

11 Reconfigurations of autonomy in digital health and the ethics of (socially) assistive technologies

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Abstract

In this contribution the ethical impact of socially assistive technologies is analyzed against the background of digitalized healthcare and medicine in a thoroughly “datafied” society in general. Socially assistive technologies such as smart home sensors and carebots raise ethical issues which are continuous with other technologies in this cluster (e. g. health-related apps, telemonitoring) but their application in the context of particularly vulnerable populations such as elderly persons also appears to expose the limitations of established medical ethics and technology assessment tools starkly. While some specified analytic and ethical tools have already been developed, the meaning and scope of the underlying ethical criteria and reference concepts themselves is changing further. This will be illustrated by focusing in on reconceptualizations of (personal) autonomy such as the shift from patient autonomy to user or consumer autonomy, the vision of empowered autonomy in participatory, democratic care and medicine, and the effects of a prospective “autonomy” of the devices themselves. A broader discussion of assistive technologies along these lines may help accommodate the often precarious internal capabilities for self-determination in the elderly and/or vulnerable, and avoid neglect of important contextual and external factors to support and promote autonomy as an ethical cornerstone also in digital health.

11.1 Introduction

Socially assistive technologies are projected as a part of addressing the growing need for care and especially elderly care in many regions, which results from the increasingly older population with similarly increasing numbers of dementia patients and other vulnerabilities and disabilities (Bennett et al. 2017; Matarić 2017; Abdi et al. 2018). Technological assistance is also expected to help realize supported rather than substitute decision-making for people with disabilities following the UN Convention on the Rights of Persons with Disabilities (Bennett et al. 2017). “Assistive technologies” (including social or intelligent social assistive technologies) refers to devices or systems which allow to increase, maintain or improve capabilities of individuals with cognitive, physical or communication disabilities, and include devices such as GPS trackers, monitoring devices, sensors and wearables or technology for smart homes. They can take the form of self-contained devices or distributed systems and often link to software applications (Dorsten et al. 2009; Ienca et al. 2017).

Assistive technologies with a focus on sociality and interaction are used for affective therapy, cognitive training, as social facilitators, for companionship, and physiological therapy. In the form of robots they include machine-like, human-like and animal-like robots with and without learning responses (Abdi et al. 2018; Buhtz et al. 2018). In terms of both functionality and ethical, social and regulatory or legal issues there is overlap with other technologies in this cluster. Due to the basis in (mobile) data collection and analysis, they are raising challenges in data security and privacy protection, and in what a broad use of such managerial rather than human-centered tools will mean for individual self-responsibility, care relationships as well as prevailing conceptions of health, disease and normality in the healthcare system and society as a whole (cf. Bennett 2017).

Digital health or medicine4.0 is characterized by the use of devices and approaches that often involve (real-time) monitoring, enhanced flexibility of application and/or ubiquity, as well as the combination of different purposes that may span lifestyle and healthcare “proper”. This is apparent in the thriving field of mHealth with its strong focus on helping to personalize, simplify and enhance care by strengthening self-monitoring and increasing access to health-related knowledge and advice, but also liberating users from traditional care structures. (Socially) assistive technologies carry a related promise in relation to autonomy broadly conceived, covering personal and cost-effectiveness²⁴ and even social and political empowerment or participation. Yet, as previously described for mHealth (Schmietow and Marckmann 2019) – sometimes assumed to be mainly for lifestyle use or chronic condition management – the underlying ethical concepts and values, in particular principlism in medical ethics, are undergoing change, and cannot be straightforwardly applied to digital health or assistance technology that should support a variety of user groups, including the elderly, frail and/or vulnerable. Some of these shifts will be the topic of this chapter, with a special focus on the kinds of autonomy at stake in the context of digitalized care.

In terms of structure, the starting point for this investigation will be the few existing (as well as adopted in practice) ethical frameworks integrating technological and social change as medicine and care are becoming datafied and progressively technology-mediated. Since they still require specification for sub-contexts and different stakeholders, this paper will proceed by introducing such models for analysis and evaluation, before presenting specifications and additions to the ethical debate on digital and assistive technology, both in terms of the role of individual autonomy as a value and as a signifier of a multitude of capabilities in health and care. Moreover, these shifts can be organized along a continuum or escalation, but are then shown to also involve a number of complexities, ambivalences and perhaps contradictions,

²⁴ For a contrasting perspective, cf. Ho and Quick 2018.

which are of particular relevance for the elderly, vulnerable or cognitively impaired user or target of such technologies.

