

ORIGINAL ARTICLE

HIV positive and treated for cancer: The convergence of pressures “invisible” in HIV and “visible” in cancer

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Abstract

Objective: An increasing number of people living with HIV are living longer and experiencing a dual diagnosis of HIV and cancer. Little is known of their experience and quality of care. This paper presents the findings of a study exploring experiences of cancer care, from the perspectives of both patients and healthcare professionals.

Methods: Thematic analysis of participant narratives provided in longitudinal, semi-structured interviews with 17 people, recruited from three London sites between 2015 and 2017. Focused ethnography comprising 27 hr of participant observation and seven semi-structured interviews with healthcare professionals.

Results: Both HIV and cancer have a powerful, combined impact; in cancer, the impact is visible; in HIV, it is generally hidden. Patients and staff experienced particular challenges in the cancer setting. Patients felt responsible for their HIV management and described being excluded from clinical trials. Both staff and patients encountered difficulties around the management of information relating to HIV.

Conclusion: This dual diagnosis has a profound and negative effect on patients' experiences and potential outcomes. Improvement depends on interventions that acknowledge the shared social narrative and impact of HIV-related stigma so that this burden is not carried by the patient alone.

KEYWORDS

Cancer, HIV, patient experiences, stigma

1 | INTRODUCTION

Cancer is a significant comorbidity for people living with HIV and is likely to affect growing numbers. Cancers traditionally considered as AIDS-defining (Kaposi Sarcoma, Non-Hodgkins Lymphoma and cervical cancer) occur less frequently in the era of effective HIV treatment but their incidence remains more common in those living with HIV compared to those without (Franceschi et al, 2010). In addition to these virally driven cancers, there is a growing incidence of more

common cancers associated with lifestyle and ageing as people live longer (Lifson & Lando, 2012; Shepherd et al., 2016). With nearly 100,000 people living with HIV and receiving care in the UK, and over 7,000 still undiagnosed (Nash, 2018), it is inevitable that an increasing number of people living with HIV will engage with cancer services. It is therefore timely to explore their experiences in order to inform the ideal of appropriate patient-centred cancer care.

The experiences of a dual diagnosis of HIV and cancer are largely unexplored in the literature. The small number of studies that exist

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suggest that both conditions combined have a powerful impact and that stigma plays a key part in influencing an individual's sense of self, the way they behave and the social responses of others (Hainsworth, Shahmanesh, & Stevenson, 2018; Maboko & Mavundla, 2006; Dodds, 2008; Molefe & Duma, 2009). The impact of each condition on its own is described extensively in the literature.

Cancer is a potentially life-threatening condition with physically debilitating symptoms and often toxic treatments which can disrupt people's normal activities. It is, however, socially acceptable to talk about and is often framed as deserving of sympathy (Lupton, 2003). This acceptability is complicated by social prohibitions that require cancer to be discussed in positive courageous terms, which downplay negativity and complexity (Reisfield & Wilson, 2004).

HIV is now a condition that can be managed easily with a minimally disruptive treatment taken once a day and routinely managed with six monthly visits to the clinic for blood tests to monitor the immune system. Providing the treatment is adhered to, people with HIV can expect to have the same life expectancy as those without. Furthermore, the "Undetectable = Untransmittable" (U = U) consensus statement based on recent evidence (Cohen et al., 2016; Rodger et al., 2016) has provided a clear message that a person with sustained undetectable levels of HIV virus in their blood cannot transmit HIV to their partners. Moyer and Hardon (2014) have described a "normalisation" discourse in which various medical, policy and institutional discourses have aimed to reframe HIV as a chronic disease like any other because of all of these features that make it easy to manage in the present day. Yet tensions remain within this discourse in large part due to the persistence of HIV-related stigma within society. In people living with HIV, this is often combined with social and economic stressors and intersecting stigmas such as being gay or a migrant. (Deacon, Stephney, & Prosalendis, 2005; Flowers, 2010; Mazanderani & Papparini, 2015).

With a growing population of people living with HIV who are ageing and more likely to engage with cancer services, it is currently important to explore their experiences of cancer care. The needs of this group are likely to be particularly complex due to their experience of stigma as outlined above. An interpretive approach, utilising qualitative research methods was adopted as the most appropriate to explore this complexity to provide the context and explanation for information requirements and for behaviour around presentation, diagnosis and adherence to treatment. This paper presents the findings of a study that explored the experiences of having both conditions, with a focus on the journey through cancer care from the perspectives of both patients and healthcare professionals.

