support accounted for 80% of total costs. Extrapolated to Germany, the annual costs of blindness and visual impairment from a societal perspective amounted to € 49.6 billion. Results of the sensitivity analyses and 95% confidence intervals showed a considerable degree of uncertainty.
Conclusion Visual impairment and blindness may cause enormous overall costs from a societal point of view, as shown here for Germany. Our findings on the costs of blindness and visual impairment in Germany add in a number of different ways to the international evidence. In particular, results show that a large proportion of the costs are not obvious per se as it is caused by self-paid deductibles, productivity loss, early retirement and informal support/care by relatives. Further research should make special efforts to investigate these costs precisely as well as their influence factors.

Keywords Blindness · Visual impairment · Costs · Cost of illness · Societal perspective

JEL Classification I19

Introduction

Blindness (BL) and visual impairment (VI) cause substantial socioeconomic consequences due to direct medical (e.g., treatment of health consequences such as falls or accidents) and direct non-medical costs (e.g., informal support, home improvements or transport) as well as indirect costs, in particular lost productivity of the affected individual and their caregivers. Chakravarthy and colleges (2017) quantified the annual economic loss due to reduced productivity from BL

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and moderate to severe VI in Europeans 50 + years at € 56.5 billion [1].

In industrialized countries VI and BL are primarily problems of old age, and the rapid aging of the population will lead to an increase in the incidence of BL and VI of up to 25% until 2030 (compared to 2010). In addition, persons with concomitant potentially blinding diseases have on general a higher life expectancy than it was a few years ago and thus have an increased lifetime risk of vision loss [2, 3].

With increasing health-care costs and the need to prioritize resource allocation, it is increasingly important to demonstrate whether and to what extent ophthalmic interventions are cost-effective and reduce or delay costs of moderate to severe VI or BL [4]. For example, Kawasaki and colleges estimated in a simulation study that screening for diabetic retinopathy in patients with diabetes would result in a significant reduction of BL in people aged 40 years or over (− 16%). The authors' sensitivity analyses suggested that to achieve not only a reduction in BL but also cost-effectiveness, the screening should be applied especially to patients aged 53–84 years [5].

A recently conducted systematic review of the economic burden of BL and VI highlighted the multitude of different cost categories contributing to the overall burden, of which direct costs were only a small amount. A much larger amount of costs was caused by deductibles, productivity loss, early retirement and informal support/care by relatives [6]. Consequently, the most adequate perspective for determining the economic burden of BL and VI would be the societal perspective. However, the majority of the included studies were usually performed as simulation studies only without real cost data or based on a top-down approach and used mainly administrative data sources [6].

An overall evaluation of the economic consequences of BL and VI from a societal perspective does not exist for Germany. Available cost studies and surveys on health-care utilizations by visually impaired and blind people are limited to individual ophthalmological conditions or include selected cost types (see e.g., [7–9]).

To close this research gap, we collected (socio) economic data from blind and visually impaired persons and their families to determine the average costs per affected person resulting from BL and VI from a societal perspective, as well as the total annual costs in Germany.

Methods

Study design

Self-reported health-care utilizations due to visual impairment or blindness as well as the out-of-pocket costs of those affected and their relatives (dyad questionnaire) were assessed in this cross-sectional study using a mixed-mode approach following the recommendations of Kaczmirek and Wolff to offer preference-oriented access to surveys by persons with visual impairment [10].

Using paper–pencil questionnaires, telephone interviews, or an online survey compatible with assistive technologies, participants were able to report their visual impairment or blindness-specific health-care utilization, time off work and out-of-pocket costs for a retrospective period of 6 months. The use of informal support/care was reported per an average week. In comparison to cost diaries, which need to be filled in daily by the affected person or relatives over several months, retrospective data collection over up to 6 months has been found to be equivalent and yield highly comparable data when surveying persons with visual impairment or blindness [11].

In cooperation with the "Deutscher Blinden- und Sehbehindertenverband e.V." (DBSV) (the German association of the blind and visually impaired), the survey was also made available as a Braille document, a tactile writing system for blind and visually impaired persons, and in DAISY format, a digital audiobook, so the preferred type of medium to report information could be chosen by the visually impaired or blind participant. Both the DAISY format and the Braille version were only available as background information for the survey and to prepare for the telephone interview, the online or paper–pencil questionnaires. Carers were allowed to assist visually impaired or blind persons completing questionnaires.

For carers, a separate questionnaire was available to document their costs in a paper–pencil or online version.

The human research ethics committee of University of Wuppertal, Germany, approved the study protocol. All participants provided informed consent.

Definition of blindness and visual impairment

In Germany, the legal definition of visual impairment and blindness differs from the definition of the International Classification of diseases-10 (ICD-10) [12, 13]. Based on the German legal classification, a person with a visual acuity of 0.3–0.05 is considered to be moderately visually impaired, with a visual acuity of 0.05–0.02 persons are considered to be severely visually impaired and with a visual acuity of less than 0.02 the person is considered to be legally blind. This classification makes the German legal classification much stricter compared to the ICD-10 classification.

Study participants reported the level of their visual impairment as well as the last known ophthalmologically documented visual acuity and disability-specific social allowances. Both VI and BL can be reliably identified using such a multi-component assessment [14].

Study population

Due to the low prevalence of BL and (severe) VI of 1.0–2.1% [15, 16] in the general population of Germany, sampling was based on self-selection. As there is no national blind register in Germany [2, 3], potential participants were informed via newsletters or members' periodicals of cooperating patient organizations. This was followed up with reminders sent by mail to all members once 2 months after the initial contact.

