



Service Users and Providers Expectations of Mental Health Care in Iran: A Qualitative Study

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Abstract

Background: Mental disorders are known to be an important cause of disabilities worldwide. Despite their importance, about two thirds of mentally ill people do not seek treatment, probably because of the mental health system's inability to decrease the negative side effects of the interaction with the mental health services. The World Health Organization has suggested the concept of responsiveness as a way to better understand the active interaction between the health system and the population. This study aimed to explore the expectations of mental health service users and providers.

Methods: Six focus group discussions were carried in Tehran, the capital of Iran. In total, seventy-four participants comprising twenty-one health providers and fifty-three users of mental health system were interviewed. Interviews were analyzed through content analysis. The coding was synchronized between the researchers through two discussion sessions to ensure the credibility of the findings. The results were then discussed with two senior researchers to strengthen plausibility.

Results: Five common domains among all groups were identified: accessibility, quality of interpersonal relationships, adequate infrastructure, participation in decisions, and continuity of care. The importance of cultural appropriateness of care was only raised by service users as an expectation of an ideal mental health service.

Conclusions: Both users and providers identified the most relevant expectations from the mental health care system in Iran. More flexible community mental health services which are responsive to users' experiences may contribute to improving the process of care for mental health patients.

Keywords: Responsiveness, Mental health, Iran

Introduction

Mental disorders are known to be an important cause of disabilities worldwide (1). According to the World Health Organization's (WHO) multi-country study, it is estimated that about two thirds of people with mental disorders do not seek treatment (2). Differential health care access provides an important explanation of this gap. Appropriate

access is defined as the availability of acceptable services. Different experiences of health care access among mentally ill patients might be explained by the quality of mental health services, the quality of rapport between service users and providers, the adherence to treatment, and the differential availability of mental health care (3).

The accessibility and cultural acceptability of mental health services will also determine the degree to which patients seeking help are able to engage with mental health providers (4).

The active interaction between the mental health system and the population is crucial for mental health care (5). Several studies have shown that when people receive appropriate mental health care and their expectations are fulfilled, the recurrence of their symptoms and their use of medical services declines (6-8). Despite the importance of having a better understanding of patients' and service providers' expectations when interacting with mental health services, little has been done to identify these expectations worldwide (5). In 2000, the WHO suggested the concept of responsiveness as a way to evaluate health systems based on the users' expectations and experiences. Responsiveness is a measure ". . . of how the system performs relative to non-health aspects, meeting or not a population's expectations of how it should be treated by providers of prevention, care or non-personal services" (9). Although few studies have assessed the applicability of the WHO responsiveness concept to mental health care (5, 10), to our knowledge, to date, none of them have identified both users and providers expectations.

This study, as part of a comprehensive investigation of mental health care responsiveness in Iran, aimed to explore the experiences and expectations of mental health service users and providers. To fulfill this aim the following questions were asked:

- What do users and providers of mental health care services expect and desire from an ideal service?
- What are their experiences of how well the mental health system responds to their expectations?

Methods

Setting

This study was carried out in Tehran, the capital of Iran. The population of the city is around 12 million (11). Based on a recent survey in 2009, approximately one third of the city's population (36.4%) was suffering from a mental disorder (12).

Mental health services have been integrated into a hierarchical, pyramid-like, primary health care (PHC) system since 1986 (Fig. 1) (13). At the base of the pyramid, there are volunteer health workers they are trained to recognize, refer, and follow mental health cases to the urban health center where trained General Practitioners (GPs) manage psychiatric patients. All cities in Iran have urban health centers that each serves a defined population of around 12,000 people. According to the mental health program, GPs are appointed to screen under-covered individuals continuously, and also to identify patients who suffer mental disorders and who need referral to psychiatric clinics. More professional mental health services are provided at district health centers (14). A specially-trained GP and on some occasions, a psychiatrist is available at district level. The district health center accepts mental health referrals from urban and rural health centers, but sometimes refers problematic cases to the provincial health center, of which there are 40 in 30 provinces. Provincial health centers are under the supervision of medical universities. Medical universities are responsible for both the health services in the catchment area of each province and medical education. The mental health units in these services are staffed by one psychiatrist and one psychologist who are responsible for the technical, organizational, and administrative management of the services on the periphery. Medical universities provide specialist mental health services to patients referred from district health centers, mostly based in psychiatric hospitals or in the psychiatry wards of general hospitals. In provincial capitals, one or more university comprehensive public mental health hospitals provide the highest level of outpatient and inpatient mental health care.

