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Eudaimonic Flourishment through Healthcare System Participation in Annotating Electronic Health Records

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Abstract

We have suggested elsewhere that technology, systems, and services designed for human use in pursuing the “good life” should consider states of eudaimonic flourishing as well as hedonic pleasure as design goals, along with traditional ergonomic factors. Here we consider how eudaimonic systemic design principles can be applied to the design challenge of creating a personal health record (PHR) system that can be owned and managed by the person the record is about. We develop an idea of a record that links the person's self-reported experience of eudaimonic flourishing to electronic medical records of a system's perspective on that person's health. The idea is to create a record for guiding salutogenesis despite a complex chronic care condition that is episodically disabling like incurable chronic pain. Using the concept of nourishment as an analogy, we advance the concept of flourishing. We define a systemic design framework for a PHR domain that can host a personal record of eudaimonic flourishing and engaged resilience (a PREFER domain). That domain needs to track personally experienced consequences of the outputs of specific healthcare system services in terms of their impact in driving a virtuous cycle of flourishing. We take the position that eudaimonic flourishing is essentially a sense-making process, and discuss the overlap between the concepts of well-being and of eudaimonic flourishing. (217).

Introduction

From a Hellenic perspective, hedonia is conceptualized as avoidance of pain and pursuit of pleasure, while eudaimonia is associated with the pursuit of one's best self (i.e., one's daemon or true spirit) towards living a flourishing life (Seaborn, Pennefather, & Fels 2015). The concept of eudaimonic flourishing has been elaborated by positivist psychologists, particularly Waterman and colleagues (2010), coming from the perspective of personal expressiveness, and Keyes (2002), coming from the perspective of mental health. Their focus has been to develop strategies for measuring eudaimonic flourishing using questionnaires and psychological trait/state scales.

Here we explore the implications of eudaimonics for the practice of systemic design applied to meeting needs of participants in an idealized patient-centred health care system. We pay particular attention to the role of such a system with regards to the person living with a chronic condition, like chronic pain, that is episodically disabling and can be managed with outputs from the healthcare system. We build on the idea that for something to be managed it must be measured and that in this case what should be measured is an ability to live a flourishing live in the face of an episodically disabling condition.

We illustrate that idea specifying a patient-centred health record systems that satisfies a fundamental but complex inclusion principle of “nothing about us without us” (Charlton, 1998). The repeated promises and failures of health records systems over the last few decades illustrate the challenge of designing solutions for situations where specific user needs in specific contexts cannot easily be imagined beforehand (Taha et al., 2013). Using the concept of nourishment as an important goal of a food system as an analogy, we suggest an important goal of a health system is to create conditions that provide personal flourishing. If the essence of health is a person is a complete state of biological psychological and social wellbeing, and the effect of health is a person with a capacity to flourish and be resilient in the face of life challenges, then flourishing outputs of the health system need to be measured if the desired impact of those outputs are to be optimized.

The extent to which outputs designed and managed to provide flourishing in fact aid a person to live a flourishing life can best be judged by that person. Therefore for those outputs to be measured and managed, the recipients of flourishing outputs of a health system will need to be engaged in recording the impact of those outputs on their capacity to flourish. The systemic design goal considered here is to create a record that helps a person seeking care for a chronic condition to deal with, and reflect upon, the meaning of the healthcare they are accessing. A record system is imagined that documents the patient's eudaimonic struggle to live a flourishing “good” life, despite episodic health challenges associated with their chronic condition.

The design principles that we have developed are anchored by a conceptual framework that describes a positive flourishing cycle involving: 1) accommodation of measurable but individuated worldviews warrants, 2) promotion of meaning-in-care, 3) verification that the consequences of receiving health care services are experienced as flourishing, and 4) recognizing the diversity of ways that brain network/mental activity systems associated with making positive sense of the person's episodically painful experiences and the flourishing consequences of their healthcare-seeking actions related to those experiences.

In the next section, a series of concepts are specified and then synthesized into the conceptual framework. This is followed by a formal description of an inclusive eudaimonic systemic design framework for developing a personal health record (PHR) to track receipt of eudaimonic flourishing from the health care system.

Conceptual Synthesis of a Design Framework

A Framework for Eudaimonic Systemic Design Thinking.

