Objective and Subjective Burden of Informal Caregivers 4 Years After a Severe Traumatic Brain Injury: Results From the PariS-TBI Study

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Objective: Prospective assessment of informal caregiver (IC) burden 4 years after the traumatic brain injury of a relative. Setting: Longitudinal cohort study (metropolitan Paris, France). Participants: Home dwelling adults (N = 98) with initially severe traumatic brain injury and their primary ICs. Main Outcome Measures: Informal caregiver objective burden (Resource Utilization in Dementia measuring Informal Care Time [ICT]), subjective burden (Zarit Burden Inventory), monetary self-valuation of ICT (Willingness-to-pay, Willingness-to-accept). Results: Informal caregivers were women (81%) assisting men (80%) of mean age of 37 years. Fifty-five ICs reported no objective burden (ICT = 0) and no/low subjective burden (average Zarit Burden Inventory = 12.1). Forty-three ICs reported a major objective burden (average ICT = 5.6 h/d) and a moderate/severe subjective burden (average Zarit Burden Inventory = 30.3). In multivariate analyses, higher objective burden was associated with poorer Glasgow Outcome Scale-Extended scores, with more severe cognitive disorders (Neurobehavioral Rating Scale-revised) and with no coresidency status; higher subjective burden was associated with poorer Glasgow Outcome Scale-Extended scores, more Neurobehavioral Rating Scale-revised disorders, drug-alcohol abuse, and involvement in litigation. Economic valuation showed that on average, ICs did not value their ICT as free and preferred to pay a mean Willingness-to-pay = €17 per hour to be replaced instead of being paid for providing care themselves (Willingness-to-accept = €12).

Conclusion: Four years after a severe traumatic brain injury, 44% of ICs experienced a heavy multidimensional burden. Key words: GOS-E, informal care, informal care time, objective burden, subjective burden, Zarit Burden Inventory

PATIENTS WITH severe traumatic brain injury (TBI) recover to different degrees, some remaining severely disabled while others enjoy good recovery, although this usually takes time.1 Thus, the long-term impact of severe TBI on informal caregivers (ICs) (ie, non-professional persons assisting a person with disability in activities of daily living2) might differ according to the patient’s level of recovery. Because of growing economic
constraints on the healthcare system, ICs frequently attend to patients’ care needs after discharge home and may experience situations of burden. Although IC distress has been documented for decades, the definitions and measures of IC burden vary widely. With regard to factors that are associated with IC burden in TBI, various studies have identified patient-related factors (mainly cognitive disorders), caregiver-related factors, and healthcare and environmental-related factors.

In this prospective study, we evaluated 3 different parameters of IC burden. First, objective burden refers to home care needs associated with time invested in caring and observable caregiving tasks. The presence of objective burden thus points out that formal support inadequately substitutes for informal support. Second, subjective burden refers to negative feelings aroused in caregivers as they fulfill their caregiving functions. Understanding of subjective burden allows intervention programs to be provided to alleviate IC burden. A third complementary measure converts subjective appraisal of IC’s experience into a monetary value using hypothetical scenarios. In the contingent valuation method, ICs are asked to determine the minimum amount of money they would want to receive for providing an additional hour of Informal Care Time (ICT) (willingness-to-accept, WTA) and the maximum amount of money they would pay a professional caregiver to reduce their own ICT by 1 hour (Willingness-to-pay, WTP). This approach is sensitive to the heterogeneity of informal care and has the advantage of capturing relevant positive and negative aspects of IC (such as fulfillment or burnout experiences).

The present study is part of a 4-year longitudinal prospective investigation of an inception cohort of home-dwelling patients with severe TBI (PariS-TBI study). The aims were (1) to measure the level of objective and subjective IC burden; (2) to explore determinants of burden among patient, caregiver, and socioeconomic variables (with inclusion of the litigation procedure variable, which is almost specific to TBI pathology); and (3) to assess ICs’ valuation of their caregiving time.