Cooperating organizations were: the Deutscher Blinden- und Sehbehindertenverband e.V. (DBSV) (the German association of blinds and visually impaired), PRO RETINA Deutschland e.V., the Deutscher Verein der Blinden und Sehbehinderten in Studium und Beruf e.V. (DVBS) (the German association of blind and visually impaired in education and occupation) and the AMD-Netz NRW e.V. In addition, all regional chapters of the DBSV were informed about the study via e-mail and asked to promote participation.

We included only persons over the age of 18 years who rated their VI as moderate, severe or blind. In addition, expenditures of relatives aged 18 years and over were included, if these expenditures were caused by caring for the person with visual loss.

Documentation of visual impairment and blindness-associated service utilization and productivity losses

Development and structure of the survey documents

Based on our previous work [6, 17] as well as work by Neumann and colleagues [18], a cost inventory for the assessment of the economic impact of both, related and unrelated to health care was developed. The inventory comprises direct medical cost components, in particular outpatient physician and non-physician services (scale unit: contacts), inpatient services (scale unit: days), rehabilitation services (scale unit: contacts) and medical devices (scale unit: quantity per item). It also covers non-medical direct cost categories, particularly transportation (scale unit: km, quantity), formal home care (scale unit: quantity) and informal care (scale unit: hours). Indirect cost components cover productivity losses (scale unit: days).

The components of this cost inventory were then operationalized in a questionnaire especially for blind or visually impaired people as well as their relatives to measure utilized resources using a bottom-up approach. The questionnaire was transferred to the various survey modes:

1. *Paper–pencil questionnaire* The questionnaire with prepaid reply envelopes were sent out via the magazines and newsletters of the self-help organizations. In addition, written information about the project as well as references/links to the other available questionnaire modes (personal telephone interview, online survey) and access to supplementary materials (Braille documents, audio files) were provided.
2. *Telephone interviews* To participate via telephone interview, participants had to initiate contact and provide their contact details including a telephone number to our interview staff. A date for the interview was arranged with the participants and all information (date, time and telephone number) was sent encrypted to the Berufsfoerderungswerk Chemnitz (engl.: vocational training center of the City Chemnitz), a rehabilitation center as well as vocational training center for mainly blind and visually impaired persons, where telephone interviews were conducted. Interviews were done by trained operators with previous experience in interviewing visually impaired persons. Collected data were encrypted and sent back to our working group.
3. *Online Survey* The online survey was created with the survey tool LimeSurvey, which enables barrier-free access. LimeSurvey has been shown to perform well in data collection with visually impaired and blind persons [19]. A summary of used question types including an example question can be found in Supplementary Material 1.

We chose a prevalence-based approach for the documentation of resource utilization and estimation of costs. This approach estimates the economic burden of a condition over a predefined period (6 months retrospective in this study).

The final questionnaire consisted of a total of 51 questions on demographics, health status, visual impairment and blindness-specific resource consumption, occupation, family, finances and emotional quality of life (see Supplementary Material 2).

Data collection took place between November 2015 and December 2016.

Pre-test of the survey documents

Survey documents were pre-tested at the beginning of the study. Cognitive interviews were conducted based on predefined scenarios and probing questions for the paper–pencil and telephone interview version. The interviews were done via telephone in cooperation with the DBSV. First, participants had to fill out the paper–pencil questionnaire or answer the telephone interview version based on the scenarios, which were different resource utilization profiles. Second, after each theme/cost category of the questionnaire, probing questions were asked. A special focus of those probing questions was the ability of the questionnaire to differentiate between VI-/BL-specific resource consumptions and resource utilization due to other reasons. As a result of the pre-test, questions on assistive advices were rephrased to provide a certain number of predefined VI-/BL-specific products. Furthermore, we included more options for the documentation of VI-/BL-specific informal care, in particular personal hygiene, communication with banks or other public institutions and traveling companions during vacations.

We further conducted a separate technical pre-test of the online survey in cooperation with the Berufsfoerderungswerk Dueren gem. GmbH (engl.: vocational training center of the City Dueren). In addition, the functionality for blind-specific assistive technology and technical requirements were checked with the Zentrum fuer Informations- und Medienverarbeitung (the center for information and media processing) of the University of Wuppertal. Usability was evaluated by the DBSV. Technical requirements were, for example, that all questions, answers and buttons are labeled, so assistive technologies such as screen readers can translate displayed information into accessible (e.g., auditory) information.

Monetary valuation of utilized resources

The costs were determined from a societal perspective. Thus both visual impairment and blindness-specific direct as well as indirect cost components were considered. We did not include productivity losses due to premature death as a result of BL or VI, as well as welfare losses. Transfer payments, such as social allowances due to BL, were also not included, as these payments are only a redistribution of financial resources between different population groups [18]. In addition, no monetary valuation of intangible effects (e.g., quality of life) was made.

Based on Krauth et al. [20] and Bock. et al. [21], unit costs were calculated for all direct medical and non-medical services and goods in euro (€) at the 2016 price level (see Supplementary Material 3). Finally, the unit costs were multiplied by the documented service utilizations (macro-costing).

Indirect costs were calculated based on work incapacity days (due to absenteeism or occupational disability) reported by each subject. The assessment of productivity losses was made using the human capital approach, multiplying workdays lost due to vision loss with the average compensation of employees for the year 2016 at € 99.14 per day [22]. Periods of job-/profession-related work incapacity were only included in the calculation of indirect costs if this incapacity resulted in productivity losses. In the calculation of the average indirect costs, only participants younger than 66 years were included, as in 2016 the retirement age was 65 + 5 months in Germany.

