

# Conscientious Objection: A Potential Neonatal Nursing Response to Care Orders That Cause Suffering at the End of Life? Study of a Concept

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**P**ALLIATIVE CARE FOR NEWBORNS HAS BEEN STUDIED.<sup>1</sup> A protocol has been disseminated.<sup>2,3</sup> Many have adopted a model of palliative care in their neonatal units.<sup>4-6</sup>

Progress has been made in identifying newborns who, despite best hopes and efforts, are not responding to intensive care support. Children with diagnoses such as extreme prematurity, absence or failure of vital organs, birth accidents, and congenital conditions are still dying in NICUs and pediatric intensive care units (PICUs). Despite the recent acceptance of the palliative care model, many dying children are denied this form of care by their parents or physicians. Reported barriers to neonatal palliative care include lack of training and support for nurses and lack of agreement about goals of care among the members of the health care team.<sup>7</sup> The goals of care related to feeding dying patients have been a particular subject of discussion.<sup>8</sup> It has been estimated that more than 40,000 children annually are not allowed a dignified and comfortable

death, being treated with life-sustaining technology and full code status to the very end.<sup>9</sup>

## ABSTRACT

This article is an exploratory effort meant to solicit and provoke dialog. Conscientious objection is proposed as a potential response to the moral distress experienced by neonatal nurses. The most commonly reported cause of distress for all nurses is following orders to support patients at the end of their lives with advanced technology when palliative or comfort care would be more humane. Nurses report that they feel they are harming patients or causing suffering when they could be comforting instead. We examined the literature on moral distress, futility, and the concept of conscientious objection from the perspective of the nurse's potential response to performing advanced technologic interventions for the dying patient. We created a small pilot study to engage in clinical verification of the use of our concept of conscientious objection. Data from 66 neonatal intensive care and pediatric intensive care unit nurses who responded in a one-month period are reported here. Interest in conscientious objection to care that causes harm or suffering was very high. This article reports the analysis of conscientious objection use in neonatal care.

## THEORETICAL PERSPECTIVES LEADING TO EXPLORATION OF CONSCIENTIOUS OBJECTION

Historically, nursing theorists have prepared us to examine and respond to the profession of nursing, the person under our care, the health of that person, and the environments in which we work and live.<sup>10</sup> From the time of Florence Nightingale, theorists have grounded us in answering a call from individual patients, families, and communities. A strong assumption of nurses in practice is that the care they give is warranted, beneficial in some way to the recipient, and meaningful to both the recipient and themselves. However, with

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advances in medical technology and the ability to extend life beyond cognition or function, nurses are facing a new situation outside of this paradigm. They are asked to deliver care that appears to be unwarranted, nonbeneficial, and causing harm instead of providing comfort and dignity to patients at the end of their lives. A new theoretical model for nurses may be needed.

## MORAL DISTRESS

Philosopher Andrew Jameton considered moral distress in nursing in 1984, defining it as arising “when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action” (p. 6).<sup>11</sup> In 2006, Rushton stated that moral distress occurs “when clinicians are unable to translate their moral choices into moral action” (p. 161).<sup>12</sup> Gordon and Hamric in 2006 discussed nursing advocacy, the moral imperative of nurses to do the right thing, and the pain experienced when they cannot.<sup>13</sup> Rushton asserted in 2004 that when unable to take the right course of action, “integrity demands that professionals...raise a conscientious voice and make a conscientious refusal” (p. 241).<sup>14</sup>

The literature on nurses’ moral distress is now extensive. When we used the search term combination of “moral distress” and “nursing,” CINAHL returned 84 articles. All of these were reviewed, and 30 studies were found to specifically discuss the attributes of moral distress in nursing. These studies led to other important studies that were sought out. In a synthesis of the literature reviewed, authors reported four thematic findings:

1. Nurses’ moral distress is most often due to the way end-of-life care is being delivered.<sup>15-21</sup>
2. Nurses feel they are inducing suffering and causing harm to patients at the end of life.<sup>15-27</sup>
3. Nurses have used the term “torturing” to describe their care of patients who should be receiving comfort instead.<sup>15,16,19,23</sup>
4. Nurses realize that their theoretical and philosophical backgrounds are different from those in the medical profession.<sup>28-40</sup>

