Costs of informal care in a sample of German geriatric stroke survivors

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Abstract Stroke is a leading cause of long-term disability. A large proportion of geriatric stroke survivors receive informal care. The assessment and monetary valuation of informal care should therefore constitute an essential part of any health economic analysis, but it is hardly measured in stroke caregiver studies. The aim of the current research was to estimate the amount of informal care provided by caregivers of stroke survivors aged 60 years and older and to calculate its economic value. Information about caregiving time in activities of daily living (ADL), instrumental activities of daily living (IADL), and supervision during the last 3 months was obtained from 122 caregivers by means of structured interviews. The proxy good method was applied for the monetary valuation of time. About 63 % of the stroke survivors in our sample were moderately cognitively impaired. The results showed that the majority of the main caregivers assisted in ADL and IADL. Supervision was delivered by 45.9 %. The median amount of help in ADL was 13.9, in IADL 22.2, and in supervision 13.9 h/week. The median overall amount of care was 42.8 h/week. Fifty percent were supported by additional

persons (2.7 h/week). The mean overall costs of informal care were calculated at 2252 €/month. Our results reveal the high social and economic costs of informal care. The main burden of caregiving appears to be carried by the primary caregiver. Consequently, support and counseling of this group is important. Furthermore, caregiver interventions should be aimed at the mobilization of informal resources.

Keywords Caregivers · Stroke · Informal care · Costs · Economic evaluation · Time measurement

Introduction

At the end of 2013 about 2.6 million persons in Germany were in need of care as defined by the long-term care insurance law, introduced in 1995 and extended several times since. Sixty-five percent of the care recipients were females and 83 % were aged 65+ (37 % were 85 years and older). Seventy-one per cent (1.86 million) received ambulatory help and care at home. Within this group, the majority (1.25 million) received support exclusively from family members or friends (Statistisches Bundesamt 2015). These numbers illustrate the importance of informal caregivers within the German health care system.

Stroke is one of the major causes of serious long-term disability, care dependency, and mortality worldwide (Günster 2011; Go et al. 2014). In 2010, about 243,000 acute inpatient stroke treatments were recorded in Germany, corresponding to a rate of 365 per 100,000 inhabitants (Nimptsch and Mansky 2012). A recent review reported comparable incidence rates in Germany, the United States (US), and other European Union (EU) countries (Zhang et al. 2012). Many studies have found a

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high economic burden associated with this disease (Gustavsson et al. 2011; Fattore et al. 2012; Go et al. 2013). About three quarters of stroke patients survive the event (Kolominsky-Rabas et al. 2006; Palm et al. 2010) and subsequently experience physical, psychological, and cognitive impairments, making them dependent on nursing care (Lai et al. 2002; Hackett et al. 2005). Data from the German federal health insurances indicate that diseases of the circulatory system are among the three most common diseases associated with care dependency (Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen e. V. 2013). However, these data do not sufficiently distinguish between sub-groups of recipients based on acute diagnoses (e.g., stroke, cardiovascular events).

Caregivers of stroke survivors often experience subjective burden, depressive symptoms, and adverse effects on social relations (Scholte op Reimer et al. 1998; Visser-Meily et al. 2009). Among the most stressful problems for caregivers are sudden limitations in personal hygiene, depression, loneliness, and anxiety, as well as cognitive impairments of the care recipients (Haley et al. 2009). A variety of intervention programs have been developed, and among them counselling programs and problem-solving approaches appear to have promising effects (Visser-Meily et al. 2005; Brereton et al. 2007; Eldred and Sykes 2008). There are also national clinical practice guidelines for stroke to improve professional support for this group (Van Heugten et al. 2006).

To date, few evidence-based caregiver programs have been implemented in either outpatient or inpatient care systems (Nichols et al. 2014). Considering the suggested effectiveness of caregiver programs, this low implementation rate is surprising and may stem from lack of knowledge about care costs, potential cost savings, health care service use, or needed resources for implementation (Gitlin et al. 2015). The monetary valuation of informal care constitutes an essential part of health economic analyses (Van den Berg et al. 2004). Fattore et al. (2012) showed that informal care constitutes 33 % of overall costs of stroke. Nevertheless, within caregiver intervention studies the amount of informal care is rarely assessed. About 96 % of the studies analyzed in a review failed to report even the quantity of average daily support (Van Houtven et al. 2011). The authors recommended that caregiver interventions should assess the quantity (and quality) of care provided, in order to evaluate the cost effectiveness of interventions and to gain insight into the competing demands of family care.

