

The added value of narratives in the understanding of adolescent's experiences with diabetes

Summary

Evidence shows that living with diabetes during adolescence is a challenging experience. Besides the disease and treatment implications, it is important to comprehend how young people make sense of and manage their illness. Illness perceptions have been associated with a range of physical and mental health outcomes in adolescents with chronic disease. In order to contribute to a better understanding of the adolescent's experiences with diabetes, this study aimed at¹ describing illness perceptions of young people with diabetes²; understanding whether and in what ways, an in-depth analysis of the adolescent's narratives, offers additional insight into their experience of living with diabetes.

Participants were 32 adolescents with diabetes, aged 12 to 18 years, who completed the Brief Illness Perception Questionnaire and wrote a text about "What it is like to have diabetes".

Narratives were analysed with thematic analysis and illustrate how adolescents experience their disease, and the strategies adopted by them to maintain a sense of normalcy. Significant associations with the scores for illness perceptions were found, as for example, adolescents who reported a better understanding of their illness, evaluated the experience of having diabetes as less restrictive ($r = -0,445$; $p = 0.011$).

The use of narratives proved very informative on the adolescent's experiences with diabetes. For clinical interventions aimed to promote the adaptation of young people with diabetes, this study findings address the need to focus on normalizing their lives, and to promote more positive illness beliefs and coping strategies, to balance the restrictive impact that diabetes has on adolescent's lives.

KEYWORDS: DIABETES MELLITUS, TYPE 1; ADOLESCENT; ILLNESS PERCEPTION.

Introduction

Type 1 diabetes mellitus (T1DM) is the most prevalent metabolic disorder among children and young people and it is estimated that worldwide about 79,000 young people are diagnosed with diabetes each year¹. The management of T1DM includes a life-long, multicomponent regimen.

Adolescence may be a demanding developmental stage by itself, and even

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more challenging with a chronic illness such as type 1 diabetes mellitus (T1DM), since complex treatments are not easily integrated into the normative developmental tasks of adolescence². In addition to facing the same challenges as their peers, adolescents with diabetes must cope with intensive medical regimens, regular clinic schedules, complex carbohydrate calculations, and frequent monitoring of blood glucose levels³. As such, during adolescence, the adherence to treatments often deteriorates, potentially leading to serious complications and early mortality⁴. This often disturbing reality places diabetes care teams as key players in the promotion of an effective management of the illness, in order to prevent major complications, and to ensure that the health condition does not negatively impact long-term physical and psychological health.

The promotion of self-management is an important goal in the transition from childhood to adolescence and therefore, health care professionals dealing with young people living with Type 1 diabetes need to have a better insight into

how these young people experience and cope with their disease.

Evidence in this topic emerges from quantitative and qualitative studies. Quantitative studies are mainly focused on exploring the adolescent's knowledge and perceptions/beliefs about T1DM⁵, while qualitative research usually addresses a more deep understanding of adolescent's views and experiences of living with the disease². In this particular study, the aim was to articulate both approaches by comparing adolescents' perceptions/beliefs about T1DM with their narratives, to identify in what ways they provide additional insight into the comprehension of how adolescent's experience and live with T1DM.

According to the Common Sense Self-Regulatory Model (CS-SRM)⁶ people develop implicit beliefs (cognitions) and emotions about their illness, sorted into five key dimensions: i) identity: perception of the label and symptoms of the illness, ii) timeline: duration of the illness, iii) consequences, and iv) cause: perceptions of the cause of the illness v) cure/control: perceptions of cure/controllability. These beliefs help the individual to respond to health threats, and to cope with symptoms and diagnosis of the illness and health information.

Illness beliefs have been associated to metabolic control in adolescents⁷ and with a range of physical and mental health outcomes, in a number of conditions including diabetes⁸. Beliefs such as perceiving an illness as having serious consequences, attributing many symptoms to the illness (strong illness identity), and perceiving the illness as a long-term chronic condition, were found to be negatively associated with physical and mental health outcomes. By contrast, knowledge about the illness, self-confidence in the ability to manage the illness, and high perceived effectiveness of the treatments, are viewed as more positive and helpful beliefs⁸. It is interesting to note that despite worse perceived consequences and identity beliefs showed low correlations with disease state (from $-.06$ to $.08$), these same beliefs were consistently associated with worse physical and social functioning, higher distress, lower well-being and vitality (with correlations ranging between $.18$ and $.67$)⁹. These associations highlight the impact of illness beliefs on the individual's well-being and functionality.

