Title: Advance care planning among older adults of Moroccan origin: an interview-based study

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Abstract

Objective: To explore advance care planning (ACP)-related knowledge, experience, views, facilitators and barriers among older Moroccan adults in Belgium.

Method: General practitioners (GPs) recruited participants for semi-structured interviews. Data were analysed using the constant comparative method.

Results: The 25 interviewees (average age, 74 years) lacked ACP knowledge and had not discussed it with healthcare professionals. After a brief explanation, most interviewees did not find ACP useful. After more explanation with a specific example, they had fewer religious objections and were more willing to have discussions with their GPs and/or relatives. ACP barriers were a lack of knowledge, current good health, **potential harm of talking about death**, trust in one's children to make care decisions and fear of worrying one's children. Facilitators were GPs' information provision, children's involvement in ACP discussions and the desire to not depend on children.

Conclusion: Many older Moroccan adults **lacked familiarity, but were** willing to discuss ACP after receiving understandable concrete information. **GPs should facilitate ACP discussions for these patients, ideally with adult children involved, with consideration of barriers, individual preferences and generally low educational levels.**

Practice implications: **GPs should provide comprehensible ACP information with case examples and consider potential barriers and facilitators in this group.**

Key words: Advance care planning, end-of-life care, general practice, elderly, ethnic minorities, qualitative study

1. Introduction

Advance care planning (ACP) **has been defined by European consensus to enable** individuals to **define** goals and preferences for future medical treatment and care, discuss **them** with family and healthcare providers, **and record and review them as appropriate**. People engaged in ACP are encouraged to appoint representatives and record their preferences for consideration when they are unable to make decisions for themselves [1]. **Patients can also document their preferences about matters such as the burial place and manner, organ/body donation and euthanasia [2]. ACP can increase patient/surrogate satisfaction with communication and decrease surrogate/clinician distress; findings for other hypothesised outcomes, such as improved goal-concordant care, quality of care and health status, are mixed [3].**

ACP is complex, especially for older adults with non-dominant social, cultural and spiritual views on the end of life [4]. Culture (entailing race, ethnicity, religion, language and origin) largely determines how people view life and death and, consequently, make end-of-life decisions [4]. Studies conducted in New Zealand, the United Kingdom and the United States have revealed significantly less ACP participation among ethnic-minority than among ethnic-majority older adults, due mainly to a lack of knowledge, the major role of family members in elder care, and **distrust of the healthcare system** [5–8]. In addition, healthcare professionals often lack communication skills and knowledge of intercultural differences regarding end-of-life issues [9].

In Belgium, 12.7% of people aged ≥ 65 years **or their parents have foreign first registered nationalities** [10]. In large cities, this proportion is 10–39.3% [10,11]. People of Moroccan origin form the largest group with non-European backgrounds in Belgium, accounting for 1.2% of the population aged ≥ 65 years [12,13]. Research conducted with older Turkish adults in Belgium has revealed unawareness of the existence of ACP, although most respondents were willing to participate and saw ACP as useful when the concept had been explained to them [14]. Little is known about discussing ACP with people of Moroccan origin. **People with Turkish and Moroccan immigration backgrounds (often Muslim) have experienced similar socialisation in Belgium due to their arrival as guest workers in the early 1960s [15]. Older people in both groups have less education and poorer health than do older people in Belgium without these immigration backgrounds [16]. Belgium is currently facing the ageing of these Muslim populations [16].** Available research on ACP aggregates various ethnic-minority populations, assuming cultural homogeneity, which leads to inappropriate generalisation and the overlooking of individual-level complexities [17,18]. Moreover, **although some early work was conducted with healthy older adults [19],** most ACP research has been conducted with patients who were seriously ill, had dementia and/or were receiving residential or palliative care [20,21]. **Although end-of-life care**

discussions with chronically ill patients are commonly considered to be appropriate, ACP should also be considered for healthy people [22,23]. Ideally, ACP discussions should be initiated in a primary care/outpatient setting [24]. ACP is dynamic and ongoing in response to changing perspectives over time, and could be initiated with older people without life-threatening illnesses by discussing healthcare proxy preferences or care goals in hypothetical debilitating or terminal situations [22]. The goals of this study were to investigate the willingness of older Moroccans in Belgium to discuss ACP, and to compare their ACP perspectives with those of elderly Turks in Belgium. **We explored this group's ACP knowledge, experiences, views, barriers and facilitators.**