METHODS

Design of the PariS-TBI study

The PariS-TBI study initially included 504 adults (aged more than 15 years) with severe TBI (Glasgow Coma Scale score of ≤8) in the Parisian area (2005-2007). The methodology and 1-year follow-up results have been previously reported. A total of 98 patient-caregiver pairs were included in the 4-year follow-up, of which 39 pairs had previously been assessed 1 year postinjury. These patients had an initial mean Glasgow Coma Scale score of 5.9 (range: 3-8) and were mainly injured in road traffic accidents (75%) or falls (20%).

Patient assessment

The 4-year follow-up assessment included (see Table 1) the Glasgow Outcome Scale-Extended that yields an index of global disability after TBI, the Barthel Index relating to personal care and mobility, the DysExecutive Questionnaire (DEX) that assesses executive dysfunctions in everyday life (self-assessment); the Neurobehavioral Rating Scale-revised (NRS-r), a semistructured assessment of cognitive-behavioral disturbances resulting from acquired brain injury (self-assessment); the Hospital Anxiety and Depression Scale that measures the intensity and frequency of symptoms of anxiety and depression (self-assessment); the presence of moderate to severe motor and/or cerebellar deficiency; current drug and/or excessive alcohol abuse; the presence of the state financial worker’s compensation benefit (when the patient was not able to work); and legal aspects (guardianship, litigation procedure related to the cause of the TBI). Use of formal paid care was assessed, and the number of hours per care day and days per care week were used to calculate the mean formal care time per day.

Informal caregiver burden assessment

The primary IC was defined as the person most responsible for day-to-day decision making and care of the patient. Objective burden was assessed with the Resource Utilization in Dementia-Part 1 that evaluates ICT in 3 different categories: Activities of Daily Life (ADL: toilet visits, eating, dressing, grooming, walking, bathing); Instrumental Activities of Daily Life (IADL: shopping, food preparation, housekeeping, laundry, transportation, taking medication, managing financial matters); and Supervision Time (ST: average time spent preventing a dangerous event). The ICs were asked whether the patient needed help in each of the 3 categories, and, if so, for how many hours per day and for how many days in the last month they had assisted the patient. These scores yielded a mean daily ICT, ICT-ADL, ICT-IADL, and ICT-ST.

Subjective burden was estimated with the Zarit Burden Inventory (ZBI) (22 questions rated on a 5-point scale ranging from no burden = 0 to overburdened = 4). Clinical cutoffs grade burden severity as mild (range: 0-20), mild to moderate (21-40), moderate to severe (41-60), and severe burden (61-88).

