

The Share of Internalized Stigma and Autism Quotient in Predicting the Mental Health of Mothers with Autism Children in Iran

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Abstract

Caring of the child with autism is very demanding and produce a huge stress for parents. **Purpose:** *The purpose of this study was investigating the roles of internalized stigma and autism quotient in predicting the mental health of mothers of children with autism.* **Method:** *93 of mothers were selected through random selection from the educational and rehabilitational special centers for children with autism in Isfahan and Shahrekord and they filled out the GHQ questionnaire, affiliate stigma questionnaire, and Gilliam Autism Rating Scale through interview. The data was analyzed through multiple regression analysis.* **Results:** *The data analysis revealed that internalized stigma predict 25 percent of variation in mental health and autism quotient had no significant relationship with mental health.* **Conclusion:** *It is suggested using of educational interventions basis on empowerment against stigma for heightening the level of mental health in mothers of children with autism in Iran.*

Key words: Mothers, Autism, Stigma, Mental Health, Autism Quotient.

Introduction

Autism Disorder is a pervasive developmental disorder with prominent impairment in social reciprocity, verbal and non-verbal Communication, and restricted, repetitive and stereotyped behaviors or interests (Diagnostic and Statistical Manual Disorders [DSM-IV-R], 2000). The diagnosis of Autism has been increased during last fifteen years and is increasing now (Baron & Cohn 2004) and it seems that it is existed not only in special races and nations but also in all social and economic groups; moreover, the possibility of to be affected by this disease in boys is four times as much as girls (Stevens et al. 2007). Increasing the rate of prevalence of Autism spectrum disorder, many researches have been done studies on the parents who have children with autism and their mental health. Parents of children with autism display a variety of Psychological symptoms including depression, anxiety and pessimism (Daniels et al., 2008; Davis & Carter, 2008; Hastings & Brown, 2002; Herring et al. 2006; Lin, 2011). There are strong evidences that mothers who have children with developmental disorders like Autism disorder report higher mental health problems compared to mothers of children with Down syndrome (Abbeduto et al., 2004), fragile X syndrome (Abbeduto et al., 2004), mental retardation (Weiss, 2002), and developmental delay without autism (Bailey et al. 2007).

Gray (2003) noted that the highest damage had been seen in what called psychological well-being. It was due to the fact that mothers compared to fathers specially in eastern countries (e.g. see Azar & Badr, 2006) probably experience more negative outcomes, because they received more medical and psychological treatments, due to this distress (Gray, 2002). Mothers strongly feel guilty and depress about their disabled children; and in less cases when they encounter with stroke or physical illness, they believe that this problem is related to the child's disability. There are mothers who mostly experience emotional distress and career disruptions due to their main role in the child's referral treatment process and the relationship with educational problems. Mothers also are considered to be responsible for the child's behavior by their husbands and other people outside the home (Gray, 2002). However there are evidences of variety in mental health problems experienced by disabled children's mothers (Davis & Carter 2008, Sawyer et al., 2009). A main factor for the explanation of this variance is perceived stigma. This subject, stigma, in mental health studies has received many considerations recently (Penn & Martin 1998). In last decades, different conceptualizations have been presented by researchers to make a better understanding of the complicated and multilevel outcomes of stigma on the mental health (Carikan & Pen 1999, Major & O'Brien 2005).

The term of stigma firstly had been used by Greeks and referred to the bodily signs referred to person's bad and unusual moral manner. Goffman was the first person who applied stigma for explanation of a specific psychological-social phenomenon (Goffman 1963). He defined stigma as "an attribute which is extremely disgracing and causes the person with this attribute change from an usual person to an unimportant and disgraced person in the society and discussed that stigma was a special connection between a trait and a stereotyped think; He also affirmed that stigma was a kind of communicative language. Basis on the definition of Goffman, Link and Phelan (2001) clarified the process of stigmatization. They discussed that stigma could be appeared when the components of labeling, stereotyping, segregation, status loss, and discrimination of stigmatized individual co-occur in a power situation. Goffman proposes two kinds of stigma: self and affiliate stigma. Unfortunately each person, in a social structure with a relation to the stigmatized person, might be exposed to the same situation (Goffman 1963). At first, stigma appears to the person who is susceptible to stigma then all stigmatized person's relatives are at the exposure of being stigmatized.

