GÜSBD 2023; 12(3): 1007 - 1017 **Gümüşhane Üniversitesi Sağlık Bilimleri Dergisi** **Araştırma Makalesi**
GUJHS 2023; 12(3): 1007 - 1017 Gümüşhane University Journal of Health Sciences Original Article

A Phenomenological Study on Anxiety, Difficulties, and Expectations from Health Care Professionals of Women with Gynecological Cancer during the COVID-19 Pandemic

COVID-19 Pandemisi Sürecinde Jinekolojik Kanserli Kadınların Kaygı, Zorluk ve Sağlık Çalışanlarından Beklentileri Üzerine Fenomenolojik Bir Çalışma

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ABSTRACT

The COVID-19 pandemic has not only been stressful for everyone but has also affected in the sensitive group cancer patients in many ways. This study aimed investigate the concerns of women with gynecological cancer, the difficulties they experienced, and their expectations from health care professionals during the COVID-19. The study adopted a qualitative design. 15 women with gynecological cancer participated in the study. Data were collected by conducting in-depth semi-structured face-to-face interviews. Four themes were obtained: "fear and anxiety", "interruption of social life and daily routines", "problems experienced when receiving health care", and "expectations from health care professionals". The factors that caused fear and anxiety in patients during the pandemic were disruptions in the treatment, care process and lack of information about COVID-19 infection. From the perspective of patients, experiencing the COVID-19 pandemic and managing the deadly process of cancer was rather challenging.

Keywords: COVID-19, Anxiety, Ovarian Neoplasms, Uterine Neoplasms.

ÖZ

COVID-19 pandemisi sadece herkes için stresli olmakla kalmamış, hassas gruplardan biri olan kanser hastalarını da birçok yönden etkilemiştir. Bu çalışmada jinekolojik kanserli kadınların COVID-19 sürecinde yaşadıkları endişeler, zorluklar ve sağlık çalışanlarından beklentilerinin araştırılması amaçlanmıştır. Çalışmada nitel bir desen benimsemiştir. Araştırmaya jinekolojik kanserli 15 kadın katılmıştır. Veriler derinlemesine yarı yapılandırılmış yüz yüze görüşmeler yapılarak toplanmıştır. "Korku ve kaygı", "Sosyal yaşamın ve günlük yaşamın kesintiye uğraması", "Sağlık hizmeti alırken yaşanan sorunlar" ve "Sağlık çalışanlarından beklentiler" olmak üzere dört tema elde edilmiştir. Pandemi sürecinde hastalarda korku ve kaygıya neden olan faktörler tedavi, bakım sürecinde yaşanan aksamalar ve COVID-19 enfeksiyonu ile ilgili bilgi eksikliği olmuştur. Hastalar açısından bakıldığında, COVID-19 pandemisini yaşamak ve kanserin ölümcül sürecini yönetmek oldukça zor olmuştur.

Anahtar Kelimeler: COVID-19, Anksiyete, Over Tümörleri, Uterus Tümörleri.

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Geliş Tarihi / Received: 02.07.2023
Kabul Tarihi/Accepted: 19.09.2023

INTRODUCTON

The World Health Organization (WHO) declared the COVID-19 pandemic in China a public health emergency of international importance, which poses a high risk to countries with vulnerable health systems.[1] All institutions and organizations providing medical services, including cancer centers, attempted to maintain patient care, minimize viral transmission, and protect staff and patients.[2,3] Therefore, many hospitals began to take measures to limit the number of outpatient visits and inpatient admissions, to reduce or prevent cross-infection by COVID-19.[4] While increasing demands on physical infrastructure and personnel resources were being met, the weak and vulnerable patient group of patients with cancer were most affected by this situation.[5] Cancer patients faced the progression of terminal illness, becoming incurable, in addition to complications that occur when they are not treated on time.[7] Gynecological oncology patients have a high burden of symptoms, regardless of their stage or type of cancer.[8] The COVID-19 pandemic led to rapid and significant changes in the care given to patients with gynecological cancer.[9] These changes in the management of diseases led to distress, fear, and anxiety in patients.[10] Most of the patients expressed concern that their disease would progress as a result of delays or cancellation of their treatment or follow-up, and they were afraid of getting infected with COVID-19 at the hospital or clinic while receiving oncological treatment or follow-up.[5] In addition, patients stated that they were worried that their treatment would be interrupted, and their prognosis would worsen with COVID-19.[11] Sudden and unexpected changes in their treatment also caused patients to experience some difficulties. Patients previously stated that while they visited hospitals with their spouses and children, it became difficult for them to do everything alone during the pandemic and have to remember everything that the doctor says. In addition, patients noted that they had difficulty getting an appointment, but also had to hurry because there was not enough time, and they could not ask the questions to their care providers they wanted to ask.[12] Determining the difficulties experienced by cancer patients and their expectations from health personnel, in cases such as epidemics and natural disasters, is important in terms of creating an emergency action plan.