Systemic design is considered to be a “strong systemic view of complex system problems addressable by intuitive and abductive approaches implicit in design thinking” (Jones, 2014, p. 92). Inclusive eudaimonic systemic design of a PHR system for tracking flourishing will necessarily deal with the complex process by which a diversity of worldviews negotiate the highly regulated and recorded ecology of healthcare transactions. Designs concerning the tracking of achievement of flourishing aims, targets, goals and objectives need to consider how the conditions necessary for a flourishing life can be measured, analyzed, and understood as the result of dynamic system interactions among structures, processes and outputs of the health system (see Lahka et al 2016) that influence individuated flourishing.

To anticipate and if possible avoid unintended consequences, that often are inevitable when dealing with complex systems, the designer's goal should be to make the representation of the system being designed for merely complicated. This representation should be no more complicated so than necessary, so that system dynamic patterns and made sense of using the framework. This can be

achieved by adapting a general conceptual framework to a particular application and allowing users to further adapt the system representation to their needs in a manner that is meaningful and helpful from their perspective. The framework allows a common ontology to be employed in building a shared understanding of how outputs are leading to flourishing so that process can be better managed in a collaborative and patient-centred manner.

Human-Centred Healthcare Design. Health systems are typically designed, implicitly or explicitly, to meet some specific set of purposes or goals dictated at a system level for the average user and constrained by always limited resources. Because those systems are rarely simple and often are complicated and complex, there can be disconnects between the intent of the system design and the experience of people using the system. That disconnect may cause frustrations that will interfere with living a flourishing life. We propose that a record of individuated eudaimonic flourishing can help health systems become more patient-centred despite those constraints. This is especially relevant to the consideration of people living with chronic pain. The concept of pain that can benefit from medical care has evolved over the last 20 years from a pathology-oriented concept focused on sensation (an unpleasant and emotional sensory experience associated with actual or potential tissue damage) to a patient-oriented concept focused on quality of life. Pain is a complex experience embracing physical, mental social and behavioural processes compromising the quality of life of many individuals.

The idea of patient-centred healthcare suggests several existing domains of design practice and study. These include human factors research principles (Dul et al., 2012) and inclusive design methodology (Newell et al., 2011). Human factors engineering is the practice of using a scientific understanding of the physical and psychological characteristics of people to guide the design of technology and systems for human use (Woodson, Tillman, & Tillman, 1992). Inclusive design considers a wide variety of possible users from the beginning of the process and allows for customizable solutions (Newell et al., 2011). The notion of human-centred design, which arises from human factors and can incorporate inclusive design methodology, is a natural choice to begin to develop a patient-centred framework for monitoring eudaimonic flourishing outputs.

Taking an individual-focused approach to technology design, Hancock, Pepe, & Murphy (2005) proposed a framework of hedonic, or 'pleasure-seeking,' design, which they called hedonomics. Key to this model was the notion of 'additive design': unlike traditional human factors, which focused on avoiding or eliminating undesirable states in the end-user, hedonomics proposed a focus on adding value to end-user experience, particularly through pleasurable components. Seaborn Pennefather & Fels (2015) went on to propose eudaimonics as an ergonomic framework for human factors research that extends the hedonomics model by explicitly considering eudaimonic factors. The extended model has three components: ergonomic factors (safety, functionality and usability), hedonomic factors (usability and positive affect), and eudaimonic factors (sense-making and flourishing affect). All three must be considered when designing to allow for, create a sense of, and co-produce end-user flourishing.

The relation between health and resilience (Huber et al., 2014) and between psychological well-being and eudaimonic flourishing (Ryff, 2013) are linked here in terms of their impact on flourishing. They can be considered two sides of the same coin, with health and resilience being a systems perspective and well-being and eudaimonic flourishing being a more personal perspective. We describe how both flourishing and resilience are descriptive outputs of the interaction of underlying mental and physical states with the system ecology in which the person and the care plan exists. Flourishing and resilience can also be characterized in terms of self-authored descriptions of how the patient experience their healthcare options and the healthcare services that they can access. For

those descriptions to be perceived as authentic, they will need to be owned and generated by an engaged patient, empowered to communicate what they experience.