1.1 | METHODS

We conducted a thematic analysis of narratives provided in in-depth, longitudinal interviews conducted between June 2015 and March 2017 by 17 people living with HIV who received treatment for cancer. We performed a separate thematic analysis of ethnographic observations including 27 hr of participant observation in seven

sessions in a healthcare setting where participants received their cancer care and seven informal interviews with healthcare professionals providing this care during the same period. Common themes were then examined from the different perspectives. All data were collected from three sites in London. Ethical approval was obtained from NRES (15/LO/0230) on 18 March 2015, and research governance approval was obtained from the local sites.

2 | SAMPLE AND STUDY DESIGN

2.1 | Patient interviews

London sites were chosen owing to their large, diverse population of people living with HIV offering perspectives from those with a wide range of characteristics. Participants were included who had prior experience of care outside the capital including other countries, and this aspect of their experience was sought. For the patient interviews, we aimed to include as wide a range of participant characteristics as possible. This included different types of cancer, men and women, prior HIV diagnosis and synchronous diagnosis of HIV and cancer, and a range of countries of origin in order to represent the diversity of people living with HIV. See Table 1 for the demographic details. Participants were given information about the study and provided written consent. Interviews were semi-structured and informed by a topic guide developed and tested using input of patient representatives. The first interviews were arranged to coincide with the start of cancer treatment, and subsequent interviews were negotiated according to patient preferences, but aimed to capture the period at the end of and beyond cancer treatment in order to reflect any change over time. All audio recordings, field notes and transcription files were saved in an encrypted secure location on the university server separate from the consent forms and other identifying information.

2.2 | Focused ethnography

The participant observations were performed at two London sites and recorded in detailed field notes and reflections. A variety of settings were selected to include different types of cancer service and different treatment scenarios. These included observations of both staff and patient interactions and staff opinions which were sought in informal conversations. The settings fell into two broadly different categories: "specialist HIV services" where staff administering cancer treatment were also trained in HIV care and "oncology services" where staff were solely trained in cancer care. A total of 27 hr of observation was performed, and field notes were typed up within two hours of each visit in order to provide accurate and rich descriptive accounts. Details describing the observations conducted are provided in Table 2.

Semi-structured interviews were also conducted with seven healthcare professionals as part of the focused ethnography. These were audio-recorded and transcribed. Interviewees were selected

TABLE 1 Demographics of interview participants

Participant number	Site	Gender	Age	Place of origin	Timing of HIV Diagnosis	Type of Cancer	No of interviews
1	1	F	50's	West Africa	Prior HIV	Non-Hodgkins Lymphoma	1
2	2	M	30's	South America	Prior HIV	Rare Lymphoma	3
3	1	M	50's	UK	Prior HIV	Head & Neck	2
4	2	M	60's	UK	Prior HIV	Colo rectal	2
5	1	M	60's	UK	Prior HIV	Myeloma	1
6	3	M	20's	Eastern Europe	Synchronous	Hodgkins Lymphoma	1
7	3	F	30's	West Africa	Prior HIV	Squamous cell	1
8	2	M	50's	UK	Prior HIV	Non-Hodgkins Lymphoma	2
9	1	M	30's	Southern Africa	Synchronous	Non-Hodgkins Lymphoma	1
10	3	F	40's	UK	Prior HIV	Hodgkins Lymphoma	1
11	1	M	30's	South America	Prior HIV	Non-Hodgkins Lymphoma	2
12	2	M	50's	UK	Prior HIV	Colo rectal	2
13	2	M	50's	East Africa	Prior HIV	Rare Lymphoma	1
14	1	M	30's	Eastern Europe	Synchronous	Non-Hodgkins Lymphoma	1
15	1	M	60's	UK	Prior HIV	Prostate	1
16	1	M	50's	Middle East	Prior HIV	Lung	0
17	1	F	30's	UK	Prior HIV	Melanoma	1

