
Applying best interests to persistent vegetative state - a principled distortion ?

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Abstract

"Best interests" is widely accepted as the appropriate foundation principle for medico-legal decisions concerning treatment withdrawal from patients in persistent vegetative state (PVS). Its application appears to progress logically from earlier use regarding legally incompetent patients. This author argues, however, that such confidence in the relevance of the principle of best interests to PVS is misplaced, and that current construction in this context is questionable on four specific grounds. Furthermore, it is argued that the resulting legal inconsistency is distorting both the principle itself and, more particularly, individual patient interests.

Editor's note

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A contextual introduction

Patients in persistent vegetative state, being incognizant, incapacitated and insensate, pose difficulties for both law and medicine. Burgeoning legal support for patient autonomy and self-determination falters on confronting patients previously possessed of such interests, but now permanently unable to express them. Incurability, coupled with potentially indefinite continued existence, raises questions of withdrawing "treatment" from a *non-terminal* patient. This involves medical professionals in action diametrically opposed to the very life-sustaining aims of "treatment". Nevertheless, a decision is needed.

Few would dispute the PVS patient's lack of legal capacity, ie the patient's inability to exercise his/her own rights, particularly the right of self-determination and, indeed, his/her unawareness of the very need for any decision. With relative ease, we can therefore conclude that the patient fails to meet the requisite "competency threshold" of consent. However, such rights are not lost simply because the patient cannot

personally exercise them - proceeding to treat may still be unlawful unless it is "justified". The chronic nature of PVS means that the situation can no longer be characterised as an "emergency" (justifying intervention as "necessary"). Without consent, continuing treatment could therefore invade privacy and constitute an illegal battery, whilst ceasing treatment may not fulfil ethical and legal duties towards the patient. Thus, some form of authorisation of the continuance (or withdrawal) is required, and this decision necessarily falls to others. "Best interests", being an established and beneficent solution, seems a safe and uncontentious route to take. Paradoxically though, PVS may involve the most contentious treatment-outcome of all consent decisions, namely the death of the patient. The relevant decision-making device must therefore withstand the closest and most critical scrutiny.

Certainly the application of "best interests" to PVS decisions is espoused at the highest levels of legal authority. Its current standing as "the law" within the United Kingdom and Ireland is unquestionable. However, doubts arise regarding the *way* in which it is applied to PVS. Are the foundations of the principle as soundly reasoned as we might expect? Is this new application a legally consistent development? Does closer inspection reveal structural weakness? This author believes that there are fundamental grounds for concern and that distortion, rather than development, is occurring. Before substantiating these claims though, it is worth considering from where "best interests" has sprung.

"Best interests" at source

"Best interests" constitutes something of a panacea in medico-legal decision-making - invoked in the treatment of severely disabled infants,¹ sterilisation of incompetent adults,² and as a "fall-back" where consent is defective.³ A principle's gradual levitation to such multi-functional status draws it inexorably away from contextual application, to more-generalised formulation. Airedale NHS Trust v Bland⁴ witnessed this shift by way of heavy cross-contextual reliance

upon Re F (a mental patient: sterilisation),² where *lawful* treatment of incompetent patients was equated with treatment in patient “best interests”, ie that which sought: “...to save their lives or to ensure improvement or prevent deterioration in their physical or mental health”.⁵

The court deemed such evaluation to be within the remit of “Bolam”,⁶ thereby effectively requiring “a responsible body of medical opinion” so to construe it. In its entirety, this formulation comprises one of the most explicit formulations of “best interests” to date.

Further support for applying “best interests” to PVS derives from its earlier application to life/death decisions on withholding treatment (Re J (a minor) (wardship: medical treatment)).¹ Here, however, a different formulation involved more overt weighing of “benefits” and “burdens” and minimal reference to “Bolam”, thus rendering Re J a more individualistic, “quality-of-life” decision than Re F.

The difficulty in extending “best interests” to PVS decisions lies essentially in the apparent similarity to other non-treatment cases. Like Re J, PVS concerns withdrawing/withholding life-sustaining treatment, but regarding an adult unable to express any consent - like Re F. The disparity of formulation, coupled with high profile, and emotive overtones of “ending life”, meant that applying best interests to PVS - though perhaps logical - was never going to be easy.

