



# On the violation of hospitalized patients' rights: A qualitative study

Nursing Ethics  
2019, Vol. 26(2) 576–586  
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## Abstract

**Background:** Nurses have always been known as an advocate for the rights of patients. The recognition of what is perceived as the violation of patients' rights can help nurses to understand patients' concerns and priorities. Thus, it helps nurses play their supportive roles more effectively.

**Objective:** The aim of this study was to explore different dimensions of the violation of patients' rights.

**Research design:** Data were collected utilizing unstructured interviews and field notes. Data analysis was conducted using the qualitative content analysis approach. Prolonged engagement, maximum variation sampling, and member check were among the factors which enriched the research.

**Participants and research context:** The sample consisted of 18 patients and 11 members of their families. They were purposively selected from two hospitals in Tehran during 2009–2012.

**Ethical considerations:** The research was approved by the Ethics Committee of the university and hospitals.

**Finding:** The patients' rights were violated in a variety of ways. There were three main dimensions to this issue: (a) care recession including deprivation of the caregiver's presence and the delay/lack of needed responses; (b) receiving mechanical care including superficiality, lack of emotion, and failure to understand the situation; and (c) being disrespected including humility and aggression.

**Conclusion:** The patients and their families consider any shortcomings in relation to the patient and the quality of care as the violation of the rights. The findings of the study imply sensitizing managers toward providing appropriate conditions as well as educating nurses to observe patients' rights. It is suggested that the processes leading to the violation of patients' rights be discovered and prevented in the future.

## Keywords

Nursing, patients', qualitative research, rights, violation of rights

## Introduction

Hospitalized patients are some of the most vulnerable recipients of the health system services; therefore, observing their rights is crucially important. The concept of "patients' rights" has a long history, but it has received more attention recently especially with regard to the contemporary challenges and has been stood out as the core of some research.<sup>1–4</sup>

The main themes of current research include clarifying the concept of patients' rights as a whole;<sup>1,5</sup> studying related topics separately such as dignity,<sup>6</sup> privacy,<sup>7</sup> mechanical restraint measures, and patients' legal rights;<sup>8</sup> and investigating patients' and professionals' awareness of patients' rights and how to observe them.<sup>3,9-11</sup> Furthermore, the term patients' right is visible in many of the contexts discussing the quality of care or interpersonal relationships.<sup>12-14</sup> In these studies, even when the term patients' right is not mentioned explicitly, it is, most of the time, implied<sup>15</sup> and contributed to the development of knowledge associated with patients' rights. Rider and Makela,<sup>1</sup> in explaining this concept, point out that it can be studied from a social, individual, or human point of view. Patients' rights being considered as social rights determine the quality and access to healthcare including rights for healthcare, access to information, selection, participation, human dignity and care, confidentiality, and compensation.<sup>1</sup>

In a phenomenological study, holistic care has been reported as a core theme of patients' rights which can be determined by patient-centeredness, understanding based on empathy, effective communication, informed participation, complete support, and meeting patients' basic needs.<sup>5</sup> In another study, it is shown that the British government's Patients Charter must be revisited and looked at differently in terms of observing patients' rights. From the perspective of patients, there are a number of issues of importance to patients such as pain relief, providing and receiving information, reception staff, and physical examinations and investigations which are needed to be added in the Patients Charter.<sup>16</sup> Observing these rights is one of the most important components of humanistic and ethical care; thus, it improves treatment, reduces the length of hospitalization and the cost of treatment, and prevents irreparable physical and emotional effects.<sup>17</sup> In some studies, subsequent to observing the indicators of the patients' rights, several positive results such as "relaxation"<sup>18</sup> as well as patients' and nurses' "satisfaction" due to the patient-centered care<sup>19</sup> and mutual "love and trust" among patients and caregivers have been reported.<sup>20</sup>