Although the illness representation model can be applied to children and young people¹⁰, in this age range, the cognitive-maturational factors are more focused on current symptoms, short-term treatment gains and more immediate consequences¹¹.

In addition to quantitative studies, research using qualitative methods has offered important insight into the experience of living with T1DM from the perspective of the adolescent. Qualitative research seeks to gain in-depth understanding of the 'essence' of the meaning and experience of living with T1DM. A recent literature review of qualitative studies exploring the perceptions and experiences of adolescents living with type 1 diabetes², synthesized the findings from eight selected studies (sample sizes ranging from 10 to 32 adolescents). Striving for normality, parental conflict, yearning for peer acceptance, and the emotional burden of living with diabetes were identified as the core themes emerging from adolescents with T1DM reports.

Feeling different from peers and striving for normality is a recurrent theme in adolescents with T1DM. In striving to manage self-care and a good control of the disease, peer support seems to play a critical role¹². The life experience of adolescents with T1DM can be described as a compromise between being normal and being different, and in particular, trying to be like their friends and feeling supported and understood by peers is an important goal for adolescents with type 1 diabetes¹³. In a study in which interviews were conducted aiming to explore adolescents' views of T1DM in relation to

their sense of self and relationships with others¹⁴ results from thematic analysis revealed that all the 40 adolescents interviewed described T1DM as a significant burden, and many described how T1DM made them feel less "normal". Adolescents reported both positive and negative aspects of self-management in social relationships, although most pointed out benefits in sharing T1DM with friends. Female participants were more likely to share information about T1DM and to describe positive changes in self-perception because of T1DM. The integration of T1DM into the adolescent self-identity should be further explored, specifically in relation to adolescents' self-esteem, social integration, self-management, and glycemic control¹⁴.

Moreover, some studies have already demonstrated the importance of subjective views and experiences on T1DM management and metabolic control. In a study in which interviews were conducted with adolescents about their perceptions of living with type 1 diabetes, it was found that those with low metabolic control levels did not believe in an imminent cure¹⁴. Significant associations have also been found between the experiences of parental conflict reported by adolescents with T1DM and reduced adherence to treatment and deterioration of glycemic control¹⁵.

Recent literature also recommend further in-depth research on adolescents' with T1DM perspectives to enable a better understanding of adolescent's experiences of living with diabetes and associated challenges, and to guide more effective interventions².

Objectives

This study aimed to understand how adolescents experience T1DM, and more specifically, it was intended to contribute:

- To explore adolescents' narratives about living with diabetes

- To describe illness perceptions of adolescents with diabetes
- To understand whether and in what ways, an in-depth analysis of the adolescent's narratives offers additional insight into their experience of living with T1DM.

By using a mixed approach in studying adolescent's experience with T1DM, this study also seeks to contribute to more innovative ways to help adolescents cope better with their condition.

Research methods

Participants

The sample was comprised by 32 adolescents with DM1, aged 12 to 18 years ($M = 14.78$; $SD = 1.70$), from a pediatric endocrinology clinic in a central Hospital of Porto. The inclusion criteria were: being an adolescent aged between 12 and 18 years old, diagnosed with T1DM at least 6 months earlier, and suffering from no other chronic condition or cognitive or sensorial impairment, who freely accepted to participate in the study. Ethical approval was granted by the hospital Ethics Committee. At first, a nurse contacted the adolescents, who, together with their parents, were informed about the study and invited to participate. The adolescents and their parents were both asked to sign an informed consent form.

Data collection

Participants were asked to complete a questionnaire that included questions with sociodemographic and clinic variables and the Portuguese version of the Brief Illness Perceptions Questionnaire (B-IPQ). An A4 blank sheet of paper was also handed to participants, who were asked to write a text responding to the following prompt "What is it like to have T1DM".