Some authors have stated that moral distress directly relates to aggressive medical intensive care with no expectation of benefit, which then causes suffering to both the patient and the nurse.<sup>15-17</sup> Others have found that providing futile care can cause exhaustion within the profession.<sup>18</sup> It also can elicit feelings of powerlessness and fear.<sup>20</sup> Nurses have described these feelings of powerlessness poignantly: “I cared for this baby (born with no vital signs) for 4 hours but my heart was not in it,” said a nurse quoted by Jacobson, “to me he was dead and I was mutilating a baby’s corpse” (p. 146).<sup>41</sup> Another told Badger, “The family members were praying for him to live while I was praying for him to die” (p. 516).<sup>24</sup>

“Torture” was a common description of morally distressful nursing activities in these papers. Hefferman and Heilig

wrote, “we poke, prod, and torture” (p. 176).<sup>26</sup> Elpern and colleagues quoted one nurse as saying, “I often equate my job with keeping dead people alive” (p. 525).<sup>15</sup> Catlin quoted a nurse as follows: “This infant’s short life was never comfortable. He struggled just to breathe, day after day, month after month without relief unless he was paralyzed and heavily sedated. I frequently felt we were torturing the child just doing daily care” (p. 744).<sup>23</sup> In one study of 108 nurses, the most frequent distress was overaggressive care given in futile cases, with 16 nurses using the words “torture,” “assault,” “violence,” or “cruelty” to describe the care they gave.<sup>16</sup> Badger stated that we must come to a consensus with families and physicians to stop “torturing the patient” at the end of life.<sup>24</sup> In Robichaux and Clark’s study, a nurse told a mother, “We’re torturing him,” but the mother responded that “she didn’t care if her son was in pain as long as he was alive” (p. 487).<sup>19</sup> In a 2005 study of 781 nurses and physicians by Solomon and colleagues, 80 percent of participants agreed with the statement that “we are saving children who should not be saved” (p. 872), 45 percent with the statement that “I have acted against my conscience” (p. 872), and 50 percent with the statement that “the treatments I offer are overly burdensome” (p. 872).<sup>27</sup> The differences between the theoretical backgrounds of physicians and nurses have had extensive discussion, including many proposals on the need to come together as a cohesive work group.<sup>19,22,25,28,35-37,39</sup> Baggs and colleagues have made many points along these lines, such as the need for nurse colleagues to support the nurse who is experiencing moral distress and the absolute requirement for collaboration among physicians and nurses.<sup>29-34</sup> All of these researchers report a relief of moral distress when nurses and physicians have similar goals.

## PERSPECTIVES ON UNWARRANTED OR FUTILE CARE

The topic of providing unwarranted care is not new. In 1983, the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research issued the report, “Deciding to Forego Life Sustaining Treatment,” in which they stated, “Care available is generally limited to what is consistent with role-related professional standards and conscientiously held beliefs” (p. 44).<sup>42</sup> In 1993, the American Nurses Association report, “Nursing’s Agenda for Health Care Reform,” called for “careful assessment of the appropriateness of providing high-tech curative medical care to those who simply require comfort, relief from pain, supportive care, or peaceful death” (p. 17).<sup>43</sup> Paris and Schreiber, respectively an ethicist and a physician, comprehensively examined unwarranted care in 1996 and stated, “When a requested intervention will not succeed in achieving its goal, the action would be ineffective or futile. In such instances the issue of patient autonomy is irrelevant” (p. 565). They urged physicians to be clear that there is no mandate to deliver care that is ineffective: “Treatments offering no benefit and serving to prolong the dying process should not

be employed” (p. 569).<sup>44</sup> In their 2002 metanalysis on futility in medicine, Lofmark and Nilstun concluded that “we must decide when health professionals ‘may, ought or should’ forego a measure” (p. 119).<sup>45</sup> Despite these recommendations, providers continue to report the overuse of technology and its use in dying patients.

