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# Vocational Counseling of HIV-infected People: A Role for Nurses in HIV Care

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*People living with HIV (PLWH) face various work-related problems, such as stigma and physical difficulties. Health care professionals can help improve the employment situation of PLWH. Nurses who work in HIV care play a central role in the care of PLWH in the Netherlands. The aim of this cross-sectional study was to investigate the contributions of nurses to the vocational counseling of PLWH, and to make an inventory of needs for future care. Our findings, collected with a self-administered survey, clarified that HIV nurses in the Netherlands regularly faced patients with problems at work, but that they didn't have the required knowledge to provide assistance. Our study emphasized the important role of HIV nurses in vocational counseling because of their central positions in care and their confidential relationship with patients. The study underlined the importance of available, up-to-date knowledge about HIV and work, as well as a clear referral network.*

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Since the availability of effective antiretroviral therapy, HIV has become a manageable chronic disease. This implies that people living with HIV (PLWH) have to deal with not only their physical situations, they also have to focus on activities in daily life and participation, such as employment (Anandan,

Braveman, Kielhofner, & Forsyth, 2006). Employment is an important quality-of-life factor for all people, including those living with chronic diseases. Research on employment in relation to various chronic diseases has shown that work brings social, economic, and emotional benefits (Boonen et al., 2001; Chorus, Boonen, Miedema, & van der Linden, 2002; Minis et al., 2013). Reduced work participation leads to fewer financial resources, reduced independence, and a higher prevalence of depression and anxiety disorders (Dutta, Gervey, Chan, Chou, & Ditchman, 2008; Heijmans, van der Veer, Spreeuwenberg, & Rijken, 2011).

The employment rate of people with chronic diseases is significantly lower than that of healthy people (Detaille, Heerkens, Engels, van der Gulden, & van Dijk, 2009). In the European Union, about 47%

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of persons with disabilities are employed, compared to 72% of persons without disabilities (Academic Network of European Disability, 2013). In the Netherlands, in 2010, a quarter of all chronically ill people had a paid job of at least 12 hours a week, compared to 67% of the total labor force (Heijmans et al., 2011). Studies in Western industrialized countries and the United States have shown that the unemployment rate among PLWH ranges from 45% to 60% (Dray-Spira et al., 2005).

People with HIV face various problems at work or when returning to work (Braveman, Levin, Kielhofner, & Finlayson, 2006; Chan, McMahon, Cheing, Rosenthal, & Bezyak, 2005; Studdert, 2002). Stigma is one of the main issues PLWH face. Lack of knowledge among employers and colleagues is a cause of stigma and discrimination. Furthermore, PLWH often experience physical and psychological complaints such as fatigue, cognitive impairment, and distress. These factors are negatively associated with work participation or productivity at work (Barkey, Watanabe, Solomon, & Wilkins, 2009; Black, 2008; Burns, Young, & Maniss, 2006; Fogarty, Zablotska, Rawstorne, Prestage, & Kippax, 2007; Jong et al., 2010; Lem et al., 2005; Martin, Steckart, & Arns, 2006; Vetter & Donnelly, 2006). In order to improve vocational counseling for PLWH and to reduce employment-related problems in the Netherlands, a multidisciplinary, evidence-based guideline, "HIV and Work," was developed (Rotterdam University of Applied Sciences, Research Centre Innovations in Care, 2012; Wagener, Roelofs, et al., 2015). This evidence-based guideline consisted of a comprehensive literature review about HIV and work. Based upon the literature and the opinions of experts, recommendations for practice were formulated. One of these recommendations was to discuss issues about HIV and work more thoroughly between patients and various professionals who provide treatment and care, such as the general practitioner, medical specialists for HIV, and nurses who work in HIV care. The consensus among the developers was that health care professionals were able to help improve the employment situation of PLWH. Therefore, attention to employment should be part of everyday clinical practice (Maurits, Rijken, & Friele, 2013). However, with regard to work-related problems, it re-

mains unclear how different health care providers can address tasks and responsibilities.

