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Research letter

Let's start by informing patients. Unmet care needs in late traumatic brain injury. Results from the PariS-TBI cohort

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Dear Editor – Long-term severe Traumatic Brain Injury (TBI) represents a major healthcare challenge. Patients face multifaceted evolutive impairments affecting physical, cognitive, and psychosocial domains. They necessitate individualized, adaptive care models integrating diverse health and social services, which are unevenly distributed across regions. In France, regional initiatives have emerged over the past decade, bringing together healthcare professionals, health authorities, and patient organizations to optimize TBI care.

To design an appropriate configuration of TBI services, a precise characterization of patient needs is required. A *healthcare need* can be defined as a need that has the potential to benefit from healthcare [1], which differs from the *need for health*—ie, a health deficit. Healthcare needs may remain *unmet* depending on service availability and accessibility. Multiple approaches, derived from patients' or health providers' perspectives, are valuable and complementary in understanding patients' needs [1].

Within brain injury research, healthcare needs have been described in qualitative studies [2,3], and quantified by a specific questionnaire developed by Corrigan and Heineman [4,5]. Andelic et al [6] expanded this approach by comparing needs against services received, thereby quantifying *unmet healthcare needs*. A complementary method involves eliciting the patient's opinion regarding services they perceive as insufficient.

The present study aimed to assess unmet healthcare needs as expressed by patients with chronic severe TBI. It analyzed the 8-year assessment data from the PariS-TBI inception cohort, focusing on care utilization, unmet healthcare needs, and relationships with patient characteristics.

The PariS-TBI study was undertaken in 2005 in Paris city and its suburbs, France. Consecutive patients were included by mobile emergency services over a 22-month period. Criteria for inclusion were patients aged 15 or more with a severe TBI (Glasgow Coma Scale score ≤ 8). Initial data and 1-, 4-, and 8-year outcomes were collected prospectively.

The 8-year assessments were realized through face-to-face interviews with neuropsychologists, in the presence of a relative whenever possible (see [7] for details on methodology and outcome).

The assessments included a section on healthcare services used in the preceding year. The evaluation of unmet healthcare needs was derived from the post-TBI needs questionnaire [5], a 27-item tool constructed in the USA, and later used in shorter versions [6]. The questionnaire was translated and adapted to the French context by a group of experts (CJO, CVA, PAZ; see supplementary material). Four items representing infrequent needs in the validation study were removed, and 4 needs often expressed in practice were added. As this is a screening tool rather than a measurement scale, its exhaustivity and dimensional structure were

Abbreviations: TBI, Traumatic Brain Injury; USA, United States of America

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Table 1Use of health care and services in the year preceding the assessment (*N* = 82).

Care and services in the preceding 12 months	<i>N</i> (%) patients or median [IQR]
Hospitalization^a	5 (6%). 2 in psychiatry unit, 2 in neurology unit, 2 in PMR unit
Visits to physicians^a	
General practitioner	71 (87%)
Number of visits	3 [2–5.5]
Neurologist	12 (15%)
Number of visits	1 [1–2]
PMR	7 (9%)
Number of visits	1 [1–1.5]
Psychiatrist	10 (12%)
Number of visits	10 [2–12]
Ambulatory regular rehabilitation	
Physical therapy ^a	16 (20%)
Transportation means for therapy (% of 16 patients with physical therapy)	
Patient coming by himself	9 (56%)
Patient driven by taxi/ambulance ^a	3 (19%)
Patient driven by a relative	1 (6%)
Therapy provided at patient's home ^a	2 (13%)
Speech therapy ^a	8 (10%)
Occupational therapy ^c	2 (2%)
Neuropsychological therapy ^c	1 (1%)
Psychological therapy ^c	5 (6%)
Orthoptist ^a	2 (2%)
Home support and help for daily activities	
Professional care attendance or nurse ^{a,b}	11 (13%)
Help from a relative (informal caregiver)	61 (74%)
Type of help from informal caregiver (% of 61 patients with help from relatives)	
Assistance in daily activities (grooming, domestic activities, transport. . .)	54 (89%)
Financial or material support (money, equipment, goods)	28 (46%)
Emotional (moral) support	57 (93%)
Social and reintegration services	
Help by a social worker ^b	5 (6%)
Social re-entry or vocational program ^b	12 (15%)
Community-based day activity program ^b	2 (2%)

Abbreviations: PMR, Physical Medicine and Rehabilitation.

