

# An Overview on the Psychological Impact of Endometriosis on Adolescent Girls' Life

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## Abstract

**Context:** Endometriosis is a chronic condition affecting 10% of women in their reproductive age worldwide. Endometriosis symptoms can seriously impact the quality of life and the mental health of women. Although it could be found in over 60% of adolescent girls and adolescents may suffer from advanced forms of it, there are not enough studies on psychological impacts of endometriosis in adolescence.

**Evidence acquisition:** In this narrative review study, research studies and systematic review studies conducted from 2000 to 2021 were searched in the PubMed, Medline, and Scopus with the following keywords: “young women OR adolescents OR adolescence” AND “endometriosis” AND “psychologic\* OR emotions OR well-being OR quality of life”.

**Results:** Endometriosis symptoms substantially affect the psychological well-being of young women. They often report physical pain, reduced general health and vitality, poor physical and social functioning, as well as limitations in emotional functioning.

**Conclusions:** These data highlighted the need for increased awareness concerning this disease for its early diagnosis and focused on healthcare assistance and psychological support for adolescent girls with this condition.

**Keywords:** Endometriosis, Adolescence, Well-being, Mental health, Healthcare assistance

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## 1. Context

### 1.1. What Is Endometriosis?

Endometriosis is a chronic condition characterized by spreading of endometrial-like tissue outside the uterus and affects 10% of women of reproductive age worldwide (1, 2). The percentage of women in reproductive age affected by endometriosis is about 6 to 10%, particularly for women aged 25 to 30 (3). The etiological cause of endometriosis is still unknown. Several factors (immunological, hormonal, inflammatory, genetic, and environmental) may influence the pathogenesis of this chronic condition (4, 5). Various clinical symptoms are associated with this disease, such as irregular menstruation, chronic pelvic pain, dysmenorrhea, dyspareunia, dyschezia, dysuria, and subfertility (6, 7). The intensity of pain seems to be not correlated to the extent of the lesions in endometriosis (1); in fact, it is possible that women with a mild form of endometriosis (in line with the classification of American Society for Reproductive Medicine) perceive intense pain and vice versa. Furthermore, women affected by this disease experience psychological and emotional difficulties (8-11). In short, endometriosis can significantly damage women's quality of life and mental health of

women, affecting several aspects of their life, namely professional, personal, social, and intimate aspects (11). According to the literature, several studies have aimed to analyze negative effects of endometriosis on women's mental health, highlighting a relevant recurrence of distress, depressive and anxiety-related disorders. On the other hand, studies on psychological impacts of endometriosis on adolescence are scarce even though endometriosis affects a significant number of adolescents. Previous studies have suggested that endometriosis could be found in over 60% of adolescent girls undergoing laparoscopic investigation for pain, 70% of those experiencing dysmenorrhea, 75% of those with chronic pelvic pain resistant to treatment, and in 50% of whom with chronic pelvic pain not necessarily resistant to treatment. Adolescents may suffer from early and advanced forms, including deep endometriosis. In fact, it has recently been claimed that deep endometriosis often begins during adolescence (12, 13).

### 1.2. Psychological Impact of Endometriosis

Endometriosis, as a chronic and painful disease, often represents a high emotional burden for women. In summary, endometriosis has been documented to negatively impact different aspects of life. Its symptoms

can decrease physical functioning (mobility and sleep), emotional well-being (distress, depression, and anxiety), and social well-being (social isolation and lost social activities) (8-11). In addition to the economic costs of treatment, women have to bear additional costs due to absenteeism at work and the loss of school days and work productivity (14, 15). Several studies have shown that the quality of life (QOL) of adult women with endometriosis is significantly impaired compared to the QOL and physical and mental health of their healthy peers (10, 11, 16). In particular, adults with endometriosis associated with severe pelvic pain and with longer diagnostic delays have reported greater impairment on quality of life (17). Women with this condition have reported feelings of anxiety, depression, isolation, and frustration (4, 18). Furthermore, the disease seems to negatively affect their personal image by generating a sense of subjective insecurity (19).

Endometriosis has also a negative effect on sexual and intimate relationships. In fact, many adult women affected by endometriosis perceive pain during sexual intercourse (dyspareunia) or for the following 24 hours. Nearly 60% of adult women with endometriosis experience dyspareunia at some point in their life (6, 7, 20-23). Beyond the physical pain, this discomfort could have a damaging effect on women's mental and emotional well-being, activating feelings of isolation and affecting self-esteem and body image.

In brief, the literature highlights how endometriosis could impair the quality of life and the social, emotional, and economic well-being of adult women (24).

### 1.3. Adolescence and Psychological Aspects

Researchers have been telling us for decades that adolescence represents a critical moment in a person's developmental, specifically in terms of identity building, identification by gender, and sexual orientation (25). Teenagers have to discern these possible identities, evaluate them, and decide how to integrate them into their subjective sense of self (26). The development of autonomy, as a psychological or interpersonal process, is believed to be closely related to identity formation (27). Furthermore, teens spend much more time with their peers than younger children and are more strongly influenced by them, revealing an ambivalence between emotional autonomy and susceptibility to peer pressure (28, 29). In the presence of a chronic pathology, this delicate developmental moment could become even more complex. Studies conducted on young people with chronic diseases have highlighted how the constraints

imposed by the disease can damage school experience and outcomes, relationships with friends and family, and lead to a change in the young person's outlook on life (30-32). A review of studies involving young people with a wide variety of chronic diseases has shown that seven issues are closely relevant to them: developing and maintaining friendships, being normal / getting on with life, the importance of the family, aptitude for treatment, school experiences, relationship with health professionals, and expectations towards the future (30).