Estimation of costs for the total study sample and for the general population of Germany

The average costs were determined for two different populations. As a first step, mean costs for the total study population were calculated for the original retrospective survey period of 6 months. This was followed by an extrapolation of the expenditures to 12 months and a transfer of these costs to the general population of Germany by multiplying visual impairment- and blindness-specific prevalence rates by the calculated 12 month costs.

Since our survey classified the degree of visual impairment based on self-assessments, we used prevalence rates for self-reported visual impairment (moderate and severe VI) and BL, which were gained separately through a computer-assisted face-to-face household interview as part of a representative population survey (DEBRA study). The study methodology of the population survey is described in detail elsewhere [23]. Self-reported visual impairment was documented in two waves of this omnibus survey from 2045 participants each in October 2017 and in January/February 2018 (total $n = 4090$). Documentation and assessment methodology of VI and BL was identical to our survey.

For the calculation of direct costs for the total population, the population as of 31 December 2016 was multiplied by the respective prevalence of visual impairment as well as the corresponding average direct costs (direct standardization). The population survey of the DEBRA study documented a prevalence rate of 3.01% for self-reported moderate VI, 0.36% for severe VI and 0.56% of the survey population reported blindness (see Supplementary Material 4). In the same way, indirect costs were calculated based on persons of working age (labor force, as at 31 December 2016). Moderate VI was reported by 2.49% of the labor force, 0.21% documented a severe VI and 0.73% assessed themselves as blind (see Supplementary Material 4).

Statistical analysis

All statistical analyses used the software packages SPSS Statistics 23 (IBM Corp, Armonk, NY, 200 USA) and STATA/SE 15.1 (StataCorp, College Station, TX, USA).

Missing values were considered missing at random (MAR) and not replaced. In this way, data records in which one or more survey features had missing values were excluded from the calculation of the total costs (complete case analysis). After the descriptive analysis, factors associated with total costs were assessed, in particular the influence of the degree of visual impairment. Because there were several subjects with zero costs, we applied two-part models [24]. These models use separate regressions for the binomial distribution (costs yes/no) and the continuous distribution (if costs, which amount of costs). We modeled the binominal component using logistic regressions. The continuous component was modeled with generalized linear models (GLMs). For direct medical and indirect costs, we used Poisson distribution as family and logarithm for the link function. Direct non-medical costs were calculated with inverse Gaussian distribution as family and logarithm as link function. Both models fit our data best.

Cost variables were all annualized and presented as mean and standard deviation (SD) or 95% confidence interval (95% CI) calculated using bootstrap methods because of their skewed distributions [25]. To evaluate how the uncertainty would impact the estimates of annualized costs of VI and BL at general population level, univariate deterministic sensitivity analyses were performed using best-/worst-case scenario analyses [26]. Therefore, we calculated in a first step prevalence ranges for each VI severity level applying different subgroup analyses, in particular analyses by gender and age. In a second step, we chose out of each prevalence range the lowest and the highest value and implemented them into the worst- and best-case scenario. The results of all univariate deterministic sensitivity analyses and the used prevalence ranges are presented in Supplementary Material 6.

Results

Respondent characteristics

Of 7638 persons to whom the study material was sent, 525 responded to the request via the paper–pencil questionnaire, 61 via telephone interview and 335 via online survey. After data cleaning, 683 self-reports (complete questionnaires) were available, corresponding to a response rate of 8.94%. An evaluation of the non-responders could not be carried out because of the recruitment via self-help organizations.

The survey involved 374 women (54.8%). The participants were on average 60.3 years old (standard deviation (SD): 17.0). 52.6% of the participants lived in a partnership, 45.9% were single and 1.5% did not provide information on their family situation. A moderate VI was reported by 177 people (27.3%). A severe VI was reported by 120 respondents (18.5%), of whom 35.0% received social allowances due to vision loss. 351(54.2%) persons reported to be blind in accordance with German legal definitions. Social allowances due to vision loss were obtained by 95.0% of the blind study participants. Table 1 describes further socio-demographic and clinical features.

Health-care utilizations and productivity losses due to VI and BL over the survey period of six months

At least one physician contact was reported by 151 (85.3%) persons with moderate VI, 102 (85.0%) with severe VI and 246 (70.09%) blind participants. Eight moderate visually impaired respondents (4.5%), seven (5.8%) severe visually impaired persons and 22 (6.3%) blind respondents reported one or more hospitalizations. The average length of stay in days was 7.7 (SD: 7.9) over all severity levels. Outpatient non-physician services were utilized by 18 (10.2%) people with moderate VI on average 19.6 times (SD: 41.0), 15 (12.5%) with severe VI on average 10.6 times (SD: 11.42) and 57 (16.2%) respondents with BL on average 10.3 times (SD: 12.76) (see Table 2). 377 participants (57.3%) documented at least one assistive/medical device. On average, assistive/medical devices were prescribed 3.8 times (SD: 6.0). Overall, 335 people (51.7%) reported informal care, and 2.9% also used home care. Home modifications due to vision loss were reported by 29 participants (4.4%).

Productivity losses occurred for 353 out of the 400 participants under the age of 66 years (88.3%) within the survey period.

Six-month costs of BL and VI for the total study sample

The average direct medical costs were € 2400.1 (SD: 5483.4) due to moderate VI, € 3342.2 (SD: 4854.4) due to severe VI and € 5115.5 (SD: 9937.9) due to BL (see Table 3). Mean direct medical costs increased statistically significantly with decreasing vision ($p < 0.001$) (see Table 4).

