

# Qualitative analysis of an intensive care unit family satisfaction survey\*

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**Objectives:** To describe the qualitative findings from a family satisfaction survey to identify and describe the themes that characterize family members' intensive care unit experiences.

**Design:** As part of a larger mixed-methods study to determine the relationship between organizational culture and family satisfaction in critical care, family members of eligible patients in intensive care units completed a Family Satisfaction Survey (FS-ICU 24), which included three open-ended questions about strengths and weaknesses of the intensive care unit based on the family members' experiences and perspectives. Responses to these questions were coded and analyzed to identify key themes.

**Setting:** Surveys were administered in 23 intensive care units from across Canada.

**Participants:** Surveys were completed by family members of patients who were in the intensive care unit for >48 hrs and who had been visited by the family member at least once during their intensive care unit stay.

**Interventions:** None.

**Measurements and Main Results:** A total of 1381 surveys were distributed and 880 responses were received. Intensive care unit

experiences were found to be variable within and among intensive care units. Six themes emerged as central to respondents' satisfaction: quality of staff, overall quality of medical care, compassion and respect shown to the patient and family, communication with doctors, waiting room, and patient room. Within three themes, positive comments were more common than negative comments: quality of the staff (66% vs. 23%), overall quality of medical care provided (33% vs. 2%), and compassion and respect shown to the patient and family (29% vs. 12%). Within the other three themes, positive comments were less common than negative comments: communication with doctors (18% vs. 20%), waiting room (1% vs. 8%), and patient rooms (0.4% vs. 5%).

**Conclusions:** The study provided improved understanding of why family members are satisfied or dissatisfied with particular elements of the intensive care unit and this knowledge can be used to modify intensive care units to better meet the physical and emotional needs of the families of intensive care unit patients. (Crit Care Med 2011; 39:1000–1005)

**KEY WORDS:** family satisfaction; communication; qualitative study; survey; ICU

Meeting the emotional needs of family members of patients in the intensive care unit (ICU) is an important aspect of patient- and family-centered care (1–3). Patients in the ICU often lack decisional capacity and family members are frequently involved in the daily decisionmaking processes for their critically ill relatives. Family members' perspectives about, and satisfaction with, the ICU experience is therefore highly relevant for gaining in-

sight into the ICU experience (4) and ascertaining opportunities for healthcare delivery improvement from the family perspective.

Typical evaluations of family satisfaction in the ICU involve surveys that assess characteristics of the ICU experience such as satisfaction with overall care, the decision-making process, and communication (1, 2, 5–7). Complementing these quantitative analyses with qualitative data yields an additional important dimension to our under-

standing (4). In free-text responses, family members are able to express which aspects of their ICU experience most significantly affected their satisfaction without being constrained by predetermined topics or response options. Furthermore, qualitative information can bring to life why families are satisfied or dissatisfied with any aspect of the ICU experience (8) and provide essential context often missing in quantitative data. A family satisfaction study was conducted using a survey instrument that included a combination of quantitative items and open-ended questions. The purpose of this article is to describe the qualitative findings from this survey to identify and describe the themes that characterize family members' ICU experiences and the relative importance of these themes to families, which is especially important as ICUs face increasing pressure to meet external performance benchmarks with fixed resources.

## METHODS

As part of a larger mixed-method study to determine the relationship between organiza-

### \*See also p. 1207.

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tional culture and family satisfaction in critical care, family members of patients in 23 ICUs from across Canada were surveyed. Patients who remained in ICU for >48 hrs and who had a family member visit them at least once during their ICU stay were eligible. After obtaining Research Ethics Board approval for this project at each site and meeting with the clinical leaders within each ICU, a local research coordinator distributed a Family Satisfaction Survey (FS-ICU) (5) to 40 consecutive family members of ICU survivors and 40 consecutive family members of ICU nonsurvivors. The FS-ICU has 24 items, each of which has five Likert response options that range from “poor” to “excellent.” Validation and factor analysis has shown that the survey measures two broad domains: satisfaction with care and satisfaction with decision making (9). Three open-ended items elicit written responses: 1) Do you have any suggestions on how to make care provided in the ICU better? 2) Do you have any comments on things we did well? 3) Please add any comments or suggestions that you feel may be helpful to the staff of this hospital. Responses to the latter questions form the basis of this qualitative study.

