UNWITTINGLY DE-HUMANIZING PATIENTS; REHABILITATING INFORMED CONSENT

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Abstract

To guide interactions in a healthcare setting, informed consent is the doctrine that incorporates and operationalizes such seminal ethical concepts as autonomy, authority, duties, rights, and truth. In everyday practice, however, informed consent has become ethically impoverished because too much is overlooked. Three evocative metaphors from Marx, Heidegger, and feminist theorists are used to illustrate what routinely is omitted: alienation, inauthenticity, and silence. Examples of typical informed consent discussions are presented with recommendations of how to rehabilitate them so as to return to an enriched version of informed consent that is, at the same time, practical.

Introduction

Martha Nussbaum's characterization of what is moral wisdom or moral competency is compelling. Defending the value of literature as a pedagogical tool for teaching ethics, she notes that the goal of such teaching should be "to make ourselves people 'on whom nothing is lost" (1985: p. 516). For her, moral knowledge is not exhausted by efficiently gathering facts and adeptly wielding theories. Instead being perceptive is pivotal in terms of all that is ethically going on (i.e., "what's really happening?") and all that is ethically at stake (i.e., "what's to be gained and what's to be lost?").

Motivated by Nussbaum's point, I challenge the doctrine of informed consent as it is routinely practiced in clinical settings. Three evocative metaphors constitute this challenge: alienation as developed by Marx, inauthenticity as developed by Heidegger, and silence as developed by feminist writers. Yet as

shown by this article's sub-title, these challenges are not fatal. Recommendations are offered as to how to rehabilitate the everyday practice of obtaining consent.

Preliminary Concerns about Informed Consent

Within the biomedical ethics community, informed consent is the ethical doctrine or principle that has commanded the most scrutiny and discussion. One way to provocatively affirm why the doctrine is so important is to say that it is a response to power; in other words, a response to the power of caregivers. This power is multifaceted. It comes from possessing specialized knowledge and skills, having access to technology and services, being able to make these resources available to others, dictating the language to be used, and having "hard won" familiarity with tragedy.

Paternalism can be defined as one person making decisions for and about another person. A utilitarian critique of paternalism posits that, in most instances, a person is able to make better decisions for himself than if someone else makes the same decisions. Yet ethical worries about paternalism go beyond pragmatics. Personal decision making should be protected because it involves both freedom and power. Accordingly when the stakes are fully acknowledged, paternalism is no longer accepted as the appropriate "default position" for physicians and nurses.

With this said, however, a demand that caregivers rid themselves of such power is unacceptable just as, I hold, a demand to equalize this power is unacceptable. There is an inherent imbalance in any patient-caregiver relationship because one party is ill, injured, disabled, or dying and the other is not and because one party needs what the other party possesses.

The doctrine of informed consent has been developed and refined so as to more equitably balance the power dimension within health care. Various court rulings have affirmed that a person has a right to privacy or non-interference, be it of body, mind, or lifestyle [Cruzan v. Director, Missouri Department of Health 497 US 261 (1990); Rennie v. Klein 720 F.2d (3d circ. 1983); Griswold v. Connecticut 381 US 479 (1965)]. Caregivers then bear a corresponding duty to obtain a patient's permission, in essence, for such interference. Caregivers are also expected to try to alleviate obstacles that hinder a patient in giving valid consent, such as treating pain, anxiety, malnourishment, or hallucinations.

In my experience in clinical and academic settings, informed consent is understood to center primarily on decisions and a patient's decision making ability. This focus, in my opinion, is regrettably narrow. The regrets are fourfold. First,

clinicians presume that the duty to seek consent arises only when there is a specific treatment in question. But I contend that patient consent is tacitly needed for any intervention, even for something as routine as using a pressure cuff or drawing a blood sample. Admittedly what is at stake ethically in using a cuff or drawing blood is not trading off immense risks for marginal benefits. Instead what is at stake, as I see it, are intimacy and bodily integrity respectively. A person's permission therefore must be sought whenever he is to be touched or whenever his body is to be entered. If permission is needed for any form of intervention or interference, the subsequent issue is how to seek permission, given the constraints of everyday practice. Examples of these constraints include limited time, minimal relationships between patient and physician, and specialization's erosion of continuity of care.