Nurses are the professional healthcare group that spends most time with patients and cares for them directly. They closely witness the fear, expectation and difficulties experienced by patients. Nurses, who are at the forefront of the fight against COVID-19, should also consider the expectations from health care professionals, concerns, and difficulties experienced by patients with cancer, who are a vulnerable group, while maintaining patient care in a time of crisis. Therefore, the aim of our study was to reveal the difficulties, anxiety and expectations from healthcare professionals of patients with gynecological cancer during the COVID-19 pandemic through in-depth interviews with the patients.

MATERIAL AND METHODS

Design

This study was designed as a descriptive phenomenological qualitative study. The phenomenological approach is a research method to deeply understand the meaning of people's common experiences of a phenomenon or phenomena, to analyze experiences from the individual perspective, and to explain the individual experience of the phenomenon in a universal manner.[13] The phenomenon of interest in this study was being a gynecological patient in COVID-19. The COREQ qualitative research reporting guide was used in the research planning, data collection, analysis, and reporting phases of the study.[14]

Study participants

This study was conducted with 15 patients diagnosed with gynecological cancer, through software that allows interviews to be conducted via the web. To maintain social distance during the COVID-19 process and not to risk patients in the hospital environment, online interviews were preferred. In the study, the purposive sampling method was used. The announcement about the study was shared in the "Patients with Lymphedema in Turkey" group on Facebook, and the participants were invited to the study to conduct the research telephone numbers were provided for patients who volunteered to participate in the study to contact the researchers. Women shared the link on their social platforms, allowing it to reach wider audiences.

The inclusion criteria were having a diagnosis of gynecological cancer, not having any mental disorders, having an internet connection for conducting the interview, and volunteering to participate in the research. The exclusion criteria were having metastatic gynecological cancer, hearing and speech impairments and inability to use technology. The researchers contacted 15 eligible participants. Five of them declined the invitation to participate in the study. The most provided reason was lack of time.

Data Collection

An introductory information form was used to determine the sociodemographic characteristics of the women, and a semi-structured interview form was used to determine the womens' experiences.

The introductory information form: This form was created by the researcher after a review of the literature. It has questions about the participant's age, marital status, number of children, education levels, occupation, diagnosis of disease and treatment and care during the pandemic process.

The semi-structured interview form: This form was prepared after a review of the literature[6,7,10] and expert opinions about its suitability were obtained from two experts. Because in qualitative research, the questions must be fully understandable by the women. Three women were chosen from the study population for the pilot study, and they were excluded from the study sample. Data were collected by conducting semi-structured face-to-face interviews using this pilot-tested interview form (Table 1).

Data was collected between October 2020 and January 2021. The researchers contacted eligible patients by telephone to ascertain a suitable time and venue for the interview. Before starting the interview, the researchers provided further information about the purpose and design of the study to the participants. Next, their oral and written informed consent was obtained. All the interviews were conducted by three researchers. The interviewers (ŞŞÇ, SEÖ) were an associate professor with a PhD degree in Obstetrics and Gynecology Nursing. The interviewer (RAI) was a research assistant with an PhD degree in Obstetrics and Gynecology Nursing. All three were female and faculty members with experience in conducting qualitative research.