Affiliate stigmatization happens afterward, in the way that people just because of having a relation to a stigma person are at the exposure of negative behaviors. To have relation with the stigmatized person such as caretaker, family member, and friends might expose the person to the common stigma in the society called courtesy stigma. Suffering from affiliate stigma, these people feel sad and helplessness due to having relation with stigmatized person. Based on these cognitive and emotional effects of affiliate stigma relatives react to show they have no relation with a stigmatized person through several behaviors such as concealing stigma situation, not attending in social relation, or even separating stigmatized person from themselves to show there is no relation between them. Therefore, like self stigma, affiliate stigma consisted of three linked elements: cognition, emotion, and behavioral responses (Neuberg, Smith, Hoffman & Russell 1994). Because parents and children have genetic connection, transferring stigma from children to parents is inevitable. Being parents of a stigmatized child causes secondary stigma and special problems for them.

Jones et al (1984) explained six main social dimensions of stigma which have special effects on the appearance of the stigma in everyday interactions as follow: concealability, course, disruptiveness, aesthetic qualities, origin, and peril. Concealability refers to the ability to see stigma situation and to control the way it is observed. This is one of the main dimensions which determinate the degree of stigma. The visibility of the situation can be explained from different perspective include whether the situation is observable by our eyes or not. Moreover, Goffman put emphasis on the observer's awareness about the situation which can differ based on people's knowledge or experience about the stigmatized person. Process, the second dimension, refers to the pattern of the stigma situation during the time. Some stigma situation might disappear through the passage of the time but some others are permanent.

The destruction of the stigma situation is self-explanatory which mean that the degree of that stigma situation destruct the social interactions. Aesthetic qualities point to the way the attractive and unattractive signs appear. Origin shows the source of the mark and to some extent the person is responsible for its existence. When the disability has genetic origin, there is an instinct and unconscious inclinations that afflicted person receive more censure rather than the situation in which the disability is due to accident because in genetic cases the person himself is considered to be responsible for the disability. This instinct and unconscious inclinations is more considerable when the stigma is the problem of relatives including parents. The last dimension, peril, focuses on the dangers from the stigmatized person (Jones et al 1984). This dimension has a great effect on the appearance and intensity of the stigma in a person.

Similarly, Katz (1981) identified visibility, threat, and perceived responsibility as significant factors in predicting how observers will react to typically stigmatized individuals...Both Jones and Katz proposed very important dimensions of the stigma. Regarding these dimensions, Parents with children with autism are at high risk to experience stigma in society. In stigma For the parents with children with autism, Because there is no physical, observable mark, trait, or deformity in Autistic children, special problems include concealed stigma happen for them and their parents. Concealed stigma refers to stigma identity that is not immediately knowable in a social interaction (Quinn, 2006). When a child misbehaves in a party with no sign of physical excuse for his behavior, he might be misjudged. Half of Americans participated in a survey feel different levels of pity towards disabled people. 77% of them said that they have sense of pity towards disabled people (Hingley-Jones, 2005). Pity may be unpleasant, but it also consists of other component like sympathy and compassionate.

Showing no external sign of disability and pitifulness, Autistic children's misbehavior may arouse negative reactions especially towards their parents .Although pity implies a negative essence but it at least can be mitigation in some situations for parents' stress .Elevated stress in parents who have a child with autism can be a result of the absence of sympathy and support from society members who cannot understand the child's problem easily.So, theoretically, the possibility of the stigmatization would be increased in the absence of sympathy; although, there is no sign of visibility .On the other Side, there are parents who conceal their children's diagnosis to escape to be stigmatized .However studies have shown that concealing stigma situation can automatically lead to psychological damage .Smart & Wegner (2000) noted that hiding stigma situation results in turmoil which can automatically, based on its intensity and the nature, affects the individual's psychological life.Perceived responsibility is another main dimension in the parents' stigmatization .In one hand regarding several autistic behaviors including low social skills, improper social behavior, oddities behavior, self-injuries, impaired language, and other improper social interactions play roles in the emergence of the stigma (Penn & Martin, 1998) . Moreover, Gray (1993)believed that the anticipation of strong destructive anti-social behavior with the children's normal appearance and lack of general knowledge about Autism led to considerable increase in being stigmatized in the children .For instance, child's improper social behavior which is a sign of disorder might be considered as a kind of stubbornness and disobedient.