Family members of ICU survivors were approached when the patient was ready for discharge from the ICU. Family members of ICU nonsurvivors were contacted by mail approximately 2–3 wks after the death of their relative. After the patient left the hospital, information was collected about the patient, including age, sex, race, primary ICU admitting diagnosis, Acute Physiology and Chronic Health Evaluation score, ICU length of stay, hospital length of stay, and hospital mortality, from the medical record. Survivorship was not prioritized or considered as a respondent characteristic in the analysis.

For the family member respondents, the survey was used to collect their age, sex, relationship to patient, and whether they had prior experience as a family member of an ICU patient. To ensure data anonymity, patients and their matching family members were identified to central research staff only by a study number on the surveys and data collection forms.

The comments and patient/respondent attributes were imported into *NVivo 8* (QSR International, Melbourne, Australia), a qualitative research software, for thematic coding and analysis. The comments were coded by a research assistant who was trained in *NVivo* and who had experience in qualitative coding. Coding was reviewed by a qualitative researcher (N.H.). All comments were read and recurrent themes were identified (Table 1). For most themes, separate codes were created to capture the positive and negative aspects of the theme. For example, the theme “communication” had two related codes: “communica-

**Table 1.** Themes that emerged from the comments<sup>a</sup>

Themes With Positive and Negative Comments <sup>b</sup>	Themes With Only Negative Comments
Access to patient and visiting hours	Lack of beds
Availability of doctor	Parking
<b>Communication</b>	
<b>Compassion/respect for family and patient</b>	
Consistency of care by staff	
Decision making of staff	
End-of-life decisions	
Equipment	
Family listened to	
Food	
Hospital ambience	
Hygiene (hospital)	
Hygiene (patient)	
Knowledge and skill	
Overall care	
Patient listened to	
<b>Patient room</b>	
<b>Staff</b>	
Volunteers	
<b>Waiting room</b>	

<sup>a</sup>Themes mentioned by at least 5% of respondents are indicated in bold; <sup>b</sup>themes with both positive and negative comments each had two codes corresponding to the theme to capture the directionality of the comment.

tion-positive” and “communication-negative,” which captured positive and negative comments, respectively, about communication in the ICU. Comments characterized by the themes “hospital ambience,” “hospital hygiene,” “patient rooms,” and “waiting rooms” were differentiated by the way in which they were mentioned by respondents in their comments. The themes could be classified as subthemes of a broader theme “hospital environment” but we kept them distinct because they appeared to be presented as separate issues by respondents. “Hospital ambience” included statements about the hospital’s atmosphere (eg, lighting, noise, air quality), “hospital hygiene” was explicitly about cleanliness of the hospital (eg, stained carpets, dirty gloves under beds), and the themes “patient rooms” and “waiting rooms” included comments specifically about these rooms rather than the overall hospital. After comments were classified into themes, they were qualitatively described (10).

Frequency of themes was analyzed to understand their relative importance for family members. Only one comment per theme per person was counted when calculating the frequency of themes, but if a respondent wrote both positive and negative comments, both were counted. This was done to avoid biasing the results if individuals made numerous comments on the same theme, which could make

a theme appear to be more robustly commented on than it really was. In the qualitative review and interpretation of the themes, all comments were included (not just one per person). The proportion of comments per theme was calculated for each site and weighted by the number of ICU admissions for that site in 2007 (the year of data collection) to take into account the varying size of the ICUs and hence capture satisfaction of family members of patients in a way that reflects the overall population of ICU families from the study sites. Consequently, larger ICUs contribute more to the frequency than smaller ICUs because they also contribute more to the overall population of ICU families. Using these weighted proportions, the overall weighted frequency of responses for each theme was calculated. We reviewed the comments within each theme. During the review, subthemes were created to capture several topics within a theme that were repeatedly commented on by respondents. As well, comments that best characterized each theme or subtheme were identified as examples cited subsequently.

## RESULTS

Surveys were distributed to family members of 781 ICU survivors and 600 ICU nonsurvivors. Completed surveys were received from 880 family members; the response rate was 69% for family members of ICU survivors and 57% for family members of ICU nonsurvivors. Eighty-four percent of respondents wrote a comment for at least one of the open-ended items with a response rate per item of: 471 (Quartile 1), 633 (Quartile 2), and 478 (Quartile 3). Most of the respondents were female, relatives of ICU survivors, and relatives of patients who stayed in the ICU for <14 days (Table 2).

