

Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: a qualitative study

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Summary

Background Euthanasia and assisted suicide, and policies to address them are the subjects of contentious debate in many countries. However, the question of why people desire euthanasia or assisted suicide has not been coherently answered. We aimed to answer this question in a specific group of patients.

Methods We did a qualitative study of 32 people with HIV-1 or AIDS, who were enrolled in the HIV-1 Ontario Observational Database at Sunnybrook and Women's College Health Sciences Centre, Toronto, Ontario, Canada. We elicited participants' experiences of deliberation about euthanasia or assisted suicide, and the meaning of these experiences with in-depth, face-to-face interviews. We analysed our data with grounded theory methods.

Findings Participants' desire for euthanasia and assisted suicide were affected by two main factors: disintegration, which resulted from symptoms and loss of function; and loss of community, which we defined as progressive diminishment of opportunities to initiate and maintain close personal relationships. These factors resulted in perceived loss of self. Euthanasia and assisted suicide were seen by participants as means of limiting loss of self.

Interpretation These determinants of desire for euthanasia or assisted suicide in people with HIV-1 or AIDS have implications for the debate on these practices, and development of policies to regulate them.

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Introduction

What gives rise to desire for euthanasia or assisted suicide? Although the traditional idea is that such deaths are wished for as a means to avoid pain and suffering, studies suggest that this explanation is insufficient.^{1,2} In fact, depression,^{3,4} hopelessness,^{5,6} psychological distress,^{3,7} and need for social support⁷ are all factors. However, how and why these factors lead people to euthanasia or assisted suicide has not been explained.

People with HIV-1 or AIDS are an appropriate group in which to investigate what causes the desire to die in this way. An estimated third of people living with HIV-1 or AIDS in the developed world have considered asking for assistance to hasten death, which is ten times the rate among seronegative controls.⁸ In the Netherlands, before the advent of highly active antiretroviral therapy, about 25% of people with HIV-1 or AIDS died by euthanasia.^{9,10} Factors such as social isolation, estrangement, alienation, and grief affect people with HIV-1 or AIDS¹¹ and their caregivers.¹² People with HIV-1 or AIDS also have a higher rate of psychiatric symptoms such as depression,¹³ and a higher risk of suicide than seronegative individuals.¹⁴

We aimed to understand why people desire euthanasia or assisted suicide. This information could be used to inform the debate on euthanasia and assisted suicide, and to aid development of policies designed to regulate these practices.

Methods

Participants

We obtained participants from the HIV Ontario Observational Database (HOOD), which is a provincial epidemiological database held at Sunnybrook and Women's College Health Sciences Centre, Toronto. Patients enrol voluntarily in the database, and can indicate whether they wish to be contacted by their enrolling physician to participate in future studies related to HIV-1 or AIDS. In October, 1996, a HOOD employee compiled a list of unique identifiers for 320 patients who had indicated their willingness to be approached about participation in research. All patients were attending three participating HIV-1 specialty clinics in Toronto. The unique identifiers were forwarded to the clinics, where clinic staff matched identifiers to individual patients and placed information sheets in patients' charts in sealed and unmarked envelopes. The information sheets described the purpose and procedures of the study, and the risks associated with participation (see appendix available at www.thelancet.com or from the authors). They also indicated that the investigators sought opinions and experiences from individuals who had decided for or against their own euthanasia or assisted suicide, or who were undecided, and those who had participated in euthanasia or assisted suicide. In September, 1997, a list of unique identifiers was compiled for another 366 eligible patients, and was combined with the first list. The new list of all 686 patients was forwarded to the clinics. This list included all eligible HOOD patients

from between October, 1996, and September, 1997. The second list was used because of a slower than expected response to the first distribution of information packages.

Clinic physicians assessed patients and approached those they thought not to be suicidal or who were unlikely to be seriously upset by participating in the study. They briefly described the study to participants, and gave them the envelope containing the information sheet and a telephone number to contact the investigators. Patients were left to call an investigator (JVL) to arrange an interview. The study was approved by Research Ethics Boards at all participating institutions. Details of research ethics issues and how we addressed them are contained in the appendix (www.thelancet.com).