The Autism spectrum disorders are neurological, not social or psychological .Due to the fact that damages are related to the behavior, it is so easy to ignore the neurologic origin and accused parents for child's misbehaviors . On the other hand , Although significant amounts of research have investigated brain abnormalities, genetic and neurochemical abnormalities, infections, and diet, among many other things, there has been little conclusive evidence pointing to any one, identifiable cause in the majority of cases. This absence of an identifiable antecedent in most cases may result in a serious misattribution of blame in the direction of the parents. Historically, there is natural tendency to blaming mothers for misbehaviors of children with autism, By labeling these mothers as refrigerator mother in 1950 by Bruno Bettelheim that conceived that the autism disorder was the result of the mother's nurturing who didn't want their children to stay alive/survive, consciously or unconsciously, which itself caused to prevent creating an emotional relation between parents and children(Wnoroski, 2008).Unfortunately Bruno Bettelheim's permanent accusation of parents with Autistic children directed irretrievable damage and accusation of being sinful to generations of parents (Scott, Clark & Brady 2000). . Previous studies indicated that family members are exposed to different kinds of stigmatization and discrimination because of having a child with Autism (Gray, 2002; Mak & Kwok, 2010)|These studies generally indicated the expanse of the courtesy stigma received by autism family members from general public (Mak & Kwok 2010).Disabled individual's relatives internalize external stigma to internal stigma in the way that they use negative self-evaluations ,experience intensive negative emotions; so, they become isolated and hide stigma situation from other people (Corrigan , 1998).

In the one of the recent studies, Mak and Kwok(2010)investigated the effects of perceived stigma on the parents' of Autistic children based on the attribution theory to propose a model to explain internalization stigma in this group .The results indicated that parents directly internalized the enacted stigma in the society about themselves through controllability, perceived responsibility, and self-blaming .The direct relationship between enacted stigma and parents' stigma in the society was due to the spread of negative attitudes about disabled people in the society especially in Eastern Countries .These parents accepted easily the negative attitudes about themselves and their children .Some of them accepted the responsibility and blaming about children's situation; therefore, internalized the current stigma in the society .In more details, those parents who believed that they have low control about their children's Autism and their troublesome behaviors more possibly experienced internalized stigma .It can be discussed that Autistic children's mother intensely expose to be stigmatized in the society and to internalize it . Wnoroski(2008) applied qualitative method to study stigma on mothers with autism children three 6,10,23 years old .The instrument he applied was 26-question open -answer interview which was developed and tested by research .All three participants had experienced the negative experience of nurturing an Autistic child .Those experiences gained in the confrontation with strangers' harsh behavior immature view. Because Autistic disorders are related to externalized behavior, strangers make guesses about child's behavior .Expressions like "I never allow my child to act the same "or "if he was my child, I slap him right now "extremely bother parents and the repetition of such sentences destruct parents' self-conception and strengthen the feeling of being guilty about child's behaviors.

Gray (1993) in a qualitative study on thirty two parents of Autism children in Australia, found out that the majority of the parents internalized stigma; although, a high percentage of them did not so. Stigmatic perceptions related to parents gender, the intensity of disability, and child's age. Parent's children with autism with higher level of disability internalized stigma more than others. Also the possibility that parents whose children with autism were in pre-adolescent period considered themselves as victims of stigma more than those whose children were adolescent. Moreover, the results of that study showed that unusual aspects of Autism disorder which interfere with usual social interaction played main roles in parents' stigmatization. Gray (2002) studied internalized stigma and enacted stigma among a sample of parents of children with high function autism. The results of this study indicated that most of parents experienced both kinds of stigma. It also related to the kind of signs relate to autism disorder in the way that parent with aggressive children experience more stigma than those with passive children. Mak and Chung (2008) by developing and validating the affiliate stigma scale on 210 caregivers of people with intellectual disability and 108 caregivers of people with mental illness in Hong Kong, investigated quantitatively demonstrated that caregivers of children having both intellectual disability and autism experience higher affiliate stigma than those of a child with intellectual disability only.

