

CANCER IN CHILDREN: THE DIAGNOSTIC ITINERARY

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This study aims to describe the trajectory children and adolescents experience from the beginning of cancer signs and symptoms until the confirmation of the diagnosis, based on their parents' report. A total of eight mothers and two fathers participated in the study. Data were collected through semi structured interviews, and data were subject to qualitative analysis. We found that this period is significant for parents, who are capable of recognizing that something wrong started to happen to their children, expressed through signs and symptoms. They precisely reported the chronological time of this trajectory. The challenges they mentioned refer to the different diagnostic hypotheses, the difficulty to performing specific diagnostic exams and to be referred to specialized care services. This search for health service care revealed to be a difficult journey, which permits to identify that the Brazilian Basic Health System's principles of accessibility and problem-solving capacity are jeopardized.

DESCRIPTORS: pediatric nursing; early diagnosis; neoplasms; child

CÁNCER INFANTIL: EL ITINERARIO DIAGNÓSTICO

Este estudio tiene por objetivo describir la trayectoria de niños y adolescentes desde el inicio de los signos y síntomas hasta la confirmación del diagnóstico de cáncer, a partir del relato de sus padres. Participaron del estudio 8 madres y 2 padres. La recolección de datos fue realizada mediante entrevistas semi-estructuradas, con análisis cualitativo de los datos. Fue evidente que este periodo es significativo para los padres, que son capaces de reconocer el inicio de algo malo con sus hijos, expresado por medio de signos y síntomas. Relataron con exactitud el tiempo cronológico de esa trayectoria. Dentro de los desafíos mencionados, refieren las diversas hipótesis diagnósticas, la dificultad para la realización de exámenes diagnósticos específicos y para ser conducidos a los servicios de atención especializada. Esa búsqueda por atención en los servicios de salud se traduce por una difícil peregrinación, identificando el compromiso de los principios de acceso y resolutivez propuesta por el Sistema Único de Salud.

DESCRIPTORES: enfermería pediátrica; diagnóstico precoz; neoplasias; niños

CÁNCER INFANTIL: O ITINERÁRIO DIAGNÓSTICO

Este estudo tem por objetivo descrever a trajetória percorrida por crianças e adolescentes desde o início dos sinais e sintomas até a confirmação do diagnóstico de câncer, segundo relato de 8 mães e 2 pais que participaram do estudo. Conduziu-se a coleta de dados mediante entrevistas semi-estruturadas, com análise qualitativa dos dados. Evidenciou-se, no entanto, que esse período foi significativo para esses pais, por reconhecerem que algo de errado começara a acontecer com seus filhos, expresso por meio de sinais e sintomas. Relataram com exatidão o tempo cronológico dessa trajetória, mencionando, dentre os desafios, diversas hipóteses diagnósticas, dificuldades para a realização de exames diagnósticos específicos e para o encaminhamento aos serviços de atendimento especializado. Essa busca por atendimento nos serviços de saúde traduziu-se em difícil peregrinação, que permitiu identificar o comprometimento dos princípios de acessibilidade e resolutivez propostos pelo SUS.

DESCRIPTORES: enfermagem pediátrica; diagnóstico precoce; neoplasias; criança

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INTRODUCTION

The advances in Medicine, especially in the field of pediatric oncology, have been very significant. About 70% of the children struck by cancer can be cured if there is an early diagnosis and the disease is treated appropriately. However, the cure is not always possible, particularly when the diagnosis occurs at a later stage of the disease⁽¹⁾.

Early diagnosis of cancer in children poses a challenge; in adults, its occurrence is often associated to environmental factors but, in childhood diseases, this association is not clear. Thus, children still come to specialized institutions with the disease at an advanced stage, due to factors like lack of parental and medical information; fear of a cancer diagnosis or even the tumor's own characteristics because, most of the times, the signs and symptoms of childhood cancer are non-specific, and may be mistaken for those of other common childhood diseases⁽²⁾.

For these reasons, we consider it important to know the trajectory of cancer-stricken children or adolescents, in order to gain enough knowledge to design actions that may contribute to the early diagnosis of childhood cancer, since therapeutic success with a possibility of total cure depends mainly on its early detection⁽³⁾.