2. Method

2.1. Study design

For this qualitative study, semi-structured interviews were conducted to explore respondents' opinions, experiences and assumptions about ACP and to determine why they were or were not interested in it. The interviews were conducted in Darija (Moroccan Arabic), the participants' native language, after receiving their written and verbal informed consent, including for the publication of anonymised findings. The study was approved by the Ethics Committee of Ghent University Hospital (B.U.N. B670201942542) and registered with ClinicalTrials.gov (no. NCT04335214, protocol ID B670201942542).

2.2. Patient recruitment

Through general practitioners (GPs) in Brussels and Mechelen, **we recruited** Belgian residents of Moroccan origin aged ≥ 65 years **in primary care without life-threatening illnesses (according to the Palliative Care Indicators Tool [25]) who could benefit from ACP discussions.** Those with incurable diseases and two or more frailty indicators were considered to be eligible for palliative care and were excluded. The GPs asked eligible individuals whether they wished to participate in a face-to-face interview study about possible future care planning by speaking to a researcher in their native language. The GPs sent consenting individuals' contact information to the primary researcher (HD). One researcher (RH) contacted these individuals by telephone to provide further information about the study and to schedule interviews with willing individuals.

2.3. Data collection

One male researcher (RH), a GP-in-training with semi-structured interview training, conducted all interviews between November 2020 and July 2021 at the respondents' homes or locations of their choosing. After the respondents had filled in the consent form with the interviewer's assistance, the interviews were recorded with two audio recorders. Information about participants' socio-demographic characteristics was collected at the beginning of each interview. After each interview, notes were made to record any further relevant information. Interviews were conducted until they revealed no new relevant information.

The interview guide used in this study **(Table 1)** was based on that used in a study of ACP perspectives among elderly people of Turkish origin [14]. Two researchers (RH and BC) proficient in Darija and Dutch independently translated the guide into Darija using a phonetic script. The translations were compared and back translated, and consensus on the final version was reached. The guide's clarity and comprehensibility were tested in two interviews with older Moroccans**, which resulted in no modification.** Participants were asked open-ended questions about their ACP-related knowledge, attitudes, experiences, facilitating factors and barriers. The interviewer introduced ACP as a means of communicating in advance about the care and/or treatment a person would or would not like to receive in the case that he/she was no longer able to communicate such preferences. Because of the known low literacy levels in the study group, we included an example case (Box 1) **and clearly, simply worded comprehensive information on ACP use (Box 2)**.

2.4. Data processing and analysis

The interviewer (RH) transcribed all interviews and translated the transcripts into Dutch. Another researcher (BC) checked the transcripts of the first four interviews to rule out subjective influence; this practice revealed no data loss and was discontinued. Two researchers (RH and BC) independently used the qualitative constant comparative method [26] to perform line-by-line iterative coding of the study-related transcript content, with comparison within and between transcripts until overarching themes were identified [27]. The code list was recorded, and analysis was performed, using NVivo 12 software (QSR International, Melbourne, Australia). Data collection and analysis were conducted concurrently with the interviews so that the topic guide could be modified slightly to pursue emerging lines of inquiry. The two researchers met regularly with other researchers (HD and SD) to reflect on the process and explore initial insights. When the analysis had been completed, the relevant content was translated into English using the forward-backward method.

Table 1. Interview guide topics

Concerns about future care
What is your current state of health?
Do you have concerns about the future?

  - Have you thought about future care?
- Familiarity with the concept of ACP
  - Do you know about ACP?
  - Do you know about certain parts of ACP?
- Experiences with ACP
  - Have you communicated your wishes to your next of kin?
  - Have you, or has someone you know, performed ACP?
- Detailed information about ACP
  - Presentation of the example case
  - **Provision of comprehensive information about ACP use**
- Opinions on ACP
  - What do you think of ACP as a whole, and about each of its parts?
  - Do you think that ACP is useful?
- Barriers and facilitators
  - What makes it difficult to talk about this?
  - What makes it easier to talk about this?
- Socio-demographic characteristics
  - Education, literacy, years in Belgium, marital status, children, profession, current living situation and emigration environment

ACP, advance care planning.