The baseline characteristics of the patients and their caregivers are displayed in Table 1.
<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean (SD; range)</th>
<th>Objective burden ICT</th>
<th>Subjective burden ZBI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographic characteristics</strong></td>
<td></td>
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<tr>
<td><strong>Patients</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender (male)</td>
<td>78 (80%)</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Age at time of evaluation</td>
<td>37.2 (13.3; 19.8-86)</td>
<td>0.27 (0.01)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.22 (0.03)&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Education at evaluation, y</td>
<td>11.8 (2.8; 6-19)</td>
<td>−0.24 (0.02)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>ns&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Primary informal caregivers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender (female)</td>
<td>71/88 (81%)</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Mother + father</td>
<td>34 + 4</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Wife + husband</td>
<td>34 + 12</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Brother/sister + Friend/colleague</td>
<td>9 + 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Four-year outcomes</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Patients</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GOS-E(1 = death to 8 = upper good recovery)</td>
<td>5.3 (1.4; 3-8)</td>
<td>−0.72 (−.001)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>−0.56 (−.001)&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Barthel score(0 = dependent to 100 = independent)</td>
<td>95.6 (10.8; 40-100)</td>
<td>−0.53 (−.001)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>−0.41 (−.001)&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>DEX (0 = no disorder to 80 = severe impairment)</td>
<td>19.3 (13.4; 0-63)</td>
<td>0.35 (0.001)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.43 (−.001)&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>NRS-r (29 = no disorder to 116 = severe impairment)</td>
<td>36.9 (6.3; 29-55)</td>
<td>0.55 (&lt;.001)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.54 (&lt;.001)&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>HAD (0 = no symptom to 42 = severe depression)</td>
<td>12.3 (7.4; 1-39)</td>
<td>0.18 (0.09)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.38 (&lt;.001)&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Motor/cerebellar deficiency (yes)</td>
<td>35 (36%)</td>
<td>.001</td>
<td>.02</td>
</tr>
<tr>
<td>Alcohol/drug use postinjury (yes)</td>
<td>17 (17%)</td>
<td>ns</td>
<td>.008</td>
</tr>
<tr>
<td>Professional activity (yes)</td>
<td>39 (40%)</td>
<td>.002</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>State financial working compensation benefit (yes)</td>
<td>45 (46%)</td>
<td>.01</td>
<td>.01</td>
</tr>
<tr>
<td>Legal guardianship (yes)</td>
<td>21/86 (24.4%)</td>
<td>&lt;.001</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Litigation procedure (yes)</td>
<td>39/91 (42.9%)</td>
<td>.003</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>Primary informal caregivers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional activity (yes)</td>
<td>66 (67%)</td>
<td>.05</td>
<td>.03</td>
</tr>
<tr>
<td>Coresidency with patient (yes)</td>
<td>76/93 (82%)</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Assistance from other ICs (yes)</td>
<td>55 (56%)</td>
<td>ns</td>
<td>.03</td>
</tr>
<tr>
<td>Formal care provision at home</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence of formal care (yes)</td>
<td>17 (17%)</td>
<td>ns</td>
<td>ns</td>
</tr>
</tbody>
</table>

Abbreviations: DEX, DysExecutive Questionnaire; GOS-E, Glasgow Outcome Scale-Extended; HAD, Hospital Anxiety and Depression; ICs, informal caregivers; ICT, Informal Care Time; NRS-r, Neurobehavioral Rating Scale-revised; ns, not significant; ZBI, Zarit Burden Inventory.

<sup>a</sup>Spearman correlation coefficients with P values within parentheses; otherwise: P values of Student t tests/Kruskal-Wallis tests; ns for P value > .05.

**Informal caregiver monetary self-valuation of their caregiving**

A contingent valuation method<sup>16</sup> was used to determine the monetary value that the ICs attributed to their ICT. Willingness-to-accept was assessed as follows:

Suppose your care recipient needed 1 hour extra care and the state compensated you for this. What would be the minimum amount of money (Euros [€]) you would want to receive to provide this additional hour of care?<sup>2,34</sup>

Willingness-to-pay was assessed as follows:

Suppose that you could provide 1 hour less of informal care by having someone else replace you so that the total amount of care for the patient remained the same. What would be the maximum amount of money (Euros) you would want to pay in order that someone else took over this hour of care?<sup>2,34</sup>

**Statistical analyses**

Student t tests, Kruskal-Wallis tests, and Spearman correlation tests were used as appropriate (α error set at 5%) to evaluate the univariate association between...
outcome measures (ZBI, ICT) and patient and caregiver variables. A linear regression model and a Tobit model were computed with ZBI and ICT as dependent variables respectively. The Tobit model was used because the ICT variable had a value of zero in half of the cases. For both predictive models, 3 blocks of independent explanatory variables were selected on the basis of previously published studies of burden after TBI: (1) patient’s personal factors (age, current drug-alcohol abuse) and clinical status (motor-cerebellar deficiency, cognitive deficits [NRS-r], mood [Hospital Anxiety and Depression Scale score], functional status [GOS-E], and professional activity); (2) caregiver’s variables (spouse status, professional activity, coresidency, and assistance from other ICs); and (3) socioeconomic variables (litigation procedure, worker’s compensation benefit, and formal care). Independent variables were previously screened for multicollinearity; because the Barthel index correlated with the GOS-E and both DEX and legal guardianship correlated with NRS-r, they were not entered into the multivariate models. Missing data were imputed twice for the multivariate analyses with the Multivariate Imputation by Chained Equations package (R v2.12.0 software; http://www.jstatsoft.org/v45/i03/). The 2 multivariate models (linear and Tobit) with introduction of the aforementioned variables were computed using an ascending strategy in which the progressive addition of the 3 blocks led to the 2 full models. A backward stepwise selection was then performed on the full models, leading to the 2 predictive final models. The Akaike Information Criterion (AIC) was computed during the procedures to verify the contribution of the successive blocks (for the full models) and of the final predictive variables (for the final models) (STATA v12). The results of both final models are shown in Table 2. Results of the multivariate models remained stable when tested on 2 sets of imputed data.

