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Retrospective Descriptive Study of Atypical & Extrapelvic manifestations of Endometriosis: Clinical Perspectives

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Abstract: ***Background: Endometriosis is commonly found in approximately 10% to 15% of women between 25 to 44 years of age, and in infertile women incidence of endometriosis is almost 25% to 40% [1]. Methods: This was a retrospective descriptive study conducted at a tertiary care teaching hospital from January 2023 to January 2025. Inclusion criteria included women with histopathologically confirmed endometriosis at extrapelvic or atypical sites. Patients with incomplete records were excluded. Data regarding demographics, clinical presentation, imaging findings, surgical management, and histopathology were collected and analysed descriptively. Results: This study found that endometriosis can present with a wide range of symptoms beyond the typical pelvic pain and infertility. A total of 48 women with atypical and extra-pelvic manifestations of endometriosis were included during the study period. The presentations included episiotomy scar endometriosis (n=6), cutaneous endometriosis (n=8), intestinal endometriosis (n=16), cesarean scar endometriosis (n=16), one case of umbilical endometriosis & one case of uterocutaneous fistula. Conclusions: This paper has highlighted the importance of recognising and understanding atypical manifestations of endometriosis. By shedding light on the various ways in which this condition can present outside of the pelvis, healthcare providers can improve diagnosis and management strategies for patients with endometriosis. Further research is needed to better understand the underlying mechanisms driving these extra-pelvic manifestations and to develop more effective treatment options. Overall, increasing awareness and knowledge of these manifestations is crucial in providing comprehensive care for individuals living with endometriosis.***

Keywords: endometriosis, extra-pelvic endometriosis, cutaneous endometriosis, scar endometriosis.

1. Introduction

Endometriosis is commonly found in approximately 10% to 15% of women between 25 and 44 years of age, and in infertile women incidence of endometriosis is almost 25% to 40% [1].

The common sites of involvement in decreasing order of frequency are the ovaries, pelvic peritoneum, deep pelvic sub-peritoneal spaces, intestinal system, scar endometriosis, urinary system and thoracic endometriosis.

The most common extra-pelvic form of endometriosis is cutaneous endometriosis, involving scar tissues occurring after obstetric or gynaecologic procedures such as episiotomy, hysterotomy, caesarean section, and even laparoscopic surgery. Scar endometriosis very rarely can get complicated with utero-cutaneous fistula. There are reports of endometriosis in almost all locations, including kidneys, lungs, and central nervous system [2]

1) Episiotomy Scar Endometriosis

Endometriosis at the scar site can be found after perineal episiotomy, cesarean, hysterectomy, laparoscopic trocar tract, or amniocentesis.[3] Episiotomy scar endometriosis is a relatively uncommon condition and is usually diagnosed late because of unawareness about the condition among general surgeons, resulting in prolonged suffering to the patient and increased morbidity.

Case selection: 6 patients were included who presented to the Gynaecology outpatient department with history of vaginal delivery with episiotomy (mediolateral or median) with the presence of a perineal/ episiotomy scar lesion.

Symptoms: Complaints of pain and swelling in the perineal region for years, both of which increased during menstruation. Four of them had complaints of dyspareunia. Their menstrual cycles were regular with average flow, not associated with dysmenorrhea.

Table 1: Summary of Clinical Symptoms in Patients

Symptoms	Total Patients (n=6)
1. Pain in Perineal Area	6
2. Swelling in Perineal Area	6
3. Dyspareunia	4
4. Dysmenorrhea	0

All 6 patients reported pain and swelling in the perineal area. Among them, 4 experienced dyspareunia in conjunction with these symptoms, while none reported dysmenorrhea.

On vaginal examination: Five patients had a well-defined nodular mass felt at the site of episiotomy, firm to hard in consistency and tender. Same nodular mass was felt on per rectal examination. Rectal mucosa was free of any mass.

Figure 1: Preoperative image showing the puckered scar.

Based on characteristic history and examination findings, a probable diagnosis of deep episiotomy scar endometriosis was considered.

Investigations: A magnetic resonance imaging (MRI) scan of the pelvis was done to rule out an extension to the anal sphincter. MRI was suggestive of a lesion at the right mediolateral site in all six cases, and the likely diagnosis was scar endometriosis.
FNAC was done in all cases to confirm the diagnosis.

Management: In all cases, episiotomy scar endometriosis excision was done under combined spinal-epidural anaesthesia. The whole endometriotic tissue, with a margin of 1 cm of healthy tissue, was excised.

On HPE, the presence of endometrial glands and stroma confirmed the diagnosis of episiotomy scar endometriosis.