Second, decisions can feel like static moments in time. Once made, they are presumed to be finished. Yet illnesses may be chronic wherein the fitting response is that they are to be "lived with" rather than "decided upon." Accepting the fluidity implied in "living with" encourages ongoing monitoring and review within the context of everyday responsibilities such as family, school, and work.

Third, a patient's cognitive abilities are a central concern whenever a decision is to be made. However affective and psychological capacities tend to be a concern only when they threaten cognition. In a healthcare setting, emphasis is placed on a patient's ability to take in, comprehend, and process information that can be complex and voluminous. Certainly, reasoning skills are important. Yet inequitable attention is directed to the person's emotions or psychology even though emotions and psychology are other aspects of individuality.

And lastly, illness, injury, and dying involve much more than sound decisions just as therapeutic relationships involve much more than candor and information. Reliance on candor and data only accords with the informative model of the physician-patient relationship as described by Emanuel and Emanuel (1992). As these authors demonstrate, the informative model is fitting for only simple or predictable medical scenarios.

Based on these four points, the doctrine of informed consent has become impoverished such that ethically-relevant details of a medical encounter are omitted or distorted. Toombs underscores the omission of the personal and the privileging of the physical in contemporary medicine. She points out that "medical education deems it necessary explicitly to remind students that patients are [indeed] persons" (1988: p. 202). In this paper, I will discuss how routine clinical practices unintentionally de-humanize patients even though the practitioners would

contend that informed consent has been obtained. More specifically, I will argue that standardized informed consent is inadequate for ethically responding to patients. As mentioned, three philosophical concepts will be utilized to illustrate the shortcomings: alienation, inauthenticity, and silence. These concepts will be applied to ordinary clinical examples to illustrate how routine is such dehumanization and, more positively, how they can help rehabilitate informed consent.

Alienation and the Loss of Context

Karl Marx was very concerned about the societal or institutional conditions that dictate the communal context of a person's life. One way to characterize Marx's writing is to say that he wrote in response to de-humanizing power. In his case, economic standing confers power, regardless of whether wealth is in the form of accumulated assets or ownership of some mode of mass production. What is most ethically worrisome, though, is ownership of productive mechanisms. In the context of human beings, "productive mechanisms" means human labor.

For Marx, the essence of the human condition is voluntary and creative activity: "the individual 'reproduces himself...actively and in a real sense, and he sees his own reflection in a world which he has constructed" (Schact, 1970: p. 76). This is importantly distinctive because "conscious life-activity distinguishes man from the life-activity of animals. Only for this reason is he a species-being" (Ibid: 78). More simply put, human activity manifests individuality and personal integrity.

Marx is critical of industrialization because it promotes alienation which means separation and loss of connection. This strips away a person's humanity, a kind of ontological evisceration. The result, suggests Marx, may well be a non-human, perhaps even a machine. So sweeping is industrialization's impact that he identifies four forms of *Entfremdung* or alienation:

- (1) alienation from the external world of sensory objects,
- (2) alienation from oneself,
- (3) alienation from one's species nature, and
- (4) alienation from other people.

In a healthcare setting, the second and fourth forms of alienation are especially relevant. To be alienated from yourself is to be disconnected from whatever constitutes your identity or whatever makes you who you are. The associated image is not a person being split in two. The fitting image is a person's

character being emptied out. This means that what remains is de-personal and so not human. Alienation from other people means that relationships are lost: you are now a stranger to other people just as they are strangers to you. Human beings are social creatures, inescapably and necessarily, and so isolation and loneliness are inhumane.

In a contemporary medical setting, patients can be treated such that they are alienated

from humanity-affirming aspects of their lives. The following scenario is illustrative:

Ms. M. has been in the cardiac unit for two days, after admission

through the emergency department. Almost like clockwork,

the rounding team of a few residents, the charge nurse, and

an attending physician (Dr. T) comes through the doorway at

8:40 a.m.

Dr. T: "Morning Ms. M. How are you?"

Ms. M: "Okay."

Dr. T: "Good. We looked at yesterday's tests and your heart is having problems pumping blood...."

Ms. M is silent, but very attentive.

Dr. T: "...the pain you had yesterday is angina, caused by coronary heart

disease."

Ms. M: "Gosh...what can be done about that?"