## NURSES' RESPONSES

What is presently done when nurses are faced with providing care that causes suffering, appears to be harmful, or seems futile? Their initial response is internal questioning of their values in response to the way the patient is being treated and why they feel that this treatment is not right. They may not have the expertise or comfort to know what to do next. They may attempt to work within the team and to change the opinions of other team members. They may become complacent and feel nothing will ever change. They may choose other patients to care for or perform the actions but suffer moral distress. They may have anger at the situation that is internally or externally focused, and this may cause them to experience burnout and leave the position. Nurses may ask that the case go to the ethics committee. They may join the ethics committee or decide to gain more power through advanced education or promotion. Expertise through ethics education may become a form of power to address moral issues.<sup>46,47</sup>

## ORGANIZATIONAL RESPONSES

One area of support for nurses may be their own nursing organizations, which are now beginning to explore the issues that cause emotional harm to those in the profession. Taking the lead in studying and responding to moral distress, the American Association of Critical-Care Nurses has created a guiding monograph called “Standards for Establishing and Sustaining the Healthy Work Environment.” It reports, “healthcare organizations recognized for attracting and retaining nurses have successfully implemented professional care models in which there is no gap between what nurses are accountable for and their ability to participate in decisions that affect those accountabilities” (p. 24).<sup>48</sup> The National Association of Neonatal Nurses has a new position statement, “NICU Nurse Involvement in Ethical Decisions (Treatment of Critically Ill Newborns).” Important new concepts in the paper are the initiation of “revisit points” to see if certain technologies and treatments have had the desired effect, increasing interdisciplinary collaboration while acknowledging the differing theoretical backgrounds of nurses and physicians, and bringing hospice and palliative care training into the NICU.<sup>49</sup> The American Nurses Association Code of Ethics is clear in its directives for nurses, stating that the nurse has the right to act nonmaleficently (to cause no harm); the nurse has the right and the responsibility to be an advocate for his or her patient; and the nurse has the right to be a conscientious objector.<sup>50</sup>

## CONSCIENTIOUS OBJECTION

What can a nurse do when professional and personal values conflict with the assigned health care delivery? Is it possible to use the concept of conscientious objection as delineated by the American Nurses Association? Would it be prudent for national nursing organizations to redefine the scope of nursing responsibility to allow objection when a patient is denied palliative care? How will nursing’s collective conscience respond to the overuse of technology at the end of life? To answer these questions, we decided to create a concept analysis of conscientious objection, using the

## Hybrid Model of Concept Development

Concept analyses have traditionally been academic work that provided a scholarly description of a concept related to nursing or patient care. Early scholars who led this form of nursing research were Wilson, Walker and Avant, Chinn and Kramer, and Rodgers and Knaff.<sup>68-71</sup> Concepts such as hope, comfort, caring, social support, and empathy were translated into clinical practice and often formed the basis for later theory generation and clinical interventions.<sup>72-76</sup> Doctoral students research and write concept analyses to form a framework for the type of research that they wish to conduct. A concept is the glue that holds a researcher’s thoughts and interventions together. Concepts tell us what something is, how it applies to our work, and what it is not. For neonatal nursing, concepts such as pain, attachment, becoming a mother, neonatal stress responses, coping, and hope have shaped our practice.<sup>77-82</sup>

The Hybrid Model, derived by Schwarz-Barcott and Kim, adds the component of immediate clinical verification to the concept analysis exercise. The Hybrid Model combines the academic development of a concept with the fieldwork component of clinical observation; one tests to see if the concept is a valid one for nursing.<sup>51</sup> In this article, we analyzed the concept of conscientious objection. We then immediately tested the concept by way of a survey of our colleagues. We heard from our colleagues that they were very interested in this concept and wished to learn more about it and that it was valid and had meaning for them. Our research team plans to continue to do work in this area.

hybrid method.<sup>51,52</sup> (See: Hybrid Model of Concept Development.)