Research on dementia caregivers indicates that even when caregiving activities are assessed, precise definitions of the caregiving tasks and/or detailed descriptions of the respective time measurement methods are lacking (Klein et al. 2015). A recently published literature

review of cost measurement of mental disorders in Germany stated that in only 13 of 48 studies formal and informal nursing activities were reported. Therefore, costs are likely to be underreported (Grupp et al. 2014). Moreover, omission of this highly relevant cost category will, a fortiori, bias any systematic cost effectiveness analysis. Consequently, future research should concentrate on precise definitions of caregiving tasks, the assessment and economic valuation of time, and the application of appropriate monetary substitutes (Van den Berg et al. 2004).

The aim of the present research is to gain a deeper understanding of the amount of informal care in a sample of geriatric stroke caregivers and to determine its economic value as a crucial input for a more comprehensive health economic analysis. This study calculates the amount of informal care provided by the primary caregivers of stroke survivors and others (e.g., relatives, friends). In addition, the economic value of time spent in caregiving is described by applying the proxy good method which values informal care time at the market price of a close substitute. The findings are relevant to similar populations in other countries, given that the assessment of caring time, its monetary valuation, and associated problems are more or less universal (Dewey et al. 2002; Van den Berg and Spauwen 2006; Oliva-Moreno et al. 2013).

Methods

Study design and recruitment of the participants

The retrospective data analyzed in the current work were obtained within a randomized controlled trial. The intervention consisted of a telephone-based psycho-educational problem-solving approach. It has been described in detail previously (Pfeiffer et al. 2014), and all materials used have been published separately (GKV-Spitzenverband). From March 2007 to October 2009, participants were identified by patient records of two large rehabilitation facilities in the greater metropolitan area of Stuttgart, Germany. The screening and information about the study was conducted by telephone ($n = 621$). For participation, written consent from the caregivers and if possible also from the care recipients was obtained. The participants did not receive any financial compensation. Recruitment criteria on the side of the care recipients were an age of 60 years or older at their (last) stroke, the need of care or supervision according to the criteria of the German statutory nursing care insurance, no additional terminal severe disease, and no planned move into a nursing home within the next 6 months. Inclusion criteria of family caregivers were an age of at least 18 years, residence in the

metropolitan area of Stuttgart (Germany), and care or supervision of the stroke survivor for at least 10.5 h/week during at least 6 months to 5 years after the (last) stroke. Furthermore, family caregivers had to have telephone access, be able to communicate on the phone, and state subjective caregiver burden (at least two of six items asking if they felt overwhelmed, needed to cry, were angry or frustrated, felt isolated, reported moderate to high levels of general stress, felt that their health had declined) (Belle et al. 2006). Exclusion criteria on the side of the caregiver were cognitive impairment (rapid dementia screening test <9) (Kalbe et al. 2003), severe unstable or progressive disease, inability to understand and speak German, as well as participation in another clinical trial for caregivers, or currently receiving psychotherapy. Figure 1 shows a detailed participation flow chart that illustrates how the $n = 621$ telephone screenings led to the $n = 122$ usable observations. The participants were interviewed during home visits. The paper-and-pencil interviews were conducted by three research associates (one physiotherapist, two medical doctors) who did not know whether the interviewees belonged to the control or intervention group (blinded).

Variables

Informal help and care of the main caregiver

The questions on informal care activities were adapted from questionnaires used in previous studies by an associated working group (e.g., Heinrich et al. 2008) and are available from the authors upon request. The amount of time spent by the main caregivers in assistance with activities of daily living (ADL) was assessed retrospectively by the question “During the last 3 months, did you assist the care recipient within the following activities: going to the toilet, personal care, eating, showering, dressing, or walking?” The amount of help in instrumental everyday activities (IADL) was assessed retrospectively by the question “During the last 3 months, did you assist the care receiver within the following activities: shopping, intake of medication, preparation of meals, financial affairs, housekeeping (incl. cleaning, doing the laundry), driving, accompaniment during outdoor activities?” A third question concerned the amount of time the caregiver spent in supervision (e.g., for safety reasons): “During the last 3 months, did you supervise the care recipient?” A

Fig. 1 Participant flow chart

positive response to each question lead to a subsequent probe: “How many days and how many hours per day did you spend in....?”

Informal help and care of others

The same questions were asked to assess the amount of help provided by additional persons such as relatives and friends who assisted within the three domains mentioned above without receiving any payment. This was reported by the primary caregivers, not by the non-primary caregivers. We acknowledge that this raises the possibility of reporting bias by the primary caregivers, i.e., their own role is overstated and that of the non-primary caregivers is understated. However, we were unable to analyze that effect.