Box 1. Example case

A 75-year-old patient has Alzheimer's disease (memory loss). She lives with her daughter. She tells her GP: ‘If I ever have a serious illness from which I will not recover, I do not want to be hooked up to machines or on drip feed in the hospital to prolong my life, like my husband. He was in pain for weeks before he died.’ Several years later, this patient becomes ill. She has a high temperature and a cough, and cannot eat or drink. Her GP wants to admit her to the hospital to give her a drip feed and antibiotics. The GP and the patient’s daughter decide to do so, but agree that if she does not improve within a few days, they will stop all treatments and discharge her to spend her final days at home. The patient recovers after 3 days and returns home.

Three years later, the patient’s dementia has become much worse and she has been admitted to a rest home. She can no longer get out of bed or out of an armchair, and she has stopped eating. Nothing gives her pleasure anymore; she doesn't recognise her own daughter either. In addition, she cannot make decisions about her own treatment. In this situation, the daughter asks the GP: 'How about feeding her with an infusion?' The GP says he doesn't think this is desirable because when the patient was healthy, she had expressed her wish to not be hooked up to machines or a drip feed if she was ever in a bad medical condition. After 2 painless months, the patient dies.

GP, general practitioner.

Box 2. Comprehensive information on the use of ACP

1. It is now possible to somewhat extend the life of someone who is seriously ill, unconscious and has no hope of recovery by giving them drips, a respirator and antibiotics. While you are in good health, you can choose to refuse such treatments should you ever fall into that condition.

How do you feel about discussing this now for the future?

2.You can specify now that you want to move to a residential home when you are very old and can no longer take care of yourself.

How do you feel about discussing this now for the future?

3. You can give someone authorisation (power of attorney) to act on your behalf. If you become seriously ill at some stage and cannot think about your treatment properly, this person can make decisions for you and ensure that your previously communicated wishes are met.

How do you feel about discussing this now for the future?

ACP, advance care planning.

3. Results

Of 31 potentially eligible individuals, 25 were interviewed. Four people indicated that they were no longer interested in being interviewed and two women wished to be interviewed only by a woman. The interviews lasted 43 minutes on average. In three cases, participants' children were present due to their interest in the topic, because of coincidence or to support their parents. None of the children interfered directly with the interviews.

3.1. Socio-demographic characteristics

The participants' average age was 74 (median, 72) years. All respondents were first-generation migrants, Muslim and Darija speakers, and had low literacy levels; 17 respondents were illiterate (Table 2). These characteristics are comparable with Flemish government statistics on elderly Moroccans [13].

Table 2. Participants' socio-demographic characteristics

Characteristic	Category	*n*
Age (years)	65–70	8
	70–80	10
	80–90	7
Gender	Man	10
	Woman	15
Highest diploma obtained	None	16
	Koranic school	2
	Military school	1
	Primary education	6
	Medium-level education	0
	University	0
Marital status	Married	17
	Widowed	7
Profession before retirement	Worker	10
	Clerk	2
	Housewife	13
Self-identified literacy	Illiterate	17
Living situation	Alone	7
	With partner	10
	With partner and children	8
Number of years in Belgium	0–20	4
	20–50	7
	>50	14
Number of children	0	4
	1–4	8
	4–6	9
	>6	4
Emigration environment	Town	18
	Rural	7

3.2. Themes

We identified from the interview data the following ACP-related themes: lack of familiarity with and awareness of ACP, reduced influence of religion after detailed information provision and impact of children on ACP views. We identified as barriers the lack of knowledge, current good health, trust in one's children to make care decisions, fear of worrying one's children and potential

harm of discussions about death. We identified as facilitators GPs' provision of information, children's involvement in ACP discussions and the desire to not be dependent on children.

3.2.1. Lack of familiarity with and awareness of ACP

All interviewees lacked familiarity and experience with ACP. One person had heard that a representative granted power of attorney could make medical decisions for a patient who could not do so.

> 'No, I have never heard of this.' (Respondent 5, 68-year-old woman)
>
> 'Yes this [power of attorney] I know, the one you choose is always someone who knows you well and has your best interests at heart.' (Respondent 9, 67-year-old man)

Some respondents had discussed ACP issues (mainly burial, also care home residence) with their children and/or other family members.

