Global Epidemiological Data on Endometriosis

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2.1 Overview

Epidemiological data suggests that one in ten women will be diagnosed with endometriosis in their lifetime. A 10% prevalence for endometriosis dates back to the 1980s and was based on a US study that examined the hospital records of women undergoing hysterectomies. Recent Australian data suggests that this figure remains

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relevant, albeit somewhat higher at 11%, but is largely dependent on the method of diagnosis [1]. The 10% prevalence estimate continues to prevail within the clinical, research and lay literature. However, estimates of prevalence and incidence of endometriosis across studies and countries paint a very inconsistent picture of the epidemiology of the disease. This chapter will review global estimates of the prevalence and incidence of endometriosis. In doing so, we discuss the wide variations in estimates according to the study design and geographical location of the research. We preface this chapter by discussing the challenges associated with diagnosing endometriosis, including the individual, social and healthcare determinants of receiving a diagnosis, and the consequences for estimating the epidemiology of endometriosis.

2.2 The Diagnosis of Endometriosis and the Dilemma for Epidemiology

A major challenge in studying the epidemiology of endometriosis is identifying women with the disease. Currently, the only method of definitively diagnosing endometriosis is via surgery followed by histological confirmation [2]. Historically, the surgical approach has been regarded as the ‘gold standard’ for the diagnosis of endometriosis, but even this method has its pitfalls leading some to argue that we haven’t yet reached that gold standard [3]. Surgery relies on visual confirmation of the disease and depends on the skills and expertise of the operating surgeon. Even when surgery is supplemented with histology, the quality and size of the biopsy taken at the time of surgery influences the histological outcome [4]. Consequently, the surgical and histological diagnoses may not always be compatible.

Surgery to diagnose endometriosis is invasive and may not be necessary, desired or even geographically or financially possible for many women [5]. Owing to the problems with surgical diagnosis of endometriosis, there has been a recent shift in the diagnostic paradigm for endometriosis [6] away from the surgical approach, to recognise the value of the clinical diagnosis that prioritises women’s symptoms [7]. Clinical practice has long supported the conservative treatment of endometriosis, with several professional bodies advocating for treatment of endometriosis prior to surgical confirmation [4, 6]. Early diagnosis is paramount to providing women with specialised, interdisciplinary care to maintain or improve quality of life. Yet tensions remain about best practice methods for diagnosing endometriosis [6, 8], amidst rapid advances in imaging of the disease [9], which has implications for estimating the epidemiology of the disease. Although improved diagnosis of endometriosis is vital, discussions about the diagnosis of endometriosis rarely address the broader social and healthcare disparities that often create insurmountable barriers for women to receive a diagnosis. The epidemiology of endometriosis will only be as good as the underlying sample population.

2.3 Individual, Social and Medical Determinants of an Endometriosis Diagnosis

In diagnosing endometriosis, the focus is largely on individuals within medical settings. Symptoms, scans and surgery often dictate who receives a diagnosis. The diagnosis of endometriosis is however more complex, incorporating an interconnecting web of social, healthcare, economic, cultural and political factors that determine who receives a diagnosis (see Fig. 2.1). Women often have to navigate their way through the multiple layers to receive a diagnosis, rendering a diagnosis of endometriosis inaccessible to many women. The challenges for women receiving a diagnosis have significant ramifications for estimating the epidemiology of the disease. Social and healthcare disparities have prevented an accurate picture of the epidemiology of endometriosis, by biasing estimates in favour of those who have financial and geographical access to healthcare [5].

2.3.1 Individual Determinants of Diagnosis

Age is an important determinant of endometriosis. Although peak incidence is between 30 and 34 years [1, 10], symptoms of endometriosis can emerge during adolescence following the onset of menarche. Lengthy diagnostic delays of between 7 and 12 years [11–13] mean that the vast majority of studies estimating the