Other variables

The long-term functional score of the Scandinavian stroke scale (SSS; Scandinavian Stroke Study Group 1985) was used to assess the care recipients' functional impairment. The total score ranges from 0 to 48, with higher scores indicating less impairment. Functional disability was assessed with the Barthel Index of ADL (BI; Mahoney and Barthel 1965). Scoring ranges from 0 to 100, with higher scores representing better ADL performance. Higher cognitive functioning (comprehension, verbal expression, social interaction, problem solving, memory/learning/orientation, and vision/neglect) was also assessed with the Extended Barthel Index (EBI; Prosiegel et al. 1996). The total score of the six items ranged from 0 to 90, again with a higher score indicating a better performance. To assess the need for care in terms of the German long-term care insurance, a further variable measured the level of care dependency. In order to be eligible for benefits, the person must be in need of assistance in ADL and IADL for at least 90 min/day. There are fixed time standards within both domains that must be reached. Overall, there are three levels of care dependency, with a higher level indicating a higher need of care and the receipt of more benefits. Persons qualifying for level-one benefits had to be in need of help and care in ADL and in IADL for at least 45 min/day, respectively. Persons receiving level-three benefits had to be in need of care in ADL for at least 4 h and in IADL for at least 1 h/day (Becker et al. 1998).

The economic valuation of informal care time

To monetarily value caregiving, various methods can potentially be applied. The proxy good method and opportunity costs (revealed preference methods) are the most common methods (Van den Berg et al. 2006; Goodrich et al. 2012). In addition, stated preference methods

such as contingent valuation (Garrido-García et al. 2015; Van den Berg et al. 2005) and conjoint analysis (Van den Berg et al. 2008) can be used to assess the monetary valuation of informal care as well as other outcomes, e.g., well-being (Van den Berg and Ferrer-i-Carbonell 2007). These methods differ with respect to measurement and valuation of time spent on informal caregiving. For the application of revealed preference methods, the time invested in informal caregiving is required, while stated preference and other methods require a more complex measurement (Van den Berg et al. 2004). Due to the nature of our data, the application of revealed preference methods was determined.

The proxy good method (also called the market or replacement cost method) uses the wage rate of a close (market) substitute (e.g., the labour market price of an equivalent service), whereas the opportunity cost method values the caregiver's benefits foregone due to caring which is mostly approximated by the individual's market wage rate (Van den Berg et al. 2004, 2006). As the majority of the included caregivers were retired, the assignment of current wage levels was difficult. Therefore, the proxy good method was applied. Doing so allowed us to calculate which costs might arise when replacing informal care by paid (professional) services. A further step involved defining the monetary equivalent of time spent in informal caregiving. The retrospective assessment of time often involves an overestimation of the provided help. Van den Berg and Spauwen (2006) showed, for example, that the recall method overestimates the amount of informal care with more than 2 h/day compared to the diary method being corrected for joint production. Therefore, a rather conservative gross wage level of unskilled nursing assistants (9.62 €/h) was initially assumed (for comparison the gross wage of professional nurses is approximately 17.36 €/h). This gross wage is comparable to other studies valuating the time of intergenerational exchange at 10 €/h in Germany (Litwin et al. 2008).

Statistical methods

Data were collected retrospectively during face-to-face paper-and-pencil interviews. The descriptive analysis of data was conducted with SPSS Version 21. Prior to the analysis, obtained data were checked for plausibility. Therefore, for each caregiver a minimum of 6 h of sleep per day was determined. This follows the assumption made in previous studies by which caregivers can spend a maximum of 126 h/week in overall caregiving activities (help in ADL, IADL, and supervision) (Neubauer et al. 2008). For four caregivers, the overall amount of weekly care exceeded 126 h, which may have been a result of double counting of activities (see discussion section). Hence, the

surplus was subtracted from supervision time since supervision is a task that easily might have been summed up twice by the caregiver (e.g., supervision during assistance in ADL).

Results

Characteristics of the study population

A total of 122 caregivers of stroke survivors were included in the analysis. Ninety-five caregivers (78 %) were female with a mean age of 66.2 years ($SD = 10.0$). The majority (86.1 %) reported caring for their spouse or their partner. The mean caregiving duration time was about 28 months ($SD = 33.1$). Care recipients had a mean age of 73.2 ($SD = 7.5$) and 38 were female (31.1 %). The care recipients had a mean BI of 55.4 ($SD = 29.2$) and a mean EBI of 62.8 ($SD = 15.9$), indicating a moderate need of help and care in ADL as well as moderate cognitive impairment. Home care nursing services were used by 38.5 % of the care dyads (Table 1).