> 'Yes, I brought all five of my children together and I discussed this [funeral wishes] with them. Afterwards, they said "Daddy, why are you bringing this up" or "Daddy, this is not nice talk". But I think this is an important subject and that is why I have discussed it with them. I also told them that this way they would always have a souvenir of me here in Belgium.' (Respondent 11, 72-year-old man)
>
> 'I told the children that if our care becomes too burdensome, they can take us to a nursing home.' (Respondent 18, 72-year-old woman)

3.2.2. Reduced influence of religion after detailed information provision

Most respondents initially stated that they did not find talking about future care to be useful or meaningful for religious reasons.

> 'We always say that the future is in the hands of God; we don't know what will happen to us. I have already reserved a place [laughs] where I will be buried in my village in Morocco, but other than that I have nothing else to think about.' (Respondent 15, 83-year-old man)

However, when ACP was explained in more detail using the example case, respondents expressed various opinions (largely positive) and had fewer religious objections. They felt that preparing for the future, especially while one can think clearly, was important.

> 'I think that it is something good. But we also need to have faith in God. I agree to commit [to ACP] from now on, because my staying at home is difficult for my family.' (Respondent 15, 83-year-old man)
>
> 'I think it is good that someone is preparing while still in good health.' (Respondent 17, 79-year-old man)

They were prepared to have ACP discussions, mainly about their desired burial location and refusal of **futile care,** immediately with their GPs and/or family members.

> ‘I will see my GP on the 15th, I will discuss it with him.’ (Respondent 6, 79-year-old man)
>
> ‘I will talk to my children about my burial place and refusing useless treatment.’ (Respondent 21, 68-year-old woman)

Some respondents still did not find ACP to be useful, for religious reasons.

> ‘I am not concerned with what might happen to us tomorrow or the day after. We cannot know what will happen to us tomorrow. God is the only one who knows. I think everything is in the hands of God, so I cannot limit my possibilities in advance.’ (Respondent 11, 72-year-old man)

3.2.3. Impact of children on ACP views

Some respondents indicated that ACP would not be useful because children typically care for parents in Moroccan culture.

> ‘I count on the support of my children here. In our culture, we continue to support our parents. I myself also supported my mother until her death. I don't think this is because of our religion. This is passed on from generation to generation. I think these are mostly traditions.’ (Respondent 19, 70-year-old woman)

They had confidence that their children would make decisions when they could not, although they had not spoken about it.

> ‘It will be my children who will decide. I have no preference. And my children will not abandon me, they will bury me where they want to. They will have to come together at that time to make a decision that suits them. I don't want to make a decision that they are going to have trouble with.’ (Respondent 13, 84-year-old woman)

Some respondents feared that their children would not take ACP discussions seriously or that such talk would trigger negative emotions (e.g. anxiety).

> ‘If I make my wishes known to my children now, I am going to cause them anxiety and stress, they are going to start crying and ask why I am bringing this up.’ (Respondent 7, 84-year-old man)
>
> ‘Yes, what can I say, I don't want them to laugh at me.’ (Respondent 5, 68-year-old woman)
>
> ‘I don't want to give my children headaches, a man should forget about this [death, illness, old age] because if you keep thinking about this, it creates other problems. As for your mental state, leave it in the hands of God and trust in God.’ (Respondent 4, 77-year-old man)

Other respondents realised that ACP could help relieve pressure on family members related to future care. They suggested that GPs should inform patients’ children about the benefits of ACP and stimulate their involvement in ACP conversations in the GP office and at home.

> ‘Indeed, ACP is useful, I don't want to be a burden on my children and wife.’ (Respondent 6, 79-year-old man)
>
> ‘It is a good idea that the GP gives information to the children, yes that is better, because then they will understand, and they will listen to the doctor.’ (Respondent 10, 65-year-old woman)

Some respondents indicated that they would like to undertake ACP in the future, after speaking to their children.

> 'Now that you have brought this to my attention, I can speak to my children about it first, and think about it.' (Respondent 1, 69-year-old woman)

In addition, some respondents with children mentioned that ACP could be useful for people who did not have children's/family members' support.