Dr. T: "A couple of things, thankfully. Drugs can help thin the blood so it's

easier to pump. Or we can examine your heart more closely to see how

blocked the arteries are. If they are blocked badly, an angioplasty

might be the answer.

Ms. M: "What's that?"

Dr. T: "An angioplasty is like a deflated little balloon that is put in an artery,

inflated and that helps to widen the artery. If the arteries are too

blocked, we could do a coronary artery bypass. What that involves is

attaching new arteries to the heart to help carry more blood. But if we

don't do anything, you will likely have more chest pain and be at more

and more risk of a heart attack."

Ms. M: "Oh dear. What do you think?"

Dr. T: "Well, the drugs have the fewest risks so I'd like to give them a try for

a while. But since you are already in the hospital, I would also like

to have a dye-test done on your heart so we get a better idea of your

heart's condition. The test is an angiogram and it involves a dye being

injected into your heart and watching what happens when the heart

pumps. It's not very risky or complicated to do."

Ms. M: "I can stay here longer if you think that's best."

Dr. T: "I do think that's best." Pause. "Do you have any questions about all

this? Anything that is unclear in what I said?"

Ms. M: "No, not right now."

Dr. T: "Good. One of the residents here will write an order to get you started

on nitroglycerine and an order to get the dye-test done sometime

tomorrow."

This dialogue's strengths are that it is congenial and unrushed, is not excessively technical or jargon-laden, and should be understandable by most adult patients. The patient is asked whether she has questions. Most clinicians likely would assign a grade of "A" to the discussion because the attending physician capably fulfills the basic requirements of informed consent.

If the objective here is for the patient to decide about a proposed medical treatment, this has been accomplished. But from a Marxian viewpoint, Ms. M has been alienated in two ways: she is alienated from herself and from other people. In

terms of alienation from the self, a description of the self is first warranted. For my purposes here, the self is that which unifies a person's choices, actions, thoughts, emotions, and hopes over time. When these are not taken into consideration, alienation occurs. In more concrete terms, none of Ms. M's commitments or responsibilities outside the hospital is discussed.

Neither is her medical history. Human beings are embodied selves: all of Ms. M's experience is known to her through her body. It is impossible to even conceive of, let along understand, *her* self without taking into account *her* body and vice versa. Campbell makes this point pointedly: "the body cannot be violated without the self also being wronged" (1995, 173). In the conversation with the physician, no time is spent talking about her experience of health or illness prior to this hospital admission. And yet she understands her body based on the accumulation of this history just as who she is now is an outcome of all that her body has enabled her to do or prevented her from doing.

No reference is made to the people in Ms. M's life. This typifies the classic view of erroneously presuming patients to be independent decision makers. Instead most people are deeply connected to other people. The depth and longevity of these connections are persuasively described in a variety of articles addressing a physician's responsibilities towards a patient's family (Bishai and Siegel, 2001; Hardwig, 1997, 1990; Nelson, 1992).

Marx is well-known for railing against the alienation of a person's labor because labor is at the core of individual agency. Labor that is alienated invariably loses its personal expression and thus becomes an object, ripe for homogenizing commercialization and control by others. In the case of Ms. M, alienation from her commitments, medical history, and relationships means that her life loses its context. Much of her life is set adrift or becomes unanchored and what remains is reduced to *this* admission to the hospital.

The situation is readily reparable however. In the discussion, the attending physician needs to include only three more questions: (1) "How does this information affect the people who are important to you? Family? Friends?" (2) "How does it affect your everyday responsibilities such as school or work?" and (3) "What's been your experience in dealing with illnesses?" The first two questions are straightforward and help to re-anchor her treatment choice to the kinds of commitments that help define who Ms. M is. The fundamental goal is not to restore cardiac function, but to try to return her to the life she lived prior to admission. This fundamental goal often is overlooked when clinicians focus only on physiology and cognition. To illustrate the point here, it is more appropriate ethically to talk about "living support" than "life support." Vitalism should not be a default goal of health care because it is void of meaning.

The proposed question that probes into Ms. M's experience is more subtle. Asking about experience is not the same as asking a patient to list her history of diseases, hospitalizations, and treatments. Such a list involves a static chronology of events and outcomes. Talking about experience, however, involves an unfolding narrative that is deeply influenced by the fact that she is an inescapably embodied being. More simply put, the third question rightfully brings her embodied self into the foreground.