Therefore, the goal of this study is to describe the trajectory of these children and adolescents since the early signs and symptoms until the confirmation of the cancer diagnosis, according to the experience and accounts of their parents. We shall use the term "diagnostic itinerary" as a reference to this period.

METHODOLOGICAL APPROACH

This is a study with a broad theoretical approach, using qualitative data analysis. We selected this analysis because it was considered to be the most appropriate to the object of study, since it enables the investigation of non-quantifiable phenomena, which cannot be reduced simply to the effectiveness of variables⁽⁴⁾.

The research was performed at the Pediatric Onco-Hematology Service of the Hospital das Clínicas at the University of São Paulo at Ribeirão Preto Medical School (HCFMRP-USP). It is a teaching hospital which, among other areas of expertise, is a reference in hospital care for children and adolescents with onco-

hematological disorders. At present, it attends 300 patients in different stages of treatment.

Eight mothers and two fathers of children and adolescents who had a cancer diagnosis confirmed in the period from September/2004 to July/2005 took part in the research, with an approximate interval of six months to one year, retroactive to the beginning of data collection.

The data collection was performed between December/2005 and February/2006, with semi-structured interviews that contained the following guiding questions: When and how did you notice that something was wrong with your child? Which signs showed that something was not right with the health of your child? Have you looked for any kind of treatment/service? Which one? Please explain how you reached these services. Each interview received a code in chronological order (E1, E2 and so on, up to E10).

The interviews were transcribed after the recording. After the end of this stage, a detailed reading of the data was performed, aiming to identify significant aspects and giving more attention to words or meanings that could lead to the comprehension of the study phenomenon, i.e., the experience of the children and adolescents' itinerary until the confirmation of the cancer diagnosis, according to the perspective of the parents.

The present study was submitted to the Research Ethics Committee at the Hospital das Clínicas of the University of São Paulo at Ribeirão Preto Medical School, according to resolution 196/96 by the National Health Council, which sets the guidelines for research involving human beings in Brazil⁽⁵⁾ and was approved on December 5, 2005.

RESULTS AND DISCUSSION

The accounts of the children's parents helped us to understand how significant this period was for the families, which could recognize, based on the signs and symptoms, the moment when something wrong started to happen to their children. Another relevant aspect was the pursuit of hospital care in the health services, which translated into a difficult journey.

The parents detected that something was not well with their children's health due to the signs and symptoms present, and also because of the behavioral changes and daily activities of the children and adolescents.

Then there were the spots... red, all over the body, on the foot... everything really tiny. He was pale, too pale, he was almost, his mouth almost blue, and his belly. His belly was large and bloated. (...). And when he breathed, he sounded as if he had bronchitis. He would play for a short time and get tired, and he only wanted to sleep, he had no energy for anything, all he wanted was to sleep (E1).

She started out with pallor, lack of appetite... she had never been a kid who would ask to be carried. Suddenly, I noticed that she would walk a block, and then she would ask to be carried, and I would pick her up, and her heart was beating fast (E9).

Differences could be identified between the accounts of parents of younger children and those of parents of adolescents regarding the presence of signs and symptoms. However, in the case of babies, these had been noticed only by the parents.

The first thing was that... some purplish spots started showing up on him, all over the body, but he was a little baby, he would only stay in the stroller, he wouldn't get hit. There was no way he would walk so he could fall down... so we started to worry about these purplish spots (E1).

When it comes to adolescents, most of the times, they made the complaints that something was wrong.

He started to complain about a sore shoulder, that he was really in pain (E7).

He complained of difficulty breathing, he was playing, and sometimes he stopped and would come home with... pale, and with his heart beating fast, and had difficulty to breath (E4).

Some parents claimed lack of experience as a limiting factor that made it difficult to reach the diagnosis, although they had looked for medical service as soon as they noticed alterations in the health of their children.

He was like that for about two months, I think... because it takes some time for you to take notice, you know what I'm saying? Because we've never been through that... so can't know what that is (E1).

It was seventeen days, and about the same for the second surgery, he stayed there for a long time wasting time, they said it was a virosis, but it was no virosis at all, it was 17 days, the same amount, we didn't have experience, but not now, now we know better (E5).

One of the mothers mentioned the contribution of a maternal grandmother for the correct referral of the child.