^a Services financed by general healthcare system (Social Security).^b Services financed by regional system of handicap support.^c Services with other financing (eg, accident insurance, out-of-pocket).

previously validated [5], and only expert-based face validity was assessed here. Items were formulated to assess *healthcare needs* (eg, motor rehabilitation) rather than *health needs* (eg, improving motor impairments). To identify unmet needs, the following question was used: “Would you need more of the following service?” Answers could be “no”, “a little more”, “a lot more”.

Descriptive analyses and figures representing rates of unmet needs for each item were realized. To compare patients with higher or lower unmet needs, the number of unmet needs per patient was dichotomized at the median, creating 2 equal groups. Groups were compared according to demographic characteristics, outcome, and care utilization, using Student's *t*-test and chi-square tests.

Written informed consent was obtained from participants or legal representatives prior to the cohort's assessments, with ethical and data protection approvals secured. The 8-year follow-up, encompassing all data and the present analyses, received ethical approval by CPP Ile de France XII (IDRBC 2013-a00881-44) and was registered on ClinicalTrials (NCT02050633).

Among 504 patients included in the cohort, 236 were alive at the 8-year follow-up, and 82 completed the assessment (128 loss-to-follow-up, 22 refusals, 4 incomplete assessments). Evaluated and non-evaluated patients at 8 years were comparable except for a higher prevalence of white-collar jobs among the evaluated group, as detailed previously [7]. Median age upon assessment was 40; 22% were women, 78% men.

According to the Glasgow Outcome Scale, 17 patients (17/82, 21%) presented with severe disability, 39 (39/82, 48%) with moderate disability, and 25 (25/82, 31%) with good recovery. Thirty-seven patients (45%) were working. Most patients (77%) lived in their own homes,

18% lived in a relative's home, and 5% in an institution. Fifty-one percent were in a couple or married. Main somatic problems concerned balance (48%), motor function (41%), and headaches (36%). The main cognitive complaints concerned memory (71%), slowness (68%), and concentration (67%).

The use of care and services is detailed in Table 1. Forty-eight patients (59%) had received a neuropsychological evaluation since the injury.

In the healthcare needs questionnaire, 78 patients (95%) expressed one or more unmet needs. Median unmet needs per patient was 8 (interquartile range: 3.3–12). Rates of unmet needs per item appear in the Fig. 1.

Patients with higher unmet needs had lower education duration, poorer global outcome, worse cognitive, psychological, and motor impairments, and more frequent visits to general practitioners (Table 2).

Eight years post-injury, unmet healthcare needs among survivors of severe TBI remain critically high: 95% of participants reported at least 1 unmet need, with a median of 8 per patient. The most frequently cited deficits concerned information and care coordination, followed by needs for neuropsychological or behavioral care, financial and legal assistance, vocational support, and access to adaptive sports.

Meta-analyses report that 10% of older adults express unmet healthcare needs when asked 1 general question [8], but screening questionnaires reveal higher figures (max. 88% for themes such as communication in cancer populations) [9]. Stroke studies show 15–98% unmet needs prevalences, depending on the assessment method (median 67%) [10]. Higher unmet needs after TBI might reflect broader ascertainment, greater distress after brain injuries, or more inadequate

Do you need more of this service?

