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RESEARCH

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# Assessment of decision-making autonomy in chronic pain patients: a pilot study

Marguerite d'Ussel<sup>1\*</sup>, Emmanuelle Sacco<sup>2</sup>, Nathan Moreau<sup>3,4</sup>, Julien Nizard<sup>5,6</sup> and Guillaume Durand<sup>7,8</sup>

## Abstract

**Background** Patient decision-making autonomy refers to the patients' ability to freely exert their own choices and make their own decisions, given sufficient resources and information to do so. In pain medicine, it is accepted that appropriate beneficial management aims to propose an individualized treatment plan shared with the patients, as agents, to help them live as autonomously as possible with their pain. However, are patients in chronic pain centers sufficiently autonomous to participate in the therapeutic decisions that concern them? As this question still remains unanswered, a pilot study was set up to that aim.

**Methods** Over a 2-month period, first-time patients within a tertiary multidisciplinary pain center underwent a systematic evaluation of their autonomy using the MacArthur Competence Assessment Tool for Treatment (MacCAT-T), considered the benchmark tool for measuring a patient's ability to consent to treatment. Demographic data and pain characteristics of the patients were collected and their respective attending pain physicians were asked to clinically assess their patients' degree of autonomy. Another physician, who had not participated in the initial patient evaluation, subsequently administered the MacCAT-T questionnaire to the same patients.

**Results** Twenty-seven patients were included during the study period (21 women and 6 men), with an average age of 50 years. The average duration of pain was 8 years. Based on their clinical experience, the 4 different pain physicians in charge of these patients considered that out of 25 assessed patients, 22 of them (89%) had full decision-making capacity, with no deficit in autonomy. According to the MacCAT-T results, only 13 of these 25 patients (48%) had no deficit, while 7 (26%) had a major deficit in autonomy. The only patient characteristic that appeared to be related to autonomy was pain type, specifically nociplastic pain. The average time taken to complete the test was 20 min, and patients were very satisfied with the interview.

**Conclusion** Results from the present pilot study suggest that patients suffering from chronic pain do not appear to be entirely autonomous in their decision to consent to the proposed treatment plan according to the MacCAT-T questionnaire, and physicians seem to find it difficult to properly assess this competence in a clinical setting. Further studies with larger samples are needed to better evaluate this concept to improve the complex management of these patients.

**Keywords** Autonomy, Decision-making, Chronic pain, MacCAT-T, Capacity assessment

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## Background

*"To live one's life, to lead a good life according to what one chooses, is to lead an autonomous life."* [1]. Patient autonomy is a central concept in medical ethics, referring to the right of patients to be actively involved in decisions about their treatment and their own health [2]. From the caregiver's point of view, patient autonomy can be perceived as a challenge, as it implies respecting the patient's choices and preferences, even if they differ from one's own [3]. Chronic pain clinicians are particularly aware of this, as they strive to put the patient at the center of the treatment plan.

The International Association for the Study of Pain (IASP) defines pain as *"an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage"*. Pain is therefore always a personal experience, influenced to varying degrees by biological, psychological, and social factors" [4]. It has been estimated that 1 in 5 adults in the world suffers from chronic pain and that 1 in 10 adults is diagnosed with chronic pain each year [5]. Chronic pain is responsible for the highest number of years lived with disability [6, 7] and is the most expensive cause of work-related disability [8–11].

Chronic pain is defined by IASP as *"pain in one or more anatomic regions that persists or recurs for longer than 3 months and is associated with significant emotional distress or significant functional disability (interference with activities of daily life and participation in social roles)"* [12]. Beyond such criteria, chronic pain is the result of specific neurological and psychosocial mechanisms [13]: it is no longer simply the symptom of a disease, i.e. a normal adaptive response to tissue damage, but a disease in its own right. Such a view led the World Health Organization in 2019 to classify chronic pain as a disease in its latest edition of the international classification of diseases (ICD-11) [14].

The biopsychosocial model of illness first proposed by psychiatrist Georges Libman Engel in 1977 [15] has been adapted to the field of chronic pain, where the philosophy of care has evolved from a biomedical model, which viewed chronic pain solely as a somatic symptom, to a biopsychosocial model, which views chronic pain as a disease or long-term condition implicating a complex entanglement of biological, psychological and social factors [16].

Accordingly, the most recent guidelines concerning chronic pain patient management consider that such complex situation requires a patient-centered, multiprofessional and, at best, interdisciplinary team approach [17], with treatment objectives that are essentially rehabilitative [18–21].

During the first consultation, after a comprehensive assessment of the patient's pain, experience and

repercussions, the multiprofessional team will propose, in consort with the patient, a personalized treatment strategy [14]. Such treatment plan is built on an integrative approach that combines available pharmacological treatments with non-pharmacological or complementary interventions [22, 23], tailored to the needs identified during the initial assessment, including:

- I. Educational interventions: information and education on the disease and its treatments, recommended or proscribed behaviors, etc.;
- II. Psychological treatments: cognitive-behavioral therapies, stress management techniques (relaxation, sophrology, mindfulness, self-hypnosis), etc.;
- III. Pharmacological treatments (analgesics, antidepressants, anticonvulsants, etc.), topical treatments (lidocaine, capsaicin, etc.);
- IV. Non-pharmacological treatments (music therapy, auriculotherapy, transcutaneous electrical stimulation, transcranial magnetic stimulation, etc.);
- V. Invasive therapies (local infiltrations, locoregional or spinal anesthesia, botulinum toxin injections, neurolytic blocks, spinal cord or motor cortex stimulation, interventional radiology, etc.);
- VI. Social interventions in the work, school and/or family setting.

The aim for the chronic pain physicians is thus to support the patient towards better pain management and coping, rather than to eliminate the pain or even treat the lesion (as it is often impossible). Such patient will thus be helped begin a new journey towards something better, which may not (only) be a diminished pain sensation [24]. Therefore, chronic pain patients cannot be managed without helping them gain new autonomy, literally *"make their own rules"*, regarding the management of their chronic painful state.

As such, patients must be sufficiently autonomous to fully participate and engage in the treatment plan that has been drawn up with and for them. To reinforce this autonomy is thus to enable them to manage their illness and put their life project into effect.