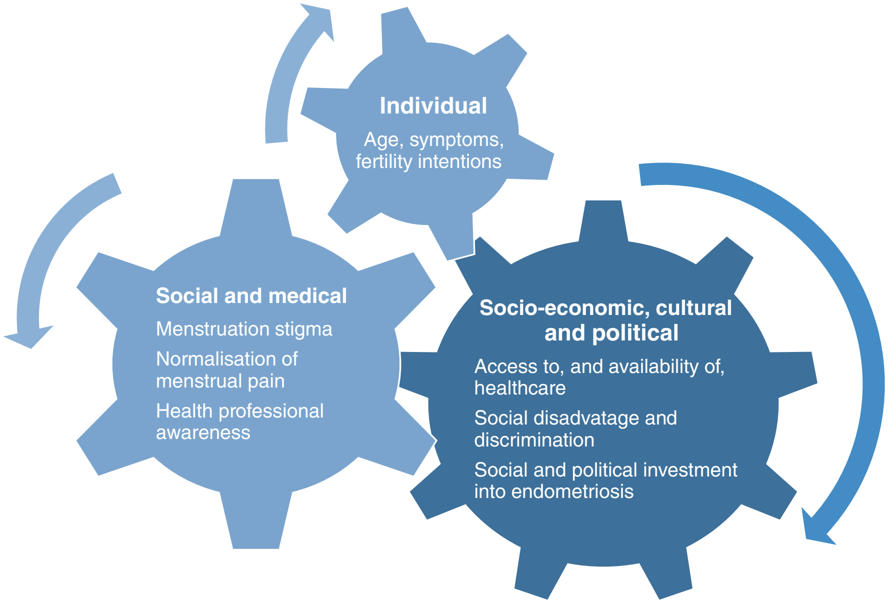

Fig. 2.1 Individual, social, medical, socio-economic, cultural and political factors that influence the diagnosis of endometriosis

prevalence of endometriosis are based on adult women presenting for surgery. Studies focusing on the prevalence and incidence of endometriosis in adolescents are limited but report high prevalence rates [14–16]. In a systematic review based on 15 studies largely from the USA, Janssen and colleagues reported that 62% of adolescents undergoing surgery for chronic pelvic pain or dysmenorrhea had endometriosis [16]. A more recent review of the literature identified only four new studies but reported similarly high prevalence rates [15]. The percentage of adolescents with endometriosis in this review varied from 36% to 100% [15]. These findings are largely due to the reliance on small, hospital-based samples of adolescents undergoing surgical investigation for chronic pelvic pain, at 'high risk' for endometriosis. Population-based studies of endometriosis in adolescents, which may be more representative of the population, are currently absent from the literature.

2.3.2 Symptoms

Endometriosis is often synonymous with severe period pain (dysmenorrhea), but there is a broad experience of symptoms including pain during sex, urination, defecation and gastrointestinal symptoms [2]. Women can report complex symptom combinations of varying severity throughout the menstrual cycle, although some women will remain asymptomatic. The unpredictability of symptoms and overlap with other conditions make it incredibly challenging to distinguish endometriosis from other conditions [17]. High rates of endometriosis among asymptomatic women with infertility suggest that infertility may be a potential marker of the disease [18]. Women's symptomatology is increasingly valued in the clinical diagnosis of endometriosis [6, 8]. Statistical algorithms for the diagnosis of endometriosis based on the common symptoms have been examined, but are not reliable enough to replace surgical methods of diagnosis [19].

2.3.3 Social and Medical Constructions of Endometriosis

The stigmatisation, normalisation and dismissal of women's symptoms of endometriosis in social and medical contexts are significant barriers to diagnosis [20]. Women are often socialised to feel considerable shame and embarrassment related to menstruation, described as 'menstruation stigma' [21, 22]. In most cultures, menstruation is constructed as a 'dirty' process that needs to be concealed and not socially discussed [22]. Some cultures and religions ascribe considerable taboo related to menstruation, such that girls and women are separated from the community during menstruation [23, 24]. These practices generate a culture of secrecy about normal, biological processes that are important to women's reproductive health. Consequently, across cultures, adolescents and women may have limited knowledge about what is and is not 'normal' regarding menstruation [25].