TABLE 2 Details of participant observations

Date	Site	Setting	Description	Hours
12-May-15	2	HIV specialist day care	Patient receiving intravenous chemotherapy	6
20-May-15	2	General oncology day care	Patient receiving intrathecal chemotherapy	3
24-Jun-15	3	Specialist HIV and Cancer service (including some general oncology)	Daycare, observation and informal chats with patients and staff	7
06-Jul-15	3	Specialist HIV and Cancer service (including some general oncology)	Observation in clinic, post-weekend handover and ward round	5
05-Oct-15	2	General oncology day care	Observation of patient having pre-chemotherapy checks	2
14-Oct-15	3	Specialist HIV and Cancer service (including some general oncology)	Teaching session with nurses working in daycare plus discussion	2
11-Nov-15	2	General radiotherapy unit	Observation of radiotherapy waiting area	2

to provide a range of perspectives from staff involved in the care of people with a dual diagnosis of HIV and cancer who came from both general cancer services and specialist HIV services (see Table 3).

2.3 | Data analysis

The interview and observation data were analysed separately. A thematic analysis was used to analyse the interview, observation

and field note data following a similar process to that outlined in Braun and Clarke (2006). This process started with a thorough familiarisation with the data, re-listening to the audio recordings and re-reading the transcripts. Initial codes which were low inference and descriptive were generated to cover as much of the data as possible and managed using the software package NVivo v10 (QSR International, Melbourne, Australia). Material with similar content or properties was then sorted into descriptive thematic categories and then organised into broader themes and sub-themes

Participant no	Date	Site	Department	Role
1	06-Jan-17	1	Haematology oncology service	Nurse
2	24-Jan-17	1	HIV Services	Doctor
3	24-Jan-17	1	Haematology oncology service	Doctor
4	14-Mar-17	1	Haematology oncology service	Nurse
5	29-Mar-17	1	Oncology service	Allied Health Professional
6	30-Mar-17	1	Haematology inpatient ward	Nurse
7	14-Sep-17	3	Haematology oncology service	Nurse

TABLE 3 Semi-structured interviews with healthcare professionals

using an inductive process linking them directly to the data. The analysis was developed by constant comparison and the moving backwards and forwards between original data and emerging interpretations (Spencer, 2003, 2003). This process was applied to the first interviews and observations, working closely with FS (a medical sociologist and experienced qualitative researcher) and MS (an HIV clinician with research expertise in social science, clinical medicine and epidemiology) to ensure that it was rigorous and of good quality. Examples of outlying or negative cases that ran counter to emerging themes were sought out in order to refine the interpretation.

3 | RESULTS

The patient interviews yielded a larger amount of rich and in-depth data than the focused ethnography, and this is reflected in the presentation of the findings. The participant observation data helped characterise the healthcare environments where cancer care was provided. Data from healthcare professional interviews have been included to provide additional perspectives to the patient accounts. Before moving on to an interpretation of the findings, it is important to say something about the heterogeneity of the patient sample group and to stress that there was far from one single narrative within the participant accounts. Perhaps the most obvious difference which had implications for the way in which people framed their experiences was the timing of their HIV diagnosis. Some of the participants were diagnosed with HIV in the late 1980's and early 1990's, in the midst of the AIDS crisis when no effective treatment was available and with their partners and friends dying around them. Obviously, the impact of this HIV diagnosis in terms of their expectations for the future was very different from those diagnosed at a time when HIV could be managed effectively on one pill a day with the expectation of good health and normal life expectancy. This experience is different again from those who were told about their HIV and cancer at the same time in a synchronous diagnosis in a situation where they were acutely unwell and hospitalised. Three participants

had this experience and for them their overwhelming concern at the time was the outcome of their cancer:

I think cancer is just deadly....it puts a stop to everything....HIV, I'd take my tablets for a little while and I'd bounce back'

(Male, 30's, Synchronous diagnosis, Participant interview)

3.1 | Both conditions had a powerful impact but they were experienced differently

For those living with a dual diagnosis who participated in the study most described both conditions as having a powerful impact on their lives. Cancer's impact lay in the uncertainty of outcome and the experience of debilitating symptoms, the toxic side effects from treatment such as nausea, pain and fatigue, all of which interfered with activities of daily living. Participants described physical changes, such as scarring from surgery, having to have a colostomy, and the experience of losing their hair, in terms which left no doubt about their visibly traumatising effects. Yet, cancer was also a socially acceptable diagnosis which was easy to talk about and garner support for and several described their relief at being able to share information about themselves and receive a sympathetic response, sometimes for the first time:

So, there I was, able to...because a lot of these friends don't know about the other one, so I sort of you know, 10 years on I was getting some support that I never had got....You know I've been pulling on that, not in a poor me type of way, but just in allowing people to rally round (Female, 30's, Prior HIV diagnosis, Participant Interview)

In contrast, HIV was well managed with an easy daily treatment that allowed life to continue. It was however kept hidden for fear of

rejection and discrimination due to persistent societal stigma, and there were many examples within the data of both patients and healthcare professionals demonstrating knowledge about HIV that lagged behind the very positive scientific developments. This was illustrated by a patient who described outdated perceptions about the transmission of HIV.

People still have this thing from the 1980's that it's spreadable, it can be passed on
(Male, 50's, Prior HIV diagnosis, Participant Interview)

It also appeared in the accounts of healthcare professionals. One practitioner described a situation he had witnessed where fears regarding the risk of HIV transmission were being shared between nurses.

So a nurse cleaned it up (the bleeding from a PICC line) and she was hurried over to a corner by another nurse to tell her this patient has HIV and be careful... but really you should be careful with any patient
(Allied Health Professional, Oncology Service, Ethnography)

No one mentioned the "Undetectable = Untransmittable" (U = U) consensus statement, suggesting that popular understandings about the threat and infectiousness of HIV had failed to catch up with scientific progress. Patients provided accounts of ill-judged attempts by healthcare professionals to talk about HIV in order to show their acceptance. This could cause offence as demonstrated by one woman's account of a conversation with a doctor:

and then he said 'do you mind me asking how did you get it? And I said 'I do mind'. I said, "you know the usual route." He said 'Oh, but not drugs then
(Female, 30's, Prior HIV diagnosis, Participant Interview)

A striking feature of the patients interviewed was their social isolation, and often the support they did have was dependent on their HIV diagnosis remaining a secret.

3.2 | Patients' lack of confidence that cancer staff were knowledgeable enough to manage their HIV care

Participants were not confident that cancer teams understood the management of their HIV and there were several examples within the data of them taking on this work themselves by reminding staff to check their CD4 count and by seeking clarification about potential contra-indicated medications with their antiviral treatment:

I'm going round making sure that, having to make sure, you know what I mean.....you know I'm not knocking any

of the staff, they're really good, they do a wonderful job here. I just, I'm not in the medical field to specialise in what I should be taking or whatever but you know I've got to check up and make sure I'm taking the right medication
(Male, 50's, Prior HIV diagnosis, Participant Interview)

Some of the healthcare professionals delivering cancer care freely admitted that they did not know much about HIV treatment or where to go to find out more. For staff accustomed to being experts in providing advice, this lack of knowledge could feel unfamiliar and be experienced as potentially undermining to their sense of professional status. One nurse described this knowledge gap feeling like a loss of control:

I definitely don't know if the drugs are doing what they're meant to be doing...with the antiviral drugs I honestly haven't got a clue. And I feel a loss of control over that in some ways
(Nurse, Haematology inpatient ward, Ethnography)

This lack of knowledge about HIV appeared to present more immediate problems for the nurses who were interviewed, rather than the doctors, as it had a more direct impact on their working day in tasks such as giving out medicines and explaining their purpose.

3.3 | Being the only person with HIV in the clinic

People living with HIV expressed a feeling of difference in the cancer clinic. The stigma associated with HIV could be layered with other stigmatising features such as being in a same sex relationship or being a migrant. This was alluded to within the study, for example when an African woman was offered a choice of straight-haired wigs or when a young man described cancer support services as prioritising older people:

When I asked for financial help...because I was a young person I felt kind of discriminated, like for the older person you could see all the attention there, I was young, so they said "you do it, you do it"
(Male, 30's, Prior HIV diagnosis, Participant Interview)

This sense of difference extended into participants' experiences of cancer treatment itself. Some participants were troubled that there was a lack of experience and precedent in caring for people like them. Looking at existing evidence online about the outcomes of their particular cancer was frustrating because they did not feel it was possible to draw the same conclusions from studies based on people who did not have HIV. Two people in the study were undergoing treatment which they had been told was the first or second of its kind to be given to someone with HIV. These two participants both independently used the term "guinea pig" to describe their management, a not entirely positive phrase

which suggests they viewed their treatment as a kind of experimentation, possibly reinforcing their feelings of difference from others.