Twenty-two themes (Table 1) were identified, six of which were mentioned by at least 5% of all respondents (Table 3). The percentage of respondents who commented on each of these themes at each site varies but the relative value of these percentages within each site is similar and similar to the overall weighted average of these percentages. Subthemes or main issues emerged for each of the six most frequently mentioned themes (Table 4). These six most frequently mentioned themes are the focus on the results.

### Theme: Staff

The most common theme identified (66% of respondents) was the high quality of the staff. The positive staff comments were either explicitly about nurses

Table 2. Characteristics of respondents

Characteristic	# of Respondents	% of Respondents
Sex		
Male	266	30%
Female	605	69%
Missing	9	1%
Survivorship		
Relative of survivor	536	61%
Relative of nonsurvivor	344	39%
Length of patient's stay in ICU		
Patient in ICU <14 days	683	78%
Patient in ICU ≥14 days	164	19%
Missing	33	4%
Relationship to patient		
Spouse	421	48%
Husband	119	14%
Wife	302	34%
Partner	19	2%
Sibling	44	5%
Brother	13	1%
Sister	31	4%
Parent	84	10%
Father	15	2%
Mother	69	8%
Other	48	5%
Missing	14	2%
Number of ICU beds		
1–10	372	42%
11–20	321	36%
>20	187	21%

ICU, intensive care unit.

Table 3. Themes mentioned by at least 5% of respondents

Theme	Positive Comments <sup>a</sup>	Negative Comments <sup>a</sup>
Staff (all)	66 (569)	23 (202)
Nurses	36 (302)	9 (77)
Doctors	20 (158)	10 (96)
Overall care	33 (277)	2 (19)
Compassion/respect for family and patient	29 (255) <sup>b</sup>	12 (103)
For family	15 (132)	6 (52)
For patient	13 (116)	6 (61)
Communication	18 (156)	20 (189)
Waiting room	1 (9)	8 (54) <sup>b</sup>
Patient room	0.4 (4)	5 (40)

<sup>a</sup>Percentage of respondents who made a comment on a given theme, weighted by the number of intensive care unit admissions per site in 2007 (year of data collection); number of respondents who made a comment on a given theme in parentheses following the percentage; <sup>b</sup>sum of the positive comments about compassion/respect for family and patients is less than the total number of positive comments because the total number includes comments that did not specify to whom the compassion/respect was directed; <sup>c</sup>includes both negative comments about the waiting room and suggestions for change.

Table 4. Subthemes and main issues for the six most frequently mentioned themes

Theme	Subthemes/Main Issues
Staff	Interpersonal skills Shortage of nurses Inappropriate/unprofessional conversations
Overall care	Competency and quality of care
Compassion/respect for family and patient	Kindness meeting individual patient/family needs
Communication	Frequency of communication Inclusion/exclusion of family and patient from communication Left waiting Directness/lack of directness when the patient is unlikely to be cured Logistics/nonmedical communication
Waiting rooms	Décor Amenities Eating area/rules
Patient rooms	Privacy Chairs Noise

or doctors, or about staff other than nurses and doctors, or were general statements that did not specify the staff roles. Twenty-three percent of respondents made a negative comment about staff. Positive comments about staff generally referred to the competency and professionalism of the staff and the attitude with which care was provided. For example, “Everyone did their best with concern and pleasant attitudes.” Negative comments about staff were rarely about their competency but were about the following subthemes:

**Interpersonal skills.** Negative comments about the physicians characterized them as rude, abrupt, insensitive, and appearing to dodge interaction with family members. For example: “I was appalled at how the doctor who treated my mother was so blunt. He ‘basically’ told me your mom will be dead by morning so come in say goodbye and make funeral arrangements tomorrow! All on the telephone.”

**Shortage of nurses.** Respondents perceived a shortage of nurses but comments were aimed at the institution rather than at the nurse. For example: “Most shifts, the nurses worked short and had two patients rather than one—they worked as well as they could.”