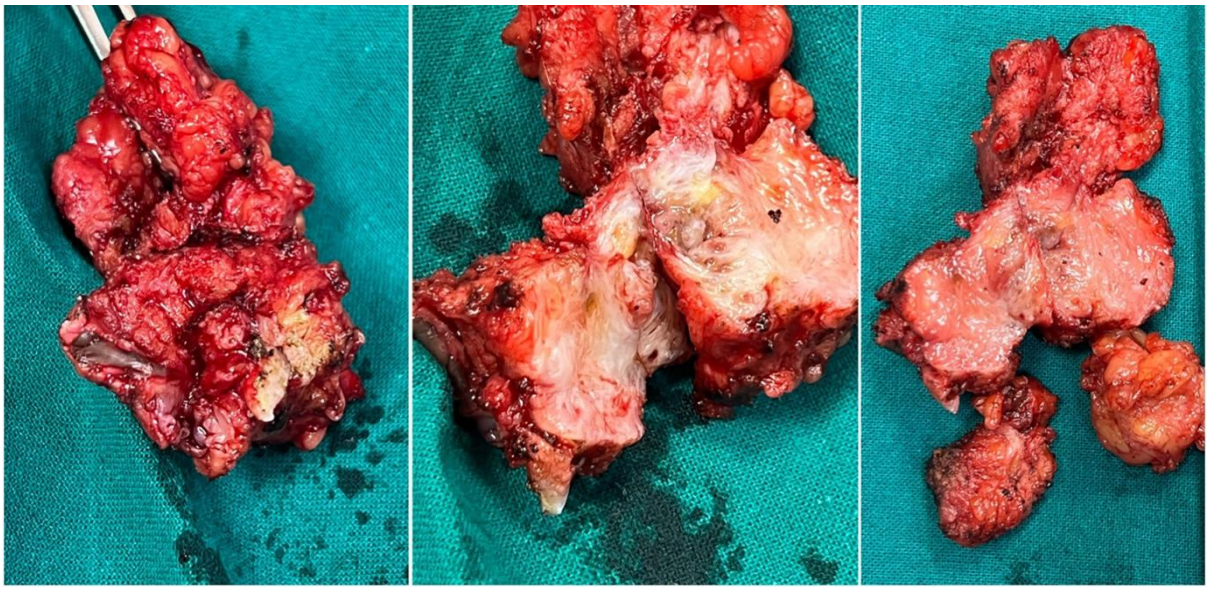


Figure 2: Excised specimen and its cut section.

2) Cutaneous Endometriosis:
Cutaneous endometriosis is a rare condition that usually affects the abdominal wall in women with a history of abdominal surgery. Clinical features include the presence of an abdominal mass and pain associated with menstruation. The treatment is usually surgery.

Case selection: A total of 10 possible cases were initially obtained, of which 2 cases were excluded due to their clinical histories were incomplete.

Out of 8 patients, there was no surgical history in 2 women, being cases of primary cutaneous endometriosis. In remaining 6, there was at least one previous surgery. Caesarean section was the main surgical history (n = 4), followed by laparotomy (n = 1) and appendectomy (n = 1).

The lesions were single in 100% of cases. They were located over the surgical scar in 6 of 8 women and umbilical region in two cases.

Symptoms: The main symptom was the presence of an abdominal mass. Pain was present in 7 of 8 women, being associated with menstruation. The mean time period between the last surgical intervention and the consultation was 6.5 years.

Investigations: As imaging tests, ultrasound was used in all women, followed by a MRI (magnetic resonance imaging)

scan in 6 patients. The main diagnostic tool used was fine needle aspiration, which was used in 6 patients.

Management: The treatment was surgical all cases. Conservative treatment was decided in the remaining cases due to the refusal of surgery by the patient or the nearness to the menopause. The usual surgical technique was excision of the endometrioma, with subsequent repair of the fascial defect[4]. A prosthetic mesh was used to repair the defect in 8 cases. The treatment was omphalectomy en bloc in 3 of the cases.

Figure 3: Cutaneous Endometriosis

Histologically, the final diagnosis was determined by subcutaneous presence of stroma and tissue endometrial glandular with frequent signs of intraglandular and interstitial bleeding and with characteristic signs of hormonal transformation into proliferative or secretory.

3) Intestinal Endometriosis

Intestinal endometriosis is a rare form of deep infiltrating endometriosis, often misdiagnosed due to its nonspecific gastrointestinal symptoms. Bowel involvement accounts for 5% to 12% of the women presenting with the disease, with the rectum and sigmoid involved in up to 90% of all intestinal lesions. [5]

This study evaluates the clinical presentation, diagnostic modalities, and surgical outcomes in 16 patients with histologically confirmed intestinal endometriosis.

Case selection: A retrospective analysis was conducted on 16 women diagnosed with intestinal endometriosis based on surgical findings and histopathological confirmation. Data on patient demographics, symptoms, imaging, intraoperative findings, and postoperative outcomes were collected and analysed.