Assessment of the chronic pain patient's autonomy is thus of paramount importance for the pain physician, in order to adapt the treatment plan (*Is the patient sufficiently autonomous to engage in the proposed treatment?*), and to be able to assess its effectiveness (*Has it led the patient to sufficient autonomy to be able to take care of himself?*). In the bioethics literature [25–27] there is a constant tendency to equate autonomy with autonomous decision-making [28]. Beauchamp and Childress themselves recognize autonomous patients as patients who are able to make *"autonomous choices"* and they identify autonomous decisions as those made intentionally and

with substantial understanding and freedom from controlling influences [29]. They therefore emphasize respect for the individual as a rational and free agent. This comes down to recognizing and valuing the ability of patients to make informed choices and manage their own lives, a central aspect of respect for human dignity [30]. Exercising autonomy therefore means exercising one's decision-making capacity, the ability to set goals, to give oneself ends, to tell others and to receive insight into how and for what one wants to live - and which allows greater access to one's own identity [31].

If decision-making autonomy defines the patient's capacity to understand information and to make voluntary decisions [32], then choosing autonomously requires decision-making capacity [33]. In practice, assessment of decision-making autonomy is necessary to determine whether patients have the capacity to make their own healthcare decisions or whether someone else should be empowered to make such decisions for them [34]. Patient decision-making autonomy is often challenged and therefore assessed in specific situations (especially psychiatric disorders), in specific contexts (e.g. decisions to withdraw life-sustaining treatment), or in specific populations (e.g. the elderly, minors, etc.). As few researchers have addressed the issue of patient decision-making autonomy in pain medicine, we carried out a pilot study to assess the decision-making autonomy of patients consulting a chronic pain center for the first time, using a validated tool, the MacArthur Competence Assessment Tool for Treatment (MacCAT-T).

## Patients and methods

We conducted a monocentric prospective cohort study of first-time patients referred to a French tertiary pain center. This chronic pain clinic takes care of 2,000 patients a year, including 900 new patients suffering from all types of chronic pain. Standard patient management consists of a medical assessment of pain, the proposal of a personalized treatment plan, and interdisciplinary follow-up based on said plan, in consort with the patient's personal primary physician.

Participants were deemed eligible if they were aged  $\geq 18$  years, were French speaking and if they were consulting for the first time in the chronic pain center. They were excluded if they had a significant visual or hearing deficit, were under guardianship or curatorship, deprived of liberty, under court protection, or objecting to the use of their data for this research. As such, patients with known deficits in decision-making autonomy, translating as being under some form of tutelage/guardianship or legal protection, were voluntarily excluded from the study, so that their preexisting autonomy deficit would not be a confounding factor in this study.

The exploratory nature of this pilot study did not allow the calculation of a necessary sample size, notably due to lack of a priori data on variability of MacCAT-T scores in context of chronic pain patients. Patients were thus recruited prospectively during a fixed study period of 2 months.

## Study design

### *Patient inclusion*

Chronic pain patients were evaluated during the first consultation at the chronic pain center by an attending physician of the pain clinic, as part of routine care. Each patient was entrusted to a specific physician depending on the characteristics of the pain, described in the referral letter received prior to the appointment. At the end of the consultation, patients were offered the possibility to participate in this study, by the attending pain physician who had assessed them and were given an information letter. This information letter defined patient decision-making autonomy, the aim of the study and what the patient could gain from this research (Annex 1). Following clarification of any questions the patients might have, the primary investigator obtained the patients' consent and included them in the study.

### *Clinician-based autonomy assessment*

The attending physician was then asked to provide a clinical assessment of the included patient's overall decision-making ability using a three-point scale (no deficit, mild deficit or major deficit), in adherence with the classification found in literature [35]. Such assessment was standardized beforehand among the various attending physicians of the pain clinic, via a presentation of the concept of patient autonomy, with its various properties and potential impact on patient care, and thorough discussion with the whole medical team.

### *Tool-based autonomy assessment*

The patient was then interviewed by a single evaluator, the primary investigator (MdU), using the French version of the MacArthur Competence Assessment Tool-Treatment (MacCAT-T), following procurement of authorization by its author, Stéphane Raffard [36], and after specific training to its use.

The MacCAT-T is a semi-structured interview that assesses a person's decision-making ability in terms of its 4 components: understanding, appreciation, expression of choice and reasoning. It is adapted to the patient's specific diagnosis and treatment; the interview is preceded by the disclosure of relevant information concerning the disorder (diagnosis, characteristics and evolution of the disorder), the treatment (name and characteristics of the treatment), and the benefits and risks of the treatment. According to the authors, administration of the

MacCAT-T takes approximately 15 to 20 min, and scoring 2 to 3 min, for those trained to administer the test. The test is accompanied by a manual [37] that clearly explains how the interview is prepared, administered, interpreted and scored, with a system generating sub-scores and a total score ranging from 0 to 20 (a higher total score indicating greater decision-making ability).

Understanding is measured using 13 items and includes subscales for understanding “disorder” (5 items), “treatment” (4 items), and “risks” and “benefits” (4 items). To assess this section, patients are asked to repeat in their own words what they have understood. If there is the slightest sign of misunderstanding, the interviewer has to redisplay the information and reassess the patient. Two items are used to assess the patient’s appreciation of the disorder and treatment (the way in which the patient appropriates the diagnosis and treatment for oneself and relates the information to his/her own situation). Next, 4 items assess reasoning, which explores whether the person mentions the consequence of treatment options (consequential thinking), the comparison between options (comparative thinking), or a consequence that was not mentioned in the disclosure (generating consequences). Finally, one item assesses the expression of a choice, which occurs when the person is able to communicate his/her choice clearly and coherently. The ratings for each item are 2 (adequate), 1 (partially adequate) and 0 (inadequate) leading to a quantitative score for each of the 4 abilities: 0 to 6 for understanding, 0 to 4 for appreciation, 0 to 8 for reasoning, and 0 to 2 for expressing a choice, for a total global score ranging from 0 to 20. The original scoring manual [37] does not propose a threshold at which a patient can be considered competent or not. Indeed, the authors state that their tool should not be used as a score, but as an assessment instrument for measuring degrees of autonomy capacity. However, more and more studies are proposing the same threshold for each of the sub-scores [38–41]:  $\leq 4$  for understanding,  $\leq 2$  for appreciation and  $\leq 5$  for reasoning. For expressing a choice, the maximum score of 2 is made necessary [39, 42]. A patient incompetent in a subdomain is considered globally incompetent.