Best interests in PVS - current aspects

Construction of “best interests” in recent UK and Irish PVS cases, essentially seeks to steer something of a middle course between the generalised and individualistic formulations and permits identification of three component elements: jurisdiction; medical involvement; and classification of interest.

JURISDICTION

Both the Scots Court of Session⁷ and the Irish Supreme Court⁸ are empowered with *parens patriae* jurisdiction, enabling them to exercise a role akin to guardianship, in respect of incompetent adults. This effectively imbues these courts with a power to consent on the patient’s behalf. This contrasts sharply with the English courts, where its absence limits jurisdiction to a power to declare a treatment decision “lawful”,⁹ ie stating that deciding to cease (or, indeed, continue) treatment will not contravene civil or criminal law.

The wider scope of the Scots and Irish courts facilitates a broad perspective, and “weighing” of the various factors involved (analogous to the Re J

formulation involving wardship). Whereas the more restrictive jurisdiction of the English courts centres the decision upon questions of infringing legal “duties”, drawing the focus away from patient need towards more generalised principles (more akin to a Re F formulation). This is not to say that such jurisdictional limits are totally distinct, nor inflexible, merely that each may predispose “best interests” to a particular type of formulation.

MEDICAL INVOLVEMENT

Medical involvement in “best interests” invokes aspects of both Re F and Re J. Thus, in Bland,⁴ continued application of “Bolam”, renders medical opinion fundamental to “best interests”, a role which is similarly emphasised in the Scots decision of Law Hospital NHS Trust v Lord Advocate.⁷ Such emphasis clearly simulates the Re F construction. However, by contrast, most of the PVS decisions also make reference to other individualistic facets of medical evaluation such as: benefits and burdens of treatment¹⁰; likely effect upon prognosis,¹¹ and invasiveness of treatment to bodily integrity¹⁰ - all essentially more representative of the “balancing” approach so evident in Re J.

It thus seems that, not only is there *considerable* medical input in determining best interests in PVS, but also that this input is then utilised in a mixed construction of formal general principle and informal individualistic balancing.

CLASSIFICATION OF “INTEREST”

The PVS context appears to have spawned a new classification of “*interest*”, and consequent restructuring of “best interests”. In previous contexts, identifying the optimal (“best”) implicitly required deriving “net benefits”, which Buchanan and Brock succinctly explain as: “... assigning different weights to the [treatment] options to reflect the relative importance of the various interests ... then subtracting costs or ‘disbenefits’...”¹²

In Re J such assessment was made openly by the court, whereas in Re F evaluation fell to the medical professionals, whose decision could be judicially verified as “lawful”. However, in PVS, continued “treatment” confers only extremely limited “benefits” (such as maintaining the *status quo*), or “burdens” (such as treatment hazards). This lack of input to the “net benefit” equation results in PVS patients’ interests being classified as “none”, and a consequent denial of any need for weighing.¹³ This rather radical classificatory departure demands - not surprisingly - an alternative formulation of “best”, which has ultimately resulted in inverting the formula to consider

whether continued alimentionation is “not in the patient’s best interests”.¹⁴

Essentially then, current application of “best interests” to PVS comprises a mixture of previous formulations (and terminology), together with a new classification designed to address the peculiarities of PVS. This may be construed as a principled development, and heavy judicial emphasis on “patient interests” in PVS decisions means that the relevance of “best interests” is undoubtedly firmly established. However, construction of principle is really a secondary step in the decision-making process. Initially let us clarify the objective of that process.

“True” objective

Essentially, we must initially ask: what is the purpose of making this treatment decision? Existing formulations focus upon whether we should treat so as to “prolong life”^{14 15} - a construction which avoids the emotive nature of “causing the patient to die”, and pre-empts suggestions of euthanistic overtones. However, formulating sound legal principle requires honesty of objective and no matter how euphemistically phrased, or finely distinguished, the inevitable consequence of withdrawing alimentionation from a PVS patient is *death*. This is simply a fact which, if one is honest, renders the decision one of life-or-death choice. The true objective should therefore be: *to establish whether artificial nutrition and hydration should be withdrawn (or withheld) from a patient in persistent vegetative state, such that the patient will die*. This is not to comment upon the moral or ethical correctness of so doing. It is merely a more truthful statement of the ultimate objective of the decision, which then enables us to seek the most appropriate principle to attain it justly and compassionately.