> 'If I see that I am not getting support from my children, then I will ask for this, yes.' (Respondent 21, 68-year-old woman)
>
> 'For someone who is alone, this is a good option.' (Respondent 1, 69-year-old woman)

3.2.4. Other ACP barriers and facilitators

Respondents mentioned their lack of knowledge about ACP as a barrier to ACP discussion; some respondents attributed this lack to their illiteracy.

> 'No idea, we don't know anything. We have never studied, and we know nothing. I think if I had been literate [educated], I would know much more and perhaps have done more, but one who isn't aware can't do anything.' (Respondent 21, 68-year-old woman)

Most interviewees had difficulty expressing opinions about (or even imagining) treatment restrictions in a medically hopeless situation, despite the example case. Those with experience of situations in which end-of-life decisions had to be made had opinions about the restriction of life-prolonging drug provision.

> Interviewer: 'What do you think about a person stating in advance that they will not receive any more life-extending treatment if they are in a coma or have an untreatable disease, with the result that they [the person's family/representatives] let that person die?'
>
> Respondent 10 (65-year-old woman): 'No you can't say that, you can't say at that moment that you are going to let that person die. And you can't say it in advance either, you mustn't give up hope.'

Another ACP barrier was respondents' **current good health**.

> 'I am currently in good health and don't need it, but if I get sicker, I might do this.' (Respondent 19, 70-year-old woman)

Other respondents indicated that their lack of organisation and taboos regarding the discussion of illness and death prevented them from discussing the end of life.

> 'The problem we [Moroccans] have is that we don't do this, that we don't live our lives in an organised way and don't think beforehand.' (Respondent 9, 67-year-old man)
>
> 'Because this is taboo. Death is something everyone fears and avoids.' (Respondent 9, 67-year-old man)

For most interviewees, GPs' provision of understandable ACP information was the primary facilitating factor.

> 'If this [ACP] is brought up, then yes [I would undertake ACP]. If he [the GP] doesn't bring it up, then

no.' (Respondent 20, 66-year-old woman)

4. Discussion and conclusion

4.1. Discussion

4.1.1. Summary

This study showed that older Moroccans had no ACP knowledge and had not discussed ACP with healthcare professionals. Many had discussed their wishes about burial and possible nursing home residence with family members. Upon being introduced to ACP as a form of advance communication, most respondents felt that ACP would not be useful or meaningful, mainly for religious reasons. However, after the provision of more information about what ACP entails, a large proportion of interviewees **had fewer religious objections** and were interested in discussing topics such as their burial location and the refusal of **futile care**. **Persisting barriers** were the lack of need or desire for ACP due to current good health, **potential harm of talking about death,** trust in one's children to handle care decisions and fear of worrying one's children. The respondents had some common reasons for starting or not starting ACP, but individual variation also existed. The facilitators mentioned were GPs' provision of information, children's involvement in ACP discussions and the desire to not be dependent on one's children.

4.1.2. Strengths and limitations

Older adults with Moroccan backgrounds in Belgium are understudied [28], possibly due to the language barrier for many researchers. The interviewer and respondents in this study shared a language and background, enabling in-depth exploration of their views on ACP.

Qualitative research entails possible selection bias [29]. Presumably, patients and family members who are willing to participate in studies of this type have good relationships with their GPs. Those who do not wish to be interviewed may provide other ACP-related insights. In addition, the study population was less educated, and grasping ACP-related concepts was challenging for some, despite the interviewer's effort to ask comprehensible questions. **Moreover, the manner in which ACP was described could have led participants to adopt a positive perspective on it. These factors** may have impacted their answers. **In future research, the type of case example used could be varied across the sample to assess the influence of this factor.**

4.1.3. Comparison with existing literature

Participants in this study attributed their lack of ACP knowledge to their low educational levels. More than half were illiterate and few had finished primary school, the highest educational level in this sample. This factor results in low health literacy [30] – limited knowledge of and participation in the health sector – which has been identified as an ACP barrier [31]. ACP knowledge has been associated with a higher ACP completion rate [32]. In contrast, language, rather than illiteracy, was an ACP barrier in an elderly Turkish population [14]. **As a solution for this lack of knowledge, a frequently mentioned facilitator was GPs' provision of ACP information. Systematic reviews have confirmed that patients and many GPs believe that the other party should initiate ACP discussions [33]. We acknowledge that information provision or education is a single step toward improved ACP implementation, which needs to be interpreted in the context of other barriers. Ethnic disparities in healthcare use could also lead to difficulty and unfamiliarity with understanding and documenting ACP [34]. Perceived discrimination in the healthcare system [35] and distrust arising from the interpretation of advance directives as a means of limiting care costs and resources at the end of life have been documented [36]. Although not directly mentioned by our respondents, their potential roles in this population should be studied further.**