With regard to the importance of observing patients' rights, several charters and declarations in different countries including Iran have been compiled.<sup>21</sup> The aim has been to inform the providers and recipients of healthcare system services and to promote and protect patients' rights. The related literature review shows that despite the publication of these documents, there are global challenges to achieve these goals. Examining the awareness of students, professionals, and patients on the patients' rights has shown fruitful results. The fair awareness of professionals (84.4%),<sup>22</sup> low awareness of medical and paramedical students toward patients' rights,<sup>23</sup> very low awareness of the patients (0.9%),<sup>10</sup> and inability (0.23%) and uncertainty (0.45%) of some other patients are among the findings of the related studies in recognizing patients' rights.<sup>9</sup> Findings related to evaluating the extent to which patients' rights are observed vary qualitatively. There are also several findings regarding the violation of patients' rights. Some indicators of the violation of patients' rights include the lack of receiving healthcare in accordance with the rights; lack of information of the staff and healthcare providers and their failure in introducing themselves; failure to request for services in accordance with patients' rights;<sup>10</sup> disrespecting patients' humanity, rights, privacy, and dignity;<sup>24</sup> and dissatisfaction with the preservation of dignity and the violation of the right to choose.<sup>25</sup> Such experiences have numerous consequences such as increased pain and sufferings,<sup>26</sup> physiological and psychological consequences,<sup>27</sup> an increase in hospital infections,<sup>28</sup> an increase in the mortality rate,<sup>29</sup> a sense of being broken down, a sense of depersonalization,<sup>30</sup> patients' dissatisfaction,<sup>31</sup> a decrease in patients' optimism toward the healthcare system,<sup>32</sup> and the violation of nurses' dignity in retaliatory behaviors.<sup>14</sup> Nonetheless, nurses have been always recognized as advocates and supporters of patients' rights. Respecting human rights is inherent in nurses<sup>33</sup> and nurses have a special commitment to protect and promote the health rights in any time and place.<sup>34</sup> However, fulfilling such commitments necessitates appropriate conditions. To play this role successfully, one has to overcome a number of obstacles and concerns.<sup>13</sup>

Like other countries, in Iran where the brilliant history of the development of the first charter of human rights is well documented, there are also heavy challenges in observing patients' rights. Moreover, patients' rights may not be fully observed due to a variety of obstacles such as limited facilities, the improper

structure of hospitals and wards,<sup>6</sup> and lack of access to appropriate prerequisites such as knowledge, competence, time, and equipment.<sup>35</sup> In a study, nurses' knowledge of the patients' bill of rights is considered to be acceptable; however, the observance of patients' rights is not. It seems that the improvement of the nurses' performance needs more extensive measures.<sup>11</sup> Evidences confirm failure in respecting patients' rights, and further research seems to be necessary to investigate the issue.<sup>3</sup> Perhaps one of the most important steps to meet this challenge is recognizing the various forms of the emergence of the violation. Most of the existing research has focused on certain elements and dimensions of patients' rights. However, few studies have investigated patients' rights as a whole. Also, according to the World Health Organization, to promote and protect patients' rights, every country should express its concerns and preferences in accordance with its social and cultural needs. The recognition of what is considered as the violation of patients' rights can help patients' rights advocates to recognize the patients' concerns and priorities and observe and support these rights accordingly.

## Objective

The aim of this study was to understand different dimensions of the violation of patients' rights.

## Research design

This qualitative study was carried out with a conventional content analysis approach. The reason is that the naturalistic paradigm and qualitative methods consider the reality based on the context and accept various structures of a phenomenon.<sup>36,37</sup>

## Data collection procedure

Data were collected through face-to-face unstructured in-depth interviews. Interviews were conducted with the agreement of the participants in a convenient and quiet place in the hospitals. In three interviews, there were ambiguities which did not allow for deep exploration of the data. Therefore, the participants were re-interviewed after the initial data collection and analysis. The interviews lasted for 15–80 min; however, one interview lasted for 2 h. At the beginning of communicating with the patients, an adequate description of their confidentiality and preserving the interviews and audio files was presented so as to gain their trust. Furthermore, it was explained that there was no organizational relationship between the researchers and the hospital staff and their interviews would have no impact on their care and services provided. However, it seemed recording interviews raised concerns in the participants and most participants seemed to be reluctant to talk when their interviews were recorded. Hence, after performing some interviews, note-taking was used instead of tape recording during some of the interviews. This action facilitated communicating with and enticing the trust of the patients, so it resulted in achieving more efficient and enriched data. In order to ensure the accurate record of the experiences of the participants, text notes were immediately reviewed and completed. General and open-ended questions were initially used in the interviews. Due to the sensitivity of the issue, to further get to know about both the context and circumstances of care and also to find out the participants who have a rich experience of rights violations, the interview began with a general question about receiving care. The patients and their attendants were asked, "How have you/your patient been cared for?" "Have you ever felt that your rights/your patients' rights have been violated? When? Please explain the situation." Then, the interviews were continued by asking exploratory questions such as "Please explain more," "Give an example, please," or "Please explain a real situation in which you have felt that your rights/your patient's rights have been violated." In addition, the field notes over the interaction of the patient/the family with the nurse(s) were recorded. The researcher continued the interviews until no new data were