The patients were stratified into 3 groups, considering as “very autonomous without deficit” those who had a score of 20/20, with “mild deficit” those who did not have 20/20 but remained above the thresholds proposed in the literature for each subscore and finally with a “major deficit” those who had at least one of the subscores below the accepted thresholds.

To the best of the authors’ knowledge, the MacCAT-T tool has not yet been tested in chronic pain patients (nor have any other decision autonomy assessment tools). However, it has been used in a wide variety of situations and patient categories: (I) in neuropsychiatric diseases:

neuro-oncological diseases [43], neurodegenerative diseases [44], schizophrenia [45], anorexia [46], depression [47], bipolar disorder [42], psychotic disorder [48, 49]; (II) in medical diseases: heart failure [47], terminal cancer patients [50], renal and neurological diseases [51], gastroenterological, musculoskeletal and infectious diseases [52]; (III) in specific populations: minor patients [53–56]; (IV) in patients in patients seeking active aid in dying [56]. It is generally considered the gold standard for studying patients’ capacity for consent and discernment [57–63], which justifies its usage in the present study.

#### **Patient follow-up**

Immediately after the interview, the patient was asked about his/her satisfaction with the interview, using a 5-point Likert scale. This survey aimed to investigate the feasibility and tolerability of such tool-based assessment of decision-making autonomy in future standard clinical practice.

Following completion of the interview and of the a forementioned survey, standard regimen of care was provided, irrespective of the subjective evaluation of the patient’s autonomy by the attending physician.

#### **Data collection and management**

The data collected were confidential and coded. Each patient was assigned an identification code. The correlation table linking the assigned identification code to the patient’s name was kept by the principal investigator in a file with restricted computer access rights. Data were entered on a confidential electronic medium. The data collected remained confidential and coded throughout the study (only the identification code appeared on the file). Data processing and statistical analysis were carried out at the hospital site where the data were collected. Patient data were stored and archived for a period in compliance with current French regulations (decree no. 2020-077 of June 18, 2020).

Data were collected from the patient’s medical records: age, gender, socio-professional category, duration of chronic pain, type of chronic pain, pain topography, associated medical history, treatments already tested, type of non-pharmacological interventions/treatments proposed, proposed drug regimens, previous chronic pain management; but also the pain physician’s clinical assessment of patient’s decision-making capacity.

Following the interview, other information were also collected: MacCAT-T score results, patient satisfaction with the interview using a 5-point Likert scale and time spent on the questionnaire.

#### **Statistical analysis**

Analyses were carried out to determine whether there were differences between the most autonomous patients,



those with mild deficits and those with major deficits in decision-making autonomy.

Quantitative variables are described according to their means  $\pm$  standard deviations or their medians and interquartile ranges [Q1; Q3], depending on their distribution. Categorical variables are reported in terms of numbers (proportions).

Non parametric Kruskal–Wallis tests were performed for between group comparisons. Fisher's exact tests were applied to compare dichotomous categorial variables. No post-hoc analyses were conducted as no multiple comparisons were performed in the study datasets.

Concordance between the MacCAT-T score and clinical assessment (by the attending physician) was performed using b-statistics. Analyses were performed using R software (R Foundation for Statistical Computing, Vienna, Austria. <https://www.R-project.org>). All tests were two-tailed, and a  $p$  value  $< 0.05$  was considered statistically significant.

#### Ethical and regulatory aspects

- Ethical clearance

**Table 1** Comparison of patients' MacCAT-T scores stratified by demographic data

	Total (N=27)	Very au- tonomous - no deficit (N=13)	Mild deficit (N=7)	Major deficit (N=7)	$p$
<b>Age (years)</b> mean (SD)	49.14 (19.15)	46.08 (15.11)	52.14 (24.71)	53.57 (22.46)	0.81 <sup>1</sup>
<b>Gender</b>					$> 0.99^2$
Female	21 (77.77%)	10 (76.92%)	5 (71.43%)	6 (85.71%)	
Male	6 (22.22%)	3 (23.08%)	2 (28.57%)	1 (14.29%)	
<b>Socio- professional background</b> (N=23)					
Craftsmen	1 (4.35%)	0 (0.00%)	1 (16.67%)	0 (0.00%)	
Executive	6 (26.09%)	5 (38.46%)	1 (16.67%)	0 (0.00%)	
Company directors	1 (4.35%)	0 (0.00%)	1 (16.67%)	0 (0.00%)	
Employees	10 (43.48%)	4 (30.77%)	3 (50.00%)	3 (75.00%)	
Students	2 (8.70%)	2 (15.38%)	0 (0.00%)	0 (0.00%)	
Intermediate professions	2 (8.70%)	2 (15.38%)	0 (0.00%)	0 (0.00%)	
Higher intellectual professions	1 (4.35%)	0 (0.00%)	0 (0.00%)	1 (25.00%)	

<sup>1</sup> Non parametric Kruskal–Wallis test

<sup>2</sup> Fisher's exact test

This research has been approved by the institutional ethics committee (institutional review board number IRB00012157, initial agreement 624) on April 21, 2023. No written informed consent was required according to French research regulation (Journal Officiel de la République Française [Official Journal of the French Republic] 0160, July 13, 2018; paragraph 110, MR-004). The patients' non-opposition to the use of their data for research was also collected in accordance with European regulations (General Data Protection Regulation).

- Data protection

Information on the rights of people taking part in this research (right of access and rectification, right to object to the transmission of data covered by professional secrecy likely to be used in the context of this research) was included in the patient information form. All study data were anonymized and coded.

#### Results

##### Description of the study sample (Table 1)

Twenty-seven patients were included during the study period: 21 women (77.7%) and 6 men, with a median age of  $49 \pm 19.15$  years. In terms of socio-professional background, patients were employees (43.48%), executives (26.10%), students and intermediate professions (8.71%), followed by craftsmen, company directors or higher intellectual professions (4.35%). Age, gender or socio-professional background did not seem to have an influence on MacCAT-T scores (Table 1).