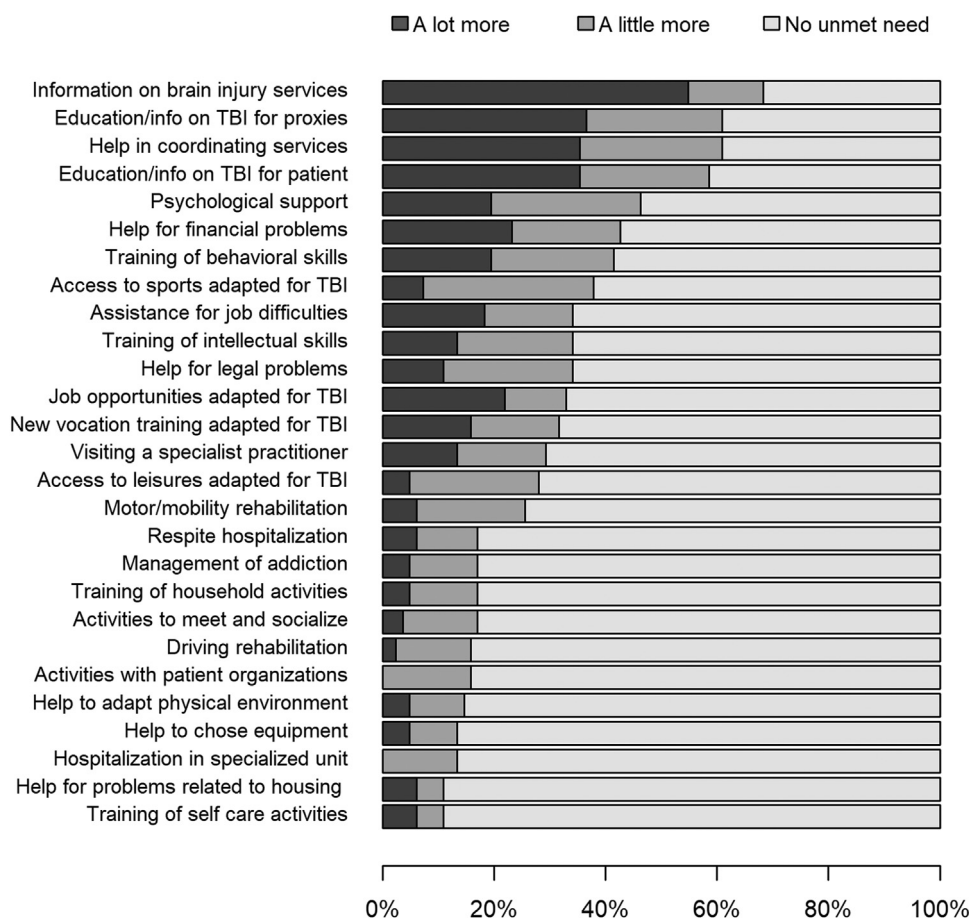


Fig. 1. Unmet care needs.

Proportion of the sample answering “a lot more” or “a little more” for each item.

care provision. Nonetheless, our rate of unmet needs exceeded figures reported using the TBI needs questionnaire (30% to 65% of patients with TBIs of mixed severity [4,11,12]). This discrepancy likely stems from the cohort’s severe injuries and recruitment upon the accident, providing a real-world perspective often missing in cohorts starting upon inpatient rehabilitation. This particularly high unmet need rate highlights the necessity to improve TBI services during the chronic phase for all patients.

Informational needs were paramount. Rarely included in quantitative TBI needs studies [4,11] information gaps are primary concerns in qualitative research [3]. It is striking that 58% of patients still reported insufficient understanding of TBI, and 60% for their relatives. This informational deficit in proxies is substantial, since 74% of patients relied on proxies for moral, financial, or activity-related support. Educational services are simple and cost-effective, and supported by evidence across various conditions [13]. Improving chronic TBI care should start with individualized information on TBI and TBI-related services to patients and proxies.

Beyond information, patients reported unmet needs related to psycho-behavioral and socio-financial services. Service use patterns showed a predominance of motor-focused interventions over cognition-focused ones, a trend previously observed in needs studies [6], as in the large European CENTER-TBI study [11]. In France, financial barriers, coupled with the scarcity of home-based services, hinder access to cognitive and behavioral care. Psychology, neuropsychology, and occupational therapy were not reimbursed at the time of the study as outpatient services,

although up to 12 psychological therapy sessions per year are now reimbursed with the national health insurance system. Likewise, care coordination, for which no financing exists, appeared as a frequent unmet need. This questions the priorities in the financing of TBI services.

In our cohort, only half of the sample had received a neuropsychological evaluation. These evaluations help identify needed services and prioritize cognitive training. Given the frequency of TBI, providing long-term follow-up to all patients appears unrealistic. Instead, specific milestones—such as the systematic provision of a neuropsychological evaluation following moderate-to-severe TBI—could serve as achievable, quality-oriented targets.