identified. After each interview, in case it was recorded, it was fully transcribed verbatim. All interviews were analyzed. In the preparation stage, a complete interview, which could be considered as a meaningful unit, was selected as the most appropriate unit of analysis. Each interview was reviewed several times to allow for immersion of the data. To organize the data, open-coding was used, and marginal notes were taken after rereading the interviews. The coded data then were recorded in coding sheets for a later reference, and grouping began after several interviews. By repeating the mentioned process for each new interview, some topics were added until the final pattern emerged. Comparing and merging groups reduced the number of categories. Sub-categories were formed based on the similar characteristics and the name of the categories was indicative of their contents.<sup>38</sup>

## **Rigor**

Prolonged engagement and spending sufficient time to communicate and collect data helped to build trust and rapport with the participants and provided in-depth data collection. Maximum-variation sampling was used based on age, gender, job, education, diagnosis, length of stay, married status, and hospitalization wards. To make sure that the analysis accurately reflected the experiences of the participants, member check was conducted with several participants and some changes were applied to the data based on this procedure.<sup>36</sup>

## **Participants and research context**

The study was carried out in two teaching hospitals during 2009–2012. The participants were purposively selected from general surgery, neurosurgery, orthopedics, oncology, and intensive care unit (ICU) wards. The sample consisted of 18 patients and 11 members of their families. The general inclusion criteria were the experience of the phenomenon under investigation, which was explored by asking a general question about receiving care at the beginning of the interview, willingness, and the ability to transfer the experience. Other inclusion criteria for the patients included being hospitalized during the interview conduction and being able to speak Persian. While the interviews were conducted, if the patient or the caregiver withdrew from the interview or if the patient suffered from pain, inconveniences, or instability of physical status, they were excluded from the study. Of course, there were no such cases. Data collection was, finally, conducted with 29 participants.

## **Ethical considerations**

The study began after the necessary permits had been obtained from the University Ethics Committee (No. 150.53132). Necessary explanations were presented to the participants over the significance, objectives, methodology, consent process, and maintaining confidentiality at all stages of the study. In addition, the participants were informed about the characteristics of the study team and how to achieve results. The decision on determining the time and place of the interviews were made with the consent of the participants. In a qualitative study, obtaining informed consents to voluntarily participate in the study is a process; thus, in the whole period of data collection, this issue should be taken into consideration and checked. In the current study, due to the sensitivity of the subject matter, the participants' consent was continuously verified, too. Although the initial consents were obtained, during the interviews it was asked about the participants' consent and convenience to participate in the study. The participants were also assured that they could liberally leave the survey at any stage.