Supporters of the informed consent could reply that an enriched rendering would avoid de-humanizing alienation. That is just the point. Everyday application of the doctrine is too thin. Yet utilizing a concept from Marxian economics and political science may appear excessive. I think not, for two reasons. First, alienation is an evocative word. Its rhetorical quality is purposively used to point out more powerfully what is at stake when a patient is in need of medical care. Second, alienation does help explain more clearly the experience of making decisions about the treatment of one's body or mind. Although such power and clarity are worthwhile, clinicians may assume that an enriched version of informed consent will require much more time and be cumbersome. The rehabilitation of the above dialogue should demonstrate that an enriched interaction can be accomplished at the patient's bedside.

Inauthenticity and the Loss of Subjectivity

Being and Time, Martin Heidegger's most well-known work, would not be categorized as a treatise on morality. Its subject area is metaphysics and more specifically, the phenomenological nature of human existence or Dasein. The concepts of authenticity, inauthenticity, and everydayness are pivotal for understanding how morality is part of his treatise. MacAvoy offers a helpful analysis of Heidegger's work that addresses past charges of confusion and ambiguity in these concepts.

MacAvoy describes authenticity as "Dasein appropriates and makes its own that to which it is already in relation" (2001: p. 468). This means that an authentic person sees and understands himself as he is and then conscientiously chooses that self for himself. Yet he is neither a narcissist nor an egotist. A narcissist continually tries to prove his superiority to others. An egotist has an excessive sense of his own worth. The authentic person does not compare himself to others and does not presume that he is the "gold standard." Instead he focuses on the evolving whole that lies before him and of which he is a part. For Heidegger, foundational to human nature is forward-looking possibility: "the self is its own possibility for existence which in projecting those possibilities comes to

define a world" (Camele, 1977: p. 287). Inherent in this way of being is responsibility and accountability.

To be inauthentic is to be less than what is possible. This way of being typifies everyday life. Heidegger does not demand perfection wherein a person always must be authentic. Rather he is critical of everyday life for two reasons and these reasons are a repository of morals in *Being and Time*. Reminiscent of Nietzsche, the everyday signals conformity, banality, and control by the "they-self." The "they-self" means societal standards and norms that are dictatorial and anonymizing. "In the realm of inauthenticity, everyone is the other and no one is himself" (Golomb, 1995: p. 100). As Guignon and Pereboom evocatively note, an everyday life is "the flattened out life of modernity" (1995: p. 202). Heidegger, I suggest, does make a prescriptive claim as to how people should be: each person should "own" his self while at the same recognizing that this self is not limited, but can be further developed by his own efforts. In this way, he strives for the fullness of himself. Reduced personalization is reduced Being which, in turn, is reduced humanity.

Turning to a medical setting, patients can lose their authenticity when they are objectified or treated as objects. A very common locus or point of objectification is a patient's body.

Ms. B. has been on the general medicine unit for almost two weeks

due to a surprisingly slow recovery from bronchial pneumonia and

a minor bout of sepsis. Again the rounding team appears for its morning

case updates.

Dr. C: "Morning. How are you feeling?"

Ms. B: "Quite good."

Dr. C: "Good to hear."

Ms. B: "Yeah, my blood pressure is staying at around 140

over 90.

See?"

She moves her upper body so she can see the monitor screen.

Dr. C: Looking at the screen, "Yes, I do. Let's see your heart rate is...."

Ms. B: "115. No, 116. That's higher."

Dr. C: "I see your temperature has dropped, too.

Ms. B: "Yes, 99 degrees. See?"

Half a minute passes as Ms. B and Dr. C look at the various monitors beside her

bed and read the brightly colored stickers that serve as reminders about allergies,

volumes, and rates

Dr. C: "And how's your breathing? Still too much stuff coming up?"

Ms. B: "Yeah..." turning back to look at the physician, "The respiratory person

says my lungs are still producing thick stuff."

Dr. C: "Yes, I read that in the chart. We'll need to change to a stronger

antibiotic to get rid of the infection."

Ms. B: "Good. I want go home as soon as I can."

Dr. C: "Then that will be our goal: to get you home as soon as we can."