In Tehran, there is one university comprehensive public mental health hospital in each division of the city (North, South, East, West, and Central) offering inpatient as well as outpatient mental health services. These hospitals have referrals from the different divisions of the city and even from other cities in the country. Referrals to these mental hospitals can be through the PHC system or directly at patients' initiative. In Tehran, several

non-governmental organizations also provide day-care services and rehabilitation facilities to mentally ill patients. All of them work under the su-

per vision of a medical university. The service costs for both public and private services are covered by social health insurance.

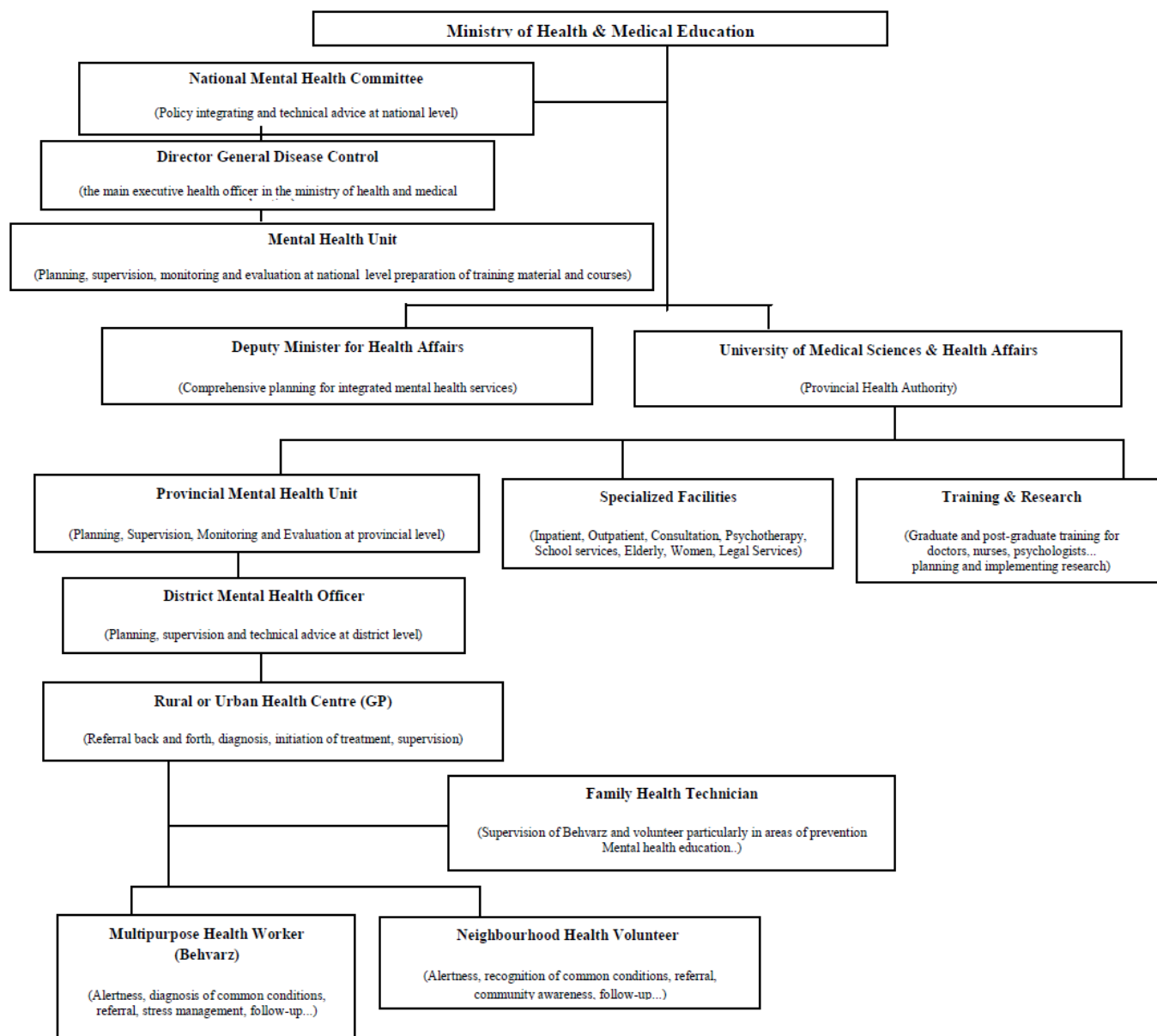


Fig. 1: Administration structure of National Mental Health Program in Iran (Source : Mohit 2000)

Study participants and sampling

Service users' sample

A sample of 53 mental health service users was selected purposively. The selection criteria for service users was: (a) being adult (18–65 years old);

(b) having at least one year's experience of using a mental health care service (outpatient as well as inpatient); (c) not being acutely ill; and, (d) being cognitively capable of participating in a group discussion, (e) not having history of drug addiction;

and (f) not being diagnosed with mental retardation. The sample was representative of the different types of services. Two groups came from an outpatient center, one from a non-governmental day care facility, and one from a non-governmental mental health rehabilitation center. The types of mental disorders were not taken into account as inclusion criteria since the current diagnoses of patients are not related to their experiences of mental health services (15). Participants were recruited from outpatient service facilities affiliated to one of the public medical university hospitals, with the assistance of mental health service providers. The group discussions were carried out at one of the outpatient mental health facilities, located in the South Division of Tehran.

Providers' sample