Informal help and care of the main caregiver

The majority of the main caregivers (92.6 %) stated that they assisted the stroke patient in ADL during the last 3 months (Table 2). All of them gave help in IADL and 45.9 % stated that the care recipient had to be supervised in order to prevent dangerous situations. Among caregivers who assisted the stroke patient in ADL, the median time spent assisting was 13.9 h/week (range = 0.5–75.3). In IADL, a median amount of 22.2 h/week (range = 1.9–84.6) was measured; and for those primary caregivers who had to supervise the care recipient the median was 13.9 h/week (range = 0.2–110.8). The overall amount of care was about 42.8 h/week (5–126). Figure 2 shows the distribution of the main caregivers' caring time in a boxplot graph. In general, ranges were higher in IADL and supervision. One extreme value occurred in ADL with about 75.3 h/week (depicted as an asterisk in Fig. 2). The analysis of further data of this care recipient showed a BI of zero, an EBI of 35, care dependency level three, and nursing care service use for about 2.3 h/week. These factors indicate a major need of help and care. Table 3 shows that with increasing care dependency the amount of informal care increased.

Informal help and care of others

Fifty percent of the main caregivers stated that they were helped in performing informal caring tasks by members of their social environment. Twenty-three percent received such help in performing ADL tasks (median 1.2 h/week),

Table 1 Characteristics of the study population

Demographics caregiver	<i>n</i> = 122	
	Mean (SD)	
Age	66.2 (10.0)	
Caregiving (total months)	28.0 (33.1)	
Social support (F-SozU)	36.1 (10.5)	
Education (years)	12.2 (3.1)	
	<i>n</i>	%
Female	95	78.0
Ethnic background		
German	100	82.0
Ethnic German repatriates	10	8.2
Other European	12	9.8
Degree in nursing	6	4.9
Previous instruction in nursing skills	59	48.4
Caring for a second person	15	12.3
Caring for CR before (last) stroke	24	19.7
Employment (yes)	23	18.9
Care recipient is spouse or partner	105	86.1
Demographics care recipient	Mean (SD)	
Age	73.2 (7.5)	
Stroke impairment (SSS)	28.7 (26.0)	
Activities of daily living (BI)	55.4 (29.2)	
Cognition (EBI)	62.8 (15.9)*	
	<i>n</i>	%
Female	38	31.1
Level of care dependency [†]		
No Level	15	12.3
Level 1	45	36.9
Level 2	53	43.4
Level 3	9	7.4
Home care nursing service	47	38.5
≥1 further stroke in the past	35	28.7

F-SozU social support questionnaire, SSS Scandinavian stroke scale, BI Barthel index, EBI extended Barthel index, SD standard deviation

* For this variable *n* = 121

[†] In order to gain monetary benefits of the German long-term care insurance, there must be a need of assistance in ADL and IADL for at least 90 min/day. There are three levels, with a higher level indicating an increased need of care and gaining more monetary benefit (Becker et al. 1998)

35.2 % in IADL tasks (median 1.9 h/week), and 32.8 % were assisted in supervision of the care recipient (median 1.4 h/week). The median overall unpaid help by others was approximately 2.7 h/week.

The economic value of informal caregiving

For the monetary valuation of caregiving time, the gross wage of unskilled nursing assistants (9.62 €/h) served as

Table 2 The weekly amount of informal care by the main caregiver and by others

	<i>n</i> (%) [*]	Mean (SD) in h/week	Median	Min	Max
Informal care by the main caregiver					
ADL (toileting, personal care, eating, showering, dressing, walking)	113 (92.6)	14.8 (11.5)	13.9	0.5	75.3
IADL (shopping, intake of medication, preparation of meals, financial affairs, housekeeping, driving, accompaniment during outdoor activities)	122 (100)	25.8 (16.1)	22.2	1.9	86.5
Supervision (e.g., to prevent accidents)	56 (45.9) ⁺	24.4 (25.8)	13.9	0.2	110.8
Total amount of care	122 (100)	50.3 (30.1)	42.8	5.0	126.0
Informal care by others					
ADL (toileting, personal care, eating, showering, dressing, walking)	28 (23.0)	3.6 (5.9)	1.2	0.1	27.7
IADL (shopping, intake of medication, preparation of meals, financial affairs, housekeeping, driving, accompaniment during outdoor activities)	43 (35.2)	5.6 (9.2)	1.9	0.0 [†]	46.2
Supervision (e.g., to prevent accidents)	40 (32.8)	4.8 (10.4)	1.4	0.2	55.4
Total amount of care	61 (50.0)	8.8 (18.6)	2.7	0.1	113.1
Total informal care (main caregiver and others)					
ADL	113 (92.6)	15.7 (12.0)	13.9	0.5	75.9
IADL	122 (100)	27.8 (16.4)	24.2	2.8	90.0
Supervision	66 (54.1)	22.8 (27.3)	13.9	0.2	113.1
Total amount of care	122 (100)	54.6 (33.1)	44.8	5.9	184.6
Use of home care nursing services	48 (39.3)	3.6 (2.9)	2.9	0.5	13.9