Ethical concerns

This study was approved by the French Ethical Research Committee (CPP-Ile de France XI), by the Consultative Committee for Treatment of Health Research Information, and patients and their families gave their consent. The study was recorded in ClinicalTrials.gov in August 2011 (identifier NCT01437683).

RESULTS

Objective informal care burden

More than a half of ICs (n = 55) reported no objective burden (ICT = 0). The others (n = 43) showed a high rate of objective burden, with a mean ICT of 5.6 h/d (SD = 6.5; range: 0.02-23) distributed across the different ICT categories. For 26 patient-caregiver pairs, mean ICT-ADL was 1.95 h/d (SD = 1.7; range: 0.1-6); for 35 pairs, mean ICT-IADL was 1.90 h/d (SD = 1.9; range: 0.02-6); and for 24 pairs, mean ICT-ST was 3.84 h/d (SD = 4; range: 0.03-11). Only 17 patients received formal paid care of a mean of 1.5 h/d (SD = 1.6; range: 0.1-5.1). Figure 1 illustrates the proportional use to formal, informal, and mixed (ie, formal plus informal) care according to the GOS-E level. It shows that when home care was needed, there was a high use of ICT with only low resort to professional formal care time. In particular, patients with the most severe disability (GOS-E 3 and 4) had recourse to only informal care in more than 60% of the cases.

### TABLE 2 Results of final backward stepwise regressions predicting ZBI (with use of a linear regression model) and ICT (with use of a Tobit model)

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>Objective burden ICT</th>
<th>Subjective burden ZBI</th>
</tr>
</thead>
<tbody>
<tr>
<td>GOS-E(^b)</td>
<td>−3.4 (&lt;=.001)</td>
<td>−4.1 (.003)</td>
</tr>
<tr>
<td>NRS-r(^b)</td>
<td>0.53 (&lt;.001)</td>
<td>0.59 (.03)</td>
</tr>
<tr>
<td>Coresidency with patient(^c)</td>
<td>−4.6 (.02)</td>
<td>. . .</td>
</tr>
<tr>
<td>Alcohol-drug abuse(^c)</td>
<td>. . .</td>
<td>16.2 (&lt;.001)</td>
</tr>
<tr>
<td>Litigation procedure(^c)</td>
<td>. . .</td>
<td>7 (.03)</td>
</tr>
<tr>
<td>(R^2)</td>
<td>. . .</td>
<td>0.35</td>
</tr>
<tr>
<td>Pseudo (R^2)</td>
<td>0.21</td>
<td>. . .</td>
</tr>
</tbody>
</table>

Abbreviations: GOS-E, Glasgow Outcome Scale-Extended; ICT, Informal Care Time; NRS-r, Neurobehavioral Rating Scale-revised; ZBI, Zarit Burden Inventory.

\(^a\)Variables that were not removed during the backward stepwise selection procedure are presented in both final models with estimates of unstandardized \(\beta\) coefficients and \(P\) values within parentheses.

\(^b\)Continuous variables.

\(^c\)Dichotomic variables.
Figure 1. Proportion of use of informal, formal, and mixed care as a function of GOS-E level. GOS-E 1 = dead, 2 = vegetative state, 3 = lower severe disability, 4 = upper severe disability, 5 = lower moderate disability, 6 = upper moderate disability, 7 = lower good recovery, and 8 = upper good recovery. GOS-E indicates Glasgow Outcome Scale-Extended.