The Portuguese version of the 9-item Brief Illness Perceptions Questionnaire (B-IPQ) (available at the questionnaire's official site <http://www.uib.no/ipq>) includes 8 items. Five items evaluate cognitive representations, (i.e. consequences, timeline, personal control, treatment control and identity); two items assess emotional representation, i.e. concerns and emotional response; and one item assesses illness comprehensibility, understanding. A five-point Likert scale (0 to 4) is used to rate the responses. The remaining item on the B-IPQ is an open-ended causal beliefs question in which individuals rank the three main causes of their illness (this item was not analysed in this study). A total score can be also computed which represents the degree to which the illness is perceived as threatening or benign. To compute the score, items 3, 4, and 7 scores are reversed and added to items 1, 2, 5, 6, and 8. A higher score reflects a more threatening view of the illness. Most studies report that the BIPQ has good internal reliability but in this study, the analysis suggested the exclusion of items 2 and 6. As such, the total score was calculated only for six items with a Cronbach alpha of 0.771.

Data collection

Since this is a mixed-method study both qualitative and quantitative analysis were performed. Narratives were analysed inductively using thematic analysis¹⁶. To enhance the analytical framework, two authors (LL, ML) identified and recorded concepts in the narratives independently, then discussed their individual coding choices. Both authors developed and refined the coding structure until it captured all the concepts about adolescent experiences of living with T1DM. The themes were inductively derived from the data through a process of analysis and comparisons.

Results from B-IPQ were analysed through descriptive analysis. To further explore the added value of studying both narratives and illness beliefs, an as-

sociation between illness beliefs and themes that emerged from narratives was tested, using non parametric Spearman correlation test.

Findings

Qualitative analysis

The texts were analysed through a thematic analysis¹⁶ and a core theme was identified named as "negotiating a sense of normalcy". The core theme emerged from 7 subthemes. Although those subthemes could be individually identified (figure 1), they were articulated in a sense that they described a process. That is, most adolescents expressed ambivalence or even apparent contradictions in what they identified as both positive and negative aspects in their experience with the disease.

The first subtheme "I'm living a normal life" in some cases worked as an entry into scene, the first statement of the text, through which participants stated that it was normal or OK for them to live with T1DM. One 14-year-old male wrote: "To me, suffering from T1DM is not something special..." and a 12-year-old female "one can be happy even suffering from T1DM". Some participants expanded their statements and justified why they thought that they felt they had a normal life, as for example "My life is the same with or without the disease, I can do everything that I did before I was diagnosed with T1DM!" (15-year-old male), "I'm used to have diabetes, I've been ill for a long time and it didn't make any difference" (13-year-old male). Some also described the process of regaining the feeling of normalcy "Over the years we just have to learn how to live with diabetes" (14-year-old female) or "some days I almost forget about T1DM... in this phase of the disease I still can find alternatives" (16-year-old female).

The second subtheme "I feel that I'm like everyone/others" describes how adolescents used social comparison processes to reflect upon their normalcy and health condition.