In the Netherlands, HIV nurses play a central role in the care of PLWH. They counsel patients on a regular basis and are easily accessible. The HIV nurse supports the HIV-infected patient on a medical and social level, by giving advice, instructing, and consulting. Additionally, HIV nurses enhance the expertise of other care providers by informing them about HIV-specific problems (Professional Association of HIV/AIDS Nurses, 2004). Because of their central position in HIV care in the Netherlands, the HIV nurse is a good candidate for a central role in the vocational counseling of PLWH. Therefore, in the guideline "HIV and Work" (Rotterdam University of Applied Sciences, Research Centre Innovations in Care, 2012), this role was recommended for the HIV nurse. However, it was unclear if this task would be entirely new for HIV nurses, to what extent it would fit into the competences that nurses had acquired in their educations, and how often nurses were confronted with work-related issues. For this reason, we conducted a cross-sectional study with the primary aim of investigating the current contribution of HIV nurses to vocational counseling for PLWH in the Netherlands. A second aim was to make an inventory of needs and recommendations in HIV nurses to acquire sufficient competencies for this task.

## Methods

### Study Design

The main goal of this cross-sectional study was to gain insight into the contribution of HIV nurses to vocational counseling for PLWH. We distributed a questionnaire with mainly closed-ended questions to obtain quantitative data. On some topics, if more insight in experiences and opinions was desired, open-ended questions were posed. The open-ended questions were analyzed as qualitative data.

### Participants

Our cross-sectional study was conducted in the Netherlands. We asked 78 nurses who specialized in adult care and were stationed in 25 HIV outpatient

centers that were all part of the same health care system, to participate in the study. According to the Dutch Medical Research Involving Human Subjects Act, the study was exempt from medical ethical review. The study complied with the Netherlands Code of Conduct for Scientific Practice from the Association of Universities in the Netherlands.

### **Instrument**

Data were collected with a self-administered questionnaire developed by the researchers. When we developed the questionnaire, no other existing questionnaires were available on this novel topic. Therefore, questions were based on the results of a qualitative study with PLWH (Wagener, van Opstal, et al., 2014). In that qualitative study, PLWH were interviewed about their experiences with work and addressed relevant themes for PLWH related to work and employment. The themes from that study provided the basis for key questions in the multidisciplinary guideline “HIV and Work” (Rotterdam University of Applied Sciences, Research Centre Innovations in Care, 2012). Our study was conducted parallel to the development of the guideline. Furthermore, we reviewed the scientific literature about HIV and employment in the context of the development of the multidisciplinary guideline. The results of this review were also used to develop the questionnaire, and Wagener, Roelofs, et al. (2015) documented the methodological development of the guideline. Finally, we conducted an exploratory open interview with three nurses in HIV care to inventory their experiences related to HIV and employment.

The compiled questionnaire consisted of 25 questions, including mostly closed-ended and some open-ended questions. Data were obtained for seven domains: participant characteristics, types of work-related concerns, knowledge and skills for work-related concerns, referral to other professionals, collaboration with other HIV nurses, role of the professional association, and quality of counseling by the HIV nurse.

The questionnaire was available in Dutch. The concept questionnaire was sent out for review by other researchers and was pretested in a small sample of nurses in HIV care. The questionnaire was adapted based on comments from the pretest. A list of expla-

nations of the key concepts was added to increase the reliability and validity of the questionnaire. Examples of the questions in every domain are shown in Table 1.

### **Procedures**

Nurses were invited to participate through the Dutch Association of HIV Nurses, which was also involved in the study. An e-mail explaining study goals and procedures was sent to all nurses. The questionnaire could be completed anonymously online using the digital survey system “Parantion” (<http://www.parantion.com/website/>). Only the researchers had access to survey responses. In case of nonresponse, a reminder was sent after 2 and 4 weeks. The inclusion period was July-August 2011.

### **Analysis**

The main goal of our study was to investigate the experiences of nurses in HIV care with counseling patients about work-related issues. Therefore, the questionnaire consisted of both closed-ended and open-ended questions.

#### **Closed-ended Questions**

The closed questions were described using descriptive statistics of SPSS 21 (IBM). Descriptive statistics are presented in the text. For some variables, tables have been created.