##### Pain characteristics (Table 2)

The median duration of pain was 5 years (60 months [3; 120]). Pain was predominantly nociplastic (66.67%), followed by neuropathic (40.74%), and nociceptive (29.63%). Pain was diffuse in 21.43% of patients and could affect any location (limbs, thorax, spine, abdomen, face, perineum, etc.). Although neither pain duration, pain location or associated comorbidities influenced patient decision-making autonomy (as assessed by MacCAT-T scores), the presence of nociplastic pain was associated with lower patient decision-making autonomy ( $p=0.036$ ) (Table 2).

Treatment proposals almost systematically combined medication and physiotherapy (96% of cases), transcutaneous electrical neurostimulation (TENS) in 59.26% of cases, psychotherapy in 35.71% of cases, therapeutic patient education (TPE) program in 10.71% of cases or hypnosis in 10.71% of cases. Prior treatments or current treatment options were not correlated to patient decision-making autonomy (Table 2).

**Table 2** Comparison of patients' MacCAT-T scores stratified by pain characteristics, comorbidities and treatment options

	Total (N=27)	Very autonomous - no deficit (N=13)	Mild deficit (N=7)	Major deficit (N=7)	p
<b>Duration of pain (months) (N=27)</b> median [Q1;Q3]	60.00 [30.00;120.00]	42.00 [33.00;120.00]	60.00 [34.00;150.00]	96.00 [30.00;120.00]	0.92 <sup>1</sup>
<b>Type of chronic pain*</b>					
<i>Nociplastic</i>	18 (66.67%)	11 (84.62%)	2 (28.57%)	5 (71.43%)	0.0364 <sup>2</sup>
<i>Neuropathic</i>	11 (40.74%)	4 (30.77%)	4 (57.14%)	3 (42.86%)	0.54 <sup>2</sup>
<i>Nociceptive</i>	8 (29.63%)	3 (23.08%)	3 (42.86%)	2 (28.57%)	0.86 <sup>2</sup>
<b>Location of pain**</b>					
<i>Lower limb</i>	6 (22.22%)	3 (23.08%)	1 (14.29%)	2 (28.57%)	> 0.99 <sup>2</sup>
<i>Upper limb</i>	4 (14.81%)	1 (7.69%)	1 (14.29%)	2 (28.57%)	0.55 <sup>2</sup>
<i>Abdomen</i>	2 (7.41%)	2 (15.38%)	0 (0.00%)	0 (0.00%)	0.48 <sup>2</sup>
<i>Diffuse location</i>	5 (18.52%)	3 (23.08%)	1 (14.29%)	1 (14.29%)	> 0.99
<i>Perineum</i>	5 (18.52%)	3 (23.08%)	2 (28.57%)	0 (0.00%)	0.54
<i>Headache</i>	1 (3.70%)	0 (0.00%)	1 (14.29%)	0 (0.00%)	0.52
<i>Orofacial</i>	3 (11.11%)	1 (7.69%)	1 (14.29%)	1 (14.29%)	> 0.99
<i>Pelvis</i>	3 (11.11%)	2 (15.38%)	1 (14.29%)	0 (0.00%)	0.78
<i>Thorax</i>	1 (3.70%)	0 (0.00%)	1 (14.29%)	0 (0.00%)	0.52
<i>Spine</i>	5 (18.52%)	2 (15.38%)	0 (0.00%)	3 (42.86%)	0.12
<b>History of breast cancer (N=19)</b>	3 (15.79%)	1 (12.50%)	1 (16.67%)	1 (20.00%)	> 0.99
<b>History of endometriosis (N=19)</b>	3 (15.79%)	2 (25.00%)	1 (16.67%)	0 (0.00%)	0.75
<b>History of migraine (N=19)</b>	3 (15.79%)	1 (12.50%)	0 (0.00%)	2 (40.00%)	0.31
<b>History of arterial hypertension (N=19)</b>	3 (15.79%)	3 (37.50%)	0 (0.00%)	0 (0.00%)	0.09 <sup>2</sup>
<b>Previous treatments:</b>					
<i>Physiotherapy (N=26)</i>	12 (46.15%)	7 (58.33%)	3 (42.86%)	2 (28.57%)	0.48 <sup>2</sup>
<i>Acetaminophen (N=26)</i>	4 (15.38%)	0 (0.00%)	3 (42.86%)	1 (14.29%)	0.0375 <sup>2</sup>
<i>Tramadol (N=26)</i>	6 (23.08%)	2 (16.67%)	2 (28.57%)	2 (28.57%)	0.72 <sup>2</sup>
<i>Antidepressants</i>	9 (33.33%)	4 (30.77%)	2 (28.57%)	3 (42.86%)	0.88 <sup>2</sup>
<i>Anticonvulsants</i>	10 (37.04%)	5 (38.46%)	3 (42.86%)	2 (28.57%)	> 0.99 <sup>2</sup>
<i>TENS (N=24)</i>	1 (4.17%)	1 (8.33%)	0 (0.00%)	0 (0.00%)	> 0.99 <sup>2</sup>
<b>Treatment proposals</b>					
<i>Psychotherapy</i>	10 (37.04%)	4 (30.77%)	3 (42.86%)	3 (42.86%)	0.78 <sup>2</sup>
<i>therapeutic patient education</i>	3 (11.11%)	2 (15.38%)	0 (0.00%)	1 (14.29%)	0.78 <sup>2</sup>
<i>TENS (N=26)</i>	15 (57.69%)	9 (69.23%)	4 (66.67%)	2 (28.57%)	0.23 <sup>2</sup>
<i>Hypnosis</i>	3 (11.11%)	2 (15.38%)	1 (14.29%)	0 (0.00%)	0.78 <sup>2</sup>
<i>physiotherapy (N=22)</i>	21 (95.45%)	12 (100.00%)	4 (80.00%)	5 (100.00%)	0.45 <sup>2</sup>
<i>Antidepressants</i>	19 (70.37%)	11 (84.62%)	4 (57.14%)	4 (57.14%)	0.34 <sup>2</sup>
<i>Anticonvulsants</i>	5 (18.52%)	2 (15.38%)	2 (28.57%)	1 (14.29%)	0.83 <sup>2</sup>
<i>preventive analgesics</i>	9 (33.33%)	4 (30.77%)	1 (14.29%)	4 (57.14%)	0.25 <sup>2</sup>
<b>Previous care in a chronic pain unit (N=25)</b>	6 (24.00%)	2 (18.18%)	1 (14.29%)	3 (42.86%)	0.50 <sup>2</sup>

<sup>1</sup> Non parametric Kruskal-Wallis test<sup>2</sup> Fisher's exact test

\*some patients had multiple forms of pain (such as nociceptive and nociplastic)

\*\*some patients had several locations of pain (such as pelvis and spine)

**Decision-making autonomy assessment (Table 3)****Clinician-based assessment**

According to the 4 pain physicians who assessed the patients included in the study, the vast majority of patients (88%) were considered having no deficit in their decision-making capacity, without using the tool. Two patients were considered having a mild deficit in this ability, and only one had a major deficit. For 2 patients, their pain physician had no opinion about their decision-making autonomy.