Subjective informal care burden

Mean ZBI score for the 98 IC was 20.1 (SD = 17.9; range: 0-75). More than half of ICs (n = 57) experienced no significant subjective burden (mean ZBI = 7.8). Of the 41 other ICs, 26 experienced a mild to moderate burden, 12 experienced a moderate to severe burden, and 3 experienced a severe burden. The comparison between the 1 and 4-year follow-ups of ICs in the PariS-TBI study showed that mean ZBI scores decreased significantly (P = .04) from 27.1 (SD = 19.6; range: 0-68) to 21.2 (SD = 16.4; range: 0-64). The most frequent ZBI items were fear for the patient’s future, stress because of caring while facing other professional/family responsibilities, not having enough time for themselves, feeling that their relative depended on them, and feeling uncertain about what to do for their relative.

Burden correlations

Objective and subjective burden scores were correlated (Spearman ρ = 0.61, P < .001). The univariate tests showed that ICT and ZBI were correlated with patient’s follow-up impairment scores (Table 1). If patients had legal guardianship, mean ICT was 6.8 h/d (vs 1.7 if not, P < .001). Patients with ICs who reported no burden (ICT = 0) had a significantly better recovery according to the GOS-E (P < .001) and NRS-r (P < .001). For the ZBI and the ICT outcomes, the 3 blocks of variables included in the full model resulted in a better goodness of fit as indicated by a better (lower) AIC than the initial model (including patient’s variables only). The AIC of the ZBI multivariate analyses amounted AIC (block 1) = 798, AIC (full model) = 745, and AIC (final model) = 732 for the model with patient variables only, for the full model and for the final model, respectively. The AIC of the ICT multivariate analyses amounted AIC (block 1) = 331, AIC (full model) = 321, and AIC (final model) = 303 for the model with patient’s variables only, for the full model and for the final model, respectively. The multivariate final models (Table 2) showed that higher levels of both burdens were significantly associated with poorer outcome (according to the GOS-E and the NRS-r). In contrast, only ICT was significantly negatively associated with coresidency status, while only the ZBI was significantly positively associated with current alcohol-drug abuse and the undertaking of a litigation procedure.

Informal caregiver economic valuation

Informal caregivers were willing to pay a mean value of €17.1 per hour (SD = 23.3; range: 0-150) to be replaced by a professional caregiver for 1 hour of care (WTP). In contrast, they were prepared to receive a statistically significantly lower mean value of €11.9 per hour (SD = 15.2; range: 0-75) to assist the patients themselves (WTA). Different patterns of relations were found between WTP and WTA on the one hand and subjective and objective burden on the other hand. Willingness-to-pay was significantly higher in objectively overburdened ICs (ICT > 0) than in nonobjectively overburdened ICs (WTP = €24.2 vs WTP = €11, respectively, P = .05), while WTA did not significantly differ between the

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2 groups. Willingness-to-accept was significantly higher in subjectively overburdened ICs (ZBI >20) than in non-subjectively overburdened ICs (WTA = €16.6 vs €7.4, respectively, \( P = .03 \)) while differences in WTP did not reach statistical significance.

**DISCUSSION**

**Patterns of burden 4 years after the injury**

Despite the initial severity of patients with TBI included in the PariS-TBI study, 4 years after the injury there was no objective burden for 56% of ICs while 44% experienced a heavy objective burden. A recent study using the Caregiver Activity Survey in various neurological conditions (including 35 TBI) reported similar findings for ICT, particularly identifying ST as being the most time-consuming activity (median = 28 h/wk).\(^3\) The high level of ICT-ST in the present study also suggests that supervision is a major component of ICT for adults with neurological disability\(^4\) and is concordant with the loss of cognitive autonomy as shown by the 24% of patients with legal guardianship. Surprisingly, ICT in the objectively overburdened group contrasted with a low recourse and amount of formal care provision. As shown in the Figure and confirmed in multivariate analyses, there was no substitution of formal care for informal care for patients with severe disability, which necessitated home assistance (no crowding out effect). These findings\(^1\) raise concern about the provision of home care by the state.