A stigmatized person does not come without its costs. There can be many cognitive, affective and behavioral outcomes. Some treatment can jeopardize stigmatized person's general health and well-being. Also these people may be ignored, to be excluded, and targeted by physical violence (Major 2006). Moreover, it is not uncommon for the victims of stigmatization to have elevated anxiety and stress as a result of all the negativity that surrounds their condition or even their identity (Major, 2006). Several theories of the effects of stigmatization have also identified a phenomenon in which stigma becomes internalized into chronic feeling of inferiority (Major, 2006). Some researcher applied structural equation models to explain the relationship between stigma and psychological well-being. For example Vauth, Kleim, Wirtz & Corrigan (2007) found used strategies to confront against stigma such as social isolationism and concealing disease might increase the stress. This increase negatively has an effect on lack of self-esteem, self-efficacy, and empowerment. The decrease in empowering has an effect on depression and decrease the quality of life (Yanos, Roe, Markus & Lysaker 2008). Studies on internalized stigma have shown that many people with mental illness have high level of stigma and this experience relates depression sign positively and to self-esteem negatively (Mickelson & Williams 2008). In some cases the relationship of stigma to minor depression is mediated by self-esteem, fear of isolation, and experienced stigma (Mickelson & Williams 2008). Those studies measured experienced stigma showed that this kind of stigma has a negative relation to the quality of life and self-esteem (Depla, Graaf, Weeghel & Heeren 2005), and decrease self-esteem which itself increase person's self – efficacy (Wright, Gronfein & Ownes 2000). Of course this effect has not proven yet in comprehensive studies; it is mostly intuitive rather than experimental.

Mak, Poun, Pen, & Shefai (2007) do meta analysis study on 808 researches about relationship between mental health and stigma from 1985 to 2005. They found that the effect of stigma was as much as high which could affect daily life. In other words stigma had an significant relationship to mental health of different stigmatized groups of people; different stigma had different psychological consequences on different individuals. Stigmatized people experience higher level of tension, depression, stress, and lower level of self-autonomy (Mak, Poun, Pen, & Shefai 2007). In a study done by Green (2003) to investigate the effects of internalized stigma on social and emotional outcomes on disabled children's mothers, it had been found that beyond objective burden of caring of these children, mothers' internalization of stigmatized attitudes toward child increase their stress. Internalized stigma in mothers with disabled children affected both subjective and objective aspects of stress (Green, 2003). In other studies investigating the effective factors on the mental health of mothers with disabled children, the severity of disability was considered as a control or independent variable (Benson, 2006). Regarding the severity of diagnostic sign of autism as a objective and internalized stigma as a subjective aspects of caring which can affect the mental health of mothers with autism children, the purpose of this study is to investigate the relationship between internalized stigma in mothers and the severity of the diagnostic signs of autism (autism quotient) on the mental health of mothers with autism Children in Isfahan and Shahre-kord cities in Iran.

2. Methodology

2.1. Participants

The participants for this study were 95 mothers with autism children who were enrolled in the Centers of Special Education for Autism Children in Isfahan and Shahrekord cities in Iran. The average age of mothers at the time of the questionnaire was 29.5 (S.D=4.2).

Children's average age also was 7.7 (S.D=2.7) and 79 percent of them were male children educated in these centers and were referred basis on child psychiatrist or clinical child psychologist diagnosis as having autism disorder.

2.2. Instruments

The Persian versions of follow instruments was used in this study

2.2.1 General Health Questionnaire (GHQ)

Since it was developed in 1972 ,The General Health *Questionnaire (GHQ)*,Goldberge,1972) has been widely used as screening measure for general psychological health and tested in various cultural and language context such as Persian. It is based on self-reporting applied to detect people with mental disorders and includes four sub-scales, each containing seven items, are as follows:(A) somatic symptoms (items 1-7) ,(B) anxiety/insomnia (items 8-14), (C) social dysfunction (items 15-21) ,(D) depression (items 22-28) .Each item scored from 0 to3. by summing the score of every question ,It is obtained the score for each subscale .and total score can be calculated through summing the scores in subscales.The higher score indicate the lower mental health level.

