PERCEPTION AND EXPERIENCES OF NURSES REGARDING PATIENTS INVOLVEMENT IN HEALTH CARE DECISIONS: AN INTEGRATIVE REVIEW

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ABSTRACT

Nurses as key healthcare professionals, have an important role in delivering high quality care, which requires positive perception, adequate knowledge and skills of implementing proper patients’ involvement in all health care aspects. Considering nurses’ perception and experiences, patients’ involvement may improve health outcomes. This integrative review aims to assess the perception and experiences of nurses regarding patients’ involvement (PI) in health care decisions as reflected in the literature. EBSCO, Science direct, Google Scholar, PubMed, Medline and Jordanian database were searched utilizing PRISMA flow chart to search related studies from 2007 up to 2017. Quality and characteristics of all studies were critically evaluated utilizing specific criteria called the Checklist for Assessing the Quality of Studies (Kmet, Lee, & Cook, 2004). In total, eight relevant studies were included with 3037 nurses as study participants. The qualitative approach was the dominant approach used, with an average quality assessment of (16/20). The included studies were conducted in Europe, Canada, Australia and Asia. The conclusion derived from the review is that most nurses have positive perceptions of the importance of patients’ involvement, yet they inadequately reflected that in their clinical practices. Cultural shift through educational interventions is required to change negative attitudes among diverse groups of nurses toward patients’ involvement.

KEYWORDS: Collaboration, Decisions Making, Experiences, HCPs, Nurses, Patient-Centered Care Patients Involvement, Perception

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INTRODUCTION

The concept of “patient involvement” (PI) has officially evolved in 2001 by the Institute of Medicine (IOM) report “Crossing the Quality Chasm: A New Health System for the 21st Century” (Wong et al., 2017). Many societal movements and human rights groups recommended a shift from the inactive role of patients to a more active role and to partnership regarding their health issues (Moret et al, 2008; Pryce & Hall, 2012; Wong, et al, 2017). This concept is
correlated with other concepts in meaning such as engagement, collaboration, empowerment, partnership and participation (Arnetz, & Zhdanova, 2014; Wong, et al, 2017) PI is defined as “shared perceptions about, and behaviors aimed at, involving patients in decisions and care processes throughout their hospitalization” (Arnetz, & Zhdanova, 2014, p 476).

Health care providers, particularly nurses are professionally well fit to engage patients fully in the treatment plan; they are key patient's advisors and advocates in all practice settings where patient involvement is pressing (Charis, et al., 2010). Therefore, nurses should be sensitive to the patients’ individual preferences and concerned about patients’ participation wishes on a regular basis during their illness (Desroches, Gagnon, Tapp & Légaré, 2008; Charise, et al., 2010; Yasien et al, 2017). Nurses are able to understand patients' needs and expectations about health issues due to their close relations with them and their families in all health care settings and they are involved in the Decision Making (D.M) process at the point of service and management levels (Ahmed & Safadi, 2013; Wong et al., 2017).

The process model developed by Towle and Godolphin (1999) represents the role of healthcare providers and patients in the shared decision-making process as mutual partners with mutual responsibilities (Dierckx, Deveugele, Roosen, & Devisch, 2013). PI in health care issues includes key components; such as shared decision making (SDM), communication, self-management, patient education as well as virtual reality (Wong et al, 2017). The ability to engage in this process depends on cognitive and psychomotor competencies as well as the abilities of both the health care providers (HCPs), including nurses, and patients (Wong et al, 2017, Khuan, & HanafiahJuni, 2017).

Many studies revealed that PI in decisions related to health issues is associated with improved patients satisfaction, medication adherence, and improved health outcomes and is considered a prerequisite for good clinical practice (Dierckx, Deveugele, Roosen & Devisch, 2013; Shortus, Kemp, McKenzie & Harris, 2013). However, PI in decisions related to health issues is rarely implemented in current clinical practice, and HCPs often do not involve their patients in those decisions and rarely respond to the preferences of patients in the decision-making process (Michael, Barry, Edgman-Levitan, & Engl, 2012; O‘Connor, Thomas, & Flood, 2004; Sheridan, Harris, & Woolf, 2004). Some studies (Derickx, et al., 2013; Légaré, et al., 2010), reported that there were incompatible preferences between both patients and HCPs regarding the PI in the decision-making process. HCPs including nurses often are not familiar with their patients opinions about being involved in health care decisions (Khuan, & Hanafiah -Juni, 2017; Derickx, et al., 2013).