Adjusted values are represented (the main caregiver can provide a maximum of 126 h/week of overall informal care)

SD standard deviation, Min minimum, Max maximum

^{*} Number of caregivers that deliver and/or receive help and care in the respective domains (yes/no)

⁺ Two missing values (two participants stated that they supervised the stroke survivor but did not report any times)

[†] Values were rounded to one decimal figure. Due to the measurement period 3 months, the average amount of time was divided in order to gain a weekly time amount. Considering that caregivers/other persons deliver only few help and care, the occurrence of low values can be explained

Fig. 2 Boxplots of the main caregivers' informal care time. The *box* shows the 25th and 75th percentiles of the amount of care. The median value is shown by the *horizontal bar* inside the *box*. The *upper* and *lower bars* show adjacent values that are not classified as statistical outliers. Single values above the *upper bars* present outliers and extreme values

Table 3 The weekly amount of informal care by the main caregiver and by others according to the care recipients' levels of care dependency

	<i>n</i> (%) [*]	Mean (SD) in h/week	Median
Informal care by the main caregiver			
ADL	113 (92.6)		
No level	10	7.6 (6.0)	6.9
Level 1	41	10.5 (8.1)	6.9
Level 2	53	17.1 (10.2)	15.4
Level 3	9	28.9 (19.7)	24.2
IADL	122 (100)		
No level	15	20.4 (10.8)	20.8
Level 1	45	25.7 (15.3)	23.2
Level 2	53	26.5 (16.0)	23.4
Level 3	9	31.0 (25.4)	26.2
Supervision	56 (45.9) ⁺		
No level	3	18.5 (4.0)	20.8
Level 1	23	19.5 (27.6)	11.2
Level 2	24	27.8 (25.2)	17.3
Level 3	4	36.3 (27.7)	32.8
Total amount of care	122 (100)		
No level	15	29.2 (15.7)	24.2
Level 1	45	45.2 (30.7)	36.3
Level 2	53	56.1 (26.2)	53.7
Level 3	9	76.1 (40.7)	66.2
Informal care by others			
ADL	28 (23.0)		
No level	–	–	–
Level 1	9	2.0 (3.7)	0.7
Level 2	15	3.2 (3.8)	1.7
Level 3	4	8.5 (12.9)	2.8
IADL	43 (35.2)		
No level	7	3.3 (4.8)	1.9
Level 1	13	5.3 (12.6)	1.2
Level 2	19	5.4 (6.7)	3.5
Level 3	4	11.8 (13.0)	9.1
Supervision	40 (32.8)		
No level	2	1.2 (0.8)	1.2
Level 1	14	5.9 (14.4)	1.1
Level 2	21	5.0 (8.5)	1.9
Level 3	3	1.0 (1.0)	0.6
Total amount of care	61 (50.0)		
No level	7	3.6 (5.4)	1.9
Level 1	19	8.9 (25.5)	2.3
Level 2	30	8.6 (14.6)	3.5
Level 3	5	16.8 (23.4)	3.7
Use of home care nursing services	48 (39.3)		
No level	1	0.9	0.9
Level 1	8	1.8 (1.5)	1.2

Table 3 continued

	<i>n</i> (%) [*]	Mean (SD) in h/week	Median
Level 2	33	3.9 (2.9)	3.5
Level 3	6	5.0 (3.4)	5.2

Adjusted values are represented (the main caregiver can provide a maximum of 126 h/week of overall informal care)

SD standard deviation

^{*} Number of caregivers that deliver and/or receive help and care in the respective domains (yes/no)

⁺ Two missing values (two participants stated that they supervised the stroke survivor but did not report any times)

Table 4 The economic value of informal caregiving applying the proxy good method

Gross wage/h	Unskilled nursing assistants 9.62 €			
	Mean (SD) in Euro/month	Median	Min	Max
Informal care in ADL				
By the main caregiver	610.11 (474.90)	571.02	18.97	3104.92
By others	147.20 (241.83)	47.41	2.47	1141.62
Total	646.58 (493.92)	571.02	18.97	3130.49
Informal care in IADL				
By the main caregiver	1063.08 (661.82)	913.21	79.16	3567.92
By others	231.55 (378.41)	76.27	1.65	1902.70
Total	1144.69 (676.32)	998.97	117.09	3710.57
Informal care in supervision				
By the main caregiver	1005.85 (1062.28)	571.02	9.48	4566.89
By others	198.87 (429.76)	57.10	6.18	2283.24
Total	939.32 (1126.74)	571.02	9.48	4661.71
Total costs of informal care				
By the main caregiver	2071.76 (1243.16)	1763.35	206.14	5194.80
By others	361.21 (766.01)	110.90	2.47	4661.71
By the main caregiver and by others	2252.37 (1364.56)	1848.28	244.07	7611.21