The direct non-medical costs also differed statistically significantly with the degree of VI (see Table 4). Moderate visually impaired persons reported on average € 1207.1 (SD: 6441.9), severe visually impaired participants € 3940.2 (SD: 21,011.3) and blind persons € 10,867.7 (SD: 115,022.3) (see Table 3). The degree of VI also had a statistically significant impact on mean indirect costs (see Table 4). Expenditures ranged from € 3061.0 (SD: 6891.2) due to moderate VI to € 3948.1 (SD: 7437.2) due to blindness (see Table 3).

Life years lived with minimal visual acuity, age, gender and further comorbidities had a statistically significant impact on costs (see Table 4). Costs of visual impairment and blindness were independent of the primary cause of visual impairment (results not reported in Table 4).

Table 5 displays the average costs per person for each cost category and stratified by the different impairment levels.

Figure 1 illustrates the share of direct medical, non-medical and indirect costs in total costs. For participants with moderate VI, indirect costs accounted for approximately 46.0% of the total cost, direct medical costs amounted to 36.0% of the total cost and direct non-medical costs accounted for only about 18.0%. In the case of severe VI, indirect costs amounted to 35.1%, direct medical to 29.8% and direct non-medical costs to 35.1% of the total costs. For

Table 1 Main characteristics of participants

	Total sample	Degree of visual impairment		
		Moderate	Severe	Blind
	$n = 683^a$	$N = 177^a$	$N = 120^a$	$N = 351^a$
Age (years)				
Mean ± SD	60.28 ± 17.02	63.79 ± 17.35	61.01 ± 17.89	57.40 ± 16.11
Gender [*n* (%)]				
Female	374 (54.84)	114 (64.41)	68 (56.67)	173 (49.43)
Male	308 (45.16)	63 (35.59)	52 (43.33)	177 (50.57)
Marital status [*n* (%)]				
Single	170 (24.93)	35 (19.77)	30 (25.00)	100 (28.49)
Married	354 (51.91)	84 (47.46)	65 (54.17)	190 (54.13)
Widowed	89 (13.05)	38 (21.47)	18 (15.00)	27 (7.69)
In a civil union	5 (0.73)	1 (0.56)	1 (0.83)	3 (0.85)
Divorced	54 (7.92)	17 (9.60)	5 (4.17)	26 (7.41)
Others	10 (1.47)	2 (1.13)	1 (0.83)	5 (1.42)
Occupational status [*n* (%)][b]				
Employed in the initially learned profession	151 (44.02)	42 (53.16)	23 (37.70)	78 (40.63)
Employed in an alternative profession	97 (28.28)	19 (24.05)	22 (36.07)	54 (28.13)
Unemployed	95 (27.70)	18 (22.78)	16 (26.23)	60 (31.25)
Job-related incapacity	85 (22.97)	20 (23.81)	18 (28.57)	45 (21.13)
Occupational disability—total	104 (27.96)	19 (22.89)	18 (28.57)	65 (30.09)
Occupational disability—partial	138 (35.94)	24 (28.92)	22 (33.85)	92 (40.53)
Onset of vision loss (age in years)				
Mean ± SD	29.77 ± 25.80	43.02 ± 26.72	35.19 ± 25.06	19.11 ± 20.36
Years lived with minimal visual acuity (years)				
Mean ± SD	20.13 ± 18.61	15.55 ± 16.92	14.18 ± 16.09	24.17 ± 19.14
Initial diseases [*n* (%)]				
Glaucoma	76 (11.14)	12 (6.78)	13 (10.83)	47 (13.39)
Cataract	101 (14.81)	34 (19.21)	18 (15.00)	43 (12.25)
Retinitis pigmentosa	237 (34.75)	45 (25.42)	28 (23.33)	160 (45.58)
Diabetic retinopathy	7 (1.03)	2 (1.13)	2 (1.67)	3 (0.85)
Age-related macular degeneration	174 (25.51)	83 (46.89)	37 (30.83)	32 (9.12)
Others	281 (41.20)	59 (33.33)	62 (51.67)	150 (42.74)
Other comorbidity [*n* (%)]				
None	243 (36.27)	68 (39.77)	35 (29.41)	135 (38.79)
One or more	427 (63.73)	103 (60.23)	84 (70.59)	213 (61.21)

n total sample, *N* sub-sample, *SD* standard deviation

[a] The number of included participants differs with the proportion of missing values

[b] Values include only participants < 66 years

blind people, 54.5% direct non-medical costs accounted for the largest share of total costs.

Annual costs at general population level

Extrapolated to 12 months and to the general population of Germany, the annual costs of VI and BL amounted to € 49.6 billion from a societal perspective in 2016 (see Table 5). Annual direct medical costs were € 11.9 billion due to moderate VI, € 2.0 billion due to severe VI and around € 5.0 billion due to BL. Annual direct non-medical costs due to moderate VI were € 6.0 billion, due to severe VI € 2.3 billion and due to BL € 10.6 billion. Annual indirect costs due to moderate VI were € 7.9 billion, due to severe VI € 0.9 billion and due to BL € 3.0 billion. Annual costs stratified by sex can be found in Supplementary Material 5.

Results of the conducted univariate sensitivity analyses demonstrated that annual costs at the general population level are highly influenced by the applied prevalences of VI and BL (see Supplementary Material 6).