**Table 1.** Demographic information of participants.

| Patients |     |        |                            | Other |     |        |                          |                     |
|----------|-----|--------|----------------------------|-------|-----|--------|--------------------------|---------------------|
| No.      | Age | Gender | Diagnosis of the patient   | No.   | Age | Gender | Diagnosis of the patient | Family relationship |
| 1.       | 23  | M      | Spinal cord tumor          | 19.   | 24  | F      | Surgery                  | Daughter            |
| 2.       | 11  | M      | Brain tumor                | 20.   | 48  | F      | fracture                 | Mother              |
| 3.       | 79  | M      | Discopathy                 | 21.   | ~65 | F      | Cancer                   | Mother              |
| 4.       | 71  | M      | Discopathy                 | 22.   | 26  | M      | Neurosurgery             | Uncle               |
| 5.       | 40  | M      | Brain tumor                | 23.   | 47  | F      | Coma                     | Sister              |
| 6.       | 20  | M      | Fracture of tibia          | 24.   | 38  | F      | Brain hemorrhage         | Wife                |
| 7.       | 26  | M      | ACL trauma                 | 25.   | 21  | F      | Brain tumor              | Daughter            |
| 8.       | 52  | F      | Fracture of tibia and ulna | 26.   | 55  | F      | Cerebral palsy           | Mother              |
| 9.       | 22  | F      | Old fracture               | 27.   | 62  | F      | Fracture of femur        | Daughter            |
| 10.      | 65  | F      | Fracture of tibia          | 28.   | 40  | F      | Fracture                 | Mother              |
| 11.      | 62  | F      | Knee arthroplasty          | 29.   | ~20 | M      | Fracture                 | Friend              |
| 12.      | 15  | F      | Spinal cord tumor          |       |     |        |                          |                     |
| 13.      | 28  | M      | Multiple trauma            |       |     |        |                          |                     |
| 14.      | 11  | F      | Fracture of ulna           |       |     |        |                          |                     |
| 15.      | 72  | M      | Fracture of femur          |       |     |        |                          |                     |
| 16.      | ~50 | F      | Herniation                 |       |     |        |                          |                     |
| 17.      | ~50 | F      | Cholecystitis              |       |     |        |                          |                     |
| 18.      | 32  | F      | Parathyroidectomy          |       |     |        |                          |                     |

**Table 2.** Dimensions of the violation of hospitalized patients' rights.

|                           |   |
|---------------------------|---|
| Care recession            | Deprivation of the caregiver's presence<br>The delay/lack of needed responses |
| Receiving mechanical care | Superficiality<br>Lack of emotion<br>Failure to understand the situation      |
| Being disrespected        | Humility<br>Aggression  |

## Findings

The sample consisted of 29 participants, who were selected from different wards and had different diagnoses (Table 1). The duration of hospitalization of the patients ranged from 2 to 30 days. The mean age of the participated patients was 40.5 years, ranging from 11 to 79 years. The mean age of the other participants was 40.54 years, ranging from 20 to 65 years. Interviews with the participants highlighted various aspects of patients' rights violation. Patients and families expressed their appreciation toward the care and respect they had received from the nurses and other members of the care team, which was indicative of the observation of their rights. However, investigating this situation was not the purpose of this study. Based on the findings of this study, the violation of the patients' rights has three main dimensions including "recession of care," "receiving mechanical care," and "being disrespected." Each aspect appears in different forms (Table 2).

### Care recession

Care recession is the lack of access to care and delay or failure to receive appropriate responses to the needs. This concept has two aspects.

**Deprivation of the caregiver's presence.** Many participants had experienced the absence of caregivers and their unavailability when needed. In this situation, the patients' rights had been partially or completely neglected. Partial deprivation occurred when the professional nurse was absent; however, the patient still had access to unprofessional caregivers or attendants. Complete deprivation occurred in the absence of both professional caregivers and the patient's family:

Nurses have to be at patients' bedside, but they're not. Exactly when they are obliged to do their tasks for example putting in the drip, you can find them at bedside. My mom is 80 years, a nurse should constantly be at her bedside, but there is not. I'm in poor health too and having pain in my knee joints, so it's so difficult for me to look after her. In case of any need, there is nobody to be of assistance. (Participant no. 27)

**Delay/lack of appropriate responses to the needs.** Many of the participants complained about lack or delay in meeting their needs when necessary. Unanswered demands were numerous and included basic needs such as food, excretion, and sanitation, and more important needs such as education and information, attention, and investigation of the symptoms and complaints, which may not be attended for even in emergencies:

Recently I had transferred from the emergency room to the ward. I was still in severe pain, but the nurse was busy with her duties and writing my medical history. I was crying out of pain, but she did pay no attention. She left me with my pain and asked someone to go to the station and inform that I had pain, but they were so late and injected me with a painkiller. (Participant no. 8)

### **Receiving mechanical care**

As mentioned earlier, care recession is the experience of the participants about the deprivation of the caregiver's presence and low levels of care and response received by the patient. Participants stated that the provided responses, if any, did not have the features of the genuine caregiver. Thus, it can be simply called mechanical. Mechanical care can be described as a kind of passive and ineffective care in which the participants believe the essential elements of care including paying attention, knowledge, affection, and understanding are rarely seen. In the participants' experiences, three characteristics were identified for this type of care, namely, superficiality, lack of emotion, and failure to understand the situation.