3.4 | Patients' beliefs that their HIV status denied them equitable cancer treatment

Some participants felt that their HIV status denied them access to treatment options which they believed would have been available if they were not HIV positive. One woman described old feelings of upset about her HIV diagnosis re-emerging when she was told this made her ineligible for a clinical trial offering cancer treatment otherwise not available. She related how this exclusion shone a light on and compounded old feelings of stigma:

*Because I'm HIV positive I'm not eligible for the clinical trials which are currently the thing that they offer somebody in my position...I was really upset, because yet again it's just another thing to make me feel um....it sort of compounds...even though you've put the HIV thing to the back of your mind it all comes to the surface again
(Female, 30's, Prior HIV diagnosis, Participant Interview)*

Staff from both the oncology services and HIV specialist services commented on this issue too. With cancer treatment entering a new era of personalised medicine, clinical trials were sometimes the only way that patients could have access to promising targeted and biological therapies for potentially incurable cancers. Some healthcare professionals felt this exclusion was unfair, with one nurse highlighting the contradiction in the idea that HIV is a "normal" chronic illness whilst denying patients the option to participate in a trial which may be their only option for further treatment. Not all were of the same opinion; however, an oncology doctor felt that there may be sound scientific reasons for this exclusion. This contradiction provides further evidence of the conflicting discourses that patients faced, reinforcing their feelings of difference.

3.5 | Fear about inadvertent disclosure of HIV status

This study demonstrated that many people with a dual diagnosis were constantly working extremely hard to manage information and keep their HIV status secret to avoid anticipated rejection: this work took a huge emotional toll at the same time that they were experiencing a debilitating and disruptive cancer diagnosis. The worry about disclosure was evident in some participants' views about involving the GP in their cancer care. The distrust that some had for GPs and their reluctance to engage with them was an area in which they felt different from other people with cancer. Participants talked about fears regarding confidentiality

and lack of knowledge around HIV. One man described this reluctance as originating from a period when he was first diagnosed HIV positive and he was worried about the GP maintaining his confidentiality:

*it sounds strange that you were going to your doctor and not telling him about this major thing but I just didn't have the confidence that it wouldn't get out
(Male, 50's, Prior HIV diagnosis, Participant Interview)*

GP surgeries are located in local communities and attended by neighbours. For some participants, their GP was informed of their HIV status by default and without their explicit permission as part of the routine practice within cancer services of sending a discharge letter containing past medical history and these individuals perceived this as a source of difficulty.

In settings such as wards or day care units where cancer treatment was administered healthcare workers described "confusion and secrets" as a feature of some of their interactions with patients who did not want the visitors present at their side to know their HIV status. They did not always express empathy in relation to the patients' wishes to protect information but talked more in terms of the impact on their established working practices, such as in the giving out and explanation about medication in the presence of others. The pressure to protect patient confidentiality made staff feel worried and inhibited from talking freely to their patient whilst delivering cancer care and potentially hampering their ability to provide quality care. One nurse described a situation where complicated instructions in handover about people who did or did not know a patient's HIV status had the effect of closing down their communication with that patient completely:

*It is made a point of in handover, they don't want anyone other than you know one or whoever, to know. And then often you wouldn't know who the person they would want to know is.....so I found myself not discussing anything really
(Nurse, Haematology inpatient ward, Ethnography)*

The issues around disclosure were framed by healthcare professionals as undermining to their clinical actions and associated clinical safeguards, as one nurse described in relation to the safe administration of medication:

*If you're being 100%..sticking to policy procedure, you're supposed to go...what's your name? date of birth? I am giving you this and this (medication) for this....but they don't want their family to know what is wrong with them'
(Nurse, Haematology inpatient ward, Ethnography)*

However, the need and importance of secrecy was clearly demonstrated by one man who recalled hearing his own brother talk about people with HIV and his feeling of horror at what he said:

Like I remember my brother....saying he wouldn't let anyone with HIV near his kids...And I thought Oh God
(Male, 60's, prior HIV diagnosis, Participant Interview)

The constant management of information about their HIV status required a lot of work by participants at a time when they were unwell, but it was felt essential as many were certain that disclosure would lead to a withdrawal of support; a potentially catastrophic consequence that some healthcare professionals did not always show an understanding of.