Table 2 Visual impairment/blindness-associated utilization of health-care services over the survey period of 6 months ($n = 683$)

	Degree of visual impairment					
	Moderate ($n = 177$)[a]		Severe ($n = 120$)[a]		Blind ($n = 351$)[a]	
	N (%)	Mean ± SD	*N* (%)	Mean ± SD	*N* (%)	Mean ± SD
Outpatient physician services	151 (85.31)	8.09 ± 16.71	102 (85.00)	5.87 ± 5.64	246 (70.09)	5.26 ± 6.68
General practitioner visits	86 (48.59)	3.11 ± 2.94	54 (45.00)	3.43 ± 2.24	146 (41.60)	3.19 ± 2.70
Ophthalmologist visits	142 (80.23)	3.45 ± 3.61	94 (78.33)	2.74 ± 2.54	200 (56.98)	2.02 ± 2.61
Surgeon visits	12 (6.78)	4.42 ± 5.68	10 (08.33)	1.50 ± 0.53	21 (5.98)	1.57 ± 1.08
Other specializations	52 (29.38)	7.91 ± 23.61	38 (31.67)	3.74 ± 3.33	92 (26.21)	4.27 ± 8.26
Inpatient services (lengths of stay in days)	8 (4.52)	4.75 ± 2.76	7 (5.83)	7.71 ± 5.88	22 (6.27)	9.27 ± 9.51
Outpatient non-physician services	18 (10.17)	19.61 ± 40.98	15 (12.5)	10.60 ± 11.42	57 (16.24)	10.32 ± 12.76
Rehabilitation (contacts)	9 (5.08)	13.11 ± 7.59	11 (9.17)	6.27 ± 9.62	39 (11.11)	8.28 ± 9.93
Occupational therapy (contacts)	10 (5.65)	23.5 ± 55.31	7 (5.83)	12.86 ± 11.36	20 (5.70)	13.25 ± 16.37
Medical devices (quantity)	93 (52.54)	2.98 ± 3.48	68 (56.67)	3.82 ± 3.68	216 (61.54)	4.26 ± 7.38
Assistive devices to support mobility, in household and disease management	24 (13.60)	3.13 ± 6.00	28 (23.33)	2.71 ± 2.68	133 (37.89)	2.93 ± 7.69
Assistive devices to support with communication	38 (21.47)	1.58 ± 1.08	45 (37.50)	1.76 ± 1.66	161 (45.87)	2.24 ± 2.50
Visual aids	81 (45.76)	1.75 ± 1.51	47 (39.17)	2.23 ± 2.11	83 (23.65)	2.05 ± 2.84
Home care (days)	6 (3.39)	103.83 ± 144.71	3 (2.50)	9.67 ± 12.50	10 (2.85)	108.7 ± 222.30
Assistance in household	5 (2.84)	51.00 ± 76.07	2 (1.67)	13.00 ± 15.56	8 (2.28)	73.88 ± 130.77
Assistance in personal hygiene	2 (1.13)	184.00 ± 255.97	2 (1.67)	1.50 ± 0.71	4 (1.14)	117.50 ± 167.76
Communication with banks or other public institutions	–	–	–	–	2 (< 1)	13.00 ± 16.97
Companionship during vacancies	–	–	–	–	1 (< 1)	12.00 ± 0.00
Informal care (h)	70 (39.55)	49.64 ± 83.19	64 (53.33)	61.46 ± 97.54	201 (57.26)	94.62 ± 154.52
Assistance in household	45 (25.42)	53.22 ± 70.03	44 (36.67)	45.14 ± 70.84	158 (45.01)	75.17 ± 110.51
Assistance in personal hygiene	8 (4.52)	10.44 ± 14.92	10 (8.33)	53.30 ± 80.10	35 (9.97)	45.23 ± 74.00
Communication with banks or other public institutions	42 (23.73)	11.62 ± 24.23	47 (39.17)	14.98 ± 28.56	124 (35.33)	25.81 ± 52.22
Companionship during vacancies	39 (27.08)	13.03 ± 26.82	34 (28.33)	20.90 ± 51.58	110 (31.34)	21.44 ± 41.82
Home modifications (quantity)	4 (2.26)	1.25 ± 0.50	4 (3.33)	1.00 ± 0.00	21 (5.98)	2.00 ± 2.39

n sub-sample, *N* proportion of respondents with at least one utilization, *SD* standard deviation

[a] The number of included participants differs with the proportion of missing; transportation is only displayed in Table 5, because no participant received a reimbursement for traveling costs and therefore documented directly the money spent for this resource utilization

Table 3 Direct medical, direct non-medical and indirect 6-month costs per person

Degree of visual impairment	Direct medical costs ($n = 683$)			Direct non-medical costs ($n = 683$)			Indirect costs ($n = 400$)[a]		
	N	Mean	SD	*N*	Mean	SD	*N*	Mean	SD
1. Moderate visually impaired	177	2400.14	5483.39	176	1207.05	6441.93	82	3060.95	6891.17
2. Severe visually impaired	120	3342.20	4854.39	120	3940.16	21,011.34	62	3933.62	7891.71
3. Blind	351	5115.54	9937.87	347	10,867.69	115,022.30	209	3948.05	7437.17