Twenty-one mental health service providers were selected purposively from all five university mental health hospitals in the city in order to capture the perspectives of those who had at least three years of working experience at different levels of the mental health care system. To maximize the diversity of views, service providers of different genders and professional backgrounds were recruited. Sampling was done by the first author with the aid of the local assisting researchers. After the selection, an invitation letter was issued which was followed-up with a telephone call. Two focus group discussions consisting of 10 or 11 participants were conducted at the University of Social Welfare and Rehabilitation Sciences.

Data collection

Data collection started in June 2010 and ended in August 2010. Focus group discussions (FGDs) were used because of their appropriateness for providing insights into how people perceive a situation and think about an issue, their range of opinion and ideas, and the inconsistencies and variations that exist in a particular community in terms of beliefs and experiences (16).

The process of data collection was the same for both groups of participants. The discussions started with an introduction to the aim of the study and the expectations. Following that, participants

were asked and encouraged to talk openly about what they expected from an ideal mental health center, as well as their experiences. Probes were used to confirm the concepts mentioned and to explore new areas.

The participants were also informed about confidentiality and their right to withdraw from the study at any time during the discussion. The nature and purpose of the study were explained to each participant before they gave their consent, which was confirmed by a signature. Permission to audiotape the interview session was sought orally prior to the interviews.

Following the discussion, a short questionnaire was filled in by the participants that collected demographic data, as well as information on their life-time contact with the mental health care services. The first author moderated all the discussions. Each focus group lasted 1 hr 45 min to 2 hrs, and ended when no new issues seemed to arise. The discussions, in Farsi, were audio-taped and then transcribed.

The study protocol was approved by the Ethical Committee and Research Council of the University of Social Welfare and Rehabilitation Sciences, Tehran.

Data analysis

Conventional content analysis was performed for data analysis (17). The transcribed interviews from the six focus group discussions were analyzed manually. Three researchers coded the transcripts independently. The transcripts were read with the intention of deriving "meaning units" (covering words, phrases, and/or paragraphs) (18).