The normalisation of women's menstrual pain often contributes to diagnostic delay [11]. This may begin in the family context where mothers and sisters construct the pain of menstruation as a rite of passage, synonymous with being a 'woman'. Reassurance from family that menstrual pain is a normal part of 'womanhood' may discourage women from seeking support for pain or heavy bleeding, even when symptoms progress, further delaying diagnosis [21]. Unfortunately, when women do seek professional support, health professionals may similarly construct a discourse of women's menstrual pain as a normal, biological imperative. Qualitative research with women with endometriosis has extensively described how health professionals dismiss the severity of women's pain and symptoms as 'normal' [26, 27]. Women may feel stigmatised by health professionals who invalidate their experience by describing their symptoms as 'psychologically' constructed [28]. Women's attempts to manage the disease for years without professional guidance can disrupt their self-concept, intimate relationships and broader social lives [20, 26, 29]. The limited awareness of endometriosis among the social and medical community remains a significant challenge in the diagnosis and management of the disease. Long diagnostic delays for endometriosis creates bias by producing low incidence and prevalence rates, particularly among adolescent and among young women because of the difficulties accessing a diagnosis.

2.3.4 Socio-economic, Cultural and Political Context

A major challenge to the diagnosis of endometriosis is that socio-economic disparities often determine who receives a surgical diagnosis of endometriosis [5]. Women from socially disadvantaged backgrounds typically have poor access to health services and may be less likely to seek professional support, forming a barrier to diagnosis [30, 31]. As the diagnosis of endometriosis necessitates surgical confirmation, research is largely based on women attending hospital who have good access to healthcare [32]. Clinical stereotypes of women with endometriosis as 'white, lean, middle class, career-driven women' typify the bias in the research samples [32]. Women who are obese may face considerable difficulty receiving a diagnosis of surgically confirmed endometriosis due to social and medical reasons [33, 34]. A previous multi-country study of women with surgically confirmed endometriosis reported increasing diagnostic delays with increasing body mass index [33]. Evidence from a systematic review also suggests that ethnic disparities exist in the diagnosis of endometriosis, with Black women less likely to be diagnosed with endometriosis than White women [35]. These disparities sum up the long-standing inherent diagnostic biases in the research related to endometriosis.

Socio-economic disparities are inextricably linked to the political and cultural context in which individuals live. Political and cultural responses to endometriosis vary considerably across countries, but are constantly evolving, and have the potential to drive significant changes in prevalence and incidence rates for the disease. Greater political investment into endometriosis helps to build research, education and healthcare initiatives that improve care for women living with endometriosis. Endometriosis support groups in several high-income countries have been central to mobilising social and political awareness of the disease. Advocacy groups have voiced women's concerns, validated their pain and experiences and advocated for improved healthcare treatment and funding into endometriosis. The 2020 national inquiry into endometriosis in the UK reported an average of 8 years to diagnosis, suggesting there has been no reduction in diagnostic times for women in the last decade [36]. In Australia, decades of lobbying from endometriosis advocacy groups led to the initiation of the Federal Government's 2018 National Action Plan for Endometriosis [37]. Almost $13 million has been invested to improve social awareness, medical diagnosis and treatment and research [37].

The impact of increasing awareness of endometriosis and a focus on education can be positive, and has been reported to have an effect, with two Australian studies reporting a decrease in time to diagnosis to 4.9 and 6.4 years [38, 39]. More recently in the USA, lobbying from the Endometriosis Foundation of America generated increased federal research funding for endometriosis from $13 million in 2019 to $26 million in 2020 [40]. Increased international awareness of endometriosis will inevitably change what we know about the disease and its epidemiology. Countries that invest in ongoing surveillance of endometriosis by ensuring that high-quality data is collected will significantly expand knowledge on the aetiology and progression of the disease.

2.4 Epidemiology of Endometriosis

Epidemiology is concerned with identifying the distribution and determinants of disease in specific populations. Epidemiologists can examine the distribution of disease in different ways, often by estimating both the *incidence* and the *prevalence* of the disease. Incidence refers to the number of new cases identified in the population during a specific period. Prevalence refers to the total number of people affected with the disease at one time point or during a specific period [41]. The number of new cases of disease in the population (incidence) over time can provide an estimate of the total number of cases within the population during a period of time (prevalence). Prevalence and incidence are therefore complementary, but are two different frequency measures that cannot be used interchangeably. In comparing incidence and prevalence across studies, it can often be difficult even if the same disease definition is used [41]. Variations in study designs including the size and type of sample and the sources used to identify women with endometriosis can yield substantially different estimates.