**Tool-based assessment**

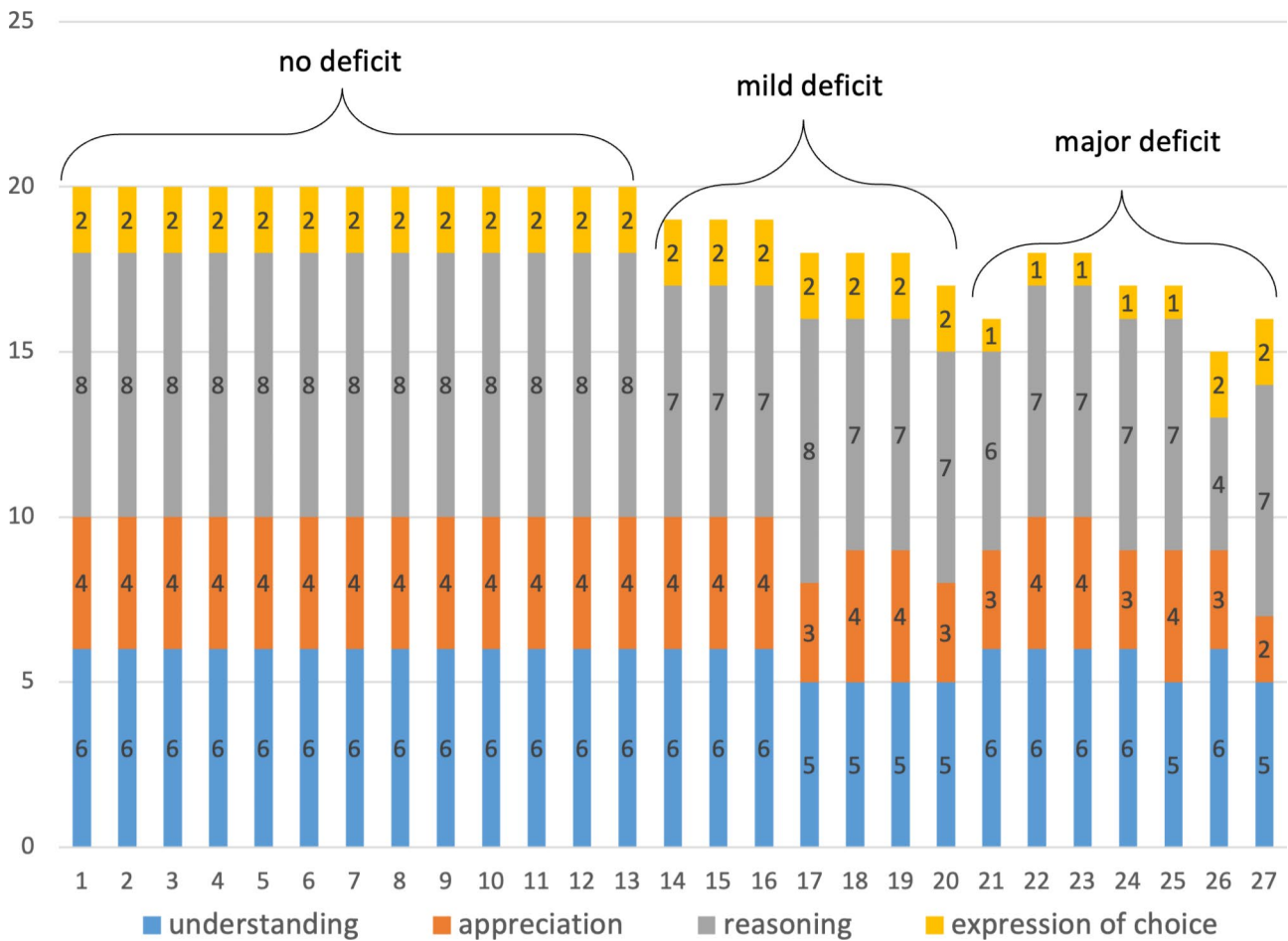
All 27 participants completed the MacCAT-T interview followed by calculation of the scores and subscores. Using the MacCAT-T tool, 13 patients (48%) were considered very autonomous (total score 20/20 i.e. no deficit), 7 (26%) had a mild deficit and 7 (26%) had a major deficit in autonomy, mainly in the area of expressing a choice. The subscore results for each patient are shown in Fig. 1.

**Table 3** Comparison of patients' MacCAT-T scores stratified by type of decision-making autonomy assessment

	Total (N=27)	Very autonomous - no deficit (N=13)	Mild deficit (N=7)	Major deficit (N=7)	p
<b>Autonomy assessment by physician (N=25)</b>					
Very autonomous – no deficit	22 (88.00%)	11 (91.67%)	6 (100.00%)	5 (71.43%)	0.66 <sup>2</sup>
Mild deficit	2 (8.00%)	1 (8.33%)	0 (0.00%)	1 (14.29%)	
Major deficit	1 (4.00%)	0 (0.00%)	0 (0.00%)	1 (14.29%)	
<b>MacCAT-T score</b>					
Mean (SD)	18.70 (1.54)	20.00 (0.00)	18.29 (0.76)	16.71 (1.11)	< 0.0001 <sup>1</sup>
<b>Duration of interview (minutes) (N=27)</b>					
Median [Q1;Q3]	20.00 [19.50;27.50]	20.00 [15.00;20.00]	25.00 [22.50;30.00]	20.00 [20.00;27.50]	0.07 <sup>1</sup>
<b>Patient satisfaction with the interview (N=25)</b>					
1- very satisfied	23 (92.00%)	11 (91.67%)	7 (100.00%)	5 (83.33%)	0.72 <sup>2</sup>
2- satisfied	2 (8.00%)	1 (8.33%)	0 (0.00%)	1 (16.67%)	

<sup>1</sup> Non parametric Kruskal-Wallis test

<sup>2</sup> Fisher's exact test



**Fig. 1** MacCAT-T results by subscore



The median duration of the interview process was 20 min [19.50; 27.50].