Each interview was conducted individually. The open-ended questionnaire took 35 min on average to complete. For the participants to feel comfortable and ensure privacy, the interviews were held on the platform created for the researchers and the participants, where there were no third parties. Individual interviews were recorded online. There were no prior relationships between the interviewers and the interviewees. During the interviews, the interviewers attentively listened to the participants' responses and questions were used to get more information about an answer or to clarify something. To achieve theoretical saturation, the researchers continued sampling and analyzing data until no new data appeared and all concepts were well developed. In qualitative studies, data saturation is reached when there is enough information to reveal data appropriate for the purpose of the study.[15]

Data Analysis

The steps followed in the analysis of qualitative data are summarized below.[16,17]

Step 1: Reading transcripts: Transcripts were read several times by the researchers, notes were taken about the sections that were considered important, and coding was performed for similar comments.

Step 2: Determination of categories and themes: Based on the codes determined, themes that can explain the dataset at a more general level and group codes under certain categories were determined. Relationships between the themes, theme sets, and sub-themes were explained.

Step 3: Organizing data according to codes and themes: After creating codes and themes for the codes, the compatibility of themes and codes was verified. The researchers prepared the collected data in a processed form without including their own opinions and comments. As a result of detailed coding and thematic coding, the researchers created a systematic structure in which they could conceptually organize the collected data.

Table 1. Semi-Structured Individual Interview Form

First, could you specify your nickname and briefly introduce yourself? (She will be asked to give information about her illness)
What do you know about the coronavirus?
What would you like to say about the diagnosis of disease you received before the coronavirus pandemic?
How has the coronavirus affected your daily life? (How were you affected spiritually? What changes did it bring in your life? / How did you continue your treatment process?)
What kind of problems/difficulties did you experience during this period?
Your surgeries/care/treatments were postponed during the coronavirus process. How did you spend time/manage your treatment during this process?
How did this situation affect you?
Has this process had any negative effects (interruptions) on your treatment? What negative effects did it have? How did you analyze them?
Considering the pandemic, can you tell us how you felt about yourself during this process?
How did you cope with the anxiety/difficulties you experienced during the COVID-19 pandemic? (What were the factors that made it easier or harder for you to cope?)
Are there any problems such as not being able to reach health personnel or communicating adequately among the difficulties you experienced?
Did you have any negative experiences with health professionals during this period? If you did, how would you expect them to treat or approach you?
What do you think are your expectations from healthcare professionals in order to overcome the anxieties and difficulties you experienced during the COVID-19 period and the ongoing normalization process and to receive medical help? (If you can list expectations from doctors, nurses, etc., it will be more understandable and solution oriented.)

Step 4: Grouping themes: Theme sets were mapped to related sub-themes in a table. After completing these steps, the themes were compared. After the authors agreed on all the themes, the findings were finalized. The final themes are presented in table 2.

Table 2. Category, Theme, and Subthemes Obtained from Individual Interviews

Theme	Subtheme
Fear and anxiety	Lack of Information
	Getting sick
	Worsening of Prognosis
Interruption of social life and daily routines	Feeling of Loneliness
	Change in Routines
	Change in Eating Habits
Problems experienced when receiving health care	Postponing Receiving Health Care

Table 2. (Continued)

	Lack of Access to Health Services
	Not Receiving Adequate Social Support While Receiving Health Care
Expectations from health care professionals	Gratitude
	Not to die alone
	Want to listen Quran
	Do not want futile treatment

Credibility and Trustworthiness

Within the scope of the validity and reliability of the study, the criteria determined by Guba and Lincoln were taken into account. These criteria are credibility, reliability, verifiability, and transferability.[18] In the study, in-depth data collection and long-term interaction with the participants criteria were fulfilled for credibility. One of the measures that can be applied for credibility is getting help from experts who have general knowledge about the research topic and are experts in the field of qualitative research methods to evaluate the research.[16, 19] In the study, expert opinions were obtained from an independent person, apart from the three researchers in the study, for transcription and creating themes, and the final form of the themes was obtained by reaching a consensus.

To ensure the reliability of the study, the interviews were conducted and recorded by the researchers using the same device, and all the interviews were transcribed without any change. The analysis process for the transcribed data was explained in detail so that measures were taken to ensure the external reliability of the research. The internal reliability of the research was also ensured by receiving expert support, apart from the researchers, during the coding of the data and the creation of the themes. To demonstrate the verifiability of the study, the findings obtained in the study were reflected directly by quotations from the statements of the participants. In addition, audio and video recordings of the research, raw data, coding, and the research report are stored on a secure computer for use when deemed necessary for confirmability. Ensuring transferability in qualitative research can be achieved by targeted sample selection and making detailed descriptions.[16,18,19]

Ethical Compliance

The study was conducted in line with the Helsinki Declaration Principles. The ethical suitability of the study was evaluated by the Non-Interventional Clinical Trials Ethics Committee (Decision No:969 / Date:17.09.2020). The names of the participants were kept confidential, and they were identified with codes (P1, P2, P3…).