Studies on involvement in health care decisions have discussed the issue from different aspects with little emphasis on nurses (Boudioni, & McLaren, 2014) as compared to physicians' (Boivin, Legare, Gagnon, 2008) and patients' (Siouta et al, 2016; Michael, Barry, Edgman-Levitan, & Engl, 2012), or on both physicians and patients' (Yasien et al, 2017; Frosch et al., 2012; Nota et al, 2016). However, within the past 20 years, the literature has not fully discussed experiences regarding patient involvement in health care decisions (Wong, et al., 2017). Such understanding is important for patients and providers have different viewpoints about D.M process and often have incompatible goals regarding the management plan of specific conditions (Peek et al, 2008). Understanding the perceptions of HCPs particularly nurses is required (Gainer et al., 2017; Arnetz, et al., 2008) to enhance patients’ involvement as well as health care practices. Therefore, the aim of this integrative literature review was to assess, analyze and explore information reflected in the literature regarding nurses’ perception and experiences on patients’ involvement in health care decisions.
METHODOLOGY

Cooper's five steps (Cooper, 1982) approach was adopted to conduct the integrative review; problem formulation, literature search, evaluation of data, data analysis, and interpretation and presentation of results. Key words regarding the title “nurses perception and experiences regarding patients’ involvement in health care decisions” were addressed from the literature. The relationship and patterns of perception and experiences of nurses on patients’ involvement in health care decisions were elicited from the relevant studies then, they were described, interpreted and the main domains and themes were formulated.

Search Strategy and Search Terms

A search strategy to identify relevant studies published over the past 10 years (2007-2017) was conducted to gain the most updated knowledge about the main topic. Online searches were performed utilizing: EBSCO, Science direct, Google Scholar, PubMed, Medline and the Jordanian database for nursing research. We based our search on key elements of patients involvement identified by Wong, et al., (2017) to embrace as possible, all aspects of the concept of patients’ involvement in healthcare (D.M).

First, separate terms were searched (Major Heading (MH); patient involvement or Patient Involvement) and/or Decision making, Nurses or health care providers or HCPs, and/or perceptions and experiences, communication and information sharing. Self-care and/or safety. Then the aforementioned terms were combined with terms such as "quantitative + or qualitative, or MH “clinician or Nurses communication” and/or collaboration”. HCPs communication and/or information sharing; Patients Self-care, and/or safety and/or nurses perceptions and/or experiences.

Inclusion and Exclusion Criteria

All inclusion and exclusion criteria were established before conducting the database searches. Original studies of different approaches and designs, published in English language and in a health care context were included. Included Studies embraced specific terms as nurses’ perception and experiences; nurses working at both management and point of service levels were included. Papers implied definition of PI concept were also included.

Studies before 2007 and those conducted on Health Care Providers (HCPs) perceptions and experiences other than nurses as physicians and for patients were excluded. Studies were excluded when they concerned the involvement of others rather than the patient in health care decision-making as a surrogate. Papers that described patient involvement in other activities such as research were also excluded.

Categorization of Studies

Totally, two hundred articles were found in the databases. All articles were reviewed concerning the concept of nurses’ perception and experiences on patient involvement in healthcare decisions in addition to its related factors and measuring tools. The PRISMA flow diagram was used to categorize and exclude studies as follows:

- Total Articles identified through database search = 200
- (50) Duplicates removed = 150
- (50) Title and Abstracts screened and excluded using selection criteria
- Full text article assessed for eligibility = 100
(50) full text screened and excluded; no nurses perception= 50

(30) excluded :no patients involvement in Health care D.M = 20

(12) Studies excluded; no health care D.M, but health care only n =8

Included studies= 8; qualitative (5) and quantitative (3).