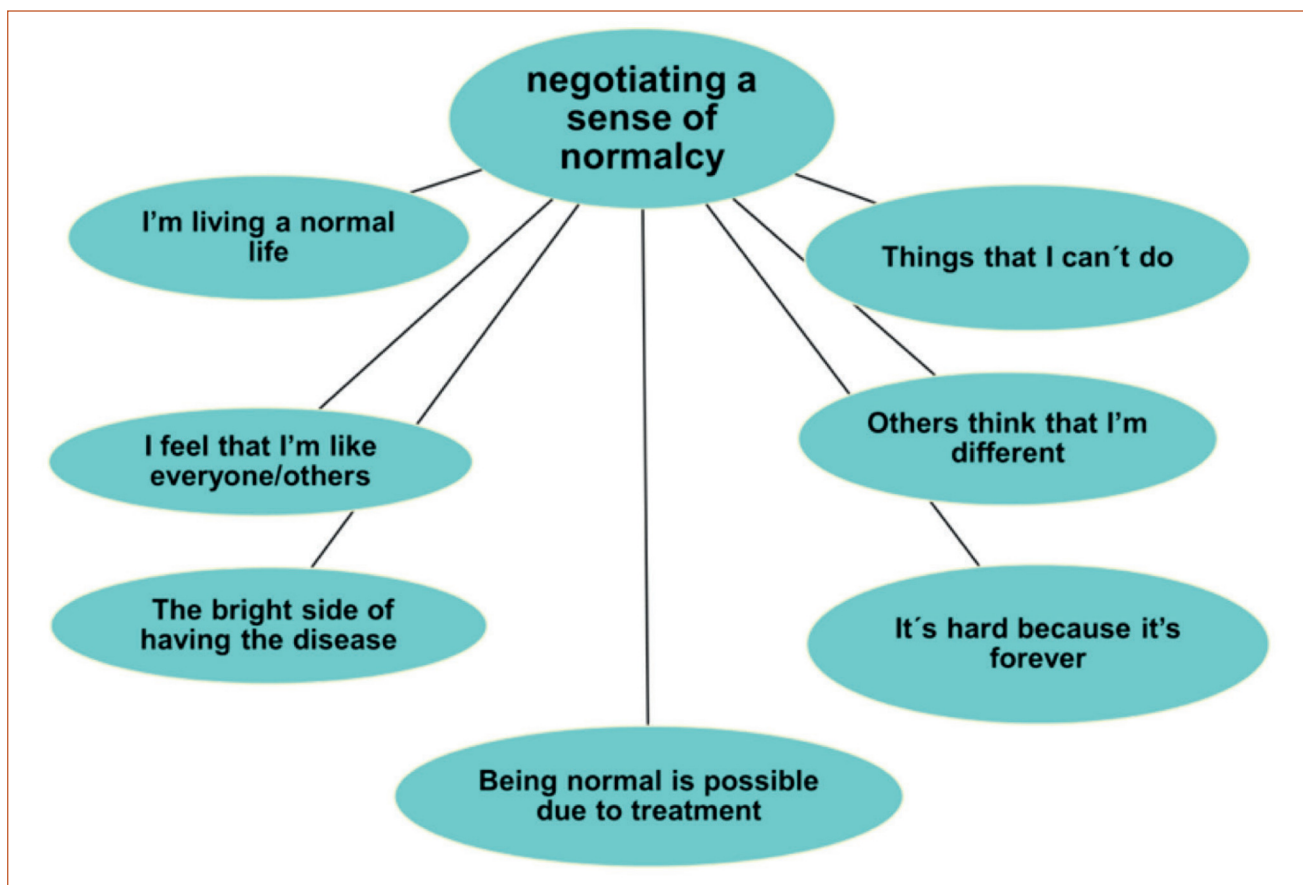


Figure 1. Thematic map – “negotiating a sense of normalcy”

They state they feel like other people, according to a 15-year-old female “I’m a girl like all the others, I’m not different” or share the same lifestyle, as a 15-year-old male “I have to have a normal life, like any other adolescent.

In the third subtheme “Being normal is possible due to treatment”, the experience of normalcy is described as a result/dependent/consequence of the compliance to therapeutic measures. Two of the citations are given as examples, “you can have a normal life if the disease is controlled” (14-year-old female), or “a diabetic person is a healthy person, without diseases, just needs some extra care” (14-year-old male). Treatment is referred as a resource for a possible experiencing of a normal life, and evaluated as simple “treatment is very easy” (14-year-old male). Some participants even referred to some aspects of the therapeutic regimen as behaviours that everybody should have “you just need to have a healthy diet as everyone should and the same with exercise” (14-year-old male).

In the subtheme “The bright side of having diabetes”, adolescents identified gains of having the disease. A 13-year-old girl wrote “Diabetes brought some advantages, as for example in relation to my diet, since I’m a diabetic my diet improved a lot” and a 15-year old girl referred “It’s good because we can control our weight”.

The remaining subthemes express obstacles and difficulties in feeling normal or living a normal life. Participants listed activities which are limited or impaired by the presence of the disease, and these were categorized as “Things that I can’t do”, one participant even used the expression “Diabetes sometimes limits my life” (15-year old male) or “I can’t sleep until late, so my life is different” (16-year old female). The most present restrictions were

related to food, especially sweets, as a 15-year old female mentioned “we can’t always eat what we want to” or another 15-year old male “You can’t eat too many sweets because it will damage your health”. Other constraints mentioned were related to social life “Our social life is also affected because when we want to go out we have to take our insulin” 16-year old male.