Limitations

There are some limitations that should be considered when interpreting the study findings. The study was conducted with women with gynecological cancer who were members of a Facebook group. Therefore, the study findings cannot be generalized to all women with gynecological cancer. Despite the limitation, this study is the first to qualitatively reveal the experiences and difficulties regarding the COVID-19 pandemic experienced by patients with gynecological cancer in Turkey.

RESULTS AND DISCUSSION

Socio-Demographic Characteristics of the Participants

The average age of the participants was 53,20±15,99 years. Of the women, 90% were primary school graduates, 70% were housewives, 50% had income less than expenses, 80% were married and all married women had children, and 50% had 2 children. Of the women, 50% had ovarian cancer, 30% had surgical treatment+chemotherapy+radiotherapy, 40% had check-ups at three-month intervals, 70% had medical treatment postponed during the

pandemic period, 50% were receiving adequate medical care and treatment during the pandemic, and a large majority reported experiencing feelings of intense fear and anxiety about their illness during the pandemic.

Findings about the Experience of Patients with Gynecological Cancer during the COVID-19 Pandemic

Four themes were obtained regarding the experiences of patients with gynecological cancer during the COVID-19 pandemic: "fear and anxiety", "interruption of social life and daily routines", "problems experienced when receiving health care", and "expectations from health care professionals".

Theme 1: Fear and Anxiety

The participants stated that they experienced "anxiety" and "fear" when the first case of coronavirus appeared in Turkey and its spread continued.

"Now, when we first heard about the coronavirus, namely COVID-19, we were very anxious" (P1)

I have cancer and I have children. I am scared, sometimes I feel mad." (P10)

The most important reason for fear and anxiety was the lack of information about COVID-19.

"The number of cases is increasing gradually. Everyone is saying something, I don't even know what to believe, who is telling the truth, which one is reliable." (P4)

"Experts also had very different opinions; that is, one was saying that the virus was hanging in the air, another was saying that it was settling on surfaces, and another was saying that it transmits through breathing, and we were more nervous at first because we didn't know much." (P7)

The participants expressed their fear and anxiety about being infected.

"We are afraid to be infected. We haven't been able to accept any guest in our house for a year. My sister cannot come inside. I can't even say come on in." (P4)

"I even talk with my mother from behind the windows to avoid transmission of the disease." (P9)

"We are afraid to be infected. I wear a double mask, for example, when I go to the grocery store or something." (P5)

The participants expressed their fear and concern that their prognosis will get worse with COVID-19.

I was a little more nervous. I mean, we completely lost our ties with the physician, we completely lost our ties with the hospital, we feared the prognosis would be worse " (P8)

"As I said, there is anxiety, there is discomfort, there is sadness, I wonder if there will be anything more, will it get worse." (P10)

Theme 2: Disruption of social life and daily routines

The participants stated that the coronavirus pandemic affected their daily lives and social lives.

"It restricted my freedom. It restricted us. We can't do anything anymore, we can't see our friends, we can't go on a trip anymore. Everything is restricted." (P3)

"I'm just going out for a walk now, there's no going out except for that. There is no social life. That is, we are afraid even in the house because of the elevator since it's a closed environment, without ventilation." (P4)

The participants stated that they distanced themselves and their relatives due to the pandemic and that they were left alone due to social isolation.

"No one visits our house since my cancer disease and COVID. When my sisters came, they gave me whatever they would give from afar. But well, I was very lonely in the process. So, we're psychologically depressed (P2).

"I was at home all the time. I was alone, I didn't see anyone." (P6)

The participants stated that their cleaning routines had changed due to the pandemic.

"I became an obsessive cleaner. Clean everything, clean all door handles used by my husband when he comes... Clean the toilets. I was affected, for example." (P8)

We started to clean more. Once the disinfectant came to our house, it settled in the middle of our house, unfortunately. We are in contact with fewer people. When we go out and come home, we completely change all of our clothing, even if we didn't touch anything." (P1)

Participants stated that their routine eating habits changed and they gained weight during the pandemic.