Quality Assessment Criteria of Included Studies:

This part presents Quality Assessment Criteria of the included studies to evaluate methodology quality of each included study. Quantitative and qualitative studies were assessed separately. The assessment was done based on the Standard Quality Assessment Criteria developed by (Kmet, Lee, & Cook, 2004).

**Quantitative Studies- Criteria**

Assessment of the quantitative studies, 14 items were scored depending on the degree to which the specific criteria were met (“yes” = 2, “partial” = 1, “no” = 0). Items not applicable to a particular study design were marked “n/a” and were excluded from the calculation of the summary score. A summary score was calculated for each paper by summing the total score obtained across relevant items and dividing by the total possible score (i.e.: 28 – (number of “n/a” x 2) (Kmet, Lee, & Cook, 2004, p 6). The 14 items included in the Quantitative studies- Criteria include the followings:

- Question/objective sufficiently described?
- Study design evident and appropriate?
- Method of subject / comparison group selection or source of information/input variables described and appropriate?
- Subject (and comparison group, if applicable) characteristics sufficiently described?
- If interventional and random allocation was possible, was it described?
- If interventional and blinding of investigators was possible, was it reported?
- If interventional and blinding of subjects was possible, was it reported?
- Outcome and (if applicable) exposure measure(s) well-defined and robust for measurement/misclassification bias?
- Means of assessment reported?
- Sample size appropriate?
- Analytic methods described/justified and appropriate?
- Some estimate of variance is reported in the main results?
- Controlled for confounding?
- Results reported in sufficient detail?
- Conclusions supported by the results? (Kmet, Lee, & Cook, 2004, p 6).

**Qualitative Studies-Criteria**

Scores of the qualitative studies were calculated in a similar fashion, based on the scoring of ten items. Assigning “n/a” was not permitted for any of the items, and the summary score for each paper was calculated by summing the total score obtained across the ten items and dividing by 20 as the total possible score. The ten items included in the Qualitative studies- The Criteria includes the followings: Question/objective sufficiently described?

RESULTS AND DISCUSSIONS

This part presents study characteristics of included studies. It includes, citation, purpose (s) /question (s), method, sampling method (s), analysis, and main results. Out of eight relevant studies, there were five qualitative and three quantitative studies. More than half of the relevant studies were published in or after 2014 (n = 6). Only three out of 8
relevant studies were exclusively conducted on nurses, while the other two studies Arnetz et al., (2008) and Shortus, et al., (2013) were conducted on different HCPs including nurses, and the last three studies Wong, et al., (2017) and Crispin, Bugge, & Stoddart, (2017) and Gainer, et al (2017) were conducted on patients and HCPs including nurses. Included studies were conducted in Europe (2 England, 2 Sweden), followed by Canada (1 study) and Australia (1 study). Only 2 studies were conducted in Asia (1 study in Hong Kong, and 1 in Malaysia).

QUALITATIVE STUDIES

Four of the five (5) qualitative studies involved 81 (male and female) nurses. The fifth study (Gainer, et al., 2017) involved 13 participants, including nurses and allied health care providers together. Thus, the number of nurses was not clear. Furthermore, three (3) out of the five (5) studies had a moderate score (16 out of 20) for the methodological quality as assessed by Kmet, Lee, & Cook (2004), one study had the highest score (18 out of 20), and one study had the lowest score (15 out of 20) for methodological quality.

The five qualitative studies were published in the year 2017, the other studies were published in 2014, 2013 and 2008. According to the quality assessment by Kmet, Lee, & Cook, (2004), most of those studies lacked the explicit discussion of reflexivity concept. It means that researchers did not reflect on the personal impacts that their experience and interests might have had on their results. However, Crispin, Bugge, Stoddart (2017) and Shortus, et al., (2013) have narrowly accounted on reflexivity.

QUANTITATIVE STUDIES

A descriptive cross-sectional design was dominant in all three relevant quantitative studies. The concordance of the study design of all those studies were poor in main characteristics of experimental or Randomized Control Trials (RCTs) in terms of the items 5, 6 and 7 in the quality assessment criteria (Kmet, Lee, & Cook, 2004). Therefore, all had similar scores of 15 out of 22 considering the extracted n / a response from the total score. The total sample of those quantitative studies was 2956 nurses; with the highest sample (n=2351) nurse in a cross sectional survey conducted by Wong, et al., (2017) (Table 1).