4 | DISCUSSION: A UNIQUE CONVERGENCE OF PRESSURES WITHIN THE "VISIBLE" CANCER AND THE "INVISIBLE" HIV

Our study found that having two serious illnesses, one which is life-long and stigmatising, and one which is potentially life-threatening but socially acceptable, added to the burden of illness experienced by patients. Cancer was experienced as a visible condition, which could be talked about widely, and patients reported their relief at being able to share information about themselves for perhaps the first time and receive sympathy. The discernible consequences manifested in the symptoms and side effects of treatment were less positive aspects of this visibility. HIV was experienced as a largely invisible condition which due to effective treatment could be hidden from view. Accounts from both patients and healthcare workers showed that it retained powerful stigmatising connotations, which lagged behind the scientific progress and exerted social and psychological pressures on patients to manage information and avoid inadvertent disclosure of their HIV status. The impact of these under the surface tensions exerted a huge emotional toll at a time when patients were receiving invasive and debilitating cancer treatment. Study participants described feelings of being an outsider within the standardised offering of cancer care; exclusion from clinical trials was one example of this. HIV is a common exclusion criteria in cancer clinical trials. In a study looking at lymphoma patients who were HIV positive (Venturelli, Pria, Stegmann, Smith, & Bower, 2015), it was found that there was no scientific or safety justification for excluding people living with HIV from most lymphoma clinical trials and no clear justification provided for the exclusion. It would seem from this study that the impact of this on patients who were aware that they were denied access was a reinforcement of otherness.

This study adds weight to findings within the literature which describe ongoing tensions within the HIV normalisation discourse (Flowers, 2010; Mazanderani & Papparini, 2015; Moyer & Hardon, 2014) and goes further by characterising these tensions within the cancer healthcare setting. It has been recognised in the literature that due to the complexity of the treatment and language, many cancer patients prefer less active participation in medical decisions (Ernst et al., 2011) and can experience "work" such as liaising between services

and managing symptoms as a burden, particularly if they do not have a social support network (May et al., 2014). There is an increasing focus on biologically stratified medicine in cancer, and it has been found that as the patient pathway becomes ever more complex, the result can be an experience of care which is more fragmented and less personal (Day, Coombes, Mcgrath-Lone, Schoenborn, & Ward, 2017). This study showed that on top of this people felt responsible for aspects of their HIV management during their cancer treatment when they were physically unwell and often very isolated. Because some of the pressures, particularly those relating to disclosure, were not immediately obvious, they were not always recognised or fully understood by healthcare workers, particularly in oncology services where limited time often meant the main focus was a standardised safe journey through treatment delivery. Long-term HIV is a relatively new phenomenon, and many healthcare professionals have low levels of knowledge and familiarity with HIV, which has historically been treated entirely within specialist clinics. All this suggests that cancer and other specialists would benefit from demonstrating more empathy to the challenges of having stigmatising conditions such as HIV and better understanding the isolation and effort that is required of patients to manage information within a dual diagnosis. Any future interventions aimed at improving these experiences would need to acknowledge the shared social narrative around HIV and the powerful impact of stigma so that this burden is not carried by the patient alone.

5 | LIMITATIONS OF THE STUDY

The interviews and observations were conducted in London. It could therefore be argued that the findings do not easily translate to other geographical areas. However, interview participants had experience from other settings outside London that they brought into the interviews.

Longitudinal interviews were only possible with six participants owing to loss to follow-up and six people who died after their first interview. This highlights a unique feature of a sample group who might normally be hard to reach and allowed their voices to be heard.

CONFLICT OF INTEREST

There are no conflicts of interest for any of the authors.

AUTHORS' CONTRIBUTIONS

EH conducted the data collection, performed the thematic analysis of the data and wrote the manuscript; MS contributed to the development of the methods used within the study, contributed to the interpretation of the findings and commented on all versions of the manuscript; FS contributed to the development of the methods used within the study, contributed to the interpretation of the findings and commented on all versions of the manuscript.

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