#### **Open-ended Questions**

Constant comparison (Boeije, 2010) was used as the basic qualitative analysis method to analyze the answers on open-ended questions. First, all answers were read and key themes were labeled. Subsequently, subcategories were created for a broader understanding of the major themes, and compared with the literature. The findings were summarized; the main findings are described below and suitable quotations are used to illustrate the findings. The results (quantitative and qualitative) are classified and described by the themes of the questionnaire.

**Table 1. Sample of Questions from the Questionnaire**

## Participant characteristics

Age:

How many HIV patients do you have under care at this moment?

## Types of work-related concerns

How often in a month are you confronted with a patient with work-related problems?

Number:

“What do you do in case of a sickness report due to HIV?” (open question)

“Which work-related problems do you meet in practice?” (multiple answers possible):

- Concerns about employment impact on health
- Concerns about reduced capability due to fatigue
- Concerns about reduced capability due to reduced cognitive functioning
- Concerns about reduced capability due to side effects of medication
- Concerns about reduced capability due to comorbidity
- Concerns about employability and career development
- Fear of losing social security
- Fear of disclosure
- Fear of stigma and discrimination by the employer
- Fear of stigma and discrimination by colleagues
- External pressure and the sick role
- Uncertainty about the rights and obligations of the patient
- Lack of facilities at work
- Choice of profession
- Other ...

## Knowledge and skills about work-related concerns

“I have enough knowledge to support and inform the HIV patient in concerns about reduced capability due to fatigue.”

Responses: *completely disagree, somewhat disagree, neutral, somewhat agree, completely agree*

## Referral to other health care professionals

“Do you ever refer to other health care professionals in case of work-related problems, such as the occupational health physician?”

- Yes, namely:
- No

“What professionals would you like to cooperate with on HIV and work?” (open-ended question)

## Collaboration with other HIV nurses

“Does consultation take place between you and other HIV nurses in your clinic?”

- Yes, how often:
- No

“Do you experience these consultations as meaningful?” (open-ended question)

## Role of the professional association

“What is your opinion about the amount of attention on HIV and work of the professional association?”

- There is much attention on this topic
- There is enough attention on this topic
- There is little attention on this topic
- There is insufficient attention on this topic
- There is no attention on this topic

## Quality of counseling by the HIV nurse

How do you rate, on a scale from 1-5, the quality of counseling on work-related problems for people with HIV provided by the HIV nurse?

- 1 (*bad*)
- 2 (*insufficient*)
- 3 (*moderate*)
- 4 (*sufficient*)
- 5 (*good*)

## Results

### Participant Characteristics

A total of 44 nurses in HIV care participated in the study, which was a response rate of 56%. As shown in Table 2, the participants were mostly women. This was to be expected because most HIV nurses in the Netherlands are female. The average age was 47 years, and the nurses had worked 8.8 years in HIV care on average for 30.3 hours a week. With regard to education level, all of the nurses had a Bachelor's or Master's degree. On average, the nurses had 330 HIV-infected patients ( $SD = 252$ ) under supervision. The large standard deviation can be explained by the way respondents interpreted the question. Some respondents mentioned the total number of patients under care in their clinic and others mentioned only their own patients. The nurses saw about 65 HIV-infected patients a month on average.

### Types of Work-related Concerns

On average, the HIV nurse was confronted 6.1 times per month with an HIV-infected patient who had experienced work-related problems. Patients usu-

ally started talking about work-related problems during consultation hours, but sometimes also did so by e-mail or telephone.

Almost all the HIV nurses (86%) registered patient work status (*employed/unemployed, full-time/part-time, occupation*) and patient work history. When a patient reported work-related problems, this was also noted (93%), mostly in the digital patient record.

Most of the nurses wanted to know the reason for absenteeism. They wanted to know if HIV or an HIV-related complication was the cause of a need to be absent from work and if intervention was possible. In cases of short-term absenteeism, patients were usually not referred to other professionals. However, in cases of long-term absenteeism, the nurses also wanted to know the patient's relationship with work and if intervention needed to be recommended by, for example, an occupational health physician.

Fear of stigma, discrimination, and disclosure were the main work-related issues that HIV-infected patients reported to the nurses. Furthermore, concerns about diminished capacity caused by fatigue and medication side effects were important issues for HIV-infected patients with regard to work. In Table 3, all work-related concerns brought up by patients are listed.