THEMES

Themes and patterns that emerged from this review included: Definition of PI, Nurses’ perception and experiences on PI and suggested improvements and actions to enhance patient involvement.

Definition of PI

The concept of PI is described interchangeably with other concepts such as patient engagement, collaboration, empowerment, partnership and participation (Arnetz, & Zhdanova, 2014; Wong, et al, 2017). Two major definitions emerged; Boudioni, and McLaren, (2014), defined PI as "the active participation of patients/ providers, as partners in their own care and treatment at various levels, i.e. health services planning, service delivery, quality monitoring and development" (Boudioni, and McLaren, 2014, p.199). While, Arnetz & Zhdanova., (2014) defined PI as "shared perceptions about, and behaviors aimed at involving patients in decisions and care processes throughout their hospitalization" (Arnetz & Zhdanova., 2014, p.476). Some authors defined it according to Charles, Whelan, Gafni, (1999) shared decision making model (Crispin, Bugge, & Stoddart, 2017), others linked the definition with patient - centered care putting patients at the center of health care as a principle of care (Khuan, & HanafiahJuni, 2017) and others defined it
within the context of humanistic values (Wong, et al. 2017). Literature highlighted different elements of PI, while the focus in this integrative review was on some elements. Boudioni, and McLaren, (2014) definition was a comprehensive one that embraces some key elements of PI as active, partner, participation, and of both patients/providers.

**Nurses Perception and Experiences Regarding PI**

Some nurses perceived PI is not one of their formal activities, rather it is considered in a pragmatic sense (Boudioni, and McLaren, 2014) this result is in accord with (Khuan, & Hanafiah-Juni, 2017) who reported the lack of role clarity as a barrier for PI. On the other hand, Shortus, et al., (2013) reported that nurses believe in the situational PI; they involve their patients in decision-making according to their objectives. Those nurses involve patients according to their needs and abilities or in other situation, according to their preferences and readiness to be involved.

Two quantitative studies revealed the negative perception of nurses on PI. Arnetz, et al., (2008) reported that PI creates problems in their work, takes time from other patients and may lead to incorrect decisions about health care. Nurses were obviously concerned about the possible negative impact of the PI. Their previous experiences and cultural backgrounds impede the PI success (Wong, et al., 2017). Additionally, nurses apparently perceive the patients as having a negative role in health care decisions (Gainer et al., 2017). Within all included studies; most nurses perceived time limit as the major issue to hinder PI in health care decisions.

**Suggested Improvements and Actions to Enhance Patient Involvement**

The main point of PI in making specific health care decisions is the provider’s responsiveness and openness to the patient’s needs and the success in creating an appropriate environment of care and respect (Shortus, et al., 2013). Although nurses believe in the importance of PI, there is a discrepancy between what nurses believed in and their actual behavior in their interactions with patients (Wong, et al, 2017; Shortus, et al., 2013; Arnetz, et al., 2008). There is a need for more emphasis on nurses’ actual behaviors, to better understand the implementation of PI in clinical areas (Arnetz & Zhdanova., 2014). Enhancing nurses’ awareness and understanding through education about the PI nature and purpose was seen as pressing (Boudioni, and McLaren, 2014).

Out of the eight relevant studies five different studies; (Wong, et al, 2017; Arnetz, et al., 2008; Crispin, Bugge, & Stoddart,. (2017); Gainer, et al, (2017), and Khuan, and Hanafiah- Juni, (2017) have explicitly reported time constrains as a major theme which limit PI. The other three studies Arnetz & Zhdanova., (2014), Shortus, et al., (2013), and Boudioni, and McLaren, (2014), implicitly indicated time constrains as a barrier, they discussed patients load and the work environment as barriers to involve patients in health care decisions.