Procedures

We analysed data from interviews with patients and developed them into a conceptual model. This process is called grounded theory by sociologists, and is a way to develop theory from data that are systematically gathered and analysed; it is appropriate for use with data that are conceptually dense and involve social processes.^{15,16} We chose a qualitative design for this study because of the lack of insights and theories to explain the desire for euthanasia or assisted suicide.¹⁷

We collected data in face-to-face interviews. At the beginning of each interview, the participants were asked a series of questions about their demographics, health status, and experience with euthanasia and assisted suicide. The interviewer then inquired:

“When I asked you, in the questionnaire, about your decision, you said that you had definitely made a decision in favour of assisted suicide. Could you just tell me a bit about that decision?”

Interviewers pursued themes as they arose and sought clarification or elaboration as required. Further open-ended questions were used to explore five themes: autonomy, role of others, dignity, suffering, and end-of-life care, which are prominent in published work on euthanasia and assisted suicide. This preliminary framework was used to guide the first interviews and was refined by analysis of data on participants' personal experiences and perspectives.

The interviews were held in private rooms at the clinics, at the Community Research Initiative of Toronto, and at several undisclosed locations in accordance with the preference of participants. Interviews ranged from 40 to 120 min; the range indicates the variability of participants' experiences with deliberating about euthanasia or assisted suicide, and their involvement in the deliberations of others. All interviews were done by one investigator (JVL), tape-recorded, and transcribed verbatim.

Data analysis

Our analysis had three main steps: open coding, which is the process of breaking down, examining, comparing, conceptualising, and categorising data; axial coding, which is the process of reassembling data into groupings or categories on the basis of relations identified in data; and selective coding, which is the process of identification and development of the central theme of the data.¹⁵ For example, one participant talked about people dying slowly, “a little piece at a time”. In open coding, we labelled this phrase as an example of disintegration. In axial coding, we broadened and refined the idea of disintegration into a distinct category by use of individual codes or labels that had been assigned in the transcripts, such as duration of illness,

symptoms, onset of symptoms, physical activity, quality of life, reliance on life-sustaining treatment, and slow disintegration. In selective coding, we identified the core theme arising from the data as loss of self; and euthanasia and assisted suicide were identified as ways to limit this loss of self. We met regularly to examine the data and analyses to ensure that the results were appropriately derived from the study data. We used ATLAS/ti version 4.1 (Thousand Oaks, USA) qualitative research software to analyse data.

In grounded theory, the appropriate sample size (theoretical saturation),¹⁵ is reached when new data consistently fail to contribute to refinement of the theory. Our sample was not sufficient to allow us to develop a comprehensive theory of the desire for euthanasia or assisted suicide—ie, one that includes a complete range of personal circumstances, cultural and socioeconomic conditions, and stages of disease progression. However, the sample was sufficient to achieve theoretical saturation for the main structural components of the theory.

Results

Participants

37 calls were received between November, 1996, and June, 1998. From these calls 32 interviews were completed, two interviews were booked but the participants did not appear for the interview, two callers chose not to be interviewed, and one interview was missed and could not be rescheduled.

The table shows characteristics of the 32 participants. At the start of the interviews, 20 participants (63%) reported that they had already decided to pursue euthanasia or assisted suicide, three (9%) said that they had decided against euthanasia or assisted suicide, and nine (28%) were undecided. These decisions arose from the participants' personal experiences of living with HIV-1 or AIDS, and their experiences of friends and loved ones who had died of AIDS. These experiences created powerful expectations about their own deaths from AIDS, which shaped their desire for euthanasia or assisted suicide:

“AIDS, that's probably—seeing as I'm 41—that's probably what I'm going to die of. That is going to be a very painful death. It is painful, I've seen it. It's painful, it's sad, it's lonely in a way, that you can be surrounded by all the loving people in your life, but you, it's lonely because you're gradually rotting away, your flesh is rotting, I hope to God in a way that your mind is rotting with it, because then you become totally, you don't know what's going on.”

The desire for euthanasia or assisted suicide resulted from fear and experience of two main factors: disintegration and loss of community. These factors combined to give participants a perception of loss of self. Euthanasia and assisted suicide were seen as ways to limit this loss of self.