His nails were a purplish color, but his nails had started getting purple like that from... three days, the nails had started getting purple. Then I showed it to my mother and she told me to take him quickly to Santa Casa. Then I took him there and he was admitted (E1).

A study performed by pediatric oncologists at the Pediatric Department of the São Paulo Cancer Hospital showed that the interval between noticing the first symptoms and cancer diagnosis is longer in Brazil than in other countries like England, Sweden and the United States; this interval may range from nine to twenty two weeks, depending on the type of disease⁽⁶⁾.

It is important to highlight the accuracy of the information the parents provided regarding the chronology of the itinerary while looking for a solution for their child's problem. They are capable of quoting precise dates and times of events that were witnessed:

I took him to the hospital on a Tuesday, no, not on a Tuesday, on a Wednesday, and he stayed there overnight from Wednesday to Thursday. I was at the hospital overnight from Wednesday to Thursday in my town, and then he was transferred here, it was twenty to noon (E1).

I came here on December 5, last year (E1).

We arrived on the 11th, she was admitted in Barretos, in the hospital, on the 11th. Then she stayed there from the 11th to the 17th (E3).

We arrived there at about eight-twenty, they paged the doctor, and he saw us at about twenty-to-eleven (E5).

A study performed in the United Kingdom investigated the accounts of 20 parents about the period prior to the cancer diagnosis in their children. To analyze the empirical data, the method of constant data comparison was used. In that study, the same accuracy was observed in the description as the information provided by the parents in our own research. It evidences that, regardless of the length of time from the beginning of the problem until the diagnosis, they were able to report dates, days and times of the events that refer to this period with great precision, as this was a very expressive time for the families.

We believe that the accuracy of details is related to the significant changes in their life history from the moment of diagnosis onward, since they started living with a severe disease that had struck their children.

The notification of the diagnosis brings intense change to their lives, affecting both the family unit and the relationship towards other people. The pre-diagnosis period is lived with feelings of angst, the feeling that something serious may happen, but, at the same time, hoping that their fears are not confirmed⁽⁸⁾.

At the moment they noticed that something was wrong with their children's health, the parents

immediately sought help in the public system, at the Basic Health Units, Emergency Care Services or private healthcare system. At this stage, they reported several hypotheses formulated by the professionals who saw the child or the adolescent, a situation that has allowed us to identify the early challenges the parents faced in the process, all of them related to the issue of non-specificity of the signs and symptoms of childhood cancer, as seen in the following accounts: .

We started going hectic in January/2004. He started complaining about a sore shoulder, that he was in real pain, so we started looking for a doctor since January. So, you go to the doctor, you go to an emergency shift, you run to one hospital after another, and they always say that this pain is related to growth, that his muscles were not keeping up with the growth of the bone, or that the bone had grown too much (E7).

Then I took him to a health unit and the doctor told me that it could be a lump in the throat, right? So she told him to go home and keep it under watch (E4).

He arrived home in the afternoon saying that he had a headache, a strong headache, so we took him to the emergency room, and when we got there the doctor told us that it was sinusitis, and then he got worse (E5).

The symptomatology shown by the child with cancer may be directly related to the tumor (including bleeding, neurological signs, pain, hematuria, obstructive symptoms, palpable masses), or it may be non-specific. Signs and symptoms may include weight loss, diarrhea, bone and joint pain, cephalaea, anorexia, fever from an undetermined source, pallor, fatigue, lowered physical activity and mood swings, which may turn the early detection of the problem more difficult^(3,9).

Based on these characteristics, the rate of suspicions of cancer among specialists is very high; however, the opposite situation is more common among generalist physicians, who are reluctant to perform this diagnosis since they are not familiar with it, and also because it is related to the fear of death, rare in children⁽⁹⁾.

In this study, this issue was detailed by one mother who mentioned the work of the specialist, who, when consulted, immediately associated the symptoms shown by the child to an oncologic diagnosis:

I called the doctor in Ribeirão, I told him... and without even seeing the boy he knew it, because if his ankle was sore and the GB [white blood cells] were low, he said, on the phone he said, one day before he was taken to the hospital, they already knew he had leukemia (E10).

Early diagnosis is fundamental for a good prognosis of the disease, but it is essential to consider the preparation of the professional who will first see this child or adolescent. Since, most of the times, the first appointment happens with either the family doctor or a pediatrician, not with a specialist, there is increased difficulty in relating the symptoms found in the child to cancer.