Although endometriosis, as a chronic condition, accounts for over 60% of adolescent girls and adolescents may suffer from advanced forms of it, studies on the psychological impact of endometriosis in adolescence are still rare.

## 2. Evidence Acquisition

This narrative review study focused on the psychological impact of the endometriosis on adolescence. Even though studies in this field are still rare, endometriosis seems to significantly impair the physical, emotional, and relational functioning of adolescent girls. For this reason, increased awareness about this condition is necessary for an early diagnosis and more focused healthcare assistance. In this narrative review study, research studies and systematic reviews studies conducted from 2000 to 2021 were searched in the PubMed, Medline, and Scopus with the following keywords: "young women OR adolescents OR adolescence" AND "endometriosis" AND "psychologic\* OR emotions OR quality of life".

## 3. Results

### 3.1. Psychological Impact of Endometriosis on Adolescence

The few studies conducted on the psychological impact of endometriosis in adolescence have shown that endometriosis symptoms substantially affect the psychological well-being of young women. They have often reported physical pain, reduced general health and vitality, poor physical and social functioning, as well as limitations in emotional functioning (33-38).

In particular, high levels of depression and anxiety were found in adolescents with endometriosis, which appears to directly affect their quality of life (QoL), as shown previously in adult patient populations (37). Furthermore, more than three quarters of adolescent and young adults (AYA) with endometriosis experience

pain with sexual intercourse (dyspareunia), which negatively impacts both physical and mental health-associated QoL scores. Considering the importance of relationships and peer engagement for identity building process during adolescence, dyspareunia could be particularly damaging. Accordingly, the impact of dyspareunia on both relationships and social functioning during adolescence and young adulthood is significantly distressing and impairs self-image as well as overall health (38, 39). These findings are consistent with what has been previously reported in middle-aged adult women. The majority of the young women recruited in the study of Bodén and colleagues also reported that they missed school and extracurricular activities due to the suffering or discomfort caused by the symptoms. Absences from school ranged from a few days missed every month up to 70% of the entire school year. The absences were not limited to menstrual cycles, but also during the ovulation. The results of the study indicated the negative impact of endometriosis on the school and social functioning. Another study highlighted the presence of a reduced quality of life in adolescents with endometriosis compared to peers without endometriosis. In this study, the perceived pain was a major source of reduced quality of life for these adolescents. In addition to pain, the adolescents' quality of life was impaired by difficulties completing daily activities due to damaged physical and emotional health, as well as difficulty engaging in social activities (for example, normal social activities with family, friends, neighbors, or groups) due to health problems (33). A study conducted by Lökvist and colleagues (40) highlighted the impact of endometriosis on different aspects of QoL in different age groups of a Swedish endometriosis population. The study showed that younger women with endometriosis experience further symptoms and a lower QoL score compared with women in older age groups. It was found that younger women experienced further symptoms, which could reflect a correlation between the activity of the disease and, for example, more worries regarding fertility and problems conceiving. In addition, in the year prior to the diagnosis of endometriosis, young women have a greater risk of moderate to severe distress than women without these conditions. In fact, it has been shown that delays in diagnosis, which are common in women with these conditions lead to increased young women's distress (34).

In the end, Gupta and colleagues underscored the importance of social context in influencing adolescents' perceptions of endometriosis symptoms as well as their emotional health. Similar to adult women

with endometriosis, adolescents express feelings of devastation facing the idea of missing educational or social opportunities due to their illness. The adolescents in the current study discussed how girls would feel compelled to conceal the symptoms and endure painful sexual intercourse due to fear of negative social impacts (being shamed or pointed out of having a sexually transmitted infection) (35).

#### 4. Conclusions

Studies have reported that adolescents with endometriosis struggle with significant pain, poor physical functioning, and several issues participating in daily activities, in addition to a reduction of their quality of life and overall well-being. This condition seems to negatively impact their self-image, restricting peer social activities and sexual relationships by generating distress, feelings of anxiety and depression, and impairing the overall physical and emotional health.

As the diagnosis of endometriosis in adolescence becomes more common and as adolescence is the time of development and change, the potential effects of the disease on QoL should be recognized and addressed. Longitudinal studies should be undertaken to determine if early diagnosis and treatment could improve women's health and wellness and increase the likelihood of a positive QoL trajectory into adulthood.

This narrative review highlighted the need for increased awareness about the disease for its early diagnosis and more appropriate healthcare assistance, such as focused pain treatment and psychological support for girls with endometriosis. Therefore, health care professionals should be perfectly aware of the potential psychosocial and healthcare needs of young women with this condition.

**Conflicts of interest:** None declared.

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