11.2 Autonomy in existing evaluative frameworks

Manzeschke et al. (2015) focus on the following moral issue: how can we serve elderly people in their neediness and help them to live lives on their own (as well as delay entry into institutional care)? Their aim is to provide a toolbox that can and should be adapted to social and technical change.²⁵ The background to their specific study and ethical assessment model are the manifold applications being developed and made available primarily for elderly people to help them live autonomously in their own households for longer (also known as ambient assisted living). Independence and autonomy are strongly highlighted as both the motive and the objective of this development: “Independent life can be taken as a reference to the key socio-political terms of autonomy and social participation” (Manzeschke et al. 2015 p. 8). More generally, age-appropriate systems should be seen as “socio-technical arrangements” which implies that these are “social” in that they are used by the elderly themselves as well as by relatives and healthcare or nursing staff.

The diffusion of this technology may raise issues of privacy protection and thus informational autonomy through complex and/or intransparent ambient data processing. In particular cognitively impaired persons could be deprived of control over

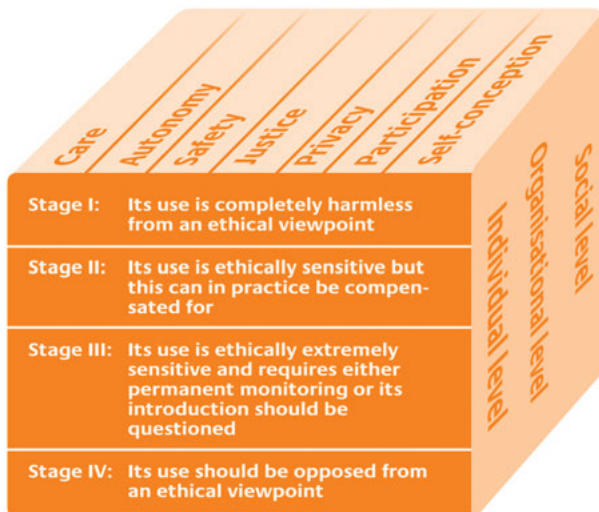


Fig. 11.1: The MEESTAR model (Manzeschke et al. 2015: 14).

²⁵ “The model should always be embedded with an iterative process [...] to ensure that the ethical status quo is observed and constantly evaluated as social, individual and technical phenomena develop” (Manzeschke et al. 2015 p-21).

the (sensitive health-related) data flows surrounding them and connected to them. Especially in case prospective technology users are unable to consent or their ability to consent is restricted, there may be a difficult trade-off between the importance to autonomy of being able to remain in one's home environment in exchange for a (potential or factual) loss of privacy as a form of restricting autonomy. Overall, the proliferation of assistive technology could lead to changing and indeed expanding expectations of what constitutes "good care", including "the attributed and increasing autonomy of people who are learning to take care of their own health" (Manzeschke et al. 2015 p. 12).

Against this backdrop, Manzeschke et al. developed MEESTAR, a "model for the ethical evaluation of socio-technical arrangements" as an analytical and practical tool to be applied to assistive technologies and beyond. This model is highlighted here since it provides a clear methodology for *normative* assessment and has also been applied to a certain range of technologies in specific studies (Weber and Wackerbarth 2017). The tool foregrounds seven ethical dimensions – care, autonomy, safety, justice, privacy, participation and self-conception – which were identified as essential from the results of theoretical ethical work as well as a series of qualitative interviews with stakeholders. Four levels of ethical sensitivity of the arrangement from complete harmlessness to complete ethical unacceptability and three levels of analysis and evaluation – individual, organizational, and social – are distinguished.