**Table 2. Characteristics of Participating HIV Nurses ( $n = 44$ )**

Characteristics	$n$ (%)
Gender	
Male	7 (15.9)
Female	37 (84.1)
Age in years, mean ( $SD$ )	45.6 (8.6)
Education level	$n$ (%)
Intermediate vocational education	2 (4.5)
Bachelor	23 (52.3)
Master	18 (40.9)
PhD	1 (2.2)
Number of years working as HIV nurse	Mean ( $SD$ )
Overall	8.8 (6.5)
0-5	14 (31.8)
6-10	17 (38.6)
11-15	3 (6.8)
>16	9 (20.5)
Number of working hours a week	30.32 (6.5)
Number of patients under supervision	329.7 (252.3)

**Table 3. Types of Work-related Concerns**

Concerns	$N$ (%)
Concerns about employment impact on health	35 (79.5)
Concerns about reduced capability due to fatigue	42 (95.5)
Concerns about reduced capability due to less cognitive functioning	17 (38.6)
Concerns about reduced capability due to side effects of medication	41 (93.2)
Concerns about reduced capability due to comorbidity	20 (45.5)
Concerns about employability and career development	28 (63.3)
Fear of losing social security	28 (63.6)
Fear of disclosure	42 (95.5)
Fear of stigma and discrimination by the employer	43 (97.7)
Fear of stigma and discrimination by colleagues	43 (97.7)
External pressure and the sick role	19 (43.2)
Uncertainty about the rights and obligations of the patient	32 (72.7)
Lack of facilities at work	17 (38.6)
Choice of profession	21 (47.7)

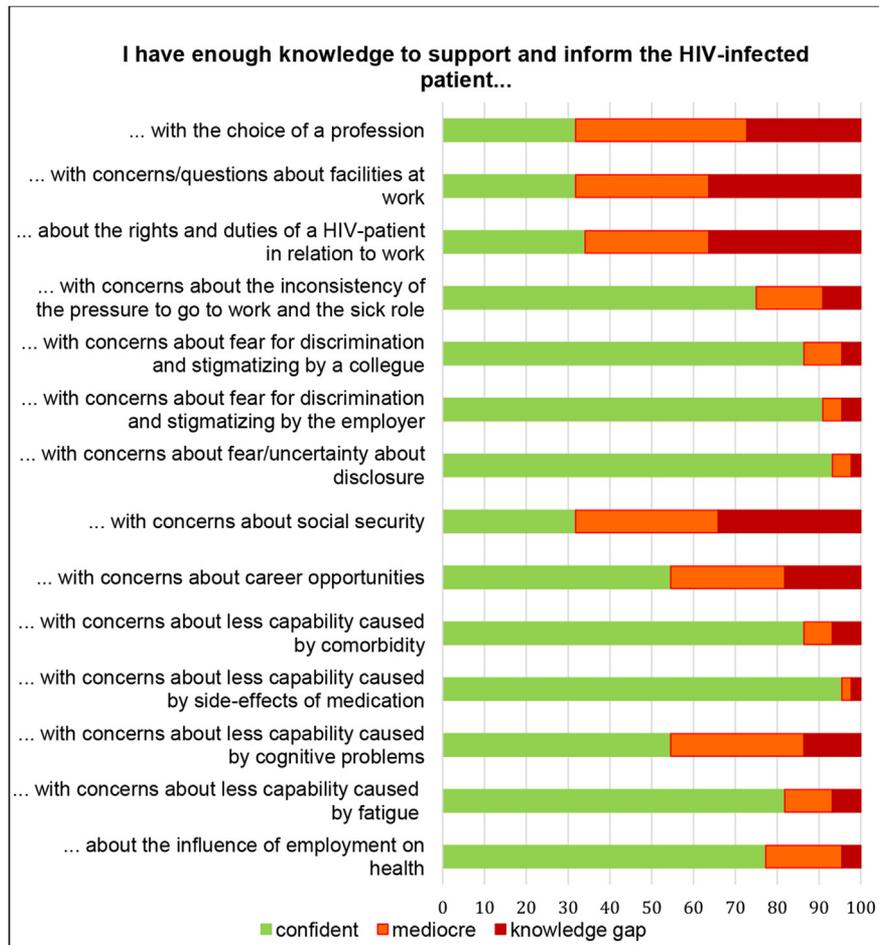


Figure 1. Knowledge about work-related issues.