"We didn't leave the house during the pandemic. I gained a couple of kilograms, which was a concern. However, I didn't go out at first. Didn't go out for a walk." (P4)

Theme 3: Problems experienced when receiving health care

The participants stated that they postponed their appointments due to the coronavirus.

"I haven't done anything during COVID-19 either. That is, I didn't go my appointments for treatment. I've probably only spoken to my physician on the phone once." (P8)

"For example, we couldn't come to treatment because of COVID." (P3)

The participants stated that they were unable to have their routine check-ups performed due to COVID-19.

"We were seeking a suitable hospital. Which one is the emergency hospital, which one is not a pandemic hospital? We were refused wherever we tried." (P5)

The participants stated that they needed social support, but they could not get adequate social support from their relatives during their treatment due to the pandemic.

"I was very lonely during the pandemic." (P2)

"I was going to all the check-ups with my daughter. I always had to go alone because of the pandemic. (P5)

Theme 4: Expectations from health care professionals

The participants stated that health care professionals did whatever they could in this period.

"Anyway, I think they are doing what they need to do. What more can they do? I mean, they're really struggling. I say God, may God bless them. "." (P6)

"I don't expect anything during this period. All physicians and others have quite a burden." (P9)

The participant stated that they do not want to die alone, and they want the health care professionals to be with them in case their health conditions deteriorate and want to listen Quran and not want to die alone.

"No one is with us in the pandemic. If my health deteriorates, I would like to die by hearing the voice of the health personnel". (P14).

"I am grateful to God for every day I live, but if my health deteriorates in the pandemic, my biggest wish is that the health personnel will allow someone to read the Quran next to me. I would love to hear the voice of the Quran." (P12).

My biggest fear in this process is loneliness. I don't want to die alone (P15).

One participant stated that she doesn't want the futile treatment due the pandemic.

"Our state of health can change at any time. My greatest wish is that if I become infected and there is no hope of recovery, they will not give me a futile treatment". (P11)

Keeping the country's health system afloat was the primary goal during the pandemic. Therefore, it was an accepted approach to direct all facilities in the national health system of countries towards the burden of diseases associated with COVID-19.[24] In this case, however, as for patients diagnosed with cancer or patients with suspected cancer,

specific problems arose in the treatment and care processes for patients with gynecologic cancer, and these problems had negative effects on both the physical and mental health of patients with gynecologic cancer. The fear and anxiety associated with COVID-19 infection and gynecologic cancer, the delays in health services, social isolation, and unavailability of support systems are some of the problems experienced by patients with gynecologic cancer during the pandemic. [5,12,20-22] In this study, the concerns, and difficulties of patients with gynecological cancer, and their expectations from health care professionals during the COVID-19 pandemic were investigated in detail, and the findings were found to be in line with the studies in the literature.

The prominent themes in our study are that the COVID-19 pandemic caused a significant level of fear and anxiety in women with gynecological cancer. Participants expressed concern and fear that they would get infected, and the prognosis of their disease would worsen due to the postponement of check-ups and treatment because of the inability to acquire accurate and adequate information about COVID-19. The findings of the studies in the literature are similar to the findings obtained in our study.[12,20-23] In our study, the fear experienced by the participants mostly included the anxiety and fear of being infected with COVID-19. In the study by Gultekin et al. (2021) most of the patients stated that cancer was an important risk factor for developing COVID-19.[5] The study by Frey and Blank reported that the question most asked by women on the webinar was about the association between COVID-19 infection and gynecological cancer and whether they had a significant risk of infection.[21] In another study, Frey et al. (2020) stated that patients with gynecological cancer participating in the study were most concerned about COVID-19 infection.[22] Similarly, we found in our study that patients experienced anxiety about getting infected and that the infection may be more severe due to the idea that their immune system is weak because of the anticancer therapy. In addition, as understood from the patients' statements, another factor that increased this fear for patients with gynecological cancer is the increased risk of encountering people infected with COVID-19 since many of the hospitals were converted into pandemic hospitals. In their study conducted with patients with ovarian cancer, Frey et al. (2020) noted that patients experienced cancer-related anxiety due to the postponement of their treatment and follow-ups during the COVID-19 pandemic.[20] Gultekin et al. (2021) found that the number of people who were afraid of COVID-19 infection was less than those who were concerned about the malignancy of their disease due to the delayed treatment, and this concern was greater in younger people.[5] In our study, patients expressed more fear of being infected with COVID-19, unlike their study. This may be due to the fact that the number of patients who continued cancer treatment was low since the majority of the participants had cancer diagnosis more than a year ago, the continuation of the treatment for recurrent patients in accordance with the conditions of the pandemic, and extended duration of follow-up for patients with remission and follow-up patients. In the study by Mogami et al (2021) were determined that anxiety levels of the patient's undergoing treatment were found to be higher than patients in the follow-up group, which supports our study findings.[10]