Adjusted values are represented (the main caregiver can provide a maximum of 126 h/week of overall informal care)

SD standard deviation, *Min* minimum, *Max* maximum

the basis. Accordingly, mean costs of 610 €/month were defined for the main caregivers' informal care in ADL, 1063 € in IADL, and 1005 € in supervision (Table 4). For caregiving activities by additional persons, mean costs of 147 € (ADL), 231 € (IADL), and 198 € (supervision) were calculated, respectively. The combined costs of informal care by the main caregivers and by others were highest in IADL and supervision. For the main caregivers, mean total costs were 2071 €/month, and for others mean total costs were 361 €/month. Consequently, we estimate the mean overall total costs of informal care as approximately 2252 €/month. For comparison, the same amount of care delivered by a professional nurse whose gross wage amounts to 17.36 €/h would double the costs to 4400 €. With increasing care dependency, the costs of informal

care of both the main caregivers and of other persons increased (Table 5).

Discussion

Overall, there is little research on informal caregiving time and related costs in stroke survivors. In this German sample, over 90 % of the main caregivers assisted the care recipient in ADL, and all care recipients received help in IADL. Care recipients in our sample were cognitively impaired to a limited extent only. This might serve as an explanation as to why supervision was delivered to only 45.9 % of the care recipients. The median amount of help in ADL was 13.9 h/week, in IADL 22.2, and in supervision

Table 5 The economic value of informal caregiving according to the care recipients' levels of care dependency

Gross wage/h	Unskilled nursing assistants 9.62 €	
	Mean (SD) in Euro/month	Median
Informal care in ADL		
By the main caregiver		
No level	314.08 (246.82)	285.30
Level 1	433.33 (335.69)	285.30
Level 2	703.64 (421.29)	634.10
Level 3	1193.52 (813.07)	999.00
By others		
No level	–	–
Level 1	82.14 (151.64)	27.62
Level 2	132.45 (156.99)	71.33
Level 3	348.90 (531.03)	114.20
Total		
No level	314.08 (246.82)	285.30
Level 1	451.36 (331.83)	356.63
Level 2	741.13 (427.08)	642.34
Level 3	1348.59 (814.55)	1065.76
Informal care in IADL		
By the main caregiver		
No level	841.31 (446.22)	856.32
Level 1	1058.82 (630.32)	954.44
Level 2	1092.76 (661.31)	963.92
Level 3	1279.14 (1047.77)	1078.13
By others		
No level	134.17 (196.19)	76.27
Level 1	216.96 (518.34)	50.71
Level 2	224.02 (276.70)	142.65
Level 3	485.16 (533.40)	374.15
Total		
No level	903.92 (442.96)	862.50
Level 1	1121.50 (637.26)	998.97
Level 2	1173.07 (684.10)	998.97
Level 3	1494.76 (1022.05)	1426.92
Informal care in supervision		
By the main caregiver		
No level	761.22 (164.72)	856.32
Level 1	804.58 (1136.37)	463.00
Level 2	1147.60 (1039.73)	713.67
Level 3	1496.08 (1143.70)	1351.06
By others		
No level	48.44 (32.36)	48.44
Level 1	242.37 (593.63)	44.32
Level 2	206.83 (351.36)	76.27
Level 3	40.68 (42.47)	25.56
Total		
No level	595.13 (370.05)	726.45

Table 5 continued

Gross wage/h	Unskilled nursing assistants 9.62 €	
	Mean (SD) in Euro/month	Median
Level 1	832.01 (1172.12)	340.96
Level 2	996.13 (1155.85)	579.88
Level 3	1526.60 (1167.70)	1363.84
Total costs of informal care		
By the main caregiver		
No level	1202.94 (648.12)	998.97
Level 1	1862.67 (1268.98)	1498.25
Level 2	2314.20 (183.75)	2211.91
Level 3	3137.59 (1679.25)	2727.27
By others		
No level	148.01 (221.62)	76.27
Level 1	365.94 (1049.25)	95.24
Level 2	352.89 (601.70)	144.30
Level 3	691.65 (965.55)	152.55
By main caregiver and others		
No level	1272.01 (668.54)	1284.27
Level 1	2017.18 (1378.14)	1640.90
Level 2	213.95 (1234.41)	2383.42
Level 3	3521.84 (1628.23)	3282.21