Various studies indicated its suitable validity and reliability in Iran. for example Nourbala, Bagherie Yazdi, & Kazem(2009) discussed that The concurrent validity of GHQ carried out by the Symptom Checklist- 90- Revised indicated that there was a significant correlation between scores of samples within the scales of these instruments. The evaluation of reliability of GHQ-28 carried out by the test- retest procedure a week after the first stage, and validation of this instrument indicated that the instrument could be used successfully in the epidemiological study of mental disorders as a screening instrument. Likert scoring method of GHQ showed a cut off point of 24 . In another study , internal consistency reliability coefficient of four subscale were found, 0.87, 0.85, 0.79, and 0.91 respectively(Ebrahimi et al.2007). Other studies on the standardization of this questionnaire in Iranian people showed suitable validity and reliability (Taghavi,2001)

2.2.2.Affiliate stigma Scale

For measuring the internalized stigma in participants, It was used from affiliate stigma scale include 22 item developed by Mak and Chung(2008) based on stigma literature and focus group discussion with caretakers of children with mental disorders and intellectual disability. Participants rated the extent to which they endorsed each item on a 4-point Likert scale from (1)strongly disagree to (4)strongly agree. The scale items measured the cognitive, affective and behavioral components of affiliate stigma. The Internal consistency reliability was reported 0.95 and total correlation of the 22 item was from 0.47 to 0.78. Exploratory factor analysis suggested that the Scale was unidimensional, with excellent internal consistency(Mak and chung,2008).This instrument was translated from English to Persian and then back translated to ensure accuracy and equivalency.

2.2.3.Gilliam's Autism ranging scale (GARS)

This scale has a forty-two clearly stated items divided into three subtests include stereotype behavior, communication and social interaction describe specific, observable, and measurable behaviors. This behavioral checklist appropriate for persons ages 3 through 22. Questions were scored from 0 to 3.A total raw score is computed for each of the GARS subtests .Obtained scores can be converted to percentiles ranks and standard scores. The sum of subtest standard scores can then be converted into the Autism Quotient .This instrument had been standardized on 1092 Autistic children and teenagers in different states of North U.S .Internal consistency and test-retest reliability was reported from 0.81 to 0.96 .Its criterion validity had been proven through the correlation of the GARS with well-known tests in diagnosis autism as ABC. The result indicated good validity (Gilliam, 2001).

3. Findings

The analysis of the data was done through SPSS-16 software .To investigate the purposes of the study Regression analysis was applied .The results are presented in Table 1 and Table 2. Based on the results in table 1, it can be perceived that about 60 %of the mothers' scores in total mental health are above 24(clinical cut-off in GHQ). Mothers who in higher ranges of mental health problems, demonstrated higher mean in stigma.

Table1-descriptive data

Range of mental health scores	N	%	General mental health		Somatic symptom		anxiety		Social dysfunction		Depression		stigma		Autism Quotient	
			X	SD	X	SD	X	SD	X	SD	X	SD	X	SD	X	SD
3-23	24	36.3	15.8	6.2	4.2	2.5	3.5	2.3	6.4	2	4	1.6	52.6	27.1	98.8	11.4
24-30	11	16.6	27.1	1.7	8.7	2.5	8.4	1.6	6.5	2.1	3.4	2.5	79	37.6	102	25.9
31-40	19	28.7	36	2.8	9.5	2.8	10	2.1	9	2.3	7.4	3.2	94.5	31	96.6	16.4
41-62	13	19.6	52.3	6.4	14.1	2.8	14.1	3.4	11.3	3.2	12.6	3	102	34	96	12

To apply Regression analysis, internalized stigma and Autism Quotient variables as predicting variables and mental health as predicted variable were inserted in regression analysis .The results of Regression analysis are presented at table 2 .

Table2-Regression analysis results

Model	Variable	β	sig
Model 1	autism quotient	-0.094	0.38
	Stigma	0.57	0.00

R=0.54 R squares=0.29 adjusted R square= 0.27

Predictors:(constant,stigma,autism quotient)

Dependent variable :General mental health

Table 2 shows that only stigma predicts general mental health significantly. Correlation of the stigma and general mental health is 0.54 (R=0.509).Moreover 29 percent of variance in mental health can be predicted from stigma (R =0.29).

The relationship between Autism Quotient and general mental health was not significant.