### Knowledge About Work-related Concerns

HIV nurses were asked if they thought they had enough knowledge about work-related problems. As shown in Figure 1, the response was positive on many of the related issues. However, knowledge about social security, rights, and duties (e.g., when on sick leave or when applying for a job) was felt to be lacking.

The nurses also indicated that they felt less competent advising patients about facilities at work, career opportunities, or choice of profession. About half of the nurses did not feel sufficiently secure to help patients with concerns about decreasing capabilities due to cognitive problems.

In one open-ended question, the nurses were asked to describe issues an HIV nurse should have knowl-

edge of in order to provide proper consultation when work-related problems were presented. One of the respondents said:

Obviously, we need to have knowledge of the physical and psychological impact of HIV diagnosis and be able to monitor this individually. Patients respond so diversely, even to medication side effects. We have to know the rights and duties and should be able to find information, and much more ...

Having knowledge of HIV and the impact of the disease on daily functioning was one important theme.

Another important theme was related to legal rights and duties, for the employee as well as the

employer. As one respondent answered: “I am barely aware of rights and obligations for patients. This makes it difficult to act as intermediary.”

Referral options were mentioned, as well as the role of stigma and side effects of medication. Good communication, conversation, and advisory skills were described as skills that nurses in HIV care needed to help patients deal with work-related problems.

### **Referral to Other Professionals**

Some respondents had doubts about the role of the HIV nurse in vocational counseling and thought that the nurse’s only function was to refer. Training or a handbook about HIV and work, and a clear referral network were mentioned as being helpful for good counseling.

Most respondents referred to the occupational health physician when a patient expressed severe work-related concerns. The main reason for this was that the occupational health physician had professional confidentiality and knowledge about employability. Satisfaction with these contacts varied. “I usually first recommend the patient to involve the occupational health physician, also because of his professional confidentiality. Unfortunately, I sometimes hear that patients cannot rely on this. There is no real cooperation.” Patients were sometimes referred to a social worker, especially in cases of financial problems.

### **Collaboration With Other Nurses in HIV Care**

Seventy-three percent of the nurses in our study had regular consultation with other HIV nurses in the same hospital about the work-related concerns of their patients. These consultations were always experienced as meaningful. Consultations with nurses from other hospitals about work-related concerns were also used at times (23%). Another 25% of the respondents stated that they would like to have consultations with more experienced HIV nurses in other hospitals.

### **Role of Professional Association of HIV/AIDS Nurses**

The opinions on the role of the Professional Association of HIV/AIDS Nurses varied: 32% of the respondents indicated that the association paid

enough attention to work-related concerns of HIV-infected patients, but 39% noted that the association should be more active. When asked about the availability of training about HIV and work organized by professional organizations, a quarter of the respondents stated that this topic was not offered, 18% indicated that training has been offered, and about 50% had no opinion. Development of training, professional guidelines, and social maps with referral options were mentioned as possible activities that could be organized.

### **Quality of Counseling by the HIV Nurse**

Two thirds of the respondents rated the quality of counseling by the HIV nurse in cases of work-related concerns as *sufficient*; another 23% rated the quality as *moderate*. As options for improving the care for HIV-infected workers and consultation in case of work-related problems, nurses in HIV care mentioned: (a) enhance the knowledge of occupational health professionals about HIV, (b) develop training for nurses in HIV care about all aspects involved in vocational guidance for HIV-infected people, (c) raise awareness about various referral options for nurses, and (d) stimulate/facilitate social acceptance for HIV-infected workers in employers and employees.

## **Discussion**

In this study we focused on the contribution of nurses in HIV care to the vocational counseling of PLWH. We found that HIV nurses in the Netherlands regularly faced patients with problems at work. Fear of stigma, discrimination, and disclosure were the main work-related issues reported by HIV-infected patients in contacts with the nurses. Furthermore, concerns about limited capability caused by fatigue and side effects of medications were important issues for HIV-infected patients with regard to work. These findings were similar to findings from previous studies (Braveman et al., 2006; Vetter & Donnelly, 2006) and support the qualitative research findings of the multidisciplinary guideline on HIV and Work (Wagener, van Opstal, et al., 2014).