The phrases and codes were identified from transcripts, providing the basis for generating subcategories. The final subcategories were examined for organization into a hierarchical structure where possible. Citations were only coded once with the category best representing the focus of the statement. The coding was synchronized between the researchers through two discussion sessions, each taking four hours, to ensure the credibility of the findings (19). The results were then discussed with two senior researchers to strengthen their plausibility.

Results

Participants' characteristics

Service users

Table 1 shows the characteristics of service users. The mean age of service users was 34.4, the gender distribution was balanced between the sexes, about one third of the service users were unemployed and about 90% of them had access to health insurance services.

Table 1: Characteristics of service users

Variables	Frequency	%
Sex		
Female	25	46.2
Male	29	53.7
Education		
Below diploma	4	7.4
High school diploma	36	66.6
Above high school diploma	14	25.9
Employment status		
Unemployed	17	31.4
Housekeeper	13	24.0
Student	3	5.5
Employed	15	27.7
Domestic employment	3	5.5
Missing	3	5.5
Insurance coverage		
No	5	9.2
Yes	44	81.4
Missing	5	9.2
Type of mental health care		
Outpatient clinic	29	53.7
Both outpatient and inpatient services	20	37.0
Missing	5	9.2

Service providers

Table 2 shows the characteristics of service providers in detail. About two thirds of them had more than ten years of professional experience and 60% reported working exclusively for the public system.

Content analysis of discussions

From the content analysis, five domains were generated inductively: 1) accessibility, 2) quality of interpersonal relationships, 3) adequate infrastructure, 4) participation in decisions and 5) continuity of care (Table 3).

Table 2: Characteristics of service providers

Variables	Frequency	%
Sex		
Female	10	47.6
Male	11	52.4
Education		
Psychiatric	7	33
Psychologist	8	38
Psychiatric nurse/ Occupational therapist	6	29
Professional experience		
Less than 10 years	7	33
More than 10 years	14	67
Affiliated to GO/NGO centers		
Governmental center	13	61
Non Governmental center	8	39

Accessibility

The statements relating to this category could be subcategorized as: physical access to acceptable care, and access to information.

Physical access to acceptable care

Both users and care providers emphasized that feasible access to care was one of their main expectations. Users discussed their experiences about improper transport to the mental health centers, long distance to the facilities, long intervals between the visits, and waiting time for the consultations.

"...they don't visit patients on time; we have to wait in their offices for a long time." (Service user)

The concern of providers in this sub-category was related to the inadequate distribution of the mental health centers in the city which could make access for some patients difficult, especially in emergency situations.

“...public services are limited and emergency rooms are almost always fully occupied...” (Service provider)

The issue of access to cultural acceptable care was only raised by the users. Several expressed that based on their experience the practice of service

providers did not always follow accepted norms and values in the society.

“It is not accepted that I talk about my private issues with a therapist from other sex. But most of the times I don't have other choice.” (Service user)

Table 3: Results from content analysis

Category	Common sub-categories	Sub-categories revealed by providers	Sub-categories revealed by users
Accessibility	Physical access to acceptable care, access to information	NO exclusive subcategory	Cultural acceptability of care
Quality of interpersonal relationships	Respectful non-stigmatizing behaviors, trusting behavior, empathetic and supportive approach, maintaining individuality	Patients safety warranty	No exclusive subcategory
Adequate infrastructure	A clean, tidy, and silent environment, enough space in hospital wards	Expectation of adequate material and administrative infrastructure	Warm and friendly environments
Participation in decisions	Preconditions for participation, maintaining partnership, and benefits of participation	No exclusive subcategory	No exclusive subcategory
Continuity of care	Coordination of the follow-up to the patient's care	No exclusive subcategory	No exclusive subcategory

Access to Information

Access to information about illness and the care process, was expected by both groups of participants. The majority of service users expected to be provided with detailed information about their disorder in plain language. “...sometimes the professional words they use make me more confused ...” (Service user). Both groups expressed that based on their experience inappropriate access to information can lead to poor treatment.