Another theme in the study was the interruption of social life and daily routines. The social isolation and quarantine were among the radical measures taken all over the world and in Turkey to prevent the COVID-19 pandemic. In our study, the participants stated that they experienced an intense feeling of loneliness since they stayed away from social support systems due to restrictive practices, that their daily household routines and eating habits changed, and accordingly they gained weight. Studies about the effects of isolation measures implemented to prevent the spread of the disease indicated that patients with cancer experienced a feeling of loneliness intensely during the COVID-19 pandemic.[22,25] The findings obtained in other

studies are in line with our study. In addition, Gallagher et al. found that individuals with cancer had a high risk of developing depression and a sense of isolation associated with this risk during the COVID-19 pandemic.[22] Therefore, anxiety and depression in patients with gynecological cancer are important problems to be addressed during the pandemic. The third theme identified was problems experienced when receiving health care. The participants stated that their follow-up appointments were postponed due to the COVID-19 pandemic and that they could not get support from their relatives during the treatment process. Treatment and care of patients with chronic and progressive diseases such as cancer should not be disrupted but patients noted difficulties in accessing health care in parallel with our study findings.[10,25-30] To reduce the number of visitors during the pandemic, relatives of patients and other non-mandatory companions were advised to stay outside the clinic during patient visits.[30] In our study, due to these restrictions to prevent crowded environments in hospitals, patients believed that they were not able to benefit enough from the social support of their relatives during the treatment period. This caused them difficulty in meeting their needs during hospital visits due to cancer. Although a companion was permitted for patients with these needs in hospitals, different practices in institutions may have caused this situation.

The last theme found in our study was the expectations from health care professionals. The participants stated that health care professionals worked selflessly during the COVID-19 pandemic and that they had no expectations for themselves or their treatment. In the study by Gultekin et al. (2021) although women with gynecological cancer wanted protection for cancer patients and the right to receive care in COVID-19-free hospitals, they also thanked their physicians and health care professionals who carried out their treatment and care, similar to our study findings.[5] Even though the COVID-19 pandemic caused problems in receiving treatment and care for women with gynecological cancer, it is believed that patients respect the increased workload of health care professionals by ignoring the disruptions in the process, which leads to increased feelings of satisfaction and gratitude. However, the important points emphasized by women are that they do not want to be alone in case their health conditions deteriorate, they want to listen to the Qur'an and not to take futile treatment. These results are important to show that psychological resilience in cancer patients varies according to the support of health personnel and religious beliefs. One participant wishes not to apply futile treatment in case of worsening of his health condition. This is because the death rates against COVID-19 are high, and an effective treatment has not been developed, so individuals do not have faith in treatment.

CONCLUSION AND SUGGESTIONS

The COVID-19 pandemic caused disruptions in the treatment and care of patients with gynecological cancer. Patients stated that they experienced intense fear and anxiety, disruptions to their social and daily lives, and radical changes, as well as problems in receiving health care. From the perspective of gynecological oncology patients, experiencing the COVID-19 pandemic and managing the deadly process of cancer was rather challenging. Oncology and women's health nurses, who provide care for patients with gynecological cancer, should address patients holistically while being aware of these challenges support them in each stage of care. Health professionals should create an action plan for emergencies and provide information about the situation to women diagnosed with gynecological cancer. These women should be encouraged to talk about the problems they are experiencing. To improve coping with stressful situations caused on by the cancer diagnosis and treatment, professional nursing support is essential.

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