Symptoms: The rectosigmoid colon was the most commonly affected site (75%), followed by the ileum (12.5%) and cecum (12.5%).

Table 3: Summary of Clinical Symptoms in Patients

Symptoms	Total Patients (n=16)
1. Cyclical Pelvic Pain	All 16
2. Constipation	12
3. Dyschezia	11
4. Rectal Bleeding	4

Investigations: Pelvic MRI demonstrated deep infiltrating lesions in 75% of cases, while colonoscopy showed limited diagnostic utility.

Management: All patients underwent surgical management: segmental bowel resection (56.2%), disc excision or shaving (43.7%). Histology confirmed endometrial glands and stroma in the intestinal wall, with muscularis propria involvement in 81.2% of cases. Postoperative symptom relief was reported in 87.5% of patients, with minimal complications and no recurrence in 13 patients followed up for 12 months.

Intestinal endometriosis poses significant diagnostic challenges due to its mimicry of other gastrointestinal disorders. Pre or intraoperative sigmoidoscopy may prove helpful in ruling out malignancy. The gold standard for diagnosis is laparoscopy and biopsy, which allows a full assessment of the pelvis as well as surgical resection if required. Surgical management, tailored to lesion extent, is associated with favourable outcomes. Multidisciplinary evaluation is essential for optimal care.

4) Umblical Endometriosis

Extrapelvic locations are uncommon; among these, umbilical endometriosis, also called Villar's nodule, accounts for less than 1%. It can occur spontaneously (primary) or after previous abdominal surgeries (secondary). Surgical excision remains the gold standard treatment, offering both diagnosis and cure. Recurrence is rare when complete excision is achieved. Due to the rarity of this presentation that case is described separately.

Case selection: A 44-year-old P2L2 with previous normal deliveries woman presented to the gynaecology clinic.

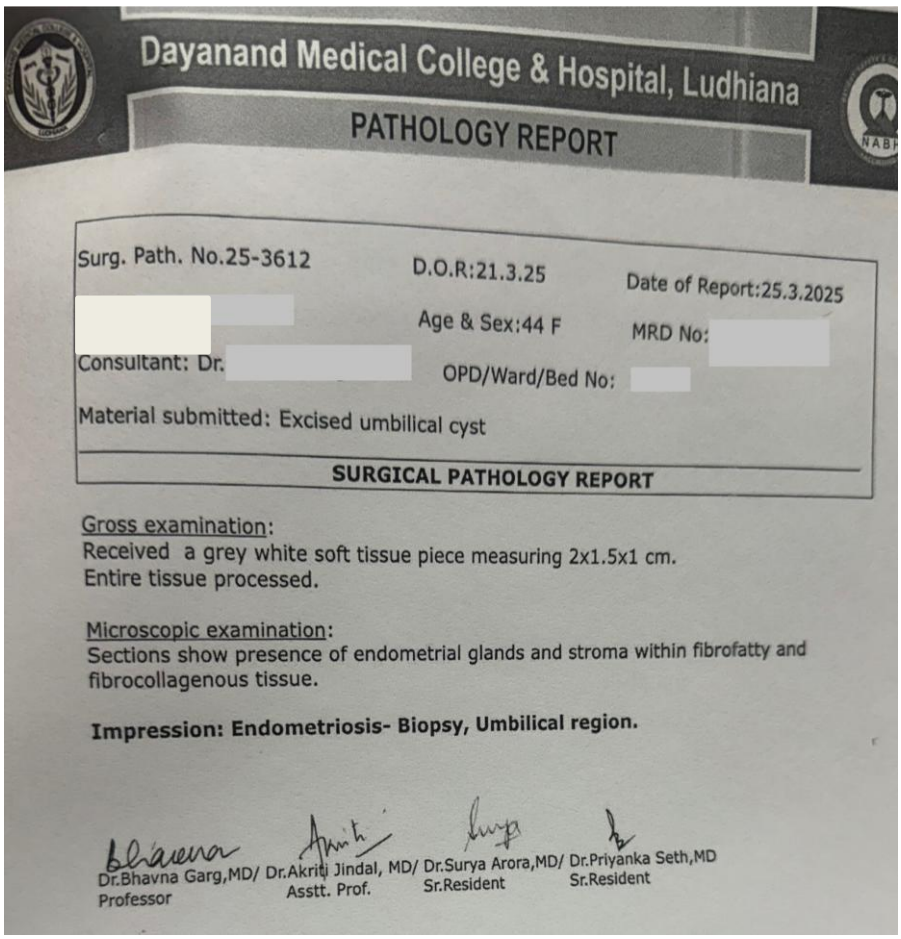
Symptoms: Pain and hemorrhagic discharge from the umbilicus during menstruation, which was cyclical & ongoing for four months. There was no history of abdominal or pelvic surgery. She denied dysmenorrhea or pelvic pain.