4. Discussion and Conclusion

In fact, stigma is psycho-social process that begins with labeling and ends to social withdrawal. The result of this study showed that internalized stigma had a significant relation to mental health (table 3) and it predicted about 25 %of the mental health variances and the intensity of diagnostic signs (Autism Quotient) had a weak and insignificant correlation to the mental health (table 2) Parents with children with autism confront to an array of specific challenges that it is not surprising why their psychological adjustment are impaired. Nurturing a child with Autism, demands a lot of care including more than thirty hours every week .They are parents who are usually responsible for managing making decisions, and treatment procedures .Many mothers have to give up their careers to take care of their children; this matter imposes additional financial pressure on the family and exposes them to an additional stressful situation .Moreover, the family experiences the tension of child's uneven intelligence development, enormous destructive behavior, and long-term caring (Baker-Ericzen, Brookman, Frazee & Stahmer 2005).

Parents' abilities to successfully answer their Autistic children's problem are significantly different; while some parents experience a lot of mental problems some others experience less amount of such problems (Benson & Karolof, 2009). The results of this study indicated that, firstly, mother's children with autism are strongly at risk for decrease in level of mental health in way that about 60 %of mothers in GHQ reported scores higher than 24 (clinical split point based on Iranian people(Ebrahimi et al.,2007) (table 1).While some mothers reported high levels of mental health problems, others(near 40 percent) reported lower levels of problems.One of the relation factors to this variation affirmed in current study was internalized stigma. Mac and Kwok(2010) found similar results in a study on parent's children with autism in Hong Kong. Deeply and qualitative studies on mothers with autism children in Iran, Australia, and U.S .showed that one of the main problem of them was stigma attitudes in the society (Chimeh, Pour Etemad, Khoram Abadi ,2009; Gray 1993,2003 ;wnoroski, 2008) .

Everything is ready that mothers with autism children to be victim of stigma .On one side, many behavioral oddities in the form of self-stimulation and inappropriate use of their bodies through flapping, smelling and mouthing objects and rocking as well as improper forms of social interactions and linkage these behavioral characteristics to stereotyped and common prejudice in society are the starting point of real stigma society and, become isolated and discrimination against these people follows it (Penn, 1998) .Moreover, Gray (1993) believed that co-occurring of strong anti-social destructive behavior with children's normal appearance and low knowledge about Autism leads to the increase of stigmatization in these children .Anti-social and destructive behaviors which are clearly observable are considered as impolite and disobedient behavior .People attribute these behavior to the mothers' way of nurturing, not to the nature of the disorder .Although public knowledge about Autistic disorder situation has been become better than other form of childhood disorders like dawn Syndrome, but the general public has a little knowledge about Autism disorder .Therefore, parents with children with autism face frequently with harsh or insensitive reactions from people, especially when their children behave improperly .Many parents internalize public stigma in the society by applying negative self-evaluation in controlling behavior's their children as well as perceiving the responsibility of the children's behavior and then choose isolation and avoidance from attending social activity (Mac and kwok, 2010) .These social avoidance behavior affected mother's mental health .The relationship between internalized stigma and mental health has been documented in many studies(e.g. See Mac et.al .2007).

One more finding of this study was about the weak relationship between Autism Quotient with mothers' mental health level .While in the mentioned studies in introduction, such as Benson (2006) the emphasis was more on mediating role of the intensity of diagnostic signs of autism on mothers' depression and health in these studies, But in our study emphasis on direct relationship .It is proposed to study the effects of the severity of signs of disorder as a mediator on mental health components .Another worth full point to mention is, instead of emphasis on autism quotient, it is suggested to study the effects of the child's level of social adjustment, co-occurring with other mental disorders, and intellectual disability in children on the mothers' level of mental health .

Autism disorder is one of life-long disorder which its signs spread all over the life and it demands frequent education and treatment .The mothers' role in the education and treatment of children has been documented repeatedly .So with regard to central role's mothers in education and treatment of children with autism, It is necessary to improve the mental health's mothers. Basis on the results of this study, it is strongly suggested using of empowerment against stigma through the different techniques .Because of strong relationship between stigma and mental health, it is proposed that short term and long term programs provide to empowerment mothers against stigma as an educational component in education of family settings. Public education and exposure to autism disorder to increase society awareness level about Autism disorder to modify stigmatic attitudes is necessary. It is also suggested to study public stigma against Children with autism and their family to understand to extend how much these people experience real stigma in society and to extend internalized it in them.

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