On a 5-point Likert scale, the patients were all satisfied with the interview they had undergone to measure their decision-making autonomy: 92% were very satisfied, and 8% were satisfied.

#### **Comparison of decision-making autonomy assessment**

Interestingly, out of the 22 patients who were assessed as “very autonomous” by the physicians, 6 of them had a “mild deficit” and 5 had a “major deficit” based on MacCAT-T scores. Furthermore, in two cases where the physician has assessed the patient’s autonomy level as “mild deficit”, the MacCAT-T-based evaluation actually found one patient to be very autonomous whereas the other was considered having a “major deficit”. Such results suggest that assessment of patient autonomy based solely on the clinician’s personal evaluation is probably insufficient and would strongly benefit from appropriate tools such as the MacCAT-T, once adapted to the clinical setting.

#### **Discussion**

To this day, the subject of decision-making autonomy in the specific population of chronic pain patients has yet to be explored. The present pilot study showed that more than half of the patients interviewed presented a deficit in decision-making autonomy, evidenced by the low MacCAT-T scores, with a homogeneous distribution of this deficit in the various subscores (understanding, appreciation, reasoning, expression of a choice). Such results suggest that some chronic pain patients might not be sufficiently autonomous to decide to follow the treatment plan proposed by their physician and to properly engage in it. From a clinical and scientific standpoint, this pilot study also shows the feasibility of using the MacCAT-T tool to assess decision-making autonomy in the setting of chronic pain. Interestingly, patients’ degree of autonomy did not seem to impact the duration of the interview (the MacCAT-T questionnaire took a median of 20 min to complete in the present study).

#### **Clinical- vs. MacCAT-T- based assessment of patient autonomy**

Of the 27 patients assessed by 4 different pain physicians, 22 were considered very autonomous (compared to only 11 with the MacCAT-T). Of the 7 patients with a major deficit according to the MacCAT-T score, 5 were -on the contrary- considered very autonomous with no deficit by their physician. Conversely, one of the 3 patients with a deficit according to their doctors actually had a MacCAT-T score of 20/20. These findings are consistent with studies comparing clinicians’ estimates of patients’ autonomy based on their own opinions with those made by a standardized tool or by a trained clinician who has

carried out many capacity assessments [64]. The literature reports an overestimation of autonomy (i.e. a failure to identify the deficit) in patients with a deficit in decision-making capacity [65, 66, 67] and an underestimation in those who actually are the most autonomous (i.e. an overestimation of the degree of deficit) in different populations [60, 66]. There would appear to be a discrepancy between global assessment of patient autonomy based on clinical impression and standardized assessment following a structured plan that measures understanding, reasoning, appreciation and expression of choice separately, as proposed by the MacCAT-T. It is therefore likely that the minor deficit assessed clinically does not correspond to the minor deficit assessed with the MacCAT-T. As some authors have suggested, it is possible that this lack of reliability in assessment is due to a lack of standardized definition for capacity assessment [68]; so a ‘minor deficit’ assessed by a clinical assessment wouldn’t be comparable to a ‘minor deficit’ assessed via the MacCAT-T, as would also be the case for a ‘major deficit’.

#### **Decision-making autonomy deficit in chronic pain patients**

As mentioned above, more than half of the patients in the present sample showed a deficit in decision-making autonomy, as evidenced by low MacCAT-T scores, with a homogeneous distribution of this deficit across the different subscores (understanding, appreciation, reasoning, expressing a choice). It is likely that impaired decision-making autonomy in this clinical context is related to the underlying mechanisms of chronic pain. Indeed, persistent pain gradually generates a series of undesirable consequences, creating a vicious circle that perpetuates and amplifies the pain [69]: functional and structural alterations of the nociceptive system (peripheral and central sensitization) [70]; behavioral changes (reduced activity, physical deconditioning) [71]; emotional changes (anxiety, depression) [72]; sleep disturbances [73]; cognitive changes (attentional bias) [74]; socio-professional changes (professional and family difficulties) and social withdrawal [75].

By influencing cognitive, emotional, cultural or psychosocial factors, the doctor-patient relationship and access to information, these pathological chronic pain condition could lead to a change in autonomy (as has been shown in other clinical contexts [68, 76–79]). However, the involvement (and respective degree of involvement) of such characteristics of chronic pain in the evidenced autonomy deficit warrants further investigation to better characterize the determinants of decision-making autonomy in such clinical context.

#### **Patient characteristics and degree of autonomy**

In this sample, patients who had nociplastic pain appeared to be less autonomous. No other characteristics

studied (demographic characteristic, location of pain, duration of pain, type of treatment etc.) appeared to be related to degree of autonomy.

IASP introduced the term “nociceptive pain” in 2017 as a third mechanistic pain descriptor in addition to nociceptive and neuropathic pain [80]. Nociceptive pain is “pain that arises from altered nociception despite no clear evidence of actual or threatened tissue damage causing the activation of peripheral nociceptors or evidence for disease or lesion of the somatosensory system causing the pain” [81]. The relationship between the presence of nociceptive pain and a deficit in autonomy will need to be confirmed in larger studies, but it does raise the question of its imputability in the autonomy deficit. It is possible that misdiagnosis [73], lack of recognition of the disease [82], personality traits associated with this type of pain [83, 84], associated cognitive problems [85], more frequent drug-induced iatrogenesis [86] and the complexity of the pathophysiological mechanisms involved [87, 88] may account for the higher proportion of autonomy deficits, in a manner still to be investigated.

#### **Is the MacCAT-T an appropriate tool for assessing global autonomy or only the capacity to consent to treatment?**

In Grisso and Appelbaum’s landmark book, they equate autonomy to self-determination and self-determination to “an interest in making autonomous decisions” [89]. To exercise one’s autonomy is to choose autonomously. In order to respect patient autonomy, one needs to rigorously evaluate the patient’s decision-making abilities, as it is not legitimate to prevent competent people from making their own decisions, and it is dangerous to let people who are no longer competent make decisions that involve major risks [76].