n total sample, *N* sub-sample, *SD* standard deviation

[a] Values include only participants < 66 years

Table 4 Results of the two-part models—factors associated with costs

Variable	Two-part model					
	Direct medical costs		Direct non-medical costs		Indirect costs	
	Logit	GLM[1]	Logit	GLM[b]	Logit	GLM[a]
	Coef. (SE)	Coef. (SE)	Coef. (SE)	Coef. (SE)	Coef. (SE)	Coef. (SE)
Degree of visual impairment						
Severe visually impaired	0.24 (0.44)	0.20*** (0.00)	0.68** (0.26)	2.81*** (0.74)	0.13 (0.44)	0.11*** (0.00)
Blind	0.19 (0.34)	0.56*** (0.00)	0.93*** (0.22)	2.13*** (0.47)	0.45 (0.35)	0.004*** (0.00)
Gender						
Male	−0.24 (0.28)	−0.08*** (0.00)	−0.34* (0.17)	1.45*** (0.41)	−0.21 (0.27)	−0.04*** (0.00)
Age groups[c] (years)						
31–60	−0.30 (0.67)	−0.23*** (0.00)	−0.002 (0.35)	1.94*** (0.36)	1.64** (0.64)	0.13*** (0.01)
61–80	−0.31 (0.65)	−0.69*** (0.00)	−0.29 (0.35)	3.23*** (0.55)	2.01** (0.67)	0.14*** (0.01)
> 80	0.22 (0.87)	−0.93*** (0.00)	−0.006 (0.44)	2.43*** (0.56)	n.a.	n.a.
Years lived with minimal visual acuity	−0.02** (0.00)	−0.001*** (0.00)	−0.006 (0.00)	−0.04*** (0.00)	−0.03*** (0.00)	−0.002*** (0.00)
One or more comorbidities						
No comorbidity	−0.26 (0.28)	−0.16*** (0.00)	0.17 (0.18)	−0.37 (0.38)	−0.35 (0.27)	−0.02*** (0.00)
N	590	528	586	309	336	83

N sub-sample, *GLM* generalized linear model, *SE* standard error, *n.a.* not applicable (because indirect costs comprises only values of participants < 66 years)

*p value < 0.05, **p value < 0.01, ***p value < 0.001

[a] Distribution family: Poisson and link function: logarithm

[b] Distribution family: inverse Gaussian and link function: logarithm

[c] Reference category (18–30 years)

Discussion

Discussion of results

To our knowledge, this is the first study that quantifies the costs of BL and VI from a societal perspective for Germany. The most important results of this study can be summarized as follows:

- In Germany moderate to severe visual impairment and blindness cause annual costs of at least € 49.6 billion from a societal perspective.
- Up to one-third of the total costs of BL and VI are indirect costs caused by loss of productivity.
- Informal support/care is, along with the utilization of assistive/medical devices, the most important resource for visually impaired and blind people.
- The degree of VI significantly impacts costs. Further, years spent with minimal visual acuity is an important influencing factor.

In our study, we determined the costs of BL and VI for a sample ($n = 683$), which far exceeds the number of cases in previous studies also using a bottom-up approach. This large sample is one major strength of our work. It allows comprehensive subgroup analyses and increases the likelihood that multiple profiles of people with VI or BL are considered in this study. In comparison, Cruess and colleagues included only 83 patients in their cost-of-illness study investigating patients with wet age-related macular degeneration [7]. Porz et al. recruited 66 patients with age-related macular degeneration, diabetic retinopathy, or retinal dystrophy for a diary survey in which out of pocket costs were documented [27]. Nonetheless, wide confidence intervals and sensitivity analyses demonstrate a large degree of uncertainty which should be considered, when using the results of this cost-of-illness study.

Further, we were able to use self-reported VI (moderate and severe VI) and BL prevalence rates from a representative population survey when calculating total population costs. The prevalence data were collected using the same assessment instruments we used in our cost-of-illness study. Therewith, we could avoid a mixture of self-assessed and medically diagnosed VI/BL. Prevalence rates for self-reported VI and BL were widely consistent with other studies for Germany reporting medically diagnosed VI and BL, e.g., [1, 28].

Table 5 Annual costs extrapolated for the German population

Costs in €	Degree of visual impairment					
	Moderate visually impaired		Severe visually impaired		Blind	
	Mean [95% CI]	Total cost for German population	Mean [95% CI]	Total cost for German population	Mean [95% CI]	Total cost for German population
Direct medical[a]	4800.27 [3579.31–7002.37]	11,923, 399,078.91 [8,890,654,391.76–17,393,199,134.26]	6684.39 [5050.61–8708.61]	1,985,784,883.55 [1,500,424,869.09–2,587,136,013.12]	1,0231.08 [8526.51–12,903.82]	4,981,285,238.09 [4,151,368,027.17–6,282,582,882.85]
Outpatient physician care	716.25 [525.72–1359.75]	1,779,094,632.23 [1,305,836,830.80–3,377,485,411.77]	466.94 [383.45–580.63]	138,717,578.35 [113,914,540.23–172,492,370.57]	355.55 [298.80–462.25]	173,109,384.97 [145,479,072.51–225,059,241.19]
Inpatient care	309.84 [138.61–672.25]	769,612,119.86 [344,293,622.30–1,669,802,955]	643.52 [276.46–1986.57]	191,175,602.90 [82,130,170.28–590,166,144.72]	831.69 [460.76–1563.93]	404,931,358.14 [224,333,793.33–761,442,723.78]
Outpatient non-physician care	344.65 [165.21–738.62]	856,076,739.96 [410,365,408.99–1,834,659,514.50]	225.23 [91.08–489.82]	66,910,866.86 [27,057,859.76–145,514,721.86]	504.24 [327.17–1028.81]	245,503,238.02 [159,291,794.35–500,904,700.76]
Medical devices	3542.32 [2462.43–6048.26]	8,798,774,865.83 [6,116,434,199.30–15,023,283,630.51]	5433.27 [4098.78–7337.49]	1,614,104,717.74 [1,217,657,163.18–2,179,806,493.22]	8691.47 [7113.49–11,312.54]	4,231,683,381.26 [3,463,400,025.05–5,507,824,052.53]
Direct non-medical[a]	2414.11 [1233.88–6171.59]	5,996,412,066.49 [3,064,836,697.83–15,329,623,233.99]	7880.32 [3229.51–23,664.21]	2,341,069,317.25 [959,416,212.89–7,030,115,014.10]	21,735.39 [7244.96–76,902.87]	10,582,477,837.26 [3,527,409,843.20–37,442,296,521.78]
Home care	3.54 [0–19.45]	8,793,012.21 [0–48,311,889.14]	0.03 [0–0.11]	8912.34 [0–32,678.57]	4.37 [0.08–19.89]	2,127,655.78 [38,950.22–9,683,998.50]
Informal care	2490.41 [1283.98–6248.50]	6,185,933,770.42 [3,189,280,175.77 –15,520,660,117.99]	8280.21 [3054.98–23,360.50]	2,459,867,818.99 [907,567,198.13–6,939,889,469.66]	22687.74 [7175.68–75,868.24]	11,046,155,865.04 [3,493,678,952.49–36,938,558,192.50]
Transportation	5.73 [1.45–21.33]	14,232,757.06 [3,601,657.55–52,981,624.44]	15.66 [5.18–50.71]	4,652,240.71 [1,538,863.79–15,064,822.89]	27.42 [13.29–59.69]	13,350,187.98 [6,470,605.33–29,061,733.06]
Indirect[b]	6121.90 [3774.40–9647.64]	7877,118,119.29 [4,856,563,261.31–12,413,727,740.14]	7867.24 [4877.69–12,394.13]	853,735,760.97 [529,316,302.02–1,344,984,010.54]	7896.10 [5997.48–10,023.73]	2,978,634,939.55 [2,262,421,129.07–3,781,237,877.25]
Loss of productivity due to absenteeism	2371.10 [1030.50–4662.50]	3,050,921,245.47 [1,325,956,030.31–5,999,291,597.57]	3126.72 [1327.26–5707.93]	339,304,848.78 [144,031,366.29–619,412,139.72]	2594.52 [1546.58–3902.15]	978,727,210.06 [583,414,245.62–1,472,002,675.92]
Loss of productivity due to occupational disability	4193.37 [2345.04–6483.00]	5,395,656,709.17 [3,017,389,548.09–8,341,749,582.21]	5511.51 [3221.12–8425.10]	598,097,068.85 [349,548,931.31–914,273,513.93]	5812.58 [4429.03–7262.89]	2,192,671,556.45 [1,670,756,893.44–2,739,770,002.42]