Quality of interpersonal relationships

The majority of statements expressed by service users were in this category. This category refers to following subcategories; respectful and non-stigmatizing behaviors, patient safety warranty, trusting behavior, an empathetic and supportive approach, maintaining individuality.

Respectful non-stigmatizing behavior

This included the expectation of mutual respect and a humanistic approach and considering patient rights. Service users said that the consequences of disrespect can be discontinuation of treatment. Not being stigmatized when dealing with service providers was discussed in all groups.

Patient safety warranty

Patients' safety warranty was the subcategory that only mentioned by service providers. They expressed that sometimes you cannot avoid involuntary treatment. In such cases then providers should be very careful that treatment dose not violates an individual's safety.

Trusting behaviour

All groups expected providers to be honest and keep the patients information confidential or ask their permission before passing it on to others.

Service users expressed that when they are not sure about how their information will be confidential they do not share their deep feelings and thoughts.

Empathetic and supportive approach

Both providers and users discussed that empathetic approach is important for mentally ill patients because of the nature of their illness. In addition, the providers discussed the barriers such as high workload, especially in emergency services and dissatisfaction with their salaries as barriers that prevent them from meeting these expectations.

Maintaining individuality

All participants expressed that it is important to know that patients are all diverse individuals, with differing personalities. Service users expressed the view that when they felt that the providers knew them well; this encouraged them to explore the deeper issues. *“He was concerned about me, not just my illness. That’s why I was encouraged to give him more information.”* (Service user)

Adequate infrastructure

The expectations of service users and providers about this category were partly different, although they also shared some commonalities. A clean, tidy, and silent environment and enough space in hospital wards were common expectations.

Service users said that they expected warm and friendly environments. *“Using decorations that make us feel at home are necessary; some of the existing ones make us feel in prison...”* (Service user)

The expectations of service providers relating to this category could be divided into expectations of the material and administrative infrastructure. The availability of testing facilities and novel medical equipment were related to material infrastructure. About two thirds of providers expressed the view that an efficient referral system, the availability of facilities for team working, and access to updated scientific literature would be desirable for strengthening the administrative infrastructure.

“We need the competence of other specialties and this needs policies that support the process of team working.” (Service provider)

Participation in decisions

A further important aspect expressed by both groups was the participation of the service users and their relatives in the mental health-related decision-making process. Common sub-categories arising were preconditions for participation, maintaining partnership, and benefits of participation.

Preconditions for participation

Several service users expressed the view that the feeling of equality was an important precondition for their engagement in the decision-making process.

Both users and providers said that psychotic and addicted patients are not capable of establishing a good collaborative contract. Several revealed that, in these cases, family members and relatives were good alternatives.

Service providers commented that health literacy and having basic information about the mental disorders were preconditions for engagement in the care process.

“When patients are thoroughly informed about their condition they are more likely to trust their capacity and to make decisions...” (Service provider)

Maintaining collaboration

Having enough time during each consultation session or visit with the service providers was said by both groups of respondents to be vital for continuing and maintaining the participation.

“During the visits, when I feel there will not be enough time to talk, I prefer just listen to what they say ...” (Service user)

Consequences of participation

Several people in both groups stated that the participation of users could reduce medical errors. Some respondents from the service users’ group highlighted the negative consequences of losing control and not participating in the treatment decisions. *“He did not let me explain the adverse effects of*

new pills. Then I decided to leave the medicine forever.”
(Service user)

On the other hand, providers emphasized that a desirable outcome of patients' participation in the caring process is that they could feel more confident of their own capacities. *“Encouraging the patients to participate in the caring process will help them to feel more confident, even in other aspects of their social life.”*
(Service provider)

Continuity of care

Coordination of the follow-up to the patient's care was expected by both the service users and the providers. There were however some differences in their expectations.

Service users reported that, based on their experience, the rotation and rapid turnover of providers had negative effects on a continuous caring relationship. In addition, several mentioned their desire for a follow-up of the care process when they were discharged.

“Each time I am referred to an outpatient clinic, I meet a new therapist. This is not desirable...” (Service user)

On the other hand, service providers discussed the importance of this issue for achieving a better health care performance.