The majority of nurses reported that they involved patients with health care D.M. However, they perceived some difficulties as reported in the included studies. Task oriented roles and conflict between nurses responsibilities (Arnetz & Zhdanova., 2014; Shortus, et al., 2013, Boudioni, & McLaren, 2014), high nursing job demands (Crispin, Bugge, & Stoddart, 2017), impracticality of PI in relation to time limits (Khuan, and Hanafiah- Juni, 2017) perceived autonomy (Gainer et al., 2017) as well as the negative impact of PI on health care process (Wong, et al., 2017) were the key perceived difficulties emerged among nurses.

Nurses in particular, were concerned about the possible negative results of the involving patients in health care decisions; they perceived PI might hinder accomplishing their workload of healthcare if they involve the patients, in addition to time limits of different health care tasks, and as a result this will affect the costs of services.
Perception and Experiences of Nurses Regarding Patients Involvement in Health Care Decisions: An Integrative Review

(Wong, et al., 2017). Moreover, nurses perceived PI as an obstacle in their work, and make incorrect health care decisions (Arnetz, et al., 2008)

This review reflects strong evidence of the need for nursing cultural shift, which means empowering nurses to be more open, (Boudioni, and McLaren, 2014), motivated (Shortus et al., 2013), and responsive to patients needs and to utilize management and clinical leadership roles in acting on patients demands (Boudioni, and McLaren, 2014).

Partnership of nurses and patient; mutual respect, communication, knowledge and understanding of factors facilitating healthcare that are tailored to patients circumstances and needs are prerequisites to PI (Khuan, and Hanafiah-Jun. 2017; Shortus, et al., 2013; Arnetz & Zhdanova., 2014). To overcome time constrains as a major barrier to PI, time of PI should be clearly scheduled and outlined within healthcare guidelines whenever health encounters occur to motivate nurses integrate PI on regular basis (Wong, et al., 2017).

LIMITATIONS

Included studies were conducted in only 6 countries which can limit generalizability of the review findings. Homogeneity of the sample; in one study all nurses were recruited from cardiac units and health care settings where the studies conducted in have a higher concern with PI than other settings (Arnetz & Zhdanova., 2014).

The concept of PI is used interchangeably with patient engagement, participation, collaboration and Patient-Centered Care (PCC) (Wong, et al., 2017; Arnetz & Zhdanova., 2014, Boudioni, and McLaren, 2014), although they could have minimal differences but they may offer divers ideas that we might have missed.

The item questions in the quality assessment tool used are general and mainly based on the study design, also not all the items on the tool were relevant to each individual study.

CONCLUSIONS

This study reviewed the findings of 8 studies (including 3037 nurses sample) reporting on perceptions and experiences of nurses regarding PI in health care decisions. The results of this integrative review are important because, they imply the perceptions of 3037 nurses from 6 countries on patients' involvement in health care decisions. Although nurses valued the importance of patient involvement in health care decisions, there was a variation on understanding, views and experiences.

The literature on PI from nurses' view is conflicting. Nurses believed strongly in the importance of PI, yet, this was not always translated into their clinical practices. Time constraint was the prominent barrier perceived by nurses to implementing PI in their clinical practice across 6 countries with different cultural and organizational contexts.

RECOMMENDATIONS

- Given that PI results in improved health outcomes, HCP particularly nurses should consider patients as equal partner in healthcare in general and in health decision in particular. As nurses have positive perception toward PI, it is recommended to plan and provide patient-oriented health care considering patients' values, preferences and needs.
• Cultural shift through educational interventions is required to change attitudes among nurses who perceive the negative impact of PI and motivate the perception that PI can enrich the nursing work, and enhance patient outcomes.

• Further studies about perception and experiences of PI should target more nurses in different health settings

REFERENCES


15. Kmet L, Lee R, Cook L,( 2004), Standard quality assessment criteria for evaluating primary research papers from a variety of fields. Edmonton, Alberta, Alberta Heritage Foundation for Medical Research.; 22