One key and measurable psychological trait likely to be important in achieving the goal of patient ownership of and engagement with their records is resonance of that content with their worldview. Kolko-Rivera (2004) has discussed how this worldview trait will warrant the person's health-seeking activities. Worldview warrants will drive maintenance of a meaning-in-life or purpose-in-life trait. The meaning-in-life trait, in turn, can be correlated with good health and is known to be a trait that can be actively and systemically promoted (Kim, Strecher and Ryff, 2014). The dynamic interplay of those traits will influence how the person makes sense of, and interacts with, the healthcare system in a flourishing manner. That sensemaking activity in-turn will colour their appraisal of options, their choices of courses of actions, and their modification and adaptation of chosen actions and options within the health system they experience.

Philosophical Neuroscience of Enactive Sensemaking. The mental activity involved in making sense of, and interacting with, the world is mediated by large-scale brain networks integrating emotional, social and cognitive phenomena in ways that increasingly are accessible to measurement and empirical characterization (Barrett & Sapute, 2013). These include salience, default and executive function networks. Those network concepts emerge from rationalizations of how electrophysiological brain activity patterns can be linked to empirically observable behaviours. Consideration of those network within the systemic design process will help to guide development of PHR features.

We start with specifying an enactive perspective on the sense-making process associated with perceived flourishing. The enactive perspective defines sense-making as a subjective act that is a consequence of the interaction between: a) the actions, activities, and experiences involved in a person's autonomous engagement with life, and b) the cognitive processes involved in making sense of decision options arising with/from those experiences (Thompson & Stapleton, 2009). Different world view warrants can influence which cognitive pathway resources are recruited and prioritized for a given sensemaking processing task.

The brain has limited resources to take in and process media and contextual information at any given time. As a result, it must assign priorities to these processing activities, and, as such, the recruitment of brain network resources will always be dynamic and episodic (see Beatty et al., 2015; Barrett & Satpute, 2013). This parallels the episodic nature of enactive sensemaking influences on performance, where semi-automatic appraisal and intrinsic ruminations about the nature of those enactive influences detract from the ability to deliberately carry out the task at hand (Beal, Weiss & Barros, 2005).

Over two millennia ago, Aristotelian philosophers theorized that different mental priorities can drive distinct types of conscious mental activities. They represented those mental activities as having two elements, their essential nature (essence) and the impact of their performance (effects). For example, the activity of theorizing (theoria) can lead to skill in the performance of science (episteme) (Ramo 2004). Table 1 considers three types of information processing warrants and meanings and proposes respective linkages to brain networks that are likely to be primarily involved in sense-making; salience, default and executive function.

For someone living with pain, the disability that the pain causes is related to the salience of the pain signals. The word salience is used here in the biological sense of how the situation is perceived as likely to impact on future survival. The experience of pain is intimately tied up with the threat perceived in the sensory signals identified as painful (Borsook et al., 2013). The salience brain

network is involved with a person's ability to recognize and analyze events dangerous for the body's integrity. Saliency overlaps with networks involved in sensory-motor and emotional-introspection integration (Cauda et al., 2012). One can imagine how the saliency network has an important role to play when a person feels warranted to empower themselves by seeking relevant information about their condition(s). They will take on a Systemic-Scholarly perspective, where they seeking meaning through a coherent integration of the information available to them so that they can judge what is possible to do about their symptoms. That perceived warrant to modify behaviour and the meaning assigned to that activity can be linked to a Theoria-Episteme Aristotelian mental activity axis (Ramo 2004).

The Executive Function network will be preferentially engaged with a Business-Professional perspective through which courses of actions that the person feels that they have agency to pursue will be pursued with a sense of purpose. For example, they may operationalize a rehabilitation plan, co-created with a therapist and make decisions about carrying out the plan in a timely manner and satisfactory manner. The Business-Professional perspective can be linked to a Praxis-Phronesis mental activity axis that recognizes the link between the acting out of specified roles and the demonstration of judgement in the choices made (Ramo 2004).

The Default network will be engaged when a more ecological Socio-Cultural perspective is required of the person. A person living with pain will need to seek meaning in significant acts. That significance can emerge from insightful means of sharing and valorizing ideas about Socio-Cultural options, risks, and opportunities to develop insight into socially appropriate behaviour. By drawing upon cultural narratives, and interacting with appropriate mentors, they may develop insights into how to re-imagine her life with the pain. That insightful priority and socio-cultural perspective can be linked to the Poesis-Techne mental activity axis that recognizes the link between a creative decision to re-imagine their situation and the proficiency with which that making process is carried out (Ramo 2004).