Both educational institutions and health service providers have to take this preparation into account, regarding either primary care or high-complexity service, so as to offer flexible action that responds to the integrality of the service. Thus, it is essential that permanent education strategies be used, adopted into the current context of the health sector, following the new Education and Development Policy for the Brazilian Health System (SUS)⁽¹⁰⁾.

It is important to highlight that, among the study participants, one of the children showed a returning disease. Even though the child had been submitted to oncologic treatment before, there was a delay in obtaining the new diagnosis when the parents attended the medical service, as follows:

So, 6 months later he started to throw up again, so we took him to the healthcare plan (...). We took him eight times to that hospital, with his mother's plan, and eight times they said it was a virosis, that he had a virosis, that this virosis would take ten days to heal up, but the virosis caused no fever, no diarrhea, only vomiting. We'd go there, they'd give him an injection, and then he wouldn't vomit for about eight hours, he would eat, and the next day it would start all over again (...). And then, after 15 days of him vomiting, I took him to another doctor and he thought it was gastritis, so he scheduled an endoscopy, and before we took him to the endoscopy I noticed that he was walking with difficulty, you know, he stepped out of the car, he tried to walk and lost his balance, then I told him, this is not right (E5).

Most of the times, since the initial visit did not result in the correct diagnosis, which would be cancer, the child or adolescent remained with the symptoms, in spite of the adopted medical recommendations. In some cases, the condition worsened significantly. In trying to solve the problem quickly, the parents started an endless quest for an assertive medical service, to the extent of heading for private medical services, even when they could not afford to pay for the costs of the treatment, as reported:

I'm not going to wait until the medicine bottle runs out, I took it, went there and paid for an exam myself, in this exam her blood count had already fallen, the hemoglobin was 3.6 (E9).

So we get worried, because this boy wouldn't walk, he was getting thinner, paler, and in the end I said that there was nothing else to do, I need to pay a private doctor to check it (E10).

Another difficulty the parents experienced in this process regards the need for high-complexity diagnostic exams. Even when these are offered by the Brazilian Public Health System (SUS), they did not meet the clients' needs, since the waiting period did not match the urgency of the situation. So, the parents opted for private services to perform the exams in order to speed up the process:

It was private, because I was taking him to the unit and there was no solution, nothing, so I started paying a private clinic, I would do it in monthly payments because there was no other way, because at Santa Casa, for example, many things are not possible, so I'd pay it privately to be sure of what was going to happen, because I was tired of medication that didn't... and the doctor was paid too, to Batatais, I took him two times, I paid an orthopaedician to see him (E10).

The difficulty in having specialized diagnostic exams occurred not only in public services; these have also been reported by parents with private healthcare plans:

Then she was directed to do a resonance exam... so we did it... three machines, one with a vacant spot only in September, the second one broken, and then we said, let's try the third one, so the guy said, there's a space on Sunday, can you come? So we did the resonance on Sunday (E7).

It's necessary to have a surgery performed, otherwise he'll lose his eyesight, so, the moment we left, he said, your healthcare plan doesn't cover anything, and he needs a resonance, you have to do it in Ribeirão, you have to pay for it (E5).

After this initial ordeal, the suspicion of cancer occurs in different ways; that is when a new challenge is presented: going to a specialized service, as follows:

So we stayed at the hospital for a few more days, trying to look for another hospital in the region that could perform the surgery. So we thought of many places, São Paulo, you know, and so we went on looking. Then my sister got an appointment in Barretos, we went to Barretos, but in Barretos, also, he said that there was no way they could perform her surgery in Barretos. So we came back home and kept on looking for another hospital... so my sister found one in São Paulo, but she said it would be in thirty days time. And the doctors urging him to have the surgery soon (...). Because it's really difficult to get a spot in (E6).

Because you know that it's difficult to get in here, there are people here from Ribeirão that I know, they took two months to get inside, this was God, this was really God (E10).

By analyzing these accounts, we observed that one of the principles of primary healthcare,

accessibility, does not seem to be efficient, since the access to specialized service is difficult and slow, and does not meet the families' needs.