Disintegration

The progression of HIV-1-related disease is accompanied by symptoms and loss of function. This process was familiar to participants as patients and as caregivers. For example:

“You turn them over, they're in pain. They're going to shit themselves, they're going to piss themselves, they're going to lie there and have someone do all their bodily functions and just, they're going to suffer the whole time, there's going to be no happiness, they're going to go down to 60–70 pounds, they're just going to, their

	Total (n=32)	Decided to have E/AS (n=20)	Decided not to have E/ AS (n=3)	Undecided about E/AS (n=9)
Demographics				
Age (median [range], years)	39 (30–66)	40	40	36
Male sex	31 (96%)	19	3	9
Female sex	1 (4%)	1	0	0
Education				
Less than complete high school	1 (3%)	0	1	0
High school graduate	7 (22%)	5	0	2
University or college graduate	24 (75%)	15	2	7
Religious affiliation				
Yes*	16 (50%)	9	3	4
No	16 (50%)	11	0	5
Religious beliefs				
Not at all religious	18 (56%)	12	0	6
Somewhat religious	6 (19%)	4	1	1
Very religious	3 (9%)	1	1	1
Extremely religious	5 (16%)	3	1	1
Health status				
Mode of infection with HIV-1				
Sex with men	30 (94%)	18	3	9
Injection drug use	1 (3%)	1	0	0
Tattoo	1 (3%)	1	0	0
CD4 (median [range])				
Lowest	139 (0–563)	139 (0–283)	180 (47–480)	110 (5–563)
Highest	230 (5–863)	262 (5–863)	220 (137–770)	172 (5–863)
Taking highly active antiretroviral therapies (HAART)				
Yes	25 (78%)	17	1	7
No	7 (22%)	3	2	2
Symptoms				
Symptom free	13 (40.5%)	7	1	5
Non-AIDS-defining	6 (19%)	4	0	2
AIDS	13 (40.5%)	9	2	2
HIV-1-related hospitalisation				
Yes	11 (34%)	9	1	1
No	21 (66%)	11	2	8
Diagnosis of depression				
Yes	16 (50%)	10	1	1
No	16 (50%)	10	2	8
Relation of onset of depression to HIV-1				
No depression	16/32 (50%)	10	2	4
Before diagnosis	10/16 (63%)	7	1	2
After diagnosis	6/16 (37%)	3	0	3

	Total (n=32)	Decided to have E/AS (n=20)	Decided not to have E/ AS (n=3)	Undecided about E/AS (n=9)
Employment and financial profile				
Currently working				
Yes	8 (25%)	4	1	3
No	24 (75%)	16	2	6
Currently looking for work				
Not applicable (working, retired, disability)				
Yes	11/32 (34%)	6	1	4
No	2/21 (10%)	2	0	0
No	19/21 (90%)	12	2	5
Financially secure				
Yes	20 (63%)	12	2	6
No	11 (34%)	7	1	3
Unsure	1 (3%)	1	0	0
Life insurance				
Yes	14 (44%)	9	1	4
No	18 (56%)	11	2	5
Relationships and community				
Partner or spouse				
Yes	16 (50%)	11	0	5
No	16 (50%)	9	3	4
Partner who is HIV-1 positive				
Not applicable				
Yes	16/32 (50%)	9	3	4
No	4/16 (25%)	3	0	1
No	11/16 (69%)	8	0	3
Unsure	1/16 (6%)	0	0	1
Partner has same attitude to euthanasia and assisted suicide				
Not applicable				
Yes	16/32 (50%)	9	3	4
No	4/16 (25%)	3	0	1
Unsure	4/16 (25%)	3	0	1
Unsure	8/16 (50%)	5	0	3
Lost friends to AIDS				
Yes	30 (94%)	20	2	8
No	2 (6%)	0	1	1
Number of friends (median [range]; n=30)				
6 (1–100)	7 (1–100)	1 (0–10)	6 (0–30)	
Participated in the care of friends who died				
Not applicable				
Yes	2 (6%)	0	1	1
No	17 (53%)	11	0	6
No	13 (41%)	9	2	2
Euthanasia and assisted suicide				
Discussed euthanasia or assisted suicide with a doctor				
Yes	16 (50%)	12	1	3
No	16 (50%)	8	2	6
Asked doctor to assist				
Not applicable				
Yes	16/32 (50%)	8	2	6
No	5/16 (31%)	5	0	0
No	11/16 (69%)	7	1	3
Doctor willing to assist				
Not applicable				
Yes	27/32 (84%)	15	3	9
No	2/5 (40%)	2	0	0
No	3/5 (60%)	3	0	0
Participated in euthanasia or assisted suicide				
Yes (euthanasia)†				
Yes (euthanasia)†	3 (9%)	3	0	0
Yes (assisted suicide)†				
Yes (assisted suicide)†	3 (9%)	2	0	1
No	26 (81%)	15	3	8