Another subtheme includes references to the negative emotional impact or the burden of having a chronic disease and it was named “It’s hard and its forever”. Many characterized the experience of having T1DM as bad, hard and difficult as for example “Having diabetes is something that I consider annoying and boring and that I do not enjoy much... people said it’s easy but I don’t think so” (14-year old male). A 18-year old male wrote “To have diabetes is not an easy thing, one has to

be extremely conscious in coping with the disease because one knows that it is a chronic illness and it will be present in our lives forever” and a 16-year old male “to have diabetes is very bad. It’s a disease that is difficult to accept and to take seriously.” Some adolescents also mention the difficulties related to treatment “one thing bad is that we need to inject ourselves many times and that is a little annoying!”.

In the subtheme “Others think that I’m different”, participants expressed that they felt that other people thought or treated them differently, as a 15-year-old female “I felt badly in telling my friends because I was afraid of their reaction”.

Moreover, narratives analysed more globally were characterized by ambivalence since some of the participants stated that they felt they had a normal life and later in the text, they listed all the constraints they encounter in the experience of living of the disease. Again, the analysis revealed that the experience of diabetes in adolescence is like an ongoing process, through which adolescents struggle to feel and act like others. As an example, a 15-year-old male expressed: “I have to have a kind of normal life, like any other adolescent. Nevertheless, diabetes imposes limitations and I have to do choices: I can act like a healthy person and suffer with my diabetes, or I can do what seems the best for me according to the management of my disease and lose the opportunity to have an experience or to have something that makes me happy. Sometimes I make the wrong choice and I damage my health”.

Quantitative analysis

In order to describe illness perceptions of adolescents with T1DM as measured by B-IPQ, mean values and standard deviation were calculated. Results evidenced that T1DM was perceived as benign by adolescents (maximum possible for total score is 24), indicating the perception of a small impact on their lives and on their emotional responses (table 1). Higher scores (indicating a more threatening perception) were found in relation to timeline, concern about illness and emotional impact. Globally, adolescents did not perceive a strong impact of T1DM in their lives and believed that they had a good control over their illness and that treatment was significantly helpful in controlling the disease. Despite the levels of concern, adolescents believed that they understood their disease very well.

To study the association between illness beliefs and themes that emerged from narratives non parametric spearman correlation tests were undertaken. Significant associations between the scores for illness perceptions and the frequency of subthemes were found, namely: more severe consequences beliefs were associated with fewer references to the subtheme “I’m living a normal life” ($r = -0.458$; $p = 0.008$); with more references to the subtheme “things I can’t do” ($r = 0.422$; $p = 0.016$) and more use of the subtheme “it’s hard because its forever” ($r = 0.385$; $p = 0.029$).

More positive treatment control beliefs were associated with fewer references to the subtheme “things I can’t do” ($r = -0.590$; $p = 0.000$). Higher coherence beliefs were associated with fewer references to the subtheme “things I can’t do” ($r = -0.556$; $p = 0.002$). Stronger emotional impact beliefs were associated to more references to the subtheme “it’s hard because its forever” ($r = 0.385$; $p = 0.003$).

Discussion

Through narratives, adolescents described living with T1DM as a process of negotiation between accepting the constraints imposed by the presence of the disease and the burden of its treatment and the desire/need to live a normal life. The idea of normality is recurrent in literature that describes

how adolescents cope with T1DM, so the findings of the present study are consistent with many other studies^{2,4,13-14,17-18}.

The young people living with T1DM wanted to maintain a sense of normalcy, and this was an area of negotiation in their lives. They struggled between feeling different and feeling the same, and their narratives balanced between stating that they felt just like everybody else but acknowledging that some people still thought they were different. In a literature review, the process of comparison with peers was found critical for achieving a sense of normality², and in another study the support from peers was identified as an important goal for adolescents with T1DM¹³. They described their lives as influenced by the limitations imposed by T1DM, and evidenced minor aspects of life that can become increasingly important as they are associated with the normality of a ‘typical’ teenager. However, they also acknowledge their effort in order to do ‘normal’ things, such as going out with friends¹⁸.