Doctors and care providers have reported that religious beliefs can make ACP discussions difficult [33], especially among older people of Moroccan and Turkish origin, who reject communication about end-of-life care [37]. In this study, however, **most respondents mentioned religion as a barrier only at the beginnings of interviews, before having received a detailed explanation of ACP with a case example**. Thus, doctors may misconceive the role of religion in migrants' resistance to ACP; the problem may be that their explanations of ACP are too brief. Our findings likely reflect our culture-sensitive approach, with the interviewer and interviewees sharing ethnicity, religion and language. Familiarity with and openness to cultural values can increase the success of ACP conversations [38,39], facilitated by or even requiring a good patient–clinician relationship.

Respondents in this study had great and diverse expectations of their children. Children's informal care provision was very important to them, as found for older adults with Moroccan backgrounds in Belgium and the Netherlands [40,41]. Some older Moroccan adults leave decisions about their future care entirely to their children and/or expect their children to care for them, as observed in African American and Latin American populations in the United States [42,43]. Our respondents indicated that children's elder care is common in Moroccan culture and passed down generationally; many did not discuss their expectations with their children (beyond burial preferences) because they feared that their children would become anxious or not take them seriously. These barriers have also been identified among elderly Turkish individuals in Belgium [14]. Similarly, Glass et al. [44] found that elderly people in the general American population trusted their children to make end-of-life choices for them, without discussion in the majority of cases. Such lack of discussion can lead to misunderstandings about expectations, which could be resolved by ACP. Our respondents indicated that their children’s involvement in ACP conversations could be useful. Care providers should consider having such conversations when their elderly patients express this wish. The children’s perspectives on such involvement remain unclear and need to be investigated.

After being introduced to ACP, our respondents had different perspectives on what actions they would take. **Some wanted to avoid such burdening discussions, consistent with findings that other ethnic-minority groups viewed talking about death, negative information or serious illness as potentially harmful [45,46].** Some wished to undertake ACP as soon as possible, whereas others preferred to wait until they had thought about it further, discussed their preferences with their children or become sick(er). Overall, the results of this study reflect great variation in the Moroccan community in approaches to end-of-life decisions and reasons for starting or not starting ACP. Common factors include religion, possibly shared cultural beliefs and migration background, but major differences in language, customs, religiosity, education level and socio-economic background exist within this community [47]. Recognition of these social sub-identities and their influences on ACP-related conversations, decision making and communication with care workers is important for the success of ACP.

4.2. Conclusion

Despite their initial lack of ACP knowledge, many older Moroccans in Belgium were willing to discuss ACP and some wished to undertake ACP after receiving comprehensible concrete information in their native language. **Persisting barriers were current good health, trust in children’s care decisions, the perceived potential harm of talking about death and fear of worrying one’s children.** GPs should facilitate ACP discussions with these patients, **ideally with adult children involved**, with consideration of individual preferences and the generally low education level.

4.3. Practice implications

To improve the ACP participation of Moroccans in Belgium, patient and migrant associations, the government and GPs should raise awareness about ACP so that individuals know what steps to take when they are ready. Awareness-raising campaigns and good patient–doctor relationships are important to achieve this goal. Physicians should remain patient centred and be aware of patients' education levels [48]. In addition, they should pay sufficient attention to the way in which they describe ACP, which can determine the impact of discussions, as in this study.

This study also revealed the strong role of older adults’ children in decisions about whether to undertake ACP. The extent to which older Moroccans assign caretaking and decision-making roles to their children varies widely, ranging from leaving all responsibility to children based on their experiences with their own parents to arranging everything themselves to avoid burdening their children. Further qualitative research on the children's views on ACP would be of interest.

Additional information

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"I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story."

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