**Superficiality.** Several experiences indicated incorrect, insufficient, or inactive care when the needs were not met efficiently and appropriately. The characteristics of this type of care included lack of adequate scientific and intellectual support and inadequate needs analysis, which may result in lack of adaptability of the patient's actual needs and immediate situation.

The following field notes show how the patient received a superficial response instead of careful examinations and appropriate actions regarding the immediate situation.

In the orthopedic ward, a middle-aged patient's attendant was cooling down the fever with a wet cloth. The nurse was prescribing the 12 o'clock medicine. The attendant worriedly said, "My patient has a fever." Regarding the mentioned situation, it was expected that the nurse would examine the patient more closely by the thermometer. However, the nurse touched the patient's forehead with his backhand and mumbled, "No fever." Another reaction of the nurse to the attendant when she said, "His temperature is sometimes very high and he sometimes gets cold and asks me to cover him," was, "He is infected, anyway," while leaving the room. So, the attendant kept cooling down the patient hopelessly, with no sufficient and profound attention paid to her condition and that of the patient.

This type of care the effectiveness and results of which are not considered by the caregiver is received by patients in a hasty manner and is characterized by attributes such as one-dimensional, non-conclusive, and inaccurate.

*Lack of affection.* A great number of the participants had experienced lack of affection, warmth, and gentleness in communication and care. This lack has been demonstrated as behaviors such as silence, violence, lack of compassion during care, and lack of emotional reaction to the patient's painful situations. Oral communication is an effective way of transferring attention and affection to the patient, and lack of this type of communication can be considered as the loss of all the important elements of care. Additionally, emotionless and cold words were other indicators of "lack of emotion":

Nurses come to do their duties and go. They don't have any compassion. They show no affection towards patients. They really are cold fishes! (Participant no. 9)

*Failure to understand the situation.* Some participants pointed out that their perceptions of the patients' situation were totally different from those of the nurses. This is usually shown by downplaying the importance of the situation, symptoms, and signs of the disease. However, from the viewpoint of the patient/family, the situation may require immediate and serious attention or the signs and symptoms may be extremely important and serious:

When you say I am in pain, they say, "where is it?" Well, they don't think people react to pain differently. Must I shout to show that I am in pain? Yesterday, I got chills. I thought, "May my pressure has fallen." I told the nurse to get my pressure. She came fast (with a figure) and took my pressure. She said, "It is what it should be. Nothing's wrong." They don't understand the patient and don't think that the pain is not visible. When I say I'm in pain, I mean I'm suffering from pain; should they see the pain? Just as I say this, they should understand my feelings. Even they don't understand that I'm really afraid of my health condition. Well, I underwent surgery, so nurses must understand that I'm afraid of the time when the shivering happens to me. (Participant no. 9)

### *Being disrespected*

Disrespecting the patient/family has two aspects.

*Humility.* Indicators of humility had been experienced by the patients in different forms including the nurses' indifference and ignorance, social etiquettes' violations such as neglecting greetings, arrogance, and reluctance in communication, and the nurses' criticism and interrogations:

They don't observe social etiquettes. They disrespect the patients and their caregivers. For example, when we say "Hi," they don't respond. (Participant no. 13)

*Aggression.* Another experience of the patients being disrespected was verbal aggression. That made the patients dissatisfied and got them to feel their rights were violated:

... I'm a human being, too. When I call one of them, s/he replies violently and bitterly, "what on earth do you want?" ... Well, they have to speak appropriately. (Participant no. 15)

## Discussion

The violation of patients' rights can be committed in different ways. According to the findings, the patients' rights violation has three major dimensions, namely, "care recession," "receiving mechanical care," and "being disrespected." Patients' rights—as social rights—determine the quality and access to healthcare services. Some of these rights include human dignity and care, access to information, selection, participation, confidentiality, complaints, and compensation.<sup>1</sup> According to this study, most of these rights are violated in hospital settings.