**Inappropriate/unprofessional conversations.** Comments categorized into this subtheme refer to inappropriate conversations by ICU staff in general, although nurses were singled out as predominantly having these “unprofessional” conversations. Inappropriate/unprofessional conversations include both the content and the mood and volume of the conversa-

tions. For example: “A nurse from the hospital who came into the ICU to collect blood samples ought to be told that it is highly inappropriate to express extreme frustrations over not finding sufficient supplies in a nearby supply room. Also, she ought not comment on how she dislikes her job and cannot wait to get out with only a few short years to retirement. How unprofessional!”

### Theme: Overall Care

Respondents had a very high regard for the competency of the ICU staff. This theme included comments about the overall medical care provided in the ICU such as: “I sincerely believe that the best care possible was provided and no one could ask for more.”

The overall satisfaction with medical care provided in ICUs is indicated by the fact that only 2% of respondents made negative comments about overall care.

### Theme: Compassion/Respect for the Family and Patient

Although considered as a distinct theme, compassion and respect for family/patient emphasizes how much of the positive experience that families have in the ICU relates to the staff and their non-medical interactions with them. Positive comments on this theme were about being treated with kindness and about how staff treated the patient and family as individuals and made accommodations to meet their specific needs. We use the term “respect” to reflect this element of individuality in dealing with patients and

family. Respondents provided many examples of staff providing care and making modifications to standard procedures because they recognized the importance of these changes for that patient/family.

In one situation, staff assisted in holding a wedding in the ICU, as the respondent wrote: “When my wife was admitted to the ICU, the staff learned that our family had planned to have a wedding in the next few days—that my wife was now going to miss. The ICU staff then went ahead and arranged for us to hold a wedding in the ICU so that my wife could be present.”

Another element of compassion that was valued by the families was being given the time and space needed to say goodbye to loved ones and to grieve. This was perceived not as an assumed right, but rather something for which they credit the kindness of the staff. For example: “They [ICU nurses] showed compassion for us and gave my family and I the needed time to be with our loved one up to the time of his death. We appreciate the support they gave us.”

In contrast to respondents who felt that they were treated with compassion and respect for individual needs, 12% of respondents commented that they had the opposite experience. The same elements were raised in the negative comments regarding compassion/respect as in its positive version of the theme—meeting individual needs, providing time and space to grieve, and overall warmth and kindness. For example: “[The ICU nurse] refused to let my eldest son stay in the waiting room the first night my husband was critical, after he had driven from [another city] in a blinding snow storm to be with his dad.”

The number of comments related to inadequate compassion/respect directed at the patient and the family were the same (6%).

### **Theme: Communication**

A slightly greater percentage of respondents wrote negative comments about their experiences communicating with ICU staff than those who wrote positive comments about communication (20% vs. 18%). Negative communication experiences were categorized into subthemes.

*Frequency of Communication.* Respondents were often displeased with the frequency with which they received information about the patient, especially from the ICU physicians. For example: “Overall, the communication needs to be im-

proved. For example, days would pass without us seeing the physician in charge of our family member. We had to request a family meeting every week to get any information about her care.”

Related to the infrequent physician communication was a more general discontent about the limited availability and lack of visibility of the physicians in the ICU. Respondents seemed extremely frustrated because they were unable to locate doctors. For example: “The care my wife received at [the ICU] was very good but again no sign of a doctor. Who was over-seeing the care my wife was receiving?”

*Exclusion of the Family/Patient From Communications.* Respondents expressed feeling excluded from discussions that the physicians were having about their loved ones. Repeatedly, respondents commented that physicians would ask them to leave the room while the patient was being discussed, that physicians would talk about the patient outside the room without including the family, or that physicians would talk among themselves about the patient in the presence of the family but would exclude them from the discussion. The tone of the comments seems to reflect frustration and anger at the family’s exclusion. For example: “Often times, we would see a group of doctors outside the room .... They would point at our family member and they would then leave .... Nothing would be said to us. What is discussed during morning rounds should be communicated to family.”

*Left Waiting.* Respondents expressed criticisms that ICU staff did not adequately communicate how long they would have to wait to see their loved ones and the reason for the wait. The criticisms were not about the wait itself, but rather not being informed about how long the wait would be and waiting without receiving updates about the patient. The tone of the comments appears to reflect frustration and anger such as: “When they ask you to leave could they be more honest on how long it will take—do not say 15 mins and 2 hrs later I am still waiting outside ICU to come in feeling like I am going to be sick because I do not know what they are doing or why it is taking so long.”