2.4.1 Incidence

Annual incidence rates for endometriosis are largely based on studies using hospital or insurance claims databases and vary anywhere from 0.97 to 1.87 cases per 1000 person-years or 0.72 to 3.5 per 1000 women [42–46]. Variations in the historical timing of these studies that cannot account for changes to the clinical diagnosis and classification of endometriosis and the increased social and health professional

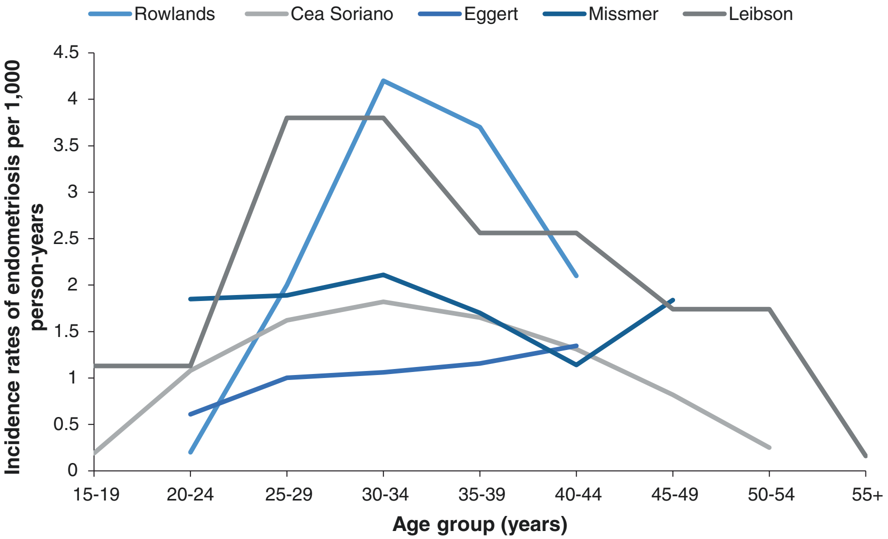

Fig. 2.2 Age-specific incidence rates of endometriosis across studies. Rowlands is based on national hospital discharge data from 2000 to 2018 [1]; Cea Soriano is based on medical records from multiple health databases from 2000 to 2010 [10]; Eggert is based on national hospital discharge data from 1990 to 2004 [47]; Missmer is based on national survey data during 1989–1999 [18]; Leibson is based on medical records from 1987 to 1999 [46]

awareness of the disease over time are likely to explain the heterogeneity in incidence rates.

Historically, endometriosis is characterised as a disease affecting women of 'reproductive age', with peaks in incidence often reported between the ages of 30 and 34 years (see Fig. 2.2). Peaks in incidence of endometriosis may reflect the timing of the first surgical diagnosis, which may be delayed due to social, medical and financial reasons or only prioritised when women experience problems becoming pregnant. Hysterectomy for the treatment of endometriosis may also contribute to peaks in incidence, but published data are lacking.

The natural incidence of the disease is limited due to the lack of longitudinal data available. However, endometriosis does occur in adolescents, with some reporting pain commencing at the time of menarche [2]. Menarche may be an important marker of onset, but inflammatory processes that give rise to endometriosis may begin from birth [48]. Life course data on endometriosis would significantly add to the evidence base.

2.4.2 Prevalence

2.4.2.1 Hospital/Clinic Samples

The literature related to the prevalence of endometriosis has historically relied on hospital-based samples of women attending surgery. These studies rely on small samples of women with underlying pathology and pain who are at ‘high risk’ of endometriosis. Prevalence in these studies range anywhere from 0.2% to 71.4% but was estimated to be 22.9% overall in a review of the literature [14]. The proportion of women with endometriosis was higher among women undergoing surgery for chronic pelvic pain (29.1%) and infertility (26.8%), and to a lesser extent a hysterectomy (15.6%), surgery for ovarian cancer (10.0%) and tubal sterilisation (5%) [14]. Studies based on women presenting for surgery often represent women with more severe forms of endometriosis, who may have better access to health services, which introduces selection bias into the study design. Estimates using small, clinical samples are therefore unlikely to translate well to the larger population of women living with endometriosis.