We reviewed the nursing literature through CINAHL and found little on the concept, with most articles discussing the more common nursing objection to participation in abortion. Often in our searches we were directed to the military literature. By using the literature, we were able to compile the actual cases and borderline cases as well as incidents that would not

constitute true objection. We then identified components of a nurse's conscientious objection. We found the initial definition of conscience as coming from the Latin *conscientia*, which means an "awareness of moral quality of action." The *Encyclopedia of Bioethics* says, "Using one's conscience implies a moral sense, internalized norms, and a sense of integrity. A crisis of conscience is an attempt to restructure one's deepest and most fundamental convictions" (pp. 469, 471).<sup>53</sup>

### **Prior Examples of Conscientious Objection in Nursing**

A search of CINAHL revealed six articles on conscientious objection in nursing. Five were related to abortion and contraception, and only one actually depicted the rights and barriers to objection.<sup>54</sup> When a nurse explains in writing upon hiring that he or she objects to an assignment related to abortion, this objection is typically respected. Nurses objecting to actions in the clinical setting have customarily been allowed to find a substitute without objection. Some hospital systems have created policies that address these traditional topics of objection.<sup>55,56</sup> In addition, nurses have objected to being placed in an unsafe situation where they lack the proper resources and experience, such as being asked to float to a unit for which they have no preparation or education or being asked to perform an action before they feel trained and ready.<sup>54</sup> Many hospitals have forms called "assignment under protest" that are used in these instances. When a nurse must take an assignment for which he or she feels proper care cannot be delivered for whatever reason, this form is filled out and sent to the nursing administration office. The nurse administrator compiles and assesses the forms, investigates the issues, and makes the necessary changes to staffing levels or other policy as needed.

### **Military Objection**

Conscientious objection is more often described in the military literature. Similar to nurses who do not wish to carry out a specific act, soldiers have objected to individual wars or specific acts of war.<sup>57</sup> These objections were often religion-based and showed a pattern of conviction to principles. Historically, soldiers were sentenced to prison or death or killed by comrades for refusing to fight. In the Vietnam era in the U.S., many Americans fled to Canada rather than serve when they were drafted. In modern-day Israel, many soldiers have objected to actions on the West Bank, and those objections have been widely debated there. The press reports Muslim citizens in England who have objected to fighting in Iraq. Presently, soldiers are court-martialed and sentenced to prison for conscientiously objecting to carrying out orders. Examples in the U.S. are those of Sergeant Kevin Benderman and Sergeant Camilo Mejia of the Army, and seaman recruit Pablo Paredes of the Navy, enlisted men who have filed conscientious objections to continuing to fight in the war in Iraq. Also being hotly debated is the case of Lieutenant Ehren Watada, the first commissioned officer in the U.S. Army to refuse to continue his service in the Iraq conflict.<sup>58-60</sup>

## **CONCEPT DEVELOPMENT**

After review of the literature, including the literature on moral distress described above, we were able to identify the attributes (the components to making an objection), antecedents (what would come before), and consequences (what would come after) that allowed us to create a definition of conscientious objection for nursing.

### **Attributes of Conscientious Objection**

- The nurse is assigned to the patient's care with treatment orders that he or she is capable of carrying out.
- There are orders for patient care that the nurse interprets as harmful.
- Based on the principles of beneficence and nonmaleficence, the nurse desires to do good and to prevent harm to the patient.
- The orders for care cause the nurse moral distress.
- The nurse sincerely believes that carrying out the order is a threat to his or her integrity. It is a matter of conscience, and the nurse has felt this way for some time.
- The nurse has examined issues of cultural diversity, but this does not relieve the distress.
- The nurse wishes to care for the patient, just not to provide specific care measures that he or she considers harmful.
- All angles have been evaluated, and all justifying arguments for the nurse to do the action have been exhausted.

### **Antecedents to Objecting**

- The nurse realizes that there may be consequences to objection.
- The nurse must accept the self-consequences and risks of the act of objection.
- The nurse must accept the consequences and risks of the act of objection to the professional community in which he or she works.
- The nurse must ensure that the patient is not abandoned and arrange for appropriate coverage.
- The nurse must be willing to stand by this commitment.

### **Consequences to Objecting**

- The individual nurse may face sanctions or lose employment if objecting to work assignments. The nurse may also face ridicule or anger from colleagues for questioning the status quo.
- However, others may agree with this objection, and the objection may effect a change in practice.

## **DEFINITION**

Using these attributes, antecedents, and consequences, we drew up the following defining statement: "For the nurse, conscientious objection may occur when the nurse interprets that the care that has been assigned for a patient is harmful or causing suffering. The nurse does not wish to provide this form of care and feels sincerely and has felt for some time that this is a question of conscience. The nurse objects to the

nature of the care orders, willing to assist in other forms of care and not wishing to abandon the patient.”