This is a simple discussion in which most clinicians would conclude that informed consent is obtained. However telling in this example, which is not uncommon in my experience, is the image of both patient and physician looking at the readings on the monitoring equipment and away from each other. In a sense, what is deemed credible are numbers and who are the credible speakers are the equipment and the chart. Ms. B. does not even say "I am still coughing up gunk," but instead relays what the respiratory person observes. Others, namely the equipment, the chart, and the therapist, are telling the story of the patient and the state of her body. No exploration occurs as to how Ms. B. is feeling or how she has experienced her body as it works to recover from the pneumonia and sepsis. Ms. B., in fact, has adopted the common parlance of treatment/care teams in using numbers as the medium with which to evaluate her progress. But is 116 a meaningful improvement over 115? It is a higher number but that does not equate necessarily with her improving or feeling better. In these various ways, Ms. B's own body has become an object to her.

Treating one's body as an object is de-humanizing because "our body is not a neutral object in abstract space; it is our way of being-in-the-world" (Sorri and Gill, 1990: p. 35). In other words, how we understand the world and interact

with t is through our bodies. Moreover embodiment allows a person to be, as Dudzenski states, the "orientational locus" wherein everything is proximate or spatially related to me qua body (2001: p. 35). Or as characterized by Merleau-Ponty, my body becomes a measuring device for everything physical (Fielding. 1998). For instance, because my eyes cannot sustain looking directly at the sun, I have learned about its brightness more deeply than if someone told me that 10^{24} times sunlight brighter than 200 (www.exploratorium.edu/snacks/solar_brightness). Or I understand better the loudness of a pneumatic drill when I walk by one being used as opposed to someone informing me that its decibels are 100. Accordingly experience can be more meaningful than numbers as demonstrated by qualitative versus quantitative descriptions of pain.

The connection of body to oneself is direct: "I am implicated in my body and my body is implicated in me" (Dudzenski, 2001: p. 43). More simply stated, part of a person's identity comes from her body and thus illness or injury represents a disarrangement of herself. She, as a subject, is in disarray until she is able to make sense once again of her body *qua* herself.

How might the principle of informed consent be modified so as to avoid objectification? After asking Ms. B. how she is feeling, the attending physician should encourage Ms. B. to relate to what her body is "telling her" and what she has been experiencing. In this way, she recovers a measure of authenticity because she accepts her body and her experience as her body and her experience. Similarly the physician treats her as an authentic person in that her body itself conveys information. Certainly the information from tests and monitors is one source of evidence, but not the only source. I suggest that the numbers should assist patient and physician make sense of the patient's experience and the physical presentation of the body itself. But the numbers should not replace the authority of the body or be the starting point for further diagnosis.

While the physician agrees that the goal is for Ms. B. to go home, the fundamental goal should be for Ms. B. to go home feeling well enough to resume her life. In recent years, people are sent home so early that their convalescence continues at home for a longer period of time. While shortened hospital stays reflect the financial limitations of the health system, they may not represent reasonable health care.

Silence and the Loss of Voice

In my opinion, American psychologist Carole Gilligan's book, *In a Different Voice*, constitutes a watershed point in contemporary ethical analysis. She challenges the conclusions drawn by Lawrence Kohlberg who held that male children become morally wise by age 8 or 9. When Gilligan used Kohlberg's methodology to study young girls' moral development, she found that they scored lower. She argued against a possible conclusion that girls have less moral acumen than boys by contending that girls have a different view of morally-charged situations.

Gilligan's position addresses two forms of power. One form centers on the authority of the male perspective or experience. Men's lives and experiences are considerably dissimilar to women's lives and experiences based on a societally-sanctioned division of valid roles and responsibilities. Power arises when the former is considered as "normal" and the correct benchmark for further evaluations or judgments. Gilligan rejects such a normative benchmark and replaces it with merely a descriptive claim. In other words, the girls' responses are certainly different from those of the boys, but neither one is implicitly superior or better. As such, she makes room for plurality in moral knowledge and experience and thus for equality of authority.