In several studies, different indicators of "care recession" have been reported. "Deprivation of the caregiver's presence" is one aspect reported as the situation when the nurse is absent at the time of request and/or does not fulfill his or her promises.<sup>24</sup> It is predictable that "deprivation of the caregiver's presence" is accompanied with the "delay in/lack of meeting patient's needs," which have been reported in previous studies.<sup>34</sup>

Failure to meet the basic needs despite their importance in maintaining the dignity of the patient,<sup>39</sup> delay and negligence in meeting information and educational needs,<sup>40</sup> inadequate relief,<sup>28</sup> and the influence of workload on timely reaction<sup>28</sup> are some examples in this regard. Nonetheless, the provision of timely and appropriate needs is of the basic rights of patients<sup>27</sup> and most of these requirements have been emphasized in nurses' codes of ethics.<sup>41</sup>

"Receiving mechanical care" is another aspect of "violating the dignity" of the patient/family which implies the "superficiality," "failure to understand the situation," and "lack of emotion." This suggests that in addition to "care recession," the patient/family is faced with ineffective functions lacking the characteristics of a genuine care such as knowledge, attention, emotion, and understanding. Many of "superficiality" indicators of care have been reported as failure to receiving individual care<sup>26</sup> and receiving routine and unrelated care.<sup>24</sup>

Indicating lack of congruence between the caregiver and the patient's perception of the situation and implying the patient/family's disapproval of the situation, "failure to understand the situation," are features of "mechanical care," which are very prominent in this study. However, the patient's approval plays an important role in his or her growth and is a crucial element in the preservation of human dignity.<sup>42</sup> One of the most important elements of care is to recognize the fact that mental, emotional, and rational perceptions vary according to the immediate situation.<sup>43</sup> According to another theory, the nurse should know the patient very well and then try to identify the patient's needs, alleviate suffering, and help find appropriate ways to communicate with him or her. Understanding the patient as a human being is one of the ways of avoiding disconnection with the patient and a major factor in care quality.

"Lack of affection" is another important feature of "mechanical care." The concept implies a kind of deficiency in nurse/personnel relationships with the patient/family. Communication is an important aspect of nursing because it helps examine the patient's needs and can be effective in improving the quality of services.<sup>44</sup> Despite the importance of human relationships, many cases of violation of interpersonal aspects of care have been reported especially the way the staff communicate with the patient and also their ignorance of the patient's physical, psychological, and social needs. Cold relationships, constraints on communications, and lack of kindness, compassion, sensitivity, and attention have been reported in previous studies.<sup>24</sup> Compassion is one of the fundamental values in care and a fundamental concept in nursing care, having the potential to promote respect for the dignity of the patient. Nevertheless, "lack of emotion" in relation to nurses and patients' attendants have been reported in terms of deficiency in appropriate communication<sup>45</sup> and lack of emotional support.<sup>46</sup> Factors such as the organization of daily work, sharing work between physicians and nurses, and nurses' approach to nursing have been reported as factors affecting nurse's (un)willingness to practice based on compassion.<sup>47</sup> The effect of workload on the lack of time to think about the required interaction methods by a particular patient<sup>48</sup> and impairment in the patient–nurse relationship<sup>49</sup> have been reported in other studies.



In this study “being disrespected” is another aspect of violation which occurs more as disrespect, humiliation, and sometimes aggressiveness. Although there is a great emphasis on care in nursing discourse, the nursing practice is different, and the patients’ humiliation and irritation are considerable. Many patients have experienced physical and verbal abuse and clinical negligence by the nursing staff. Interactions between organizational issues, the professional insecurity, the need to claim control over the environment, and the inferiority ideology of the patient are important factors in this regard. “Disrespecting” to the patient usually continues due to a lack of accountability and the reaction of the managers.<sup>50</sup>

## Limitations

In a qualitative research, the patterns are dependent on the context. This influences the applicability of the findings. However, maximum variance sampling is one of the strengths of this study, increasing its applicability.

## Conclusion

The patients and their families consider any shortcomings in relation to the patients and the quality of care as the violation of the rights. Findings of the study imply sensitizing managers toward providing appropriate conditions as well as educating nurses to observe patients’ rights.

Future research investigating the causes and processes leading to the violation of patients’ rights and related consequences can help to improve the current knowledge in this regard. In addition, designing a tool to measure to what extent patients’ rights are observed can help to examine the current situation quantitatively and to investigate the effectiveness of future interventions.

## Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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