At a fundamental level, brain networks influence the cognitive work that the mind needs to invoke to process emotional, social and cognitive signals. For a person living with chronic pain, this will be dominated by a need to find meaning-in-care through, for example, appraisal of how that care is salutogenic, guiding resilient responses to care setbacks, and rumination concerning how to modify care plans to better suit needs and desired well-being outcomes. The factors that enable a capacity for finding that meaning-in-care combined with factors that warrant autonomy will lead to flourishing outputs that are experienced by the person but also are documentable and measurable using self-evaluation tools accessible from the PHR platform. Reflective appraisal of those observable and experienced outputs could also allow for further sense-making by the person and others involved in her life, creating a virtuous flourishing cycle.

Meaningful Healthcare Worldviews. Martela and Steger (2015) have published a theoretical overview of how the concept of meaning-in-life can be understood in three ways, all of which contribute to the experience of that meaning: coherence-, significance-, and purpose-in-life. Meaning-in-life is motivated by a comprehensible and therefore coherent sense of meaning in what is being achieved. That meaningfulness is derived from a future-looking sense of purpose that is often related to an overarching higher purpose. It also is derived from a capacity to make day-to-day choices that are experienced as being significant (Martela & Steger, 2015). There are several instruments for measuring this meaning-in-life trait that can be correlated with both eudaimonia and hedonia in distinctive ways (McKenna & Reken, 2011). In developing PHR tools for helping their users to derive meaning from the care that they are receiving, we suggest adapting those

instruments to measure meaning-in-care. Those measured could then guide actions aimed at enhancing meaning-in-care and thereby making the care truly patient centred.

For almost two decades, national policy goals of patient engagement and patient-centred care have been advanced to address the disconnect between patient concerns and expectations, and the reality of the care they experience, as well as to improve the overall quality of healthcare system outputs (Ferlie & Shortell, 2001). Some countries and scholars go further and seek to promote an “empowered patient,” or an ability for coherent autonomy (self-determination) that is promoted through a health system process for building and supporting that ability in patients (Pulvirenti, 2014; Tengland, 2012).

Those policy development recommendations reflect a more general transformation of the healthcare system from one focused exclusively on treating disease to one that aims to promote dynamic engagement along several lines. These include: salutogenesis, which imagines healthcare aimed at generating health (salut) through a sense-of-coherence (Antonovsky, 1984; Erickson & Lindstrom, 2008); resiliency, or a purposeful capacity to deal with setbacks and episodic changes in their state of disability (Huber et al 2011, Frenk & Gomez-Dantes, 2014, O’Brien, et al., 2014); and patient-driven engagement with the care experience (Tengland, 2012). We propose that PHR users need to be assisted in recording, reflecting upon and communicating: 1) the meaning and warrants that the patient is using to guide their choices within the healthcare system, and 2) how their goals to live a flourishing life, despite episodic disabilities, influence those choices. We suggest that documenting those experiences will also benefit the system stakeholders involved, as they strive to make their interventions more effective and efficient.