“Now patients' health care needs cannot be met by a single professional; we need a continuous caring relationship between different professionals.” (Service provider)

Discussion

Although there are commonalities in the expectations and declared experiences of users and providers, some differences can be found.

The main domain that came to forefront in all groups was the quality of the interpersonal relationships between service users and providers. This might be interpreted as giving priority to this domain, which corresponds to prior studies (20-21). Despite the importance of this, the service providers discussed the difficulties of addressing this issue because of the high workload and other organizational factors. This concern is highly relevant since the shortage of psychiatric services in urban areas in Iran (22) and the poor and disor-

ganized mental health service delivery reported in other studies (14).

Accessibility of care was another domain that both providers and users expected from an ideal mental health service. The highly centralized professional care facilities in large cities as well as shortage of home care, aftercare services, and community mental health centers can partly explain this concern (14).

The importance of the cultural appropriateness of care was only raised by service users as an expectation from an ideal mental health service. Cultural factors influenced how the caring process is perceived by the mental health service users (23-25). In a country such as Iran with different ethnic groups this issue is even more important. Patients from different ethnicities and cultural backgrounds may have different expectations of seeking care. Yet the term “cultural competence” elicits varied responses from health care professionals, ranging from complete acceptance to outright derision (26). In our study professionals did not mention this topic spontaneously and it seems that they overlooked this issue.

There were different expectations of the domain of adequate infrastructure from users and providers. Providers emphasized the material and administrative infrastructure more, while users expected a warm and home-like environment. As shown in other studies, service providers are more concerned about the outcome of care and the availability of health facilities and services which are scientifically and medically appropriate (27). For patients the process of care is more important. A systematic review of over 600 papers shows that design and environmental enhancements can have a positive impact on the health and well-being of patients in mental health care settings (28). Considering the low quality of mental care centers in Iran, this expectation is particularly relevant.

Participation in the care process was another shared domain where users and providers had different expectations. The citations in this domain could be assigned to the main categories of autonomy and freedom of choice of care discussed in the WHO responsiveness concept (29). Greater clarity is needed about what user participation

means in practice, for example, what competencies and contexts are necessary to facilitate it (30). From the providers' point of view the role of the patient in the care process was accepted, but they emphasized that the level of mental health literacy is an important precondition for patient participation. Previous studies have shown that patients can be educated to participate in the care of chronic illnesses and that their participation can improve disease control (31).

Although there have been efforts to enhance mental health knowledge in the community during recent years, particularly after the integration of mental health care into PHC in Iran, (32) it seems that still more is needed in this regard.

When discussing issues related to the maintenance of participation, service providers again emphasized the system barriers. The lack of community mental health services of good quality which can provide a context for better participation might partly explain this concern. On the other hand, service users were more concerned about the quality of the interaction with the care providers and its effect on their willingness to participate in the care process. This finding is congruent with other studies in this field (31, 33).

The domain of continuity of care was important for both users and providers. When talking about this issue, users expected a long-term secure attachment to mental health workers and services, and providers were more concerned about the negative effects of the segregation of mental health services on the outcome of care. The strong expectation of continuity in mental health care seems to be related to suffering a chronic illness (4). The complaints and negative experiences of both groups are explicable, especially in urban areas, because of the weak coordination within mental health services and with the rest of the health care system (34).

Conclusion

In conclusion, paying more attention to the expectations of service users and providers might help

to improve the responsiveness of the mental care health system.

This could be achieved by improving the quality of the interpersonal relationships, the physical infrastructure of the facilities, and the involvement of users in the care process. Implementation of these changes could impact positively on the service users' sense of dignity and autonomy, and reduce their negative feelings. In addition, more flexible community mental health services, which are responsive to users' experiences and facilitate their participation, would give new direction to the Iranian mental health reform process in future.

Ethical considerations

Ethical issues (Including plagiarism, Informed Consent, misconduct, data fabrication and/or falsification, double publication and/or submission, redundancy, etc.) have been completely observed by the authors.

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