The dimension of autonomy here refers primarily to the following interpretations in current debate: an individual's maximum freedom of decision and action, its role as one of four bioethical principles (principlism), as well as the socio-political discourse around the integration and inclusion or social participation of individuals with disabilities. Although the authors do not propose a specified definition, they outline relevant questions in relation to autonomy when applying the tool:

- How can people be assisted in their autonomy on the basis of practices oriented consistently around the individual's right to autonomy?
- How can people be supported in their autonomy when their usual criteria of autonomous decision-making and action have become questionable or even untenable?
- How do we deal with the fact that ascribing autonomy can conflict with the right to care and support? (Manzeschke et al. 2015 p. 15)

They further emphasize as part of their overarching recommendations that (in this case) age-appropriate assisting systems should help users to lead an autonomous life (i. e. decide and act autonomously) and specify that the assisting systems themselves should not make decisions, unless this has first been configured with the consent of the user, and that fully automatic, self-deciding systems require separate assessment. In case of restricted autonomy on the part of the user the systems should only be used to help cognitively impaired people following a dedicated assessment taking into consideration the probable wishes of those who are expected to interact with the device.

Finally, this analysis points to the necessary balance between aspects of empowerment or disempowerment and the additional concern of a delegation of autonomy to technology:

Care must not be subverted by the structures and surroundings of a care system which, although well intentioned, aims to return the activity of caring back into the autonomous and independent charge of those receiving care [...]. What is at issue is to shape the structures of care systems such that both poles, autonomy and care, are treated sensitively so that care does not become a type of besiegement and autonomy does not become a means by which to cloak our ignorance of the needs of others. (Manzeschke et al. 2015 p. 31; cf. Perry et al. 2009; Mittelstadt 2017)

The proposal for the systematic evaluation of eHealth applications such as for example, telemonitoring and mobile health by Marckmann (2016) chiefly consists in an evaluation matrix combining aspects of medical ethics (i. e. principlism with its four principles respect for autonomy, non-maleficence, beneficence, and justice) and ethics of technology or respectively technology assessment. It is based on a coherentist approach described as building on moral convictions found in a particular community rather than invoking some ultimate basic moral principle, with the purpose of connecting the former in a coherent structure of reasoning (cf. Marckmann 2016 p. 86f).

Similarly to the MEESTAR model and analysis, although developed with reference to eHealth, it is assumed to function in a flexible manner and be able to accommodate

Table 11.1 Ethical criteria and their justification for the evaluation of eHealth applications. Translated and adapted from Marckmann (2016).

Criteria for ethical evaluation	Ethical justification
Functional capability	Means-end rationality
Possible alternatives	Means-end rationality
Potenzial benefit	Beneficence
Potenzial harm	Non-maleficence
Integrity of doctor-patient-relationship	Respect for autonomy; beneficence
Respect for/ promotion of autonomy	Respect for autonomy
Privacy/ data protection	Informational self-determination
Data security	Non-maleficence
Cost-benefit-ratio	Efficiency; distributive justice
Autonomy of medical decision-making	Beneficence
Medical decision-making competency	Non-maleficence; beneficence
Attributability of responsibility	Non-maleficence
Equal access and distribution	Justice

technological innovation. In any case, since it suggests a stepwise approach bridging contextualization and evaluation of the technology, a specific description of the technology in question and also an adjustment or “fine-tuning” of evaluation criteria is part of the approach. The process includes six steps: the description of the technology to be examined, a specification of the evaluation criteria, an evaluation for single criteria specified, a synthesis regarding the overall evaluation, recommendations for development and application of the technology, and monitoring (as well as potentially adjusting) the concluding ethical implications.

Some aspects that are relevant to such adjustment for (socially) assistive technologies will be outlined below. The adapted framework could eventually be tested out in theoretical scenarios of application and/or empirical case studies.

11.3 Reconfigurations of autonomy in digital health and assistance

Ethical assumptions around autonomy and especially a potential for strengthening it continue to play a prominent role in academic and public debate on the impact of digital health and socially assistive technologies. Yet, the more concrete meaning of “autonomy” in this context is often pre-supposed or left open to interpretation. This might be due, on the one hand, to the importance of informed consent in medical ethics as a main means of realizing the principle of respect for autonomy, and the relative lack of tools for the ethical evaluation of digital health applications that also explicitly cover aspects of technology assessment. The focus on the procedure of competent and informed decision-making, however, may not apply analogously to digital assistants and apps used outside of traditional care contexts, where conditions of data collection and use in relation to consumer products are not mediated by a health or care professional (or where this is the case, these might not have the adequate expertise) (cf. Groß and Schmidt 2018).