E=euthanasia, AS=assisted suicide. *Includes Roman Catholic (2), Protestant (6), Mixed affiliation (1), Non-denominational church (1), Buddhist (1), and Traditional Native (1). †Some of the reported events might not constitute euthanasia or assisted suicide, although participants characterised them as such.

Participants' characteristics

whole last weeks of life is just going to be pain and agony and people coming in, people being upset, them being upset.”

Symptoms and loss of function can give rise to dependency on others, a situation that was widely perceived as intolerable for participants:

“I’m inconveniencing, I’m still inconveniencing other people who look after me and stuff like that. I don’t want to be like that. I wouldn’t enjoy it, I wouldn’t, I wouldn’t. No, I’d rather die.”

Participants frequently used the notion of dignity to describe the experiences associated with disintegration:

“You’ve become a bag of potatoes to be moved from spot to spot, to be rushed back and forth from the hospital, to be carried to your doctors’ appointments or wheeled in a wheelchair, and it really does take away any self-worth, any dignity, or any will to continue to live.”

Loss of community

Loss of community entailed the progressive diminishment of desire and opportunities to initiate and maintain close personal relationships, owing to loss of mobility, exclusion and alienation by others, and self-isolating actions by participants:

“I was in a situation, in a, in a clinic where a pregnant woman was standing beside me. And ah, she looked down and saw the form, and realised that she was 4 inches from my arm and promptly started to scream and yell. And ah, you know, and screamed at the nurse that, you know ‘I’ll come back when, when that *thing* is out of here’, and ah, stuff like that. She, the nurse, was very good and handled it, and ah but didn’t ask me how I felt, and what this was doing to me. And there are other people in the room and they were like, with their faces hanging, and absolutely shocked and, and I had a, and I felt extremely devalued.”

These experiences engender a fear of rejection that can also lead to avoidance of community and a sense of existential isolation, which often compound the experiences of alienation that were reported by participants:

“I think it’s very important for every single person to feel that they belong, and, and that they fit in a community, in a city, in a country, in a world, ah, in nature. The, the ah, and I think when, when we no longer feel that you have these linkages, and that the linkages are valued for everything that you’re connected with, whether it, you know, family or friends or, you know, associates, or whatever, and your community, and city, and all the rest of. Once the, once, once you perceive that, that your relationships, all the links with, with other living things have deteriorated, and then, and they’re not valued, then you’ve lost face. Dignity, then, has for me, has an awful lot to do with face.”

Loss of self

Participants’ experience of disintegration and loss of community create a perception of loss of self; the perception by participants that their fundamental nature or essence had been irrevocably eroded, or that this was at risk of occurring:

Participant: “I think we should all be allowed to die with our dignity intact.”

Interviewer: “OK and what do you mean by dignity?”

Participant: “Um, the ability to perform simple things like, you know, going to the bathroom on your own and not through a bag, um, breathing with your own lungs, not dependent upon a machine to keep the body parts functioning, um being able to do anything, I mean as long as you can think then you can live, but if you can’t [sic] no longer even formulate a thought due to dementia or you know the ravages of the disease. You know, if you were to stand there in your former self, would you want to see yourself in that position? I know I wouldn’t. You get to the point where there’s no return, you know, I can understand somebody saying, well geez, you know, like I used to be somebody, but now, like I mean, you know, I’m no better than like a doll, somebody has to dress me and feed me and I guess it’s uh, I don’t know how to explain it, really.”