Accessibility is defined as a strategy that aims to guarantee individuals' access to health services. In this context, the term "entry door" refers to primary healthcare, where the individual should initially look for medical services, and will only be directed to a specialist when the solution for his or her problem goes beyond the reach of this care level⁽¹¹⁾. We observed that the study participants followed the correct route, i.e., initially turned to a primary healthcare service; however, reaching the specialized service took a long time, which shows the fragility in healthcare service organization. The principle of accessibility cannot be used to hamper the usage of specialties because, if the entry door is not sufficiently able to perform diagnoses or to handle problems, the whole medical care will be postponed and jeopardized⁽¹¹⁾.

One of the principles of the SUS, which is also being jeopardized according to the data in this study, is integrality, which requires interconnected health actions so as to wholly provide the individual with adequate service. In this view, the health system is responsible for providing health care to the population and to recognize specialties as a necessity in this organizational process⁽¹²⁾.

In the events experienced by the parents in this study, we identified that the integrality of the actions was not guaranteed, as they were forced to use private services to guarantee that their children would have specialized care. The parents' access to the tertiary level happened most of the times with strategies that involved the organization of the health services:

Then he started having a fever and the lump grew a lot, so they sent me here, they said urgent but it started to take a long time... and his fever wouldn't break. So I paid for an appointment with another doctor, Dr. A., he works here, and he's an infectologist. Then he talked with Dr. E. here and they scheduled an appointment for him, and so he's here (E4).

So I arrived there in her office on Thursday and she had already directed me to an appointment here, she knows a doctor here and explained the situation, and he told her to sent me here immediately, so everything was really fast (E9).

Even tertiary-level professionals show difficulties to elaborate the diagnosis, needing to transfer the child or adolescent to other specialized services, as the account shows:

Then, her eyesight was getting worse and worse (...). Then it was there where they couldn't find anything [specialized service], that they said, look, we're having her sent to Ribeirão, because here we could not find out what she has, and they'll find it there (E3).

Such experience was also reported by another father, whose daughter was undergoing follow-up care with the physical therapy team of a tertiary-level hospital, after having been submitted to an orthopedic surgery in her forelimb. In this period, the adolescent started to complain about a sore lower right limb, and that was when the physical therapy team requested medical assessment.

The physical therapist wanted to take a look, she wouldn't let him, she wanted to have her arm taken care of. Then she started limping very, very, very much... And then he said no, we're going to make this work... then he called a doctor, he said it was tendonitis, she started doing physical therapy and nothing was working, it would only get worse. Then the physical therapist told the doctor that he had to see it, because it shouldn't be only tendonitis, and that's when they suspected (E2).

In the current health context, the need for the implantation of interdisciplinary practices that respond to the difficulties resulting from excessive specialization has been highlighted; however, we should reflect on the meaning of such interdisciplinary practices, which should not be restricted to the division of care, where each professional does only his or her own part. Although the particulars should be considered, the articulation of actions is imperative for the feasibility of integral care, so that these actions can be grouped into a common project⁽¹³⁾.

Another aspect to be taken into account regards the ethics of the professionals involved in this kind of service. While some emphasize ethical action, respecting the conduct of other colleagues, others take advantage of the family's moment of weakness and disregard ethical principles, as shown:

Dr. E. said... I could do it, but, because of medical ethics, since it was them who requested everything, I'd rather have them do it... (E7).

Then the doctor was sort of harsh with us, talking about our looking for other doctors (...). He said, look, I'd have done the same, but I'm being sincere here, he who has a doctor has a doctor, he who has many doctors has none (...). Oh, it's your responsibility, and he wanted us to fill out a deposit check to do all the procedures (E7).

This study has shown the importance of the pre-diagnosis period for the parents of children and adolescents struck with cancer, because, even after

the confirmation of the diagnosis, the parents mentioned this period, trying to imagine the different paths they could have taken in order to anticipate the diagnosis and, consequently, the treatment. This question becomes even more relevant when the child or the adolescent is found to be in a worsening process of the disease. Even if there is no direct relation between the time spent until the diagnosis and the prognosis of the disease, the feelings of guilt emerge:

Maybe we made a mistake because we saw that the pain would get better, and then it wouldn't, and when it would come back, we'd give him an anti-inflammatory, everything was Cataflan. Then it would get better... So we thought this pain would really be related to growing up, because the orthopaedicians said that (...). We feel like this... why didn't we look into it, why didn't the doctor looked further into the problem and so, but... we never know. We have no study, we have no clue about treatment... we blame ourselves a little, like, if we had looked into it before, but we don't know what it is... what had to happen. And because of what S. told us, Dr. E., this tumor is very similar to osteoporosis, very hard to detect (E7).