Another theme that emerged was related to the emotional burden of having a lifelong, chronic illness. The psychosocial implications of living with T1DM were also identified as a core theme in a review² and in the present study adolescents evidenced the challenge of living with a condition that is perceived as hard to cope with, can be a serious threat if not treated and for which there is no cure. Nevertheless, the fact that adolescents also recognized the efficacy of treatment was important for attaining a sense of normality. Some adolescents described treatment as hard and intrusive but recognised it as a condition to control the disease and having a normal life. A theoretical model about the concept of “normalizing” was developed in order to understand the adolescent’s experiences of living with diabetes⁴, and “taking on the burden of care” was identified as one of the tasks that

DESCRIPTIVE STATISTICS OF B-IPQ

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	N	Min.	Max.	Mean
Age	32	12	18	14.78
B-IPQ				
1- Consequences	32	0	4	1.47
3- Personal Control	32	0	3	1.44
4- Treatment Control	32	0	3	.63
5- Identity	32	0	4	1.50
7- Coherence	32	0	3	.81
8- Emotional impact	32	0	4	1.78
Total B-IPQ	32	0	17	7.62
2- Timeline	32	2	4	3.84
6- Concern about illness	32	1	4	2.69
Age	32	12	18	14.78
B-IPQ				
1- Consequences	32	0	4	1.47
3- Personal Control	32	0	3	1.44

youngsters had to achieve in the process. An interesting result from this study, not recurrent in previous studies, is the fact that adolescents also pointed out some gains in living with diabetes. In particular, girls identified the advantage of treatment allowing an easier weight control and the maintenance of healthy lifestyles.

Scores from the Brief IPQ showed that adolescents perceive their illness as relatively nonthreatening as the scores that were obtained from B-IPQ were globally low. The higher scores were found for the items related to timeline, concern about the illness and emotional impact, which is consistent with the chronic nature of the disease. It is also expected that the level of concern and emotional impact depend on the severity attributed to the condition. Evidence associates longer perceived timeline with more negative physical and mental health outcomes⁹ and the belief that cure is not eminent has been also related to low metabolic control¹⁹.

The adolescents participating in this study showed positive beliefs about T1DM, more specifically they reported having a good knowledge about the illness, confidence in their ability to cope with T1DM and a high perceived effectiveness of treatments. All these beliefs have been previously associated with positive outcomes, both in terms of physical and psychosocial adaptation⁹.

The association between the illness perceptions, as measured by B-IPQ, and the use of themes that emerged from the analysis of narratives also showed interesting results.

Some results demonstrate that despite the methodology used to access adolescents' perceptions, similar important issues are evidenced. In fact, associations were found between similar ideas/beliefs, as measured by the B-IPQ or mentioned more freely through narratives. As an example, an association was found between stronger emotional impact beliefs and more references to the subtheme "it's hard because its forever".

Nevertheless, the study of the associations also helps to deepen the understanding of adolescents' experiences of living with diabetes. The adolescents who scored greater perceived consequences in the questionnaire

were the ones who, in their narratives, were less likely to describe their life as normal, who described more restrictions and limitations associated with diabetes, and the ones who evidenced the physical and emotional burden of the illness. More positive treatment control beliefs reported in the B-IPQ were found to be associated with fewer references to the subtheme that described restrictions, reinforcing that the adaptation to treatment is critical for achieving a sense of normality. Although significant correlations were found, findings derived from the adolescents' narratives do not totally overlap with the questionnaire results, and provide richer, more in-depth and nuanced insights into the experiences of living with diabetes.

Finally, higher coherence beliefs were associated with fewer references to the subtheme that included statements to limitations, which suggests that promoting a greater comprehension about the illness helps adolescents to cope with the restrictions imposed by diabetes. The development of educational programs to increase knowledge and supportive behaviors are also recommended⁴.

Conclusion

This study evidences that the experience of having diabetes is complex and is more fully understood when in addition to the evaluation of illness perceptions, as described by the Common Sense Self-Regulatory Model, adolescents are asked to describe it in a more open way. Although in the Brief IPQ adolescents reported their illness as relatively benign, their narratives illustrate where they experience limitations and the negative impact of chronicity. An interesting result is that adolescents who understand more about their illness and are more confident in the control provided by treatment, experience their disease as less restrictive.

In what concerns to clinical interventions aimed to promote adaptation of young people with diabetes,

findings of this study highlight the need to focus on normalizing their lives and to foster more positive illness beliefs, namely through the development of psychoeducational programs, as a way to balance the restrictive and undesirable impact that T1DM has on their lives.

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