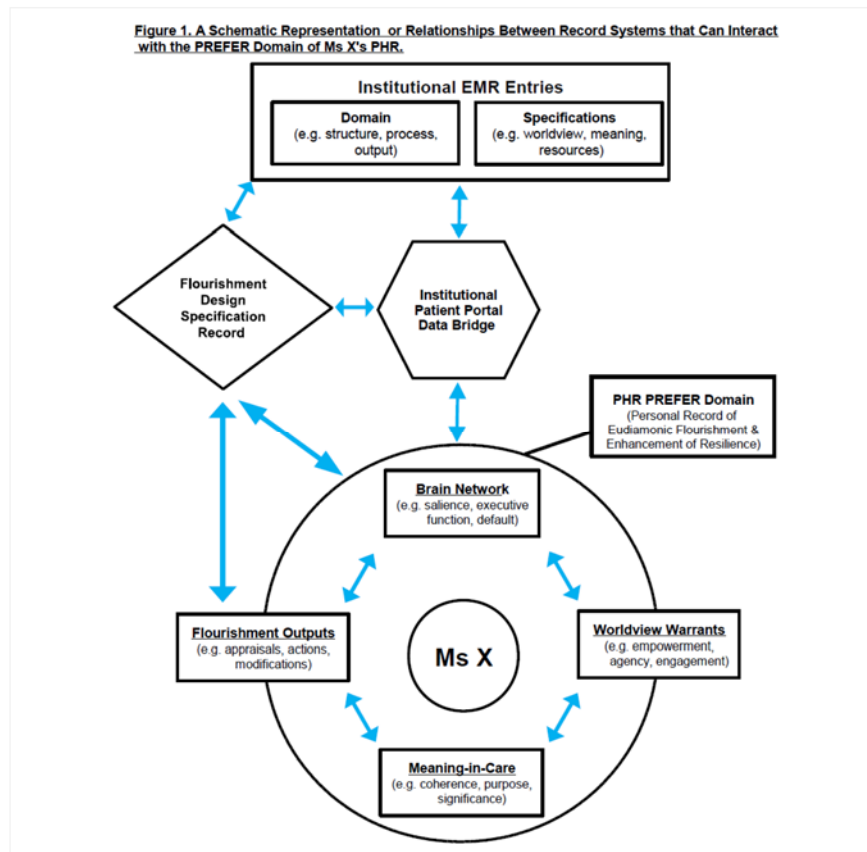
A PHR Domain Hosting a Personal Record of Eudaimonic Flourishment and Engaged Resilience (PREFER Domain) for Recording a Flourishment Cycle. The eudaimonic flourishing framework presented here is built around the concept of a flourishing cycle. A high-level description of that cycle starts and ends with mental sense-making around perception of eudaimonic flourishing. This will influence how personal worldview warrants will enable personal empowerment, agency and engagement that in turn will initiate and guide a person’s health-seeking actions. The personal legitimacy of those actions will be assigned individuated meaning to the extent that they are perceived and coherent, purposeful and significant. Together, self-justified actions and how they are meaningfully preformed will be amenable to appraisals, actions and modifications. Activities seen by the person as contributing to their eudaimonic project will be motivating because they directly reflect and tangibly represent enhancement of the person’s state of eudaimonic flourishing.

Kish and Topol (2015) describe how healthcare systems currently have difficulty accommodating patient input into, let alone control over, records of their diagnoses and care. Basic principles of medical ethics recognized that patients have the right to access and view that data recorded by the health system for and about them. However, there is little room for patients to usefully build on those records and create or even co-create, something new. We imagine that a PREFER domain within a PHR could serve as a location where patients track how they make sense of their healthcare choices and electronic medical record entries that have more instrumental meaning. For example, natural language descriptions of perspective and experiences could be linked to diagnostic, and procedural codes used in managing the care from an operational perspective. A user-centred focus that recognizes the user’s worldview and how that impacts their position relative to the record system may increase their meaningful use of that record system (Huvila et al., 2015; Kish and Topol, 2015).

A PREFER domain within a PHR could serve the role of respecting a person's worldview by aggregating a person's data related to how their healthcare experience is expected to promote personal eudaimonic flourishing and enhanced resilience. Such a system of record entries would allow comparison of expected outcomes and actual experiences in a pragmatic and transparent manner. It would do so in a way that the person's worldview, and how that warrants their well-being seeking activities, is recorded and made evident to themselves and to people around them from whom they are seeking and receiving support and care. This would allow system-level as well as personal-level tracking of the extent to which the healthcare system user finds meaning in the care that they are receiving for a chronic condition that is dominating their life experience.

Conceptual Framework

A Flourishment Cycle Framework. Figure 1 provides a schematic representation of how distinct facets of the flourishing design framework can be organized and applied for a person living with chronic pain (Ms. X).. Each different shape in Figure 1 refers to a different type of design consideration related to components of interacting record systems. The boxes reflect domains that can be represented by record entries. The diamond refers to the flourishing framework developed for the particular case of supporting the process of bridging the institutional record of Ms X's healthcare with a PHR record of that care owned by her. That framework can be adapted and elaborated through consideration of entries that enable systematic reflective analysis the system usability. The circle refers to interacting fields of entries within the PREFER domain of Ms X's PHR. The boxes inside the circle refer to measurements and assessments that are reliant on Ms X's powers of reflection, although these may be augmented by self-assessment measurements made using on-line tools that can be accessed through hyperlinks built into the PREFER domain. The boxes spanning the edge of the circle refer to measures and assessments that can be co-created and co-curated by both Ms X and people and those supporting her and providing her with healthcare services.