On the other hand, if approached from a broader perspective of health-related technology in a thoroughly datafied society, these technologies appear to be characterized by a strong ambivalence between enhancing some form of autonomy and undermining or diminishing it by, for example, fostering self-care and simulating valuable social interaction, or by creating dependence on technology and blurring the boundaries concerning responsibility for health and care.

Yet, what kind of autonomy is at stake here, and how can we approach this apparently very ambivalent potential of digital applications in the care context? Is it possible to base such judgment on a unified conception of autonomy and the autonomous user?

11.3.1 A multi-stage model of enhanced autonomy

To approach an answer to these questions, in the following a contextualization and possible limitations to applying core assumptions of the value and ability of autonomy in medical ethics to digital health use are considered, before outlining shifts in background assumptions about the ethical impact on autonomy in this debate. These shifts can be systematized as forming a multi-stage model of enhanced autonomy by way of digitalizing healthcare, moving from patient to user or consumer autonomy, via increasing health literacy, and the empowerment of users, to eventually lead to significantly democratized, participative medicine and healthcare.

A starting point for this discussion is the mainly procedural and action-oriented conception of autonomy often based on principlist medical ethics as developed by Beauchamp and Childress in the 1970 s. Differently from a conceptual and normative characterization of autonomy as of moral value and as a general ability of individuals, it strongly focuses on the concept and procedure of informed consent to treatment or research participation or contribution. Autonomy as realized through informed consent is therefore conceptualized as being based on competent decision-making, voluntariness, understanding of relevant information provided, and freedom from external influence in coming to a decision. While there are various philosophical accounts of autonomy such as for example those in post-Kantian, relational or feminist terms, these are sometimes considered as too demanding and/or narrow to provide practical guidance in real-world clinical, research or healthcare contexts. Still, patient autonomy plays a central role in current models of relationships in medicine and healthcare, either by way of informed patient choice or by the even stronger emphasis on autonomous decision-making and individual responsibility in the consumerist model of doctor-patient-relationships or respectively relationships in healthcare (Krones and Richter 2008).

Digital healthcare technologies focusing on social assistance display similar characteristics to other areas of eHealth such as often enabling real-time monitoring and enhanced flexibility and comfort through the possibility of ubiquitous access and communicative interfaces. These interfaces may also exceed former communication patterns in healthcare by involving health and care professionals flexibly into everyday contexts, while at the same time being able to connect more easily with other patients or users of similar technology via dedicated networks or platforms. This flexibility may have an impact on how these applications are used and categorized, and even on how they are regulated because they may transgress the medical and healthcare realm and its evidential and ethical standards. A carebot and the relevant software may monitor medical parameters and feed these into standard care; but they may additionally provide lifestyle, social and mental support or gather data on behavior preemptively, i. e. without, for the time being, established or specific medical or care use. The increasingly blurry boundaries of health and care are widely suggested to help sustain or increase abilities relevant to autonomous action and the respect for

it by healthcare professionals and relevant others. At the same time, continued and routinized use of the technologies already presupposes such capabilities and may require supplementary training and customization in the vein of “patient-centricity” (Pino et al. 2015).

11.3.2 Consumer autonomy, empowered care, and democratized medicine

A first shift in the ethically relevant concepts of autonomy in this field is marked by the distinction between patient autonomy and consumer autonomy. The latter model has been gaining a certain prominence in medical ethics but appears to be of particular relevance to the extent that healthcare is complemented and delivered increasingly through direct-to-consumer and digital services and technologies (Ho and Quick 2018). The autonomous patient and the autonomous consumer however are relying on considerably different background assumptions in terms of values and necessary capabilities to realise the status of “autonomy”. Patients are assumed to be in a situation of involuntary need or even emergency, which often involves forms of insecurity or powerlessness as well as limited information on remedies, benefits and risks. Even if their level of relevant knowledge is relatively high, the special situation of often in this sense dependent patients includes them being likely to discount or ignore costs – in terms of financial or other investment – to anything that might be able to help them.

While simplified, clearly the basic situation of the prototypical consumer is on the opposite side of a spectrum of individual autonomy and responsibility. Consumer choices as part of transactions or contractual relationships in healthcare or elsewhere are assumed to be fully voluntary, well-informed and thus imagine confident independent action on the side of the consumer. Healthcare and medicine, on the other hand, are charged with normative assumptions – and regulations – around concepts such as trust, collaboration and compassion rather than the maximization of mutual and usually quantifiable advantage in transactional relationships.