The other form of power that concerns Gilligan involves speech. Through linguistics, human beings manifest their communicative natures. A significant portion of human interaction and relating occurs in the guise of communication. Furthermore words represent power in terms of demanding to be listened to or to be read. Words imply presence or "I am here." Gilligan underscores the inevitability or need for humans to express themselves by predicting that if a person has been forcibly muted, then "feelings and thoughts move into the only place they can still live, and vibrate in silence in the inner sense, until it becomes possible to bring them back into the word" (1995: p. 121). When a person is not listened to, this is equivalent to being silenced. Forced silence is de-humanizing because a person is being treated as if he is absent or not present.

Voice is not reducible to just sharing opinions. It has a more significant ethical component to it. Voice can be defined as "what people mean when they speak of the core of the self" (Ibid, 1982: p. xvi). From this light, each person has his own voice whenever he selects the words and phrasing that best reveal him and his experiences. Accordingly adopting another person's voice is de-humanizing because it undermines self-determination.

This ethically-rich notion of "voice" is typically unknown in many medical settings, as portrayed in the following case:

Mr. D. is elderly and has the body of a very frail man. Yet every

morning, he spends an hour or so reading the morning paper from

front to back. He is in the outpatient dialysis clinic for his routine

cleansing. A nurse, J, approaches him:

Nurse J: "We got a telephone call from your son yesterday afternoon. He said that

you felt that it was taking too long to get through dialysis. He was

wondering if there was any way to speed up the process because he would

be picking you up 20 minutes early. So I am going to go ahead and

change the rates on the machine so that you'll finish sooner. Okay?"

Mr. D: "Oh, okay."

A clinician who reads this interchange might immediately say that it is ethically unacceptable on the grounds that patient confidentiality and privacy have been disrespected by the nurse. This is a valid comment. But there is more at stake here that the notion of silence helps to illuminate.

Though likely unintentional, the actions of the son and the nurse result in Mr. D. losing his voice and being silenced. Admittedly it can be helpful for one person to take on errands and small tasks for another person. But falling into a habit of being the agent or spokesperson for someone is ethically questionable. Since speaking out affirms presence, people should be supported in speaking for themselves. This applies to the authority to choose the words that will to convey information. Such authority acknowledges the uniqueness of the experience; in other words, Mr. D should be the speaker because it is his illness and his experience of dialysis. No one else is as knowledgeable as him in trying to characterize what is happening.

Similarly nurse J's confirming question of "Okay?" is insufficient in terms of transferring voice in a substantive way to Mr. D. By this I mean that this is a binary question that typically prompts either and "Okay" or a "No." The question does not seek reflection or discussion; it seeks an immediate response. It is

ethically important to ensure that people are given "temporal space" wherein listeners are prepared to devote time, a type of scarce resource, to listening. Allocation of scarce resources to something indicates that it is deemed worthy of such distribution.

Once again, it is not onerous to "repair" the practice of obtaining informed consent so as to be able to preserve a patient's voice. Nurse J should frame the details about the son's telephone call as information that she is conveying to the patient. Then she simply asks Mr. D. if getting finished sooner is what will really help him or not. Key here is helping. Rather than remained focused on "doing" for patients, caregivers should focus on helping patients. Helping is an ethically richer notion because it implies beneficence, service, and holism; doing implies unilateral-ness, action, and immediacy. In the previous paragraph, an argument offered in support of listening to Mr. D held that listening reflects respect for the speaker. Another reason that listening is not valued in a clinical setting is that it not considered equivalent to "doing" something. Yet many people would be helped more if their caregivers just listened to them and refrained from starting "to solve the problem," ordering tests, or arranging treatments.

Conclusion

This paper has endeavored to illustrate the shortcomings of informed consent in the ordinary clinical setting wherein informed consent focuses on discrete decisions, actions, and accurate information only. The doctrine can be strengthened ethically by ensuring that patient alienation, inauthenticity, and silence do not occur. Alienation is preventable if patient values and commitments are actively sought out as being relevant referents for the design of any treatment/care plan. Inauthenticity is minimized whenever a patient's body is consider the starting point and enduring authority as to what might be pathological and what should be the medical response. And lastly, silence can be limited by empowering patients to interpret, describe, and explain, not just accept or refuse.

One of the lasting advantages of teaching Beauchamp-Childress' ethical principlism is that medical students and residents remember the four principles years after studying them. Recall is one of the reasons for choosing the three metaphors as a means to help busy clinicians "get" what is at stake in any medical encounter. The metaphors involve imagery and have rhetorical power that hopefully makes them memorable.

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