The framework begins with characterizing dimensions of the media system under consideration. Most institutional EMRs now include a patient portal option (see Irizarri et al 2015). The framework draws the designer's attention to different dimensions of the media design challenge. For example, the designer should start by considering the system domains that will impact on care plan consequences. These can be considered at the structural level, the process level or the output level (see, Lahka et al., 2016). The designer should also consider design constraints such as the expected range of: 1) worldview warrants that Ms X brings to the system; 2) meanings-in-care that the media might engender for her; and 3) resources associated with meeting her range of goals. At the next level, the designer needs to consider how to enable creation a bridge between the institutional patient portal media set up for Ms X and a personal record system owned by her and implementing PREFER domain. This data bridge would be designed to allow both a system user, like Ms X, her circle-of-care and system designers/administrators to record entries relevant individuated flourishing cycles.

The next part of the schematic diagram illustrates the different phases of the flourishing cycle supported by a PREFER domain within a PHR. Information from the patient portal media will be processed first by the different neural networks operating within Ms X's brain, that activity in turn is processed by her brain to feed her experience. How she interprets that experience will then be influenced by how the health system constraints are accommodating her worldview warrants. The extent to which her empowerment warrant is perceived as appropriately accommodated will be dependent of her perception of the coherence of the information served by the media. The exact way that she uses her agency, as warranted by that information, will be determined by her sense of purpose. Her engagement in executing that agency will be dependent on how significant she finds the information. The combination of worldview warrants and meaning-in-care derived from executing those warrants will allow Ms X to experience and exhibit flourishing outputs such as: reflective appraisals that are salutogenic; considered actions that are resilient; and self-initiated modifications to care plans that demonstrate salutogenic judgement.

Those flourishing outputs of reflective appraisals, resilient actions and justified modifications will be experienced by Ms X as inputs to her brain's neural networks in a way that will drive the flourishing cycle forward. This will be especially true if the media allows Ms X to record those reflections, actions and modifications in a way that allow her to re-consolidate the record's information content in light of those new activities, while at the same time allowing Ms X to re-consolidate her take on how the care is progressing. This re-consolidation activity can be accompanied by direct probes of the person's effective states ranging from eudaimonia and depression and those entries can be anonymized and observed by the system designer who can adapt the media technology to better support individuated flourishing cycles.

Conclusion

The model of flourishing design that we have proposed is an initial effort towards providing designers, practitioners, researchers, and end-users—the people living with chronic conditions—with an actionable, understandable framework of a complicated and often overwhelming system. This framework can serve as a guide for designing features such as a PHR domain that allow users to engage in actions that result in eudaimonic flourishing. Those flourishing features are imagined to promote a virtuous cycle.

Participants in a patient-centred healthcare system must have empowerment, agency and engagement to actively participate in such a system. They must find coherence, purpose and significance in that participation. For that participation to be perceived as flourishing, it must be

associated within personal appraisals, actions and modifications to the care program that are perceived by the participant as improving and promoting a flourishing life. That perception will be dependent on mental activity emerging from the operations of brain networks. Many of the elements underlying the proposed flourishing cycle now can be monitored using validated measurement methodologies that can allow users to track their eudaimonic flourishing progress within their care plans. These also could be used by the system to justify resource allocation for helping people living with chronic pain to live well and prosper.

Going forward, we encourage a range of interested parties to join us in designer-oriented and empirical investigations of the model within a healthcare context through an inclusive, human-centred approach: practice and research that involves and carefully considers the patient as an individual primed for flourishing. Looking to the future, creation of patient controlled and owned PHRs with PREFER domains, that are nevertheless synced with institutional EMRS and validated by health care institutions and providers, may provide a venue for gathering user-experience data concerning therapies where there is no clear mechanism of action. Those patient-reported outcomes should help all system participants to re-imagine and re-design healthcare options so that users can drive their care plan outputs towards the helpful pole of the help-harm continuum.

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