*Lack of Directness When the Patient Is Unlikely to Be Cured.* Respondents stated that they want physicians to be direct and honest when it is unlikely that the patient will be cured. They believe that they are able to handle the information

and that full and realistic information about the situation better enables them to make treatment and end-of-life decisions and to cope with the patient’s situation. For example: “Always be honest with family members about the situation at hand, it is much easier knowing what is really happening then to guess.”

*Logistics/Nonmedical Communication.* Family members’ comments expressed a need for logistic information. Respondents needed information about how the ICU operates (such as when patients can be seen) and practical details like where to find water and how to contact a chaplain. For many, the ICU experience is overwhelming and they need assistance in how to function within this novel context, including being informed about what resources are available. Comments also included multiple requests for an initial orientation to the ICU. For example: “The ICU is a ‘scary place.’ It would be helpful if, on arrival, a volunteer could explain how things work and give a bit of comfort as well.”

In contrast to the negative comments about communication, 18% of respondents expressed positive comments about communication in the ICU. Positive aspects of communication included observations that the doctors and other staff were readily available, that updates on the patient were given with sufficient regularity, that information was provided with honesty and directness, and that questions were thoroughly answered. The first three of these are the same dimensions of communication that other respondents felt were inadequate, thus highlighting the variability of the ICU experience and a potential lack of consistency across and within ICUs. For example: “The doctors readily made themselves available and were patient and informative. For the most part, nurses encouraged me to telephone for updates which I did frequently.”

### **Theme: Waiting Rooms**

Eight percent of respondents commented negatively on the waiting rooms or provided suggestions for change. Their comments stated concrete problems and recommendations for improving these rooms. Only 1% of respondents made a positive comment about the waiting room. Some of the features that many respondents suggested including in waiting rooms are free phones, couches/more chairs, television, tissues, a brighter/cheerier décor,

coffee/snacks, and a separate room for eating or a rule against eating in the waiting room. Common complaints about the waiting room were that the rooms are dirty, unwelcoming/dreary, uncomfortable, and too small.

### **Theme: Patient Rooms**

Five percent of respondents made negative comments about patient rooms in the ICU. The primary criticisms were that the rooms need more chairs, lack privacy (especially when the patient is dying), and are too noisy.

## **DISCUSSION**

In this study of responses from 880 family members of ICU patients, family ICU experiences were found to be variable. Of the 23 themes that emerged from the comments, only six were expressed by at least 5% of respondents. It may be the case that these six themes characterize elements of the ICU experience that have the greatest impact on families' satisfaction. The fact that these themes were expressed in both positive and negative terms by respondents suggests that when these elements of care are handled well, then satisfaction may be high, whereas when they are handled poorly, satisfaction may be low. The identification of these key elements can help ICU and hospital administrators prioritize their efforts on the aspects of the ICU that most significantly impact family satisfaction.

In addition to identifying key elements of satisfaction, the comments reveal the components of large problems, which can be used to address the issues by breaking them into manageable parts. The aggregate analysis of the comments provides a good overall understanding of what may be the most important issues to family members. However, because of the variability across sites, it is also important for hospitals to do site-level analyses to determine the specific strengths and weaknesses in their ICU.

The findings from this qualitative assessment provide insight that aids in interpreting the quantitative survey data. For example, the FS-ICU 24 showed that families are least satisfied with how often physicians communicate with the family about the patient's condition. The frequency of negative comments about physician communication identified in this qualitative study supports this finding, but also illuminates families' expecta-

tions and needs regarding frequency of communication and underscores the emotions (eg, frustration, anger) associated with insufficient communication. Enhanced interpretation of the survey results with these qualitative results can facilitate a more effective response to the findings.