Corresponding to these values are dedicated patient rights such as the right to emergency care, confidentiality or being informed about the availability of alternatives to a treatment. Transparency concerning what is involved in the purchase and use of a consumer product, on the other hand, is usually determined by the provider (Goldstein and Bowers 2015). Klugman et al. (2018) accordingly note that “informed consent is primarily for the benefit of the patient, but user agreements are primarily designed to benefit the companies” (Klugman et al. 2018p.40). Overall, the consumer therefore tends to be seen as ideally autonomous and as such fully self-responsible, whereas the patient can rely on the protection of her welfare and autonomy, which are widely considered fundamental values in healthcare and medicine. These areas of life are enjoying a special status and corresponding safeguards, which are called into question by what has been called the “lifestylisation of healthcare” (Lucivero

and Prainsack 2015), as exemplified by the distinction of apps and assistance systems into medical and/or lifestyle products. An assistance technology that is convenient but used without a clear medical purpose would not require regulation and informed consent to treatment based on the traditional conditions outlined above, and instead straightforwardly ask for agreement to data processing and acceptance of terms and conditions. Apart from regulation and questions of payment or refunding, autonomy and responsibility are conceptually and practically transferred to the realm of lifestyle and consumer transactions, in which users or consumers are relatively independent and able to navigate different positions of power.

Since assistive technologies rely on the datafication of health²⁶ and the interactive nature of digital devices, an increase in personal autonomy is also linked to an emphasis on digital and health literacy (Kim and Xie 2017; Ho and Quick 2018). The relevant health competences can be defined as the “knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion” (Kim and Xie 2017p.1074). These are both a precondition and a result of some form of technologically mediated enhanced autonomy. Health and digital literacy were arguably part of realizing autonomous patienthood *avant la lettre*. Yet, the use of assistive devices in more flexible contexts of care means that a further stage of autonomy as empowerment makes health and digital literacy a virtually indispensable demand, especially if technology serves to replace traditional personal care.

The promise of such independence on a social and political level again hinges on self-management or even self-tracking in user-friendly, participant-centric contexts. Autonomy can then take the form of “empowerment” which has long been discussed in some parts of health research, and before the advent of digital health applications was also a main normative tenet associated with personalized medicine.

11.3.3 Ambivalences and limitations

The shift to be noted here concerns the emphasis on health maintenance and prevention through active and responsible self-care. Although no general definition of empowerment has been agreed upon, the expectation of advocates of such self-care by means of technology is that it may lead to a “post-informed-consent-medicine” and instead help create “P4-medicine” which is predictive, preventive, personalized and participatory (Hood and Flores 2012; Topol 2015). Some commentators claim that

²⁶ I. e. the conversion of qualitative aspects of life, in particular clinical and self-care practices, into quantified data (digitization) and the processing of data to generate new information and knowledge from data already made available by means of predictive analytics (Schmietow and Marckmann 2019).

this may be the beginning of a new form of participative and democratized medicine and healthcare (Topol 2015; Ho and Quick 2018). On the other end of the spectrum, technology-mediated empowerment has been criticized not only as interfering with autonomy as underlying the protection of privacy, leading to a depersonalization of medicine and care, and a pathologization of daily life (cf. Rubeis et al. 2018), but could even be seen as contradictory since it also presupposes demanding forms of autonomous capabilities such as health and technology literacy.

This raises the question whether empowerment as active health management can address relevant target groups such as those most in need or may on the contrary increase inequalities in health (Manzeschke 2015; Ienca et al. 2017; Ho and Quick 2018). The delegation of social interaction and partly medical decision-making to technology could eventually lead to an undermining of autonomy or even disempowerment by way of automated, decontextualized health assessment and care (Pino et al. 2015). A further concern is an accelerated regression of basic abilities, especially those of elderly users (Manzeschke et al. 2015 p. 28; Mittelstadt 2017). Again, the ambivalence and delicate balance in technologically assisted care as outlined by Manzeschke et al. (2015) cannot be realized by a care system that “aims to return the activity of caring back into the autonomous and independent charge of those receiving care—and that includes if this is done by way of technical support” (Manzeschke et al. 2015 p. 31; cf. Godwin 2012).