What is being suggested is that “best interests”, as currently formulated, fails to address this “true” objective, thereby distorting both interests and principle - a claim which must now be substantiated.

The distortion of a principle?

Despite “best interests” value in other medico-legal areas, doubts concerning its construction in PVS decisions are founded on four specific grounds: delusory objective; illogicality; medicalisation, and range of “interests”.

DELUSORY OBJECTIVE

Current construction seeks to constrain “best interests” within strictly delineated parameters. This, in itself, may be no bad thing. However, the

means used to achieve this are less well founded, insofar as suggested substantive conceptual distinction often transpires - on closer inspection - to be merely semantic, and delusory as to true objective. Recurrent judicial distinction between “letting die” and “euthanasia” is a prime example.¹⁶ Judicial motivation for avoiding “slippery slopes” may well be valid, but in terms of PVS this distinction is negligible, as withdrawing “treatment” results in the death of a patient who is not “terminally”, but rather “chronically”, ill. Thus we are not merely “letting” an already imminent death occur. The choice of a particular label, and use of supporting terminology such as “natural death”, whilst suggestive of a more remote, less direct consequence, lying only on the very periphery of our sphere of influence, cannot change the character of the event. In truth, as McLean suggests: “... the actual decision, however reached, is a decision for or against death. We are, in its purest form, considering euthanasia”.¹⁷

Further judicial semantics skirt this by construing euthanasia as requiring positive, direct action. But as Mason and Mulligan indicate, this constitutes “... a very limited definition of euthanasia”.¹⁸

These semantic distinctions are similarly paralleled in promoting “*ceasing to prolong life*” as differing from “*terminating life*”,¹⁹ and devolves from Re J. However, withholding reventilation where death is already imminent (through cessation of breathing, as would occur in Re J) possesses a natural, preliminary factor such that “ceasing to prolong” and “terminating” may be distinct. This is simply not apparent in PVS - where the death only becomes imminent as a result of withdrawing or withholding the life-sustaining treatment, thus it is difficult to see how “not prolonging” differs substantially from “ending”, when life would not otherwise cease. Craig suggests that such semantic juggling arises from the vagaries of English criminal law,²⁰ whilst Mason and Laurie emphasise the designation of “cause of death” as a factor.²¹ Whatever the origin, the effect of such fine distinction implicitly suggests “not extending” to be somehow more legally, morally and ethically acceptable than “ending”. This exemplifies judicial delusion as to the decision’s true objective and consequences.

This delusion is supported by further semantics categorising withdrawal of treatment as an “omission” rather than an “act”,²² thereby averting problems of criminal liability, and facilitating a shift of focus towards “*duty*” and Bolam-relevance. Such distinction is therefore, perhaps, a means to an end rather than substantive in itself and, indeed, its suitability in the PVS context was doubted by Lord Mustill in Bland.²³

In totality, it therefore seems that the current formulation of “best interests” is derived from a number of semantic distinctions. These distinctions, though seemingly “substantial”, are - on closer inspection - euphemistic at best. Realistically, they perhaps represent delusion as to the true objective of the decision, and comprise a practical means of circumventing the contentiousness of outcome - ie the patient’s death. However, this semantic juggling merely creates inherent inconsistency within the principle itself, which results - ultimately - in a disservice to the individual patient.

ILLOGICALITY

The delusion extends beyond semantics though, to more fundamental illogicality. This arises from the particular difficulties of making a life/death decision, without encountering a problematic valuation of “death” - an unknown concept - or risking intimation of euthanasia. In addition, the generally relevant factors do not possess the same significance in PVS as they have in previous contexts. The patient feels no pain, hazards are few, benefit is minimal, prognosis unalterable, and treatment “futile”. This lack of “input” renders weighing of tangible, measurable “interests” near impossible, and has led the courts to conclude (apparently logically) that the patient really has “no interests”, thereby denying the need to “weigh” the potentially contentious issues. Such a multiplicity of problems does not, however, justify distorting or misapplying legal principle, yet this is exactly what occurs in seeking to derive “best interests” from “none”. Irrespective of whether we believe that the PVS patient does or does not retain interests,²⁴ once we declare “no” interest then surely “best” becomes superfluous - no pool exists from which to draw the “best”. The derivation is, therefore, simply not logical, yet this seems overlooked in judgments thus far.