2.4.2.2 General Population Samples: Hospital Records/Insurance Claims Databases

To obtain larger, more nationally representative samples of women with endometriosis, several studies have used hospital records or insurance claims databases to identify women with disease, often via International Classification of Diseases (ICD) diagnostic coding. These studies offer a different perspective on the prevalence of endometriosis by looking at extent of the disease within larger samples, often at the population level. Relative to the hospital-based samples of women with endometriosis, prevalence rates tend to be lower in studies relying on hospital and insurance databases. A review of the literature estimated a 5% endometriosis prevalence rate among samples from hospital and insurance databases, but crude percentages ranged from 0.8% to 23.2% [14]. The availability of data in these studies ranged from 5 to 15 years [14]. However, some studies estimated prevalence at one time point during this period, known as ‘point prevalence’, often yielding low prevalence estimates. A point prevalence may underestimate the prevalence of endometriosis because the data only captures a select group of women diagnosed at a single point in time. Certain groups may be underestimated using this approach, including young women who may be less often referred for surgery, contributing to biased estimates. The alternative approach is to look at a ‘cumulative’ or ‘period’ prevalence for the population over the entire period available. Given the long diagnostic delays experienced by women with endometriosis, a period prevalence will be more robust than a point prevalence.

2.4.2.3 General Population Samples: Self-Reported Endometriosis

While the literature largely focuses on women with surgically confirmed endometriosis, there has been a recent shift in the diagnostic paradigm [6] to recognise the value of the clinical diagnosis and the importance of women’s symptoms [7]. The prevalence of endometriosis in studies based on general population samples where endometriosis is largely self-reported ranges from 0.7% to 8.6%, with an estimated overall prevalence of 3.4% [14], which is only slightly higher than studies relying on endometriosis diagnoses from hospital or insurance databases. Most studies relying on women’s self-reported endometriosis do not clinically confirm diagnoses of endometriosis, potentially limiting the validity of the studies. However, the value of these estimates from these studies lies in capturing women who are treated more conservatively, who cannot access or afford surgery or who decide against surgical intervention. These are most likely to be younger women, women from disadvantaged backgrounds and those residing outside of metropolitan areas where access to clinical expertise for endometriosis may be limited.

2.4.2.4 Geographical Variations in Prevalence

Global data on endometriosis are largely from high-income countries, with low-income countries underrepresented in the literature. The 2013 Global Burden of Diseases Study estimated the global prevalence of endometriosis was 4.8% during 2006 and 2013 [49] and more recently estimated a 3.0% decline in age-standardised rates from 2007 to 2017 [50]. A recent review of the literature during 1989 and 2019 identified 69 studies estimating the prevalence and incidence of endometriosis, with most originating in Europe (38%) followed by Asia (27%), North America (22%) and to a much lesser extent Africa (10%) [14]. Only two studies from Australia were identified [14]. Wide variations in the prevalence of endometriosis were reported both within and across regions, largely due to the methodological heterogeneity across the studies (see Fig. 2.3). The prevalence of endometriosis was highest for Asia at 20.7% but dropped to less than 1% when weighting by study sample size [14]. Moderately high prevalence rates were reported in the Americas (13.0%), followed by Europe (11.5%) and Africa (10.6%), with substantially lower rates reported in Australia (3.6%). A more recent estimate of endometriosis prevalence in

Fig. 2.3 Global geographic spread and variation in endometriosis prevalence [14]. Darker colours represent higher prevalence

Australia was 11%, based on nationally representative self-reported diagnosis combined with ICD diagnoses from national hospital databases [1].

2.4.2.5 Is the Prevalence of Endometriosis Increasing?

Identifying potential changes in disease over time helps determine whether there is increasing burden in the population. Ongoing surveillance of endometriosis has been largely neglected despite the severity and chronicity of the disease. A review of the literature related to the epidemiology of endometriosis did not find consistent evidence that the prevalence or incidence of endometriosis was changing over time [14]. True changes in the prevalence of endometriosis are difficult to identify because of the large methodological variations between studies and countries, in addition to the changing social and medical landscape related to the diagnosis and treatment of endometriosis. The limited availability of high-quality, longitudinal research on endometriosis also prevents meaningful conclusions to be made about changes in prevalence and incidence over time.