An interesting finding here is the decrease in subjective burden in the longitudinal follow-up of the same patient-caregiver pairs between 1\(^2\) and 4 years after the injury. This is in accordance with previous studies\(^4\) although contrasting results have also been reported.\(^1\) This decrease might be related to the improvements in the patients' autonomy\(^5\) and also maybe the result of a dynamic process in which caregivers acquire greater coping capacity over the years.\(^5\)

**Cross-sectional determinants of IC burden**

The multivariate analyses showed that global disability (GOS-E) and cognitive impairments (NRS-r) were independent significant determinants of both objective and subjective burden. This is in line with previous findings from the PariS-TBI study showing that poorer 1-year GOS-E and DEX scores are independent predictors of caregiver subjective burden.\(^2\) The significant relation between the GOS-E and both objective and subjective burden was not surprising as it relates to the patient’s functional status and subsequent needs.\(^2\) The results of this study also confirmed the major impact of patients’ cognitive-behavioral impairments on IC distress.\(^1\) Identifying patients with severe disability and cognitive disorders using validated tools\(^2\) such as GOS-E, DEX, and NRS-r would allow programs to be proposed to decrease the burden for ICs.\(^1\) Intervention programs targeting ICs are expanding,\(^2\) including cognitive-behavioral therapy and skill building,\(^5\) psychoeducation,\(^5\) counseling and solution-focused therapy,\(^5\) coping strategies\(^5\) and/or peer support.\(^5\)

Coresidency status was associated with decreased objective burden. Cohabiting ICs might indeed provide less ICT because of so-called “IADL-shared activities” and “ST-joined activities.”\(^5\) When IC and patients live in the same household, they have common domestic tasks (IADL). Also, ST might be, in fact, “part-time” supervision because the IC might perform multiple tasks at the same time. As expected, alcohol-drug abuse after the TBI was a major factor associated with IC subjective burden.\(^3\) Finally, the undertaking of litigation as an additional determinant of burden is an original finding. The influence of litigation on patients’ complaints after mild TBI has been previously documented,\(^3\) but to our knowledge, the negative impact on caregivers’ outcomes has not. That litigation procedures are burdensome might seem contradictory since the aim is to gain monetary compensation to improve the patient-caregiver situation. However, guilt depending on the type of injury, uncertainty until there is official recognition of another person’s fault, the 3-year wait to have sufficient hindsight for forensic neuropsychological evaluation,\(^6\) and additional medicolegal appointments might account for this.

**Economic valuation of IC’s preferences**

The WTP-WTA scenarios showed that on average, IC did not value their care time as free (with extreme values up to €150 for 1 hour of professional care). This suggests that they considered themselves part of the production function of healthcare (with a given price) and did not consider their involvement as neutral or natural.\(^9\) Informal caregivers’ preferences showed that they attributed a lower value to their own hour of care provision than to that of a professional caregiver (WTA inferior to WTP). A WTP-WTA gap has been reported when people are discontented with the market mechanism for a public good (in this case, home care).\(^6\) Further explanations for these preferences after TBI might also be a sense of guilt, a feeling of family duty or responsibility toward a relative, or, conversely, associated fulfillment and positive benefits through caring for a loved relative.

The association between WTP and objective burden suggests that some burnout process directly linked to the duration and/or intensity of the caregiving; ICs were prepared to pay a lot of money to be replaced.\(^7\)
assistance between WTA and subjective burden suggests that in some cases, ICs become resilient when the caregiving continues for a long time.73 Lower values but similar patterns have been found for caregivers of elderly persons with a mean WTP of €14.2 and WTA of €8.2.74 These findings raise concern regarding the lack of proper financial compensation for ICT. In France, a modest newly introduced indemnity for ICT compensation (€3.62–€5.43 per hour of care) in the form of the disability compensation benefit is a first step toward an official recognition and support of ICs’ involvement.75 Further financial propositions for indirect forms of compensation (tax relief, vouchers for respite) could also be appropriate alternatives. Meeting the needs of caregivers should facilitate their continued involvement in the caregiving relationship.

REFERENCES