It would be logical to justify withdrawal by saying that the patient has “no interests” and therefore no claim on treatment. Alternatively recognising “minimal” (ie *some*) interests, in PVS (or particularly near-PVS) patients, would enable determination of “best interests”. However, no logic lies within mixing the two. Such confusion probably arises from judicial reluctance to classify withdrawal of treatment in PVS as a “quality of life” decision,¹⁴ whilst seeking simultaneously to use a principle evolved from exactly that type of case. Such inconsistency is, however, both inappropriate and unnecessary. A treatment decision in the context of PVS surely requires evaluation of “quality of life” - even if only to establish an answer of “nil” or “minimal”. Brock and Bucha-

nan suggest that evaluating “interest” “...depends upon how it affects that patient’s life ...”, thereby rendering “quality of life” judgments unavoidable.¹² If so, then “best interests” in PVS cases *either* should involve “quality of life” (together with recognition of *some* interests), and current construction is therefore incorrect, *OR* the decision *not* being a “quality of life” one, (the patient having *no* interests to assess), “best interests” is inapplicable.

Furthermore, it is difficult to see how “best” *cannot* involve comparative evaluation, ie weighing, of some sort. McLean rightly identifies a fear factor involved in acknowledging that “...there may be conditions which make death preferable to life”,²⁵ and judicial concern has been voiced in categorising one life as “... intrinsically worth less than another”.²⁶ Such judicial fears are misplaced however, as they misconstrue “quality of life” as comprising an (offensive) external valuation, rather than an (inoffensive) valuation of that life to that individual. (Brock and Buchanan appropriately term the former a “social” sense and the latter an “intrapersonal” sense²⁷). This judicial misinterpretation fundamentally distorts the evaluative character of “best interests”. A valid assessment of intrapersonal “quality of life” (requiring explicit consideration of the patient’s likely wishes and feelings, similar to Re J) would, in fact, represent a protection rather than derogation of patient “interests”.

Judicial conclusions of “no interests” and “no weighing”, combined with marked reluctance to suggest death as being “in the patient’s best interests”, ultimately result in reversed construction. Thus courts have seen fit to indicate what is “not in best interests”,¹⁴ to the effect that: where treatment is futile, and the PVS patient no longer has any interest in being kept alive, then it is *not* in his best interests to have his life artificially prolonged - consequently duty to treat ceases and withdrawal is lawful. This eventual construction remains, however, illogical in several respects. Primarily, the derivation of “best” from “none” is questionable. Furthermore, the accepted negative construction of “not in best interests to prolong life” is logically no different from the refuted construction that “it is *in* this patient’s best interests to die” - the two are merely mirror images of the same equation, possessing the same outcome, by way of the same passive route. In addition, despite denying the relevance of “quality of life”, judgments still refer to “invasiveness” and “futility” of treatment²⁸ - suggesting *informal* weighing of burdens/benefits. Current construction of “best interests” is therefore inherently illogical, and distorts previous formulations. It is also questionable

whether we are any longer deciding “in” the patient’s “best interests”, rather than implementing solutions “not in” those interests - a contortion running a gamut of inappropriate possibilities.

Finally, we may doubt whether “best interests” was ever a logically analogous application in PVS decisions. Despite superficial similarity to both Re J and Re F there is, after all, one fundamental *dis*-similarity. Both of those cases concerned patients who had never been legally competent - in stark contrast with most PVS patients. “Best interests” may therefore even be a “misapplication” in this context, causing patients’ previous wishes to be under-valued. An alternative principle might, therefore, have been warranted and avoided the need for contortion. However, at present, “best interests” still prevail.