Consistent with previous studies [4,11,12] high unmet needs were associated with the severity of impairments. Our results could not determine whether these unmet needs reflected a true *capacity to benefit* versus unrealistic rehabilitation expectations. This raises the question of whether patients’ underlying needs concern functional improvements or rather support for adapting to disability—promoting a “life worth living”. Nevertheless, several interventions have documented benefits in chronic TBI: cognitive rehabilitation [14], vocational programs, psychological care [15], and goal-oriented community rehabilitation [16]. Improving knowledge about TBI sequelae may help patients set realistic goals, guide effective rehabilitation, and enhance patients’ perception of self-efficacy, an important determinant of psychological outcome [17].

A limitation of this study is the high attrition rate (65%), common in this hard-to-follow population [18]. As loss-to-follow-up was related to pre-TBI occupational status and social vulnerability

Table 2
Determinants of high or low unmet care needs^a.

Patients' characteristics		Lower unmet needs (n = 42)	Higher unmet needs (n = 40)	p-value (t-test)/(Chi ² test)
Demographic and environmental characteristics				
Age (n = 82)		42.5 ± 2.3	41.9 ± 2	0.9
Gender (n = 82)	Female	6 (33.3%)	12 (66.7%)	0.1
	Male	36 (56.2%)	28 (43.8%)	
Living place (n = 82)	Own home	35 (55.6%)	28 (44.4%)	0.08
	Home of a relative	4 (26.7%)	11 (73.3%)	
	Institution	3 (75%)	1 (25%)	
Family status (n = 82)	In couple	25 (61%)	16 (39%)	0.1
	Single	17 (41.5%)	24 (58.5%)	
Study duration (years) (n = 81)		13.5 ± 0.6	10.4 ± 0.6	0.0003
Eight-year outcome				
Glasgow Outcome Scale (n = 81)	Good recovery	19 (76%)	6 (24%)	0.008
	Moderate disability	18 (46.2%)	21 (53.8%)	
	Severe disability	5 (29.4%)	12 (70.6%)	
Working (n = 82)	Yes	21 (56.8%)	16 (43.2%)	0.5
	No	21 (46.7%)	24 (53.3%)	
Motor impairment (n = 80)	Yes	10 (30.3%)	23 (69.7%)	0.004
	No	31 (66%)	16 (34%)	
Balance impairment (n = 80)	Yes	16 (42.1%)	22 (57.9%)	0.2
	No	25 (59.5%)	17 (40.5%)	
BICoQ cognitive complaints (n = 76)		8.3 ± 0.9	12.7 ± 1	0.002
HADS-anxiety (n = 76)		4.7 ± 0.6	7.8 ± 0.8	0.002
HADS-depression (n = 76)		4 ± 0.6	7.1 ± 0.8	0.003
Care and services received (n = 82)				
Number of GP visits in the last 12 months		2.8 ± 0.4	5.7 ± 0.9	0.007
Visits with a specialist practitioner (neurologist, PMR, psychiatrist)	Yes	11 (45.8%)	13 (54.2%)	0.7
	No	31 (53.4%)	27 (46.6%)	
Ambulatory rehabilitation (physiotherapy or speech therapy)	Yes	9 (47.4%)	10 (52.6%)	0.9
	No	33 (52.4%)	30 (47.6%)	
Neuropsychological assessment since TBI	Yes	29 (60.4%)	19 (39.6%)	0.08
	No	13 (38.2%)	21 (61.8%)	

Abbreviations: BICoQ, Brain Injury Complaint Questionnaire; HADS, Hospital Anxiety and Depression Scale; GP, general practitioner; PMR, physical medicine and rehabilitation; TBI, traumatic brain injury.

^a The 2 groups of patients (higher/lower unmet needs) were defined by dichotomization of the number of unmet needs per patient by its median. Groups were compared using Student's *t*-tests for quantitative variables, and chi-square tests for qualitative variables. Cells contain numbers and line percentages or means ± standard errors.

in the cohort [18], unmet needs may be underestimated in the present sample.

In conclusion, long-term survivors of severe TBI face persistently high levels of unmet healthcare needs, particularly regarding informational and coordination needs. Beyond providing systematic neurobehavioral assessments and individualized goal-oriented care, our findings support the need to strengthen patients' health literacy, coping strategies, and self-efficacy. The development of specialized resource centers dedicated to individuals with brain injury and staffed with the appropriate healthcare professionals appears crucial. Resource centers would improve the quality of care, ensure consistent care across territories, provide structured information for patients and professionals, and help with services.

Data availability

The authors do not have permission to share data.

Declaration of competing interest

None.

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Supplementary materials

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