Adjusted values are represented (the main caregiver can provide a maximum of 126 h/week of overall informal care)

SD standard deviation, *Min* minimum, *Max* maximum

13.9 h/week (median overall assistance 42.8 h/week). Fifty percent of the caregivers were helped by relatives and friends in performing care tasks (median overall assistance 2.7 h/week). This suggests that the major burden of caregiving clearly falls on the principal caregiver. However, it has to be taken into account that non-primary caregivers' informal caregiving hours are reported by the primary caregivers and could have therefore been subject to bias. The mean overall cost of informal care was approximately 2252 €/month. Where the care provided by professionals, the monthly costs would have almost doubled.

Relevant comparative data can be found in dementia caregiver research (Jakobsen et al. 2011; Costa et al. 2013). However, differing levels of care dependency, methodological differences concerning definitions of care tasks, and varying economic valuation methods as well as presentation of the data prevent the detailed comparison of results, even in similar approaches. To exemplify this, results of a somewhat comparable Australian study are presented (Dewey et al. 2002). The authors classified three caregiving categories: personal ADL (comparable to our definition of ADL), domestic activities, and community-based activities. A combination of the two latter categories

would be equivalent to our IADL variable. Supervision was not assessed. In the Australian sample, fewer caregivers assisted in ADL than in our sample (33 compared to 93 %), accompanied by lower average caring times (3–4 compared to 14 h/week). In our sample, all main caregivers assisted in IADL, whereas in the Australian sample, help provided in domestic and community-based activities varied between 97 and 47 % at different time points. In our study, the weekly caregiving hours within this dimension were almost twice as high. Concerning informal help and care by other persons, our findings are in line with the results of Dewey et al. The differences in regard to the principal caregivers' activities might be explained by different sample characteristics. In our study, we included caregivers with significant burden which might be associated with increased impairment of the care recipient and subsequently higher care needs. Mean age of the stroke patients is comparable, whereas in our study more spouses were providing care (86 and 42 %, respectively). The samples of both studies are also hardly comparable due to missing data; in the Australian study, only pre-stroke BI was assessed including a different response scale. Yet, despite the poor comparability of the two studies, large ranges of caregiving time were reported in both cases.

The long caring time spans reported by the caregivers of our study and also reported in other publications (Fattore et al. 2012; Oliva-Moreno et al. 2013) need further discussion. The current study showed the increasing ranges for IADL and supervision compared to the smaller range in ADL. These differences might be explained by various aspects. Assistance in ADL, as for example in dressing or bathing, is easier to clearly distinguish from other tasks by the respondents and, therefore, the measurement might be more valid. IADL tasks and supervision, which are not completely distinct from other activities, might be subject to double counting or may simply be overestimated. The aspect of joint production has been discussed within other research activities (Juster and Stafford 1991). So far, many studies do not identify whether other activities were undertaken during the same time (Goodrich et al. 2012) which can lead to reduced validity of data.

With regard to IADL, the differentiation between activities that arise additionally due to caregiving and activities that would have been done anyway is particularly difficult for spouses or informal caregivers sharing one household (Van den Berg et al. 2006). Within the interviews in our study, it became clear that this differentiation is easier for children and other non-cohabiting persons. To illustrate this, a caregiver spends 180 min during a trip to the city to visit the care recipient's health insurance in order to clarify a reimbursement issue (30 min), conducts some bank errands (cash withdrawal, transfers, getting a new cheque book) for both the recipient and herself

(50 min), gets a haircut for herself (50 min), and spends 50 min in transfer on a bus. Clearly, not all the 180 min might be assumed to have been spent on IADL. In addition, previous research has shown that the retrospective assessment of caregiving activities might always involve an overestimation of time (see further discussion) (Van den Berg and Spauwen 2006).

Despite those methodological weaknesses within the assessment of time, we must be aware of the fact that informal caring situations are extremely heterogeneous constructs. The amount of assistance provided might be influenced by various aspects as the nature of the stroke survivor's physical and cognitive impairment, the use of additional health care services, the relationship between the caregiver and the care recipient, and many more (Van den Berg et al. 2004).

The two most prominent methods for assessing time budget data are the recall and the diary methods (Van den Berg and Spauwen 2006), of which we used the former. Although the diary is known as the gold standard (Juster and Stafford 1991), both approaches have their strengths and weaknesses. Completing a diary is very time consuming and might therefore not constitute a feasible approach for burdened respondents, especially over longer time periods. On the other hand, estimates using this method seem to be lower than those assessed by the recall method. The reported time spans within different publications vary between 1 week and 3 months, and there are no recommendations on ideal intervals to be measured. Ultimately, no method can be preferred over another. Instead, more guidelines for the application of these methods as well as more detailed descriptions of the assessments within the publications are needed (Van den Berg and Spauwen 2006). Moreover, progress in information technology (telematics) may greatly facilitate the collection of such data in the future.