MEDICALISATION

The inherent medicalisation within the Re F formulation (commented upon by the Law Commission)²⁹ is similarly apparent in Bland,⁴ despite the Bolam standard finding disfavour in its original negligence context in recent years.³⁰ Accepting a “responsible body of medical opinion” as evincing “best interests” essentially subjugates patient interests to professional duty and, whilst reliance upon medical evidence is necessary, it should remain purely evidential - not determinative. Importation of Bolam into PVS decisions insupportably abrogates the decision, thereby failing to protect those individuals *most* in need of court protection regarding the ultimate decision: life or death. Although its invocation was not universally embraced, (doubts being cast by the Court of Appeal, and subsequently Lord Mustill, in Bland),³¹ the Scottish courts appear to have similarly accepted medicalisation as a foundation for “best interests”.¹⁵ By contrast though, the Irish courts retain a more patient-oriented, individualistic approach, deeming the judge the ultimate decision-maker.³² Subsequent attempts by English law to reserve final authority to the court, though explicitly expressed in Frenchay Healthcare NHS Trust v S,³³ implicitly lack substance - in view of the alarming speed, lack of full investigation and weighty emphasis on medical evidence apparent in that case.

The danger in medicalisation is its denial of the patient’s previous, and continuing, *non*-medical interests. In addition, the minimisation of judicial involvement in this new legal area, concerning decisions laden with ethical and social implications, is highly questionable and risks courts merely “rubber-stamping” medical decisions. Once combined with judicial willingness to categorise artificial hydration and nutrition as

“medical treatment”,³⁴ and contrasted with judicial *unwillingness* to countenance alternative patient-oriented tests,³⁵ the distortion becomes yet more exaggerated. How might this distorted principle cope with circumstances yet to arise? What if all family members (rather than just one - as in Re G³⁶) oppose withdrawal? Or if strong evidence of “patient wishes” contradicts medical opinion? Could courts justifiably construe the interests of a near-PVS adult as “none” thereby denying any “balancing”, when Re J would be more closely analogous? Reliance on medical opinion, and British Medical Association guidelines,³⁷ is no substitute for clear judicial guidelines founded on sound, consistent principle. This begs the serious question: just whose interests are currently being served?

LIMITATION OF RANGE OF INTERESTS

Medicalisation admits only a narrow conception of “interests”. A broader perspective, seeking “best interests” in totality, might view medical best interests as just one segment, others perhaps comprising: “*personal*” interests, incorporating non-medical aspects such as religious belief; “*familial*” interests, admitting views of those emotionally closest to the patient; and even “*societal*” interests, considering a decision’s effect upon society or other, similarly placed patients, potentially including the issue of resource allocation.

Undoubtedly the non-individualistic interests are contentious but, before rejecting them out of hand, it should be borne in mind that they may already play an *unofficial* role in PVS decisions. Judgments are, after all, sprinkled with references to *familial* opinion,³⁸ and “indignity”³⁹ - a state which is perceived by those associated with the patient, whilst the repeated distinction from “euthanasia” surely indicates evaluation of potential *social* implications.

So, where does this current construction, of formal medical interests and informal non-individual interests, leave the actual PVS patient? Where are his personal, non-medical interests incorporated? The short answer is that they are not - a result of imputing “no interests”, or even “no relevant personality”,⁴⁰ to PVS patients. However, in Re J,¹ concerning withholding reventilation from a severely brain-damaged baby, the Court of Appeal did view the patient’s perspective as being relevant to “quality of life” - itself an element weighed in determining “best interests”. Thus, the court emphasised that “quality of life” should be viewed “... from the assumed point of view of the patient ...”, and that “... the test must be whether the child in question, if capable of exercising sound judgment, would consider the

life tolerable".⁴¹ The irony of this is, of course, that in the PVS context "best interests" takes no account of a genuine, previously existing personality. However, a *non-existent* opinion is imputed regarding a severely disabled baby who has never actually possessed competence, opinions, or beliefs.¹ This distorts, beyond recognition, the very thing supposedly sought, ie the "interests" of that individual PVS patient.