In the present study, the MacCAT-T tool was used to measure chronic pain patient autonomy. It appears to be currently the most reliable tool to assess decision-making autonomy according to different reviews of structured instruments for the assessment of healthcare decision-making capacity [58, 61, 63]. As the tool is indicated by its authors for the assessment of the ability to consent to treatment, one can question the legitimacy of using the MacCAT-T for a broader assessment of autonomy. To address such issue, it is necessary to explore the notion of autonomy in terms of medical ethics and whether or not its constituents are actually explored in the MacCAT-T tool. In their ethical theory known as “principlism” [26], following the pragmatic trend forged by William James for whom the strength of an idea is measured above all by its practical utility [90], Beauchamp and Childress do not seek to determine what the “true” definition of autonomy might be but rather how various conceptions of autonomy are able to make themselves productive, give it a concrete form and, through the legal requirement of free

and informed consent, come to adequately fulfill their social function [91]. In that regard, many items that are explored by the MacCAT-T can be included as part of the concept of autonomy:

#### **I. Authenticity and identity**

They might be the reflection of a person’s values, personality and life history [92]. Several authors consider that the notions of authenticity and identity are not evaluated by the MacCAT-T [93–95]. However, one can beg to differ, as the MacCAT-T tool does indeed take into account the interests of each individual, thanks to the interpretation that the interviewer makes of the patient’s answers, not in relation to his or her own value system but with specific reference to the person’s reasoning, life history and personal experiences, particularly in the area of assessment.

#### **II. Independence and self-determination**

Independence and self-determination determine “the ultimate capacity that an individual would have to think and act, with full knowledge of the facts, according to his or her opinions, beliefs, values and desires” [96]. In short, it is the ability to say yes or no to something [97]. By assessing whether a person is capable of making a given decision alone, the MacCAT-T does evaluate decision-making independence or self-determination [98].

#### **III. Will**

Competent decision-making involves more than cognitive ability, the absence of emotional involvement and the existence of appropriate values. It also involves the ability to make an authentic choice (to practice volition i.e. to feel the freedom to formulate a choice and exercise one’s free will [32]) and the ability to translate that choice into action [99]. By asking the patient to express a choice and to justify it, the MacCAT-T does seem to take the patient’s volition into account.

#### **IV. Freedom**

Human beings often consider themselves free to make choices, follow their desires and make decisions, but this freedom can be limited by factors that are often beyond their control: “This is that human freedom, which all boast that they possess, and which consists solely in the fact, that men are conscious of their own desire, but are ignorant of the causes whereby that desire has been determined.” [100]. It has been argued that human desires and impulses are caused by unconscious factors and external influences, such as social conditioning, cultural pressures, emotions and past experiences. In other words, humans are not so free in their desires and choices, as they are determined by forces largely beyond their control. A number of authors have also questioned whether

loss of autonomy is akin to “weakness of will”, when the patient “acts against his or her own judgment about what to do” [101–103]. The MacCAT-T does seem to enable the perception of such “weakness of will” by assessing the patient’s appreciation of his/her diagnosis and treatment. In fact, during the interviews, several patients had perfectly understood the information concerning their disorder and the treatment plan, but, as if in spite of themselves, were unable to appropriate it for themselves, suggestive of akrasia [104] (i.e. acting against one’s better judgment) [105].

#### **V. Sovereignty, authority, agentivity, control, reflexivity**

The concepts of sovereignty, authority, agentivity, control and reflexivity all refer to a form of social autonomy, involving interactions between the individual and his or her environment (political, medical, family) [106]. To be autonomous, it is necessary to interact with “the Other” and to use one’s agentivity and reflexivity to exercise one’s critical sense with regard to the impact of the Other’s will or one’s own actions on one’s freedom. Agentivity can be defined as a person’s ability to have an effect or impact on the world. This capacity does not presuppose independence from social power relations or the absence of constraints [107, 108]. The MacCAT-T, by exploring the consequences generated by the choice and by questioning the patient’s appreciation, does seem to integrate the evaluation of the critical sense he exercises in reasoning.

#### **Study limits**

Apart from the foreseeable limitations of such a pilot study (i.e. a small sample size, unknown information on a priori variability of MacCAT-T scores and limited external consistency of the results) several specific limitations of the present research need to be addressed, to draw proper conclusions on these preliminary results:

##### **I. No specific assessment of cognitive and emotional abilities in the study**

Appelbaum (one of the fathers of the MacCAT-T) [76] as well as numerous authors [109–112] suggest that decision-making ability is closely linked to cognitive ability and is one of its strongest predictors. Several teams that have explored this theme consider cognitive abilities to be a necessary condition (enabling the understanding subscore to be met) but not sufficient to satisfy the various requirements of decision-making autonomy [113, 114]. An individual assessment, ideally by a trained neuropsychologist, would be needed to classify cognitive disorders in this heterogeneous population. Furthermore, in the absence of systematic evaluation of the patients’ emotional characteristics during the study period (the Hospital Anxiety and Depression Scale [HADS], a good measure of anxiety and depression [115], was used

inconsistently by some attending physicians), it was not possible to investigate the possible link between emotional wellbeing and degree of autonomy.

Further studies will need to encompass such issues, for example using a cognitive test such as the Montreal Cognitive Assessment (MoCA) [116] and a measure of emotional state such as the HADS.

##### **II. No assessment of health literacy in the study**

In chronically ill patients, it has been suggested that a low level of health literacy could be detrimental to the full mastery of skills enabling disease self-management and treatment monitoring [117, 118], by impairing the patient’s ability to understand and appreciate (i.e. his/her decision-making skills) [79, 119, 120]. Health literacy is defined by the WHO as “knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in every-day life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course” [121]. In the European Health Literacy Survey, 12% of respondents had an insufficient level of health literacy, and 35% had a limited level of health literacy [122]. This is therefore a very common health and healthcare access problem, which could have affected the study’s patients’ decision-making autonomy. A review of the literature over the past 30 years [123] has reviewed all the instruments used to measure health literacy and promotes the European Health Literacy Survey Questionnaire (HLS-EU-Q16) [124] that could be useful to explore such literacy in future studies.