For the economic valuation of time, we decided to apply a rather conservative wage rate of unskilled nursing assistants. The reasons for this were the probable overestimation of time according to the application of the recall method, the consideration that unskilled informal caregivers might need more time for caring tasks than professionals, and the application of the same wage rate for ADL, IADL, and supervision. A recent review confirmed our approach by stating that in applying the proxy good method, the wage of a paid caregiver or cleaner is used irrespective of the concrete nature of the informal care undertaken (Goodrich et al. 2012). The application of concrete wages according to certain care tasks is difficult, not least because of wage differences within a country and within the health care system itself. In our analysis, the hourly wage of an unskilled nursing assistant corresponds approximately to the German minimum wage and therefore

describes the most conservative interpretation of the data. It should further be pointed out that potential wage losses were not considered in our analysis, as the majority of the included caregivers were retired.

To better illustrate our results, the monetary value of informal care was related to benefits granted by the statutory nursing care insurance. Here, monthly care allowances range between 244 and 728 €, depending on the level of care dependency (Bundesministerium für Gesundheit 2015). In our analysis, the mean overall costs of informal care were about 2252 €/month. This comparison indicates the gap between monetary compensation by the care insurance and the actual economic value of care provided by family and friends. About one-third of the main caregivers (34 %) were under 65 years of age and could therefore still be part of the workforce where hourly wages will be considerably higher than the wage rate of 9.63 € that we used. This again underscores the conservative approach to costing we adopted.

There are various methods to assess informal care and to estimate the time amounts on a monetary level (Van den Berg et al. 2004; Goodrich et al. 2012; Costa et al. 2013). Therefore, it is most important to clearly define every method and assessment used in order to enable the data to be understood and interpreted. Our results correspond with other data indicating that costs of informal care account for a significant portion of the economic burden of stroke (Fattore et al. 2012; Joo et al. 2014). Therefore, reasons for excluding informal care in economic evaluations of caregiver intervention studies should be stated (see also Drummond et al. 2005).

A further interesting facet is the association between psychological aspects and informal care. Several international stroke studies showed correlations between caregiver burden and the amount of care delivered (Scholte op Reimer et al. 1998; Bugge et al. 1999; Hasemann et al. 2007). This topic was not the focus in our analysis, but its importance should be mentioned. It implies that it is imperative to assess informal care not only in health economic terms but also in interventional related terms. In addition to the quantitative amount of informal caregiving, a further important issue is the measurement of qualitative aspects of family care. Thus far, such qualitative aspects are neglected within caregiver intervention studies (Van Houtven et al. 2011; Klein et al. 2015).

Our data show that care recipients with no care level receive more help in IADL and supervision than those in level 1. Moreover, they receive about as much help in IADL and supervision as those in level 2. This indicates that the previous classification in care levels 1–3 is based mostly on the need for ADL support. These data are in line with the new German nursing care legislation that redefine and expand care levels and corresponding beneficiaries to

better address the care needs of persons with cognitive impairment (Federal Ministry of Health 2014). In light of the aging of the population, our data underpin the importance of informal care within our health care systems. While various promising interventions for caregivers have been developed, a major effort is still required to implement these approaches with proper case-finding procedures in routine settings. Only a few such programs have been evaluated so far (Nichols et al. 2014). The emerging future role of monitoring and assistive devices in this context thus needs further research.

We should point out that the current study sample consisted of home-dwelling geriatric stroke survivors aged 60 years and older who received informal care by a family caregiver. Readers should be aware that the results can therefore not be extrapolated to the general population of stroke caregivers in Germany. Generalization is not possible both for geographical limitation in the sample selection and for the strict inclusion and exclusion criteria applied.

Conclusions

The results of our analysis reveal the importance of informal care by German caregivers of stroke survivors due to the high social and economic costs. Additional comparison illustrates the gap between monetary compensation by the care insurance and the actual economic value of care provided by family and friends. In our sample, it became evident that the main burden of caregiving is borne by the primary caregiver. We conclude from this that support and counselling of this group is important. Furthermore, caregiver interventions should be aimed at the mobilisation of informal resources in order to strengthen the family care dyads.

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Compliance with ethical standards

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

Ethical approval Institutional review board approval was obtained by the Ethics Committee of the University of Tübingen. The study was registered at www.isrctn.org as ISRCTN 86289718.

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