[a] Total population (31.12.2016)

[b] Labor force (< 18 and < 66 years) (31.12.2016)

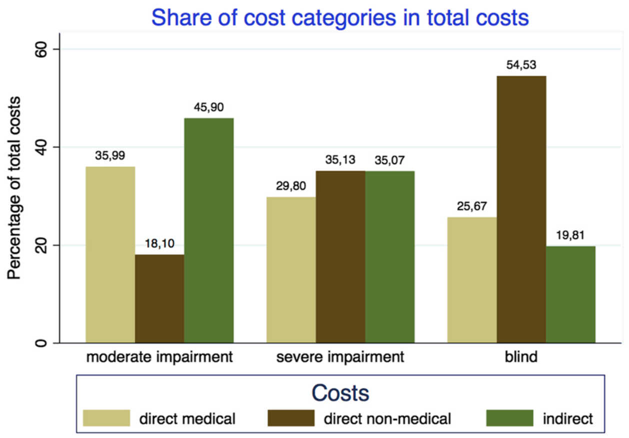

Fig. 1 Share of direct medical, non-medical and indirect costs in total costs

The detailed questionnaire allowed a comprehensive documentation of resource utilizations and the inclusion of manifold VI- and BL-specific cost components. The use of medical services for the underlying disease (for example glaucoma) was not considered. In contrast, other papers available for Germany estimate medical expenses highly aggregated and based on literature [8] or described only the importance of cost categories for disease-specific cost studies without estimating them [29]. Hirneiß and colleges for example reported total yearly macroeconomic costs between € 4 and 12 billion only for the treatment of cataract, diabetic retinopathy, age-related maculopathy, glaucoma and refractive errors as well as disease-related productivity losses [8]. As Hirneiß and colleagues' study is exclusively literature based [8], a detailed documentation of VI- or BL-related resource utilization, informal care and productivity losses was not possible, which means that costs likely were underestimated. Also, a direct numerical comparison to their results is not possible, because the authors used a different approach compared to our study (top-down vs. bottom-up; costing of specific diseases vs. costing of VI/BL). Further studies for Germany take into account isolated individual cost categories such as productivity losses which were derived from secondary data [1] or report costs for selected age groups only [30]. Chakravarthy et al. estimated in a top-down approach indirect costs due to blindness and moderate to severe visual impairment for 28 European countries. Using different models, the authors reported productivity losses for Germany to be between € 3.93 and 17.5 billion for visual impairment and between € 1.39 and 4.25 billion for blindness [1]. These values correspond well with our results (see Table 5). Pauleikhoff and colleges documented in a cross-sectional study of older patients with age-related macular degeneration annual mean direct costs per person of 9871 €. Direct costs were six times higher than costs for a control group without macular degeneration. Cost drivers were medical treatment of age-related macular degeneration and direct non-medical-related costs (assistance of activities of daily living or social benefit) [30]. Especially, the utilization of assistance in household is comparable with our study: 26.5% of the participants used those services [30]. In comparison, our sample showed a proportion of 25.42% (moderate VI) to 45.01% (BL) (see Table 2).