In summary, traditional ethical approaches to the use of socially assistive technologies for elderly and/or vulnerable populations are undergoing change, which adds to the existing complexity of autonomy as a key reference concept for ethical evaluation and socio-political orientation. This is illustrated most clearly by the focus on procedural, formal and internal (i. e. capability-oriented) aspects of individual autonomy in principlist medical ethics. Previous work has added important considerations of the social context – and thus the dynamic “external” aspects – of technology development and implementation specifically for assistive technology and digital, data-based applications (Manzeschke et al. 2015; Weber 2015; Marckmann 2016).

The implications of assisting primarily non-fully autonomous users with such technology against the background of economically and politically driven digitalized (health-) care should be integrated even more extensively into bioethical debate. As can be illustrated with the help of an “escalation model” of assumed autonomy via technology use, individual autonomy (based on mainly formal criteria) appears to rather straightforwardly generate a vast potential for empowered patienthood or sometimes even a true paradigm shift towards fully bottom-up medicine and care. Yet, the various forms of enhanced autonomy in this model spanning consumer power (rather than patient dependence) through to personal health management (rather than social systems of care) can also be analyzed as ambivalent or in fact harboring internal contradiction.

These limitations are exposed most clearly if future scenarios involve elderly or vulnerable users. Health literate users and consumers of digital technology suggest

market-conform “ideal” autonomy while it is improbable that such target groups will have a wide spectrum of relevant choice available to them, even if they retain some forms of autonomy and should be respected as autonomous agents as such. Will they have access to or the necessary capabilities including social, economic and intellectual capital to use the market to their own advantage?²⁷

11.4 Conclusion

The assumed increase in empowerment thanks to broad use of assistive technology mainly refers to datafication as well as optimized self-care and self-responsibility. This quantum leap, however, presupposes that already very capable individuals are not the primary target group. Care relationships, including non-digital ones that foster social participation would need to remain central, particularly if there is a risk of simply delegating care and user autonomy to technology that in turn becomes invisible rather than obtrusive and increasingly “autonomous” (cf. Weber 2015; Mittelstadt 2017). The superior level of democratized healthcare for all on this basis therefore appears as highly disputable in relation to the elderly and vulnerable. In addition to a variety of risks to interference with informational privacy and decisional autonomy if tracking-based, it may even be considered a sort of category mistake, i. e. the attempt of a chiefly technological “solution” to the social and political at least as much as individual problem of fostering self-determination and participation.

This paper has sketched out some of the shifts in discussing autonomy as an ethical cornerstone also in digitalized healthcare. These concern the shift from patient autonomy to user or consumer autonomy, the vision of empowered autonomy in participatory, democratic care and medicine, and the effects of a prospective “autonomy” of the increasingly interconnected devices themselves. The concept of autonomy as conceived in principlism in particular may, however, not be able to accommodate the often precarious internal capabilities for self-determination in elderly and/or vulnerable user groups, and in addition contribute to the ethical neglect of the various contextual and external factors in helping respect and promote patient and user autonomy in the application of socially assistive devices.

By way of contrast, it was suggested that this context is key: conditions for autonomy should be established with reference to a specific application, and external in addition to merely internal conditions for self-determination should be highlighted for ethical assessment and policy intervention. These factors are the impact of social-

²⁷ Cf. Manzeschke et al. (2015): “As long as age appropriate assisting systems continue to be organised through a co-payer or selfpayer market, we can expect people with little capital (social, economic and intellectual) not to participate sufficiently in this care (cf. Bauer, Büscher 2008)” (Manzeschke et al. 2015 p. 12).

ly assistive technologies on existing care structures (on a system and individual level), user control and participatory technology development, as well as digital technology and health literacy. Adjustments of this type may enrich the conceptualization and assessment of the technology alongside established ethical frameworks, and would ideally be tested out in further work as part of dedicated, empirically informed ethical scenarios. Not the least, a broader conceptualization of the ethical impact of framing autonomy bears on regulation, such as the importance of both informed consent and user agreements or self-responsibility versus recovery of costs by the state or community for the use of digital and assistive technology.

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