We cannot conclude from this, however, that "best interests" is completely inapplicable to PVS, but rather that its current construction is inappropriate. Would it not be preferable to adopt the broader perspective, enabling other interests to be formally incorporated and permitting proper relevance to the patient's *non-medical* interests? Although a PVS patient appears to have no current or future interest in living, this does not automatically equate to "no interests". Interests deriving from his previous personality are surely still attributable to him, and potentially relevant. These "subsisting interests" include religious beliefs, former opinion as to his present situation, feelings towards his family, and perhaps even beneficence towards others (for example, strong personal belief in organ donation). By adopting a fuller, rounder view of "*interests*" a truer picture of the whole individual is formed, providing a firmer basis for formulating "*best*" interests. Its invocation would require us to turn the Bland decision upon its head, and to go beyond "Re J individualism" in making explicit which interests are relevant. So far only one judgment (by Denham J) has even approached this, by identifying and applying fifteen "factors" in determining "best interests".⁴² These included, for example, the patient's life history and previously expressed views; the family/carer's view; privacy, dignity and autonomy; and the "common good" involved in protecting life. Until this clearer-visioned, non-delusory approach is adopted, both principle and "interests" seem set for distortion.

In conclusion...

Medico-legal decision-making faces difficulties in addressing persistent vegetative state (PVS) due to the condition's chronic nature, potentially contentious outcome, and intrinsic patient incapacity. Law has tried to address these difficulties using the beneficent solution of "best interests". This is a valuable decision-making device in areas such as emergency treatment and (perhaps) treatment of patients who have never been competent. However, its relevance to PVS decisions - and patients previously possessed of competence and opinions - is less readily apparent. Dismissing its applicability out of hand is overly simplistic though, and

untested in terms of viable alternatives. "Best interests" should, therefore, be seen as *potentially* relevant, but needing careful formulation.

Whilst the judgments correctly identify the PVS situation as a product of technological and medical advances,⁴³ they fail to acknowledge that this novel situation may warrant a more innovative legal approach to "best interests". Earlier formulations of "best interests" have varied considerably and are essentially contextual in construction.^{1 2} Judicial attempts to "fit" PVS into these formulations have distorted the concept of "best interests", resulting in an illogical mixed interpretation. In addition, denying that the patient still possesses any real interests distorts the focus of the decision. This has been exacerbated by judicial delusion regarding the true nature of treatment withdrawal in PVS, perhaps due to fears of confronting the all-too-real life/death issues involved.

Judgments are peppered with semantic distinctions, which are dubiously founded, lend nothing to clarity and, indeed, the very need to invoke such distinctions is a telling criticism in itself. Denying PVS to be a "quality of life" decision is also highly questionable, (virtually non-existent quality of life surely must be a major factor in the decision), and is at odds with its central relevance in previous constructions of best interests. The related disinclination to openly "weigh" relevant factors contradicts the very essence of *best* interests itself. Thus, the path of "best interests" is now effectively strewn with interpretational debris.

Furthermore, judicial use of "*best* interests" has persisted, despite simultaneously declaring PVS patients to possess "*no*" interests at all. This approach lies far beyond this author's understanding of logic as, even setting aside problems of linguistic vagueness and viewing from a purely logical perspective, it is difficult to see how "something" may be derived from "nothing".

Meanwhile, overly heavy reliance upon medical determination of PVS patients' "best interests" causes other relevant interests - such as individual, personal (non-medical) interests - to be displaced entirely.

This current, contorted approach is doing no one any favours: PVS patients are ill-protected; the burden on medical opinion is heavy, and the law is on course for castigation when case circumstances arise such as to highlight weaknesses. It may well be that a reformulation of "best interests" to comprise elements outlined by Denham J, or perhaps those of the Law Commission,⁴⁴ could provide a better reasoned, more productive approach. Alternatively, hierarchical structuring of decision-making "devices" could primarily

emphasise patients' wishes, and use "best interests" only in a fall-back capacity.⁴⁵ Whichever the preferred solution, the essential focus must lie with the interests of the individual patient, admitting other interests only where relevant. Any such development will however require a preliminary step of honesty - as to issues and objective.

Admittedly, the PVS patient may well be legally incompetent, physically insensate and ultimately incurable. However, we would do well to remember that the decision to withhold nutrition is the "ultimate" one of life or death, and - no matter how beneficent or "right" the outcome - it should not consist in a legal formulation which is illogical, or inimical to that patient's former and subsisting interests. Otherwise it is, by definition, most certainly not in his "best interests".

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News and notes

Seventh International Congress on Ethics in Medicine

The Seventh International Congress on Ethics in Medicine is to be held from June 8-10 1998, in Stockholm, Sweden. The focus of the first day of the conference will be Oncology and ethics, that of the second day, Research ethics and that of the final day, Ethics and the allocation of health care resources.

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