This issue has also been evidenced in another study that emphasizes the importance of this period, especially for the parents of the children who have died⁽⁷⁾.

The difficulties experienced by the families of children and adolescents with cancer in the pre-diagnosis period imply dimensions that transcend bureaucratic and organizational issues in the health sector, since they also involve subjective aspects. The intersubjectivity was highlighted in another study, where it was shown to be very important, because it allows the discussion of the need for incorporation and valorization of work on these issues, in practical terms, aiming to innovate and build a healthcare that can really meet the actual needs of the population⁽¹⁴⁾.

The actions proposed by the Ministry of Health have stressed the search for the humanization of healthcare services. Thus, in May/2000, the Ministry of Health itself established the National Program for the Humanization of Hospital Healthcare, proposing a set of integrated actions to improve the quality of the health services, having defined the humanization of the service and quality of the professionals interacting with the users as priorities, along with the strengthening of ethical service policies and the valuation of human life. This program, expanded in 2003, sought to involve all health production units at the primary, secondary and tertiary levels and, thus,

the National Policy of SUS Care and Management Humanization⁽¹⁵⁻¹⁶⁾.

Nowadays, the Ministry of Health, through this National Policy of Humanization, releases the "Letter of Rights of the Health Users", whose proposal is to promote changes in care and management practices in order to strengthen citizens' autonomy and rights. This letter contains six principles, among which we highlight two: the first guarantees "orderly and organized access to health systems" to the citizen, and the second also guarantees adequate and effective treatment of their condition⁽¹⁷⁾.

Therefore, we notice that there already is a concern with considering accessibility and resolution as "humanizing" practices, which might be seen as a progress, since the guarantee of system access in every level of complexity and the resolution of problems are essential for the humanization of the health process, as we see it. We cannot forget that policies are fundamental, but their implementation involves such complex factors that they might constitute challenges that can hamper the establishment of the process.

FINAL CONSIDERATIONS

This study allowed us to review the itinerary of cancer-stricken children and adolescents in the pre-diagnosis process, according to accounts by their parents, which is a difficult journey among the health services.

Based on the accounts, we could notice that, although the parents dealt with subjective issues, such as the fear of the diagnosis of a serious disease, they never stopped looking for specialized help to solve their children's problem. Thus, we agree that interventions aimed at encouraging the parents to recognize the signs and symptoms of childhood cancer may achieve some positive results when it comes to shortening the delay of the diagnosis, because, based on their accounts, we noticed that the search for

service was immediate. However, it was evident that the greatest challenges were the non-specificity of the signs and symptoms and the difficulties of access to health services.

Thus, considering the importance of early diagnosis for a higher quality prognosis of childhood cancer, we acknowledge the need for effective action that may shorten the time spent from the onset of the disease until the diagnosis.

We believe that such actions imply the concomitant action of health organizations and educational institutions, in order to promote the valuation of the human being and the wholeness of the topic, i.e., looking for strategies that favor integral care, which consider not only the biological dimension of human beings, but also their other dimensions. We have already observed in another study that the preparation of the professional, considering only the biological dimension, limits the care taken of specific dimension, since it reduces the human being to a single piece, and does not consider it as a whole⁽¹³⁾.

We noticed that, in their accounts, the parents strongly emphasized commitment to the principles of both accessibility and problem solving, hence the importance of reflecting about the principle of integrality proposed by the SUS. To guarantee this principle, the system has to be able to meet the needs of the population at every level, offering access to all kinds of care and to the many available types of technology, which may enable the resolution of individuals' health problems, a fact that was not observed in the present study.

As seen, the greatest difficulties the families experienced regard two principles that were devised almost twenty years ago, so we believe that only the effective integration between the spaces of health production and those of education of health work, with the involvement of every professional, can promote the necessary changes in care and management practices, so as to really provide for citizens' autonomy and rights.

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