## CASES

In a classic concept analysis, cases are created to define what the concept is and what it is not. We defined the following five cases of when the nurse would be called to make a conscientious objection.

### Model Case

A neonatal nurse is assigned to care for Baby X. Baby X was born at 23 weeks with gastroschisis. The baby is now four weeks old, has sepsis, and is on a ventilator. Dopamine is used continuously to maintain vital signs. The parents insist that technologic support continue. The nurse is asked to continue full code status on this infant. The nurse believes this form of care is causing the child to suffer. The nurse wishes to care for the child, but not to continue technologic support for a dying child.

### Real Case

We found one model case of objection, that of Sun Hudson. Sun Hudson was a 5-month-old baby boy who was born at full term with a fatal form of dwarfism. He had no lung expansion and no ability to live off a ventilator. The health care staff went to court to remove his ventilator against his mother's wishes. The hospital contacted 40 other hospitals, but none would accept him as a transfer. The Texas courts allowed cessation of technologic support.<sup>61</sup>

### Borderline Case

A nurse feels uncomfortable assisting with a male infant's circumcision, because she believes that the harm of the action outweighs the benefit to the child. The circumcision is being done with a lidocaine block, topical anesthetic cream, and a sucrose pacifier. The circumcision is a cultural component of the family's faith. The nurse wishes to care for the child, but not assist in this procedure.

### Related Case

Baby X is born prematurely with a hypoplastic left heart. The parents decide to take Baby X home to live, as long as he lives, in the center of his family. Not all providers in the unit agree with this, and conflict occurs. The nurse agrees with the palliative care, but does not wish to speak up. Instead, she volunteers to do home health visits for the infant and family.

### Contrary Case

A nurse is uncomfortable giving morphine for pain to a dying patient because she feels the patient will become addicted and she believes the patient is not really in pain. The nurse does not speak up, but simply denies medication to the patient.

## Pilot Study

In the hybrid model of concept development, after a concept for nursing is analyzed, one must go to the clinical arena to obtain information on nurses' acceptance or rejection of the concept. Thus, we developed a short survey tool to obtain information on conscientious objection as a concept for neonatal nurses. Institutional review board approval from the university was obtained. The pilot study was announced at a local research conference, and nurses from local hospitals were asked to help us with the concept analysis. Questions were posted on the university website. The definition of conscientious objection was given. Informed consent was obtained. There were four demographic questions and then eleven multiple choice and open-ended questions asking the nurses to describe their knowledge about, use of, desires to use, barriers to and interest in conscientious objection.

## FINDINGS

Sixty-six neonatal (53 = 80 percent) and pediatric critical care nurses (13 = 20 percent) reported caring for critically ill infants. Seventy-five percent of the NICU or PICU respondents had been nurses for more than 10 years, with a range of 3 months to 44 years. Thirty-four percent had a diploma or associate degree in nursing, 40 percent had a bachelor's degree, 27 percent had a master's degree, and 1 percent had a doctorate. Seventy-five percent reported previously thinking about conscientious objection, with 88 percent having moderate to high interest in the topic. Few respondents were aware of Joint Commission (23 percent aware) and American Nurses Association (24 percent aware) policies supporting the ability to object.

The first open-ended question asked respondents to name instances in which they had objected or would have liked to object. Fifty-two percent of the nurses reported that they would like to object to aggressive interventions that do not change outcomes. An additional 41 percent specifically mentioned wanting to object to technologic interventions for the 22–24 week gestational age newborn or newborns with conditions incompatible with life. Thirty percent of respondents stated that they wished to object to pressure from families who would not agree to a change to palliative care.

The second question asked participants how they felt if they wanted to object but were unable to. Terms used in fairly equal proportions were “helpless,” “powerless,” “angry,” “frustrated,” and “sad.” A number of respondents (10 percent) specifically used the term “torturing” when describing keeping a baby alive.

The third question asked participants if they had ever acted in a way that could be considered a personal conscientious objection, without formally objecting. About half (45 percent) of the nurses reported that they had. These nurses had voiced their opinions to the physician (17 percent), documented disagreement in the chart (2 percent), asked another nurse to take the assignment (10 percent), called the ethics committee (3 percent), looked for another physician who would agree

to change treatment orders to palliative care (3 percent), or overtly or covertly refused to follow an order (10 percent). The other 56 percent of nurses stated “no, they had never objected.” This group of nurses stated that they had put their personal beliefs aside and followed doctors’ orders for care whether they agreed with them or not.