The nurses in our study stated that their knowledge about work-related problems was not sufficient.

Nurses in HIV care experienced gaps in their knowledge and competences with regard to a number of work-related topics. Knowledge about social security, rights, and duties, for instance when on sick leave or when applying for a job, was felt to be lacking. The nurses also indicated that they felt less competent advising patients about facilities at work, career opportunities, or choices of professions. As described in several studies on interventions with the aim to improve work participation, addressing work participation in interventions for people with a chronic condition is beneficial (Martin et al., 2012; Varekamp, Verbeek, & van Dijk, 2006). Additional training on work and health could be provided for the nurses in HIV care to support their roles in the guidance of PLWH on work-related concerns.

However, some respondents had doubts about the role of the HIV nurse in vocational counseling and thought that the nurse only had a responsibility to refer. In our opinion, the nurse in HIV care is a key professional in this guidance. Because of nurses' central position in care and their confidential relationships with patients, they can provide important vocational guidance, including that of referrer. Therefore, they should have basic knowledge about HIV and work and various local referral options. A firm recommendation for practice is that a clear referral network be created in order to facilitate cooperation and to make the responsibilities and qualities of all other involved professionals clear.

The professional association could incorporate competencies with regard to work-related problems in the job profile of HIV nurses and develop specialized training to support them in the performance of these tasks. In nurses' current job descriptions, no specific attention is paid to work-related problems. In this respect, the job profile of the nurse in HIV care in the Netherlands is comparable to that in other countries. It includes more general competencies, such as contribution to multidisciplinary work and recognition of the impact of HIV stigma on PLWH, but does not mention specific work-related duties. The addition of competencies to assess participation in work activities would help nurses pay more holistic attention to the daily lives of PLWH.

On the other hand, many of the findings in this study were not HIV specific, but are part of living with any chronic disease. Research has shown that self-management skills are essential to manage a chronic

disease. Self-management encompasses three elements: medical management, role management (i.e., work participation), and emotion management (Lorig, 2003). Interventions that aim to improve self-management skills are essential to increase work participation for people with a chronic condition, including HIV (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Trappenburg et al., 2013). The nurse in HIV care could play an important role in improving the self-management skills of PLWH.

### Reflections on the Method

The moderate response rate of 56% should be mentioned as a limitation of the study. One of the reasons for this might be that the study was conducted during the summer months. We have no information about differences between responders and nonresponders. Furthermore, there might have been self-selection (in or out) by responders due to the subject of the study. It is possible that nurses who already pay attention to work-related problems were more willing to complete the questionnaire. As a consequence, it is likely that the number of nurses in HIV care who supported work-related counseling as part of their tasks and the competences with regard to vocational counseling were overestimated.

Because this study was conducted in the Netherlands, the results and recommendations may not generalize to other countries. In the Netherlands, an HIV nurse is present in every outpatient clinic and, because of this central position, a role in vocational counseling seems crucial. Whether the results are applicable to other countries depends on local health care systems and situations. In the United States, for example, rehabilitation professionals play an important role in the vocational guidance of PLWH (Hergenrather, Rhodes, & Clark, 2005). However, the nurse in HIV care also has a central position in counseling PLWH in the United States and may, therefore, also be involved in vocational guidance.

### Conclusion

Our study emphasized the important role of nurses in HIV care in vocational counseling because of their

central position in care and their confidential relationships with PLWH in the Netherlands. Because work-related problems are a considerable issue for PLWH, the possibilities of the HIV nurse in vocational counseling should be further investigated. In order to develop this role, available up-to-date knowledge about HIV and work, and a clear referral network are needed.

### Key Considerations

- Nurses in HIV care should play a central role in vocational counseling for people living with HIV (PLWH).
- It is important to define the responsibility of every professional involved in the counseling of PLWH for work-related concerns.
- Up-to-date knowledge about HIV and work, and a clear referral network are essential to provide proper counseling.

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### Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

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