Euthanasia or assisted suicide were seen by many participants as means of limiting this loss of self. For

example, one participant justified euthanasia or assisted suicide in the following way:

Participant: “. . . if I’m going to be rolling around in my own faeces because I have no control, then forget it.”

Interviewer: “OK. Why—why is that such an important thing?”

Participant: “Oh, it’s the dignity and wholeness of my body, as well as spirit. And, it is, it’s cruel too for others to have to do this when there’s no end in sight, other than death. To just, to clean me up. I just don’t want that . . . Dignity is that I have control over my body, when, when, not, not a virus that is going to take my life. I’m the one who’s going to decide when my life will end, not a virus, and not with great pain. Not anything else other than in, in my control. It is my control, my choice to do.”

Euthanasia and assisted suicide were not desired as ends in themselves. None of the participants, including the most adamant supporters, desired euthanasia or assisted suicide outside of the circumstances that led to their perception of loss of self.

Discussion

We have found a plausible and testable answer to the question, “why do people desire euthanasia or assisted suicide?”. Participants desired euthanasia or assisted suicide because of disintegration and loss of community, which combined to create a perception of loss of self. Euthanasia and assisted suicide were seen by participants as a means of limiting the loss of self. Factors thought to influence these decisions have been identified,¹⁻⁷ and these motivating factors can change as death approaches.¹⁸ Our results provide a coherent explanation of how individual factors work together to lead people with HIV-1 or AIDS to desire euthanasia or assisted suicide.

Our results also show the importance of social influences on euthanasia or assisted suicide. Although investigators continue to identify familial and psychosocial context,¹⁹ need to be appreciated,²⁰ and avoiding loss of dignity²¹ as factors associated with the desire for euthanasia or assisted suicide, the precise role and significance of these influences has not been reported. For our participants, loss of community was as important as disintegration in leading to the desire for such deaths. Loss of community was experienced in a wide range of ways by participants, including disownment by families, histories of physical and sexual abuse, homophobia and stigmatising events related to HIV-1 status, deterioration of social role and function because of physical disintegration, drug addiction, and self-sequestration. We believe that these experiences might predispose individuals to consider euthanasia or assisted suicide. These experiences also suggest that the decisions to have euthanasia or assisted suicide that were reported by 63% of participants could change with meaningful changes in individuals’ social circumstances, independently from disease progression. We might never eliminate the desire for euthanasia and assisted suicide without also addressing influential broader social circumstances.²²

Our results suggest that an understanding of loss of self, which is a metaphysical phenomenon, is essential to understand desire for euthanasia or assisted suicide. Loss of self is rooted as much in individuals’ perception of their loss of integration and status within a community, as in the more well known results of disease-related disintegration. Callahan²³ has written about “deforming the dying self”, but loss of self has not

been recognised as an explanation for the desire for euthanasia or assisted suicide.

Our results related to loss and integrity of self are similar to Antonowski's²⁴ "sense of coherence", which is the extent to which an individual experiences life as comprehensible, manageable, and meaningful. Furthermore, our finding of the importance of integration within a community concurs with his account of the relationship between the people and resources available to an individual as they confront difficult life events and the importance of "being involved as a participant in the process of shaping one's destiny as well as one's daily experience".²⁴ Our findings are also similar to Yalom's²⁵ account of existential suffering in relation to his universal "ultimate concerns": death, freedom, existential isolation, and meaninglessness. Similarly, in distinguishing between critical and experiential interests, Dworkin²⁶ notes about patients facing death that "their sense of integrity and of the coherence of their lives crucially affects their judgement about whether it is in their best interests to continue to live." We believe that these similarities provide some theoretical corroboration for our findings and should help to reinforce the value of using our results to add to the ideas and theories that drive investigations into assisted suicide and euthanasia.

Although our sample was very homogeneous, experience of loss of self is probably not unique to people with HIV-1 or AIDS. Many disabling and debilitating conditions, especially chronic degenerative neurological diseases,⁶ and diseases affecting elderly or otherwise socially marginalised populations, are also likely to give rise to similar experiences. We also expect that culture, ethnicity, and socioeconomic circumstances can influence people's perception of self.