##### **III. No integration of possible fluctuation of autonomy during the course of treatment**

It is likely that emotional [125] and cognitive [126] factors, health literacy [127] but also other factors influence patient’s decision-making ability. As these factors can change during the course of treatment, and in order to limit bias, we decided to evaluate all patients at the same stage of their follow-up, i.e. just after their first consultation in the chronic pain structure. Nevertheless, it is probable that patient autonomy does fluctuate during the course of treatment. Future studies will have to take this possible fluctuation into account in the study design.

##### **IV. Categorization of MacCAT-T scores**

The original scoring manual [37] does not propose a threshold at which a patient can be considered competent or not. Indeed, the authors state that their tool should not be used as a score but as an assessment instrument for measuring degrees of autonomy capacity. However, an increasing number of studies are proposing the same threshold for each of the subscores. For each patient included, every physician was asked to clinically

assess his or her autonomy by classifying them according to 3 gradation levels: no deficit, mild deficit, and major deficit, in adherence with the existing literature [35]. To compare this clinical assessment with the results of the MacCAT-T, the patients were arbitrarily stratified into 3 groups, considering as “autonomous without deficit” those who had a score of 20/20, with “mild deficit” those who did not have 20/20 but remained above the thresholds proposed in the literature for each subscore and finally with a “major deficit” those who had at least one of the subscores below the thresholds.

#### V. Choice of criteria for non-inclusion

Considering the difficulty in properly defining and assessing patient autonomy, we decided not to include patients who from a legal perspective could not provide an informed consent so as to limit any possible bias that may have arisen from such specific population. Conversely, excluding patients with known autonomy deficits does in itself induce a selection bias, that will need to be addressed in future studies, once the determinants of decision-making autonomy are better characterized.

#### Conclusion

A significant proportion of chronic pain patients present a deficit in decision-making autonomy, that could impact their appropriation and engagement in the treatment plan proposed during their visit in the pain center, as suggested by results of the present pilot study using a specific evaluation tool, the MacCAT-T.

Furthermore, there were significant discrepancies between clinician-based and MacCAT-T-based assessment of patient autonomy suggesting that pain specialists are not able to properly assess said autonomy without proper tools or training.

Autonomy is of paramount importance for chronic diseases clinicians, not only because of their ethical questions but also because of the impact this concept of autonomy can have on disease management and health. This is particularly true in the specific context of patients suffering from chronic pain as a better understanding and assessment of the patients' degree of autonomy will allow a more effective (and therefore more beneficial) personalized treatment plan, eventually making practitioners more available for further patients awaiting this type of care.

Future studies will be required to assess the underlying determinants of patient autonomy in the specific context of chronic pain. This should allow the development of specific tools for the clinical setting, aimed at helping the clinician properly assess patient autonomy and adapt the proposed treatment plan accordingly.

#### Abbreviations

CNIL	Commission Nationale de l'Informatique et des Libertés
GDPR	General Data Protection Regulation
HADS	Hospital Anxiety and Depression Scale
IASP	International Study of Pain
MacCAT-T	MacArthur Competence Assessment Tool-Treatment
MoCA	Montreal Cognitive Assessment
TPE	Therapeutic patient education

#### Supplementary Information

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Supplementary Material 1

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#### Author contributions

MU designed the work, collected the data, analyzed it and wrote the initial version of the manuscript. ES made substantial contributions to the design of the work. She helped collect and manage the data and performed the statistical analysis. NM substantially modified the version of the manuscript. JN was a contributor to the design of the work and analyzed and interpreted the patient data regarding his expertise in the field of pain and his in-depth knowledge of patients suffering from chronic pain. He substantially modified the version of the manuscript. GD made substantial contributions to the conception of the work. He analyzed and interpreted the patient data regarding his precise knowledge of the concept of patient autonomy in ethics. All the authors have contributed to the reviewing of the manuscript. He substantially modified the version of the manuscript. All the authors have read and approved the final manuscript.

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#### Data availability

The datasets used and analyzed during the current study are available from the corresponding author upon reasonable request.

#### Declarations

##### Ethics approval and consent to participate

##### Ethical clearance

The protocol has been performed in accordance with the Declaration of Helsinki and approved by the institutional ethics committee: the GERM (Groupe Ethique et Recherche Médicale) from the Hospital Paris Saint-Joseph (institutional review board number IRB00012157, initial agreement 624) on April 21, 2023.

In the context of the present study, French research regulation (Journal Officiel de la République Française [Official Journal of the French Republic] 0160, July 13, 2018; paragraph 110, MR-004) states that the patient's written consent is not mandatory but investigators are required to give the patient an information leaflet explaining the purpose of the research. The patients' non-opposition to the use of their data for research was also collected in accordance with European regulations (General Data Protection Regulation). The data recorded on the occasion of this research have been the subject of computerized processing in compliance with Law no. 78 – 17 of January 6, 1978 relating to information technology, files and freedoms, amended by Law no. 2018 – 493 of June 20, 2018 (Decree no. 2018 – 687 of August 1, 2018) and Order no. 2018 – 1125 of December 12, 2018, as well as in compliance with

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#### Data protection

This research was subject to Law no. 78 – 17 of January 6, 1978 relating to information technology, files and freedoms as amended by Law no. 2018 – 493 of June 20, 2018 (Decree no. 2018 – 687 of August 1, 2018) and Order no. 2018 – 1125 of December 12, 2018, as well as to the GDPR. Information on the rights of people taking part in this research (right of access and rectification, right to object to the transmission of data covered by professional secrecy likely to be used in the context of this research) was included in the patient information form.

#### Information and non-objection form.

In accordance with Articles 13 and 14 of Regulation (EU) 2016/679 of the European Parliament and of the Council of April 27, 2016 (GDPR), individuals who undergo research must be informed. This information is the subject of a written document.

The investigator gave the information form to the patient during the consultation in the department. If the patient did not object, he or she was included in the study. The non-objection was recorded in the patient's medical record. Patients were free to participate or withdraw from the study at any time in accordance with Article 21 of the GDPR. The person undergoing the research were informed of the overall results of the research in the manner specified in the information document.

#### Competing interests

The authors declare no competing interests.

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