The importance of non-medical resources identified in our study, in particular the workload of informal caregivers, is also consistent with international literature [1, 6, 31]. In agreement with these studies, our results demonstrate that the use of informal care is a primary cost driver of overall costs from a societal perspective. Furthermore, indirect costs (productivity losses) are an essential economic burden [1, 6, 31]. However, a direct (numerical) comparison of our results with other existing international studies is as difficult as with the German studies, even when adjusting for the different purchasing power parities, since those studies are very heterogeneous, especially in the applied definition of VI and cost components as well as in the chosen study design. Compared to our approach, international studies consider a broader range of cost components which are not specific to VI and BL. For example, studies from Australia [32], the UK [31], Japan [33] and the US [34] have additionally included the cost of treating the underlying disease as well as R & D spending for new therapies treating those diseases. Further differences between studies are related to the chosen survey methodology. In this regard, we opted for a bottom-up approach to collect VI- and BL-related costs by interviewing only visually impaired and blind people. This allowed us to query in detail visual impairment- and blindness-specific resources which are unknown to individuals with normal visual function and also out-of-pocket costs, which must be considered if a societal perspective is used. Pezzullo and colleagues, who recently published their UK results, chose a combination of a top-down and bottom-up approach [31]. To quantify the service utilization, the authors used mainly administrative data sources (e.g., claims data) as well as information from national statistics [31]. Both data resources do not cover out-of-pocket costs. Additionally, the employed recruitment strategy impacts the comparability of the different studies. Participants recruited through existing self-help organizations in Germany likely differ from participants recruited during a specialist consultation or hospital stay (see for example [27]). The participants of our study have lived on average already for 20 years with a VI, which could lead to an under-representation of expensive initial purchases or other initial costs incurred shortly after onset of VI. Also, our sample was on average younger than samples focusing on mostly age-related VI such as those included by Porz et al. [27] and Cruess et al. [7]. Thus, the total costs differ considerably between studies [6] (for an update of Ref. [6], see Supplementary Material 7).

Limitations

One limitation is that the extent to which our survey sample is representative of blind and visually impaired people in Germany cannot be fully assessed due to a lack of national registries. Results from the SHILD study suggest that women more often participate in self-help organizations than men, members show a higher degree of VI than non-members and are more socially engaged in their leisure time [35]. Comparisons with the blind and visually impaired participants in the DEBRA study [23] allow us to draw initial conclusions about the representativeness of our sample. A contrasting juxtaposition of demographic characteristics showed that both samples are quite similar in their age (DEBRA study: 62.5±18.4; survey: 60.3±17.0) and gender distribution (DEBRA study: 54.8% female; survey: 58.5%).

A further limitation is that a certain selection bias among the participants is likely due to the employed recruitment strategy. The response rate was 8.94% in our study. People with visual impairment who were most at risk of having disability-related additional expenses could be more likely to participate. In addition, participating in a cost-of-illness study poses a particular challenge, especially for people with visual impairments. If, as a result, more people participate, who have various aids or extensive support for coping with their everyday life and thus also for participating in the study, this in turn could be reflected in divergent costs. An evaluation of the non-responders could not be carried out, because we recruited via self-help organizations and therewith had no direct access to address files. Also, costs were calculated retrospectively over a period of 6 months, which makes a complete coverage of all VI- and BL-associated costs unlikely. However, by applying a mixed-mode approach as recommended [10], the selection bias of respondents was likely reduced.

In addition, it has to be considered that the validity of our results depends on the survey documents' ability to differentiate between VI-/BL-associated resource consumption and resource utilization due to other reasons. We addressed this aspect through special probing questions during the pre-test and revised the documents based on the gained results (see "Pre-test of the survey documents"). Further, the non-significant impact of participants' comorbidities on the probability of VI- and BL-specific resource utilization (see Table 4) may indicate a good discriminatory power of the survey documents. However, it is not possible for us to completely exclude the remaining uncertainties attributed to this aspect, because it was not feasible to include a control group in this study.

Another limitation is that VI and BL were self-reported with no confirmation by objective data, i.e., a medical diagnosis. This needs to be considered if the results of this study are to be used in health economics models (e.g., Markov models) and be combined with prevalences of VI and BL which were derived from randomized controlled trials using medical diagnosis as a base for VI and BL classification. Nonetheless, the subjectively assessed classification of the degree of VI in this study was based on the same applicable German classifications as medical diagnoses would be. To receive valid self-assessments of VI, we drafted our questions on the basis of a nationwide population-based survey carried out in France in 2006 as part of the local micro-census. The French study was able to show that the self-reported prevalence corresponded well with a prevalence calculated on the basis of medical diagnoses [36]. Although some studies are critical of the use of self-reported vision in clinical research [14], self-reports for assessing vision-related costs are extremely well suited from the societal perspective, as health-care utilization is determined by the subjectively perceived need, which immediately results from the self-perceived visual impairment [37].

Conclusion

Visual impairment and blindness may cause enormous overall costs from a societal point of view, as shown in this cost-of-illness study for Germany. Results demonstrate that a large proportion of the costs are not per se evident as it is caused by self-paid deductibles, productivity loss, early retirement and informal support/care by relatives. Further research should make special efforts to investigate these costs precisely as well as their influencing factors. Based on those results, concepts for the remuneration of VI-/BL-specific informal care and supportive networks should be developed. Especially in light of the demographic changes, this research desideratum becomes more and more important, since, despite the steadily improving treatment options, an increase in VI and BL, especially in old age, is to be expected.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Informed consent The study was approved by the responsible ethics committee of the University of Wuppertal prior to beginning of the study. All participants were informed about anonymity and voluntarily participation. Participants, who chose the paper–pencil or online version of our questionnaire, provided their implicit informed consent during the recruitment phase by agreeing to participate and by sending back the anonymous questionnaire. Respondents answering via personal telephone interview gave explicit informed consent during the recruitment phase by agreeing to participate and providing a telephone number for a re-call. The personally identifying information was not stored and participant responses were anonymized prior to analysis.

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