APPENDICES

Table 1

<table>
<thead>
<tr>
<th>Citation</th>
<th>Research Question (RQ), Aim or Purpose</th>
<th>Method</th>
<th>Sampling Method(s)</th>
<th>Analysis</th>
<th>Findings</th>
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<tbody>
<tr>
<td>1- Crispin, V., Bugge, C., &amp; Stoddart, K. (2017)</td>
<td>To explore the sufficiency of, and intentions behind, information exchanged by patients and nurses in surgical and medical ward settings using a recognized model of shared decision-making.</td>
<td>A multiple-case study design.</td>
<td>Purposive sample of 19 cases. 22 Nurses and 19 patients</td>
<td>A systematic approach was taken to analyse the data. QSR NVivo 10.</td>
<td>Most nurses perceived the demands of their job as a hindrance to information exchange. Nurses felt that patients would hold back asking questions if they perceived that the nurse was busy and that nurses’ busyness may cause patients to feel ignored. Nurses felt unable to spend necessary time with patients.</td>
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<td>2- Arnetz J.E., Ulrika W., Arnetz, Bengt B., Höglund, Anna T., 2008. Swedish</td>
<td>To measure perceptions and behaviour regarding patient involvement among physicians and nursing staff caring for patients with acute myocardial infarction</td>
<td>A Descriptive cross-sectional study. Three groups of Physicians, Registered nurses practical nurses, completed a questionnaire included six scales measuring staff views and behaviour</td>
<td>Three groups of Physicians (53). Registered nurses (303). Practical nurses LPN (132).</td>
<td>Statistical analysis. The SPSS statistical software package version 13.0 Both non-parametric (Kruskal–Wallis) and parametric (one-way analysis of variance) tests were performed</td>
<td>The three groups did not differ significantly in their views of patient involvement, but did differ significantly in behaviour (p&lt;.001) Physicians and registered nurses viewed time constraints as a hinder for patient involvement, while practical nurses felt unsure in communicating with patients. Nearly all respondents (97%) agreed with the statement that an involved patient enriched their work.</td>
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<td>3- Arnetz J., Zhdanova L., (2014). Canada</td>
<td>To introduce and define the patient involvement climate and</td>
<td>Cross-sectional, self-report questionnaire</td>
<td>All RNs who worked with MI patients on a regular basis</td>
<td>A one-way analysis of variance. &amp; Spearman</td>
<td>Climate quality and strength were greatest for the dimensions measuring nurses’</td>
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<td>Study</td>
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<td>4-Wong, E.L.Y., Lui, S., Cheung, A.W.L., Yam, C.H.K., Huang, N.F., Tam, W.W.S. and Yeoh, E. (2017). Hong Kong</td>
<td>To explore the gap between healthcare professionals and patients on patient engagement in hospital.</td>
<td>A cross-sectional survey. Participants were interviewed using structural questionnaires.</td>
<td>Of the 4531 questionnaires distributed to the doctors and nurses, 2774 were completed, giving a response rate of 61.2%. Although both groups valued the importance of patient engagement, there was a discrepancy on understanding, views and experiences. More healthcare professionals particularly in nursing were concerned about the possible negative impact of the engagement. The majority of healthcare professionals reported that they engaged well with patients, and perceived more difficulties than patients did.</td>
<td>View of patient involvement, the nurse–patient information exchange process and nurses’ responsiveness to patient needs. Climate quality and strength were weaker for the dimensions measuring nurses’ views of the hindrances associated with patient involvement.</td>
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<td>5- Boudioni, M. and McLaren, S. (2014). England</td>
<td>To explore senior nurses’ experiences of PPI</td>
<td>A qualitative exploratory design utilising focus groups with senior nurses</td>
<td>Five sub-themes of PPI experience: provision of information and raising awareness (1 category), informal generic PPI-activities not perceived as PPI (3 categories), formal generic PPI (3 categories), involvement of specific groups (5 categories) and PPI in commissioning and strategy (4 categories).</td>
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<td>6- Shortuset al., 2013 England</td>
<td>To investigate provider perspectives on the role of patient involvement in chronic disease</td>
<td>A qualitative, grounded theory study using Interviews</td>
<td>Providers described a conflict between their responsibilities to deliver evidence-based diabetes care and to respect patients’ rights</td>
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decision-making

two endocrinologists

Grounded theory methodology

to make decisions.

Impact Factor (JCC): 4.8764

NAAS Rating 3.73

Table 2: Quality Assessment of Included Studies

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