Recent data from a longitudinal, population-based Australian study reported evidence of generational differences in the prevalence of endometriosis [51]. Women with endometriosis were identified using multiple data sources including self-reported physician diagnoses of endometriosis and administrative health records including hospital databases. The prevalence of endometriosis was estimated in two separate cohorts of women born in 1973–1978 and 1989–1995, who were first surveyed when both aged 18–23 years. When both cohorts of women were aged 25–29 years, the prevalence of endometriosis was almost double among women born in the 1989–1995 cohort (6.6%) compared to women born in 1973–1978 (4%) (see Fig. 2.4) [51]. Recent shifts in the sociocultural and diagnostic context related to endometriosis, producing increased social and health professional awareness of

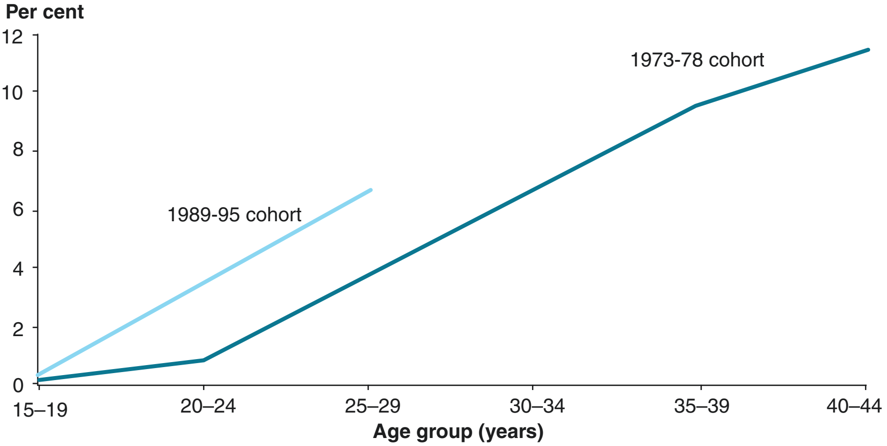

Fig. 2.4 Cumulative prevalence of endometriosis among two cohorts of young women from the Australian Longitudinal Study on Women's Health, by age. (Source: Australian Institute of Health and Welfare [51])

endometriosis, may explain these findings. A recent Australian study found that women diagnosed with endometriosis after 2005 when there was a change in clinical guidelines had fewer visits to a doctor before receiving a diagnosis and experienced shorter diagnostic delays than women diagnosed prior to 2005 [38]. The increased political investment in endometriosis in Australia has also prioritised the need for high-quality epidemiological data on endometriosis [37], which is likely to accelerate changes in the prevalence of endometriosis in future generations of women.

2.4.3 The Epidemiology of Endometriosis: Where to Next?

2.4.3.1 Endometriosis Diagnosis: Stages, Subtypes or Syndrome?

There is active, ongoing debate about faster, less invasive methods of diagnosis [6, 8, 52]. Shifts in how endometriosis is diagnosed from the surgical diagnosis to the clinical diagnosis based on symptom profiles and ultrasound will inevitably influence the epidemiology of endometriosis. There are increasing data reporting the reliability of sonography for diagnosing endometriosis, and staging systems that predict the severity of disease, within an interdisciplinary environment of endometriosis specialists [53]. Symptom-specific systems have been successful for predicting fertility outcomes for people with endometriosis, with the Endometriosis Fertility Index being a reliable and reproducible tool for this purpose [54]. Symptoms such as pain and systemic features including fatigue are yet to have similar systems that determine outcome, although the publication of core outcome sets for research may improve these factors in the future [55].

The classification of endometriosis is ongoing with the traditional revised American Society for Reproductive Medicine (rASRM) staging system challenged due to its poor prediction of clinically meaningful outcomes [2]. There is recognition that a life course approach is important to identifying, managing and aligning an endometriosis diagnosis with the individual’s symptoms and goals [52]. Staging methods that reflect severity of the disease, and not the person’s lived experiences, have prompted a re-evaluation of how to classify the disease [8]. Future research may lead to more symptom-specific methods of classification that take these parameters into consideration and can be translated into clinical practice. Recognition that subtypes of the disease are likely to occur, and may impact response and non-response to different treatments, is likely to direct and determine future management options. Challenging long-held dogma around endometriosis being a ‘disease’ and consideration of the presence of lesions and symptoms as a syndrome [8] may further refine what we are seeing and treating and how best to care for women with such broad-ranging problems and needs.

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