The fourth question asked nurses about barriers to objecting to certain actions. Nurses perceived many barriers to being able to voice objections to types of care being assigned to them. Forty-four percent of the nurses felt physicians’ orders for futile care were a barrier to objecting, 42 percent felt administrative policies and legal consequences prevented objection, and 19 percent felt undue influence from parents. Nurses also worried about job loss and sanction.

The fifth question asked participants if they had any additional questions they wanted to ask about conscientious objection. Respondents felt the need to object to therapies that did not change the underlying condition of a dying patient, but wanted guidance from nursing organizations on how to do so. They wished for some universal policy to guide practice. They asked for help in analyzing the risks and benefits of objecting and help with the possible consequences of objecting. They expressed curiosity about the role of the hospitals and health care organizations, the use of ethics committees, and the national and worldwide views on objecting to certain forms of care. They asked what the patient’s or family’s rights would be in response to objected care. Nurses were very interested in conscientious objection as a method of being able to live within their own moral frameworks.

## DISCUSSION

There are many anxieties associated with the use of conscientious objection. Nurses have a need for employment and income and must work within a bureaucracy that might not always support independent decision making. Nurses and physicians are coming closer together in interdisciplinary decision making, but physician goals of “saving life” and “furthering the advancement of science” often support continued technologic interventions beyond the comfort level of the nurse. Some providers think they must give life-extending care regardless of circumstance. The Baby Doe laws, the Born Alive Bill, and the Emergency Medical Treatment and Labor Act (EMTALA) have all influenced physician decision making. Authors have urged rejection of the Baby Doe rules as having any present influence on neonatal practice.<sup>62,63</sup> The Born Alive Bill has been interpreted by the Neonatal Resuscitation Steering Committee as not impacting practice. The committee wrote that any child born alive should be assessed and appropriately treated, including palliative care treatment if that is the appropriate model of care.<sup>64</sup> Others have urged more analysis of this bill and its impact on normative neonatal practice.<sup>65</sup> EMTALA says patients coming to the emergency room for service must be treated, and some have interpreted this as the need to resuscitate a nonviable infant.<sup>66</sup> Romesberg refines the definition of EMTALA as

not impacting futile care outside of the emergency room and also states that all three laws, once thought of as protecting infants, are now being viewed as potentially causing harm to them.<sup>66</sup>

## RECOMMENDATION FOR PRACTICE AND FUTURE RESEARCH

Is it possible for conscientious objection protocols to support the refusal to provide end-of-life interventions that cause suffering, appear to be harmful, or seem futile? It is certain that these actions are not for the individual nurse to take alone. In our opinion, this is the role of our national nursing organizations. Presently, both the National Association of Neonatal Nurses and the American Nurses Association have begun dialogs on this topic. Nurses in their own local neonatal and obstetric units could also begin this dialog. Paris and Schreiber implied support of such dialog when they urged physicians to avoid delivery of unwarranted care by developing “well reasoned substantive guidelines for practice policy” (p. 569).<sup>44</sup> An important goal for nurses now is to reach across disciplines to come to consensus with physician colleagues on what are appropriate forms of care to offer and to whom. In addition, the education of pregnant women on the necessary length of time needed for healthy fetal development may assist a mother’s understanding of when a premature newborn will benefit or will not benefit from life-extending technology.<sup>67</sup>

Nurses want to know how we can maintain our fidelity to our patients and their families, follow orders from our physician colleagues, work in a family-centered interdisciplinary team, yet follow our consciences when the care ordered appears harmful to a child, especially at the end of life. Nurse researchers must move beyond descriptions of moral distress. It is time to specifically test actions and find solutions that will prevent futile care as well as to protect and defend nurses from the pain of powerlessness and participation in such care that appears to be harming the patient. Empowering nurses to advocate as we were meant to do will decrease moral distress and aid in keeping nurses in the workforce. The theory behind nursing practice may need to be amended to reflect a change in nurses’ participation in nonbeneficial life-sustaining technology.

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