The findings are consistent with elements from other studies (3, 5, 7, 8, 11). In a study of six Canadian ICUs, families were least satisfied with the waiting room atmosphere and with the frequency of physician communication (5). A qualitative study in an American ICU concluded that family members need more regular updates on the patient, to receive information directly from physicians, and that resources need to be provided to meet the physical and psychosocial needs of family members (8). Similarly, a study on satisfaction with communication in a Brazilian ICU (7) found that satisfaction was positively associated with more frequent communication from staff, especially physicians, clarity about prognosis, and good interpersonal skills. A questionnaire-based study in 43 French ICUs concluded that among the factors associated with family satisfaction is sufficient time spent getting information from physicians about the patient (11). These findings are compatible with the comments made by our respondents about a lack of contact and information in general, and specifically from physicians, poor interpersonal skills by some physicians, a desire for direct information, a need for more information about nonmedical aspects of the ICU, and dissatisfaction with waiting rooms. Davidson et al (3) developed practice guidelines (ACCM/FCCM Guideline for Support of the Family in the Patient Centered ICU) for support of patients and families in ICUs based on a meta-analysis of >300 studies. There is significant overlap between these guidelines and what we found families are concerned about in the ICU. Consistent with the guidelines, families want frequent communication with healthcare providers (especially physicians) and to be included in discussions about the patient during rounds. Also consistent with the guidelines, family members indicated in their comments that they want improved waiting rooms and information that aids them in navigating the ICU. Some comments referenced positive and negative experiences around visitation, which is compatible with the guideline related to open, flexible visitation. Comments re-

lated to cultural and spiritual needs, decision making, and family support around death were extremely rare, which is in contrast to the guidelines emphasis on these elements.

Qualitative evaluations in ICUs yield insights and descriptions about behaviors, beliefs, experiences, concerns, and relationships related to the ICU experience (12). Taken either independently or in collaboration with related quantitative studies, the narratives and observations from qualitative research can be used to develop theories about how ICUs operate and are experienced, which can be used to improve their operation and the services provided (12). Using a qualitative approach to research family satisfaction is consistent with other qualitative studies that aim to improve our understanding of experiential aspects of ICUs such as communication with family members (13, 14), behavior change (15), and end-of-life care (16, 17).

### **Strengths of the Study**

By providing respondents an opportunity to share their opinions on any aspect of their ICU experience, the study yields insight into the elements of their experience that were most salient or significant to them. The open-ended format of the responses provided anecdotes and examples that complement and provide context for findings from quantitative satisfaction surveys. Furthermore, our qualitative assessment is based on 880 surveys, more than any other qualitative study in critical care of which we are aware.

### **Limitations of the Study**

Inferences from our findings are limited by the sampling frame of our survey. Given the large sample size, these comments likely capture the diversity of opinions from families in participating ICUs, but our results may not represent the experience of all families in all Canadian ICUs or fully reflect the variability in the relative importance of each theme across participating sites. As well, respondent characteristics were not evaluated to determine whether the respondents were representative of their sites. Although application to other healthcare systems, cultures, and countries is uncertain, it is likely that some experiences are universal. Recruitment of family members of survivors and nonsurvivors was different (in person vs. mail, respectively), which

may have resulted in people who have different views responding to the different recruitment approaches, although the likelihood or direction of such an hypothesis cannot be predicted. Furthermore, we have no information about the perspectives of family members who chose not to respond to our request to complete the surveys; it is possible that these families have different perspectives from the ones that we have observed.

## CONCLUSIONS

In this qualitative survey, family members' experiences of critical care were found to be variable. However, six themes consistently emerged as central to families' satisfaction with their ICU experience: quality of staff, overall quality of medical care, compassion and respect shown to the patient and family, communication with doctors, waiting room, and patient room. If these elements are handled correctly, satisfaction is likely to be high and when these elements are poorly handled, satisfaction is likely to be low. Several suggestions to improve these aspects of care are recommended subsequently. These recommendations are based on the ease of implementation and the importance/impact of making the change with each recommendation, which addresses a concern expressed by at least 5% of respondents: 1) establish regular meetings among physicians, family members, and patients, especially when patients are most acutely ill; 2) provide workshops for improving physicians' interpersonal and communication skills; 3) educate all staff about professional discussion taking place in front of patients and family members; 4) provide more chairs inpatient rooms; 5) provide informational pamphlets and orientation to the ICU; and 6) make waiting

rooms more welcoming, providing basic amenities such as tissues and coffee. These recommendations are also found in the American College of Critical Care Medicine/Fellow of the American College of Critical Care Medicine Guideline, with the exception of recommendations 3 and 4.

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