Although we did not do this study with patients in end-of-life care, our results might help to draw attention to the role of notions such as hopelessness,⁵ burden on others,²⁷ psychological distress,^{3,7} need for social support,⁷ and depression,^{4,5,18} that are factors associated with the desire for euthanasia or assisted suicide. Our results are also consistent with our previous research on quality of end-of-life care, which suggests that we might pay inadequate attention to fundamental issues related to the integrity of self in end-of-life care.²⁸

Our results also suggest that development of policies on euthanasia or assisted suicide mainly within the doctor-patient relationship might obscure the role of broader social influences. For instance, Dutch guidelines require that the patient must be a mentally competent adult; the patient must request euthanasia voluntarily, consistently, and repeatedly; the patient must be suffering intolerably; and the doctor must consult with another physician.^{29,30} The Oregon *Death With Dignity* act permits physicians, with corroboration from another physician,¹ to provide lethal prescriptions, but not to do euthanasia, for patients who are terminally ill (defined as a prognosis of 6 months or less). These criteria do not provide a framework to address social circumstances that contribute to the desire for euthanasia or assisted suicide.²² Our findings should stimulate analysis of broader social influences on the desire for these means of death, identification of what exactly existing policies are designed to remedy, and whether these policies are congruent with, and adequately address, social factors.

A limitation of our study is the difficulty in access that we had to participants, owing to the stringent requirement of anonymity, because of the criminal nature of euthanasia and assisted suicide in Canada, and

because Canadian researchers have no statutory protection from subpoena of research data (see appendix). This legal difficulty restricted our ability to pursue theoretical sampling strategies that are frequently used in grounded theory studies, which permit more thorough specification and elaboration of the theory than we were able to do. Furthermore, the demands of anonymity made it impossible to follow up participants to determine the durability of their expressed intentions, and the ultimate outcomes of their deliberations. Although our study was based on the personal experiences of a small number of people living with HIV-1 or AIDS, we were able to use the appropriate method, "theoretical saturation", to determine the sample size necessary to support the main features of the theory. However, because of the study limitations, the theory that we developed might not be applicable to other populations—eg, women with HIV-1 or AIDS, or even all men with HIV-1 or AIDS.

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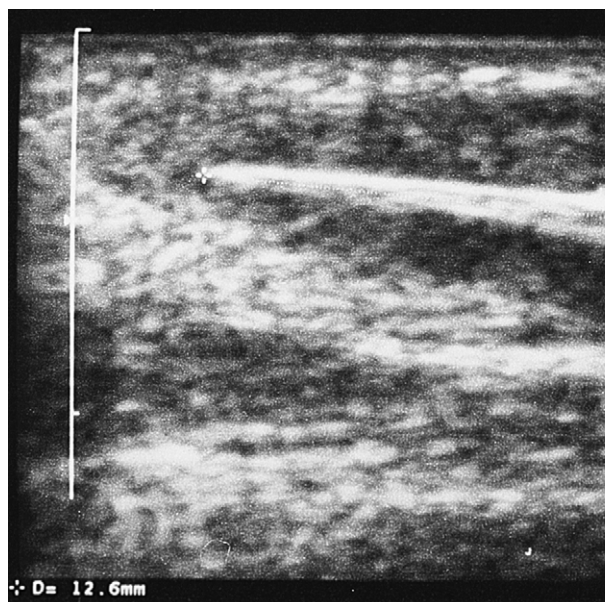
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Clinical picture: A forgotten thorn

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My 6-year-old daughter showed me a painless swelling on the dorsum of her right hand, over the second metacarpal bone. It was mobile relative to the bone, but adherent to the subcutaneous tissue and tendons. The skin was normal in colour. A paediatrician and a plastic surgeon were baffled, and suggested computed tomography. This investigation contributed no information as to the nature or cause of the tumour. Surgical resection and histological analysis was advised, because malignant disease could not be excluded. By chance, before the planned surgery, she visited our department and my colleague suggested ultrasound examination. The cause of the tumour was immediately obvious (figure). A foreign body, 12.6 mm long, was clearly visible. She remembered that she had hurt herself on a thorn about 8 months before. At the time she was not sure whether the thorn had gone into her hand and had soon forgotten about it. The thorn and surrounding scar tissue were surgically removed. One should always start with the simplest and most likely causes of pathological change and the simplest diagnostic methods.

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