On physical examination, the umbilicus showed a bluish, tender nodule measuring approximately 1.5 cm, with a small amount of sero-hemorrhagic discharge. There was no abdominal wall defect or signs of herniation.

Investigations: Pelvic ultrasound was normal, and an MRI of the abdomen revealed a localised soft tissue lesion confined to the subcutaneous umbilical region, with no intra-abdominal extension. Differential diagnoses included umbilical granuloma, neoplasm, or endometriosis.

Figure 4: Umblical Endometriosis

Management: The patient underwent wide local excision of the umbilical lesion under local anaesthesia. Histopathological examination revealed endometrial glands surrounded by stroma, confirming umbilical endometriosis.



Dayanand Medical College & Hospital, Ludhiana

PATHOLOGY REPORT

Surg. Path. No.25-3612 D.O.R:21.3.25 Date of Report:25.3.2025

Age & Sex:44 F MRD No:

Consultant: Dr. OPD/Ward/Bed No:

Material submitted: Excised umbilical cyst

SURGICAL PATHOLOGY REPORT

Gross examination:
Received a grey white soft tissue piece measuring 2x1.5x1 cm.
Entire tissue processed.

Microscopic examination:
Sections show presence of endometrial glands and stroma within fibrofatty and fibrocollagenous tissue.

Impression: Endometriosis- Biopsy, Umbilical region.

Dr.Bhavna Garg,MD/ Professor
Dr.Akriti Jindal, MD/ Asstt. Prof.
Dr.Surya Arora,MD/ Sr.Resident
Dr.Priyanka Seth,MD Sr.Resident

Figure 5: Histopathology report showing biopsy report of excised umbilical cyst

Postoperatively, she was started on GnRH analogues for hormonal suppression. At 8-month follow-up, she was asymptomatic with no signs of \recurrence.

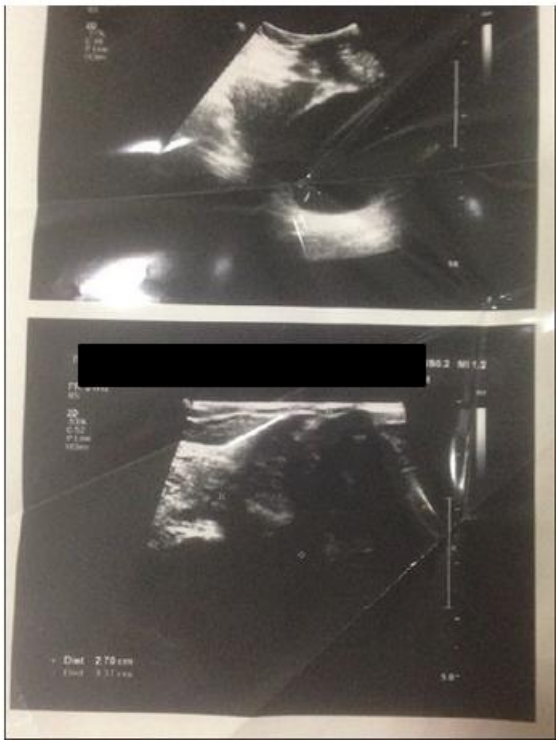
5) Endometriotic Uterocutaneous Fistula

Utero-cutaneous fistula (UCF) is mostly seen after post-partum or postoperative complications [6]. Although uterovesical, utero-colonic fistulae are not uncommon, Utero-cutaneous fistula is a rare clinical entity with less than 15 cases reported worldwide in the last 20 years. Fistula between the genital tract, bowel and skin results more commonly due to underlying co-morbidities like tuberculosis, Crohn's disease, endometriosis to inadvertent retention of swabs (gossipyboma) [7]. Due to the rarity of this presentation that case is described separately.

Case selection: A 36-year-old female P2L1 presented in October 2013 with the complaint of pain and swelling on the cesarean scar on and off for 11 years. In addition, she described cyclic bleeding along with pus from this cesarean scar for 11 years. She previously had one spontaneous vaginal delivery 14 years ago and a cesarean section 12 years back in view of non-progression of labour. She described pain over the cesarean scar at the lower end that increased during the menstruation and then noticed a swelling over the cesarean scar at the lower end. She noticed mild bleeding from the scar within the 1st days of her menstruation followed by pus.

Examination revealed a well-healed cesarean scar, a moderately pigmented area, and tenderness at the lower end of the vertical infra umbilical scar on palpation.

Investigations: Ultrasound [Figure 1] showed that an ill-defined hypoechoic lobulated lesion 3.3 cm × 2.7 cm is seen in relation to the superior surface of the uterus to the skin surface at the site of the scar. A linear fluid-filled tract was also seen within it.



Based on characteristic history and examination findings, the most probable diagnosis of scar endometriosis with uterocutaneous fistula was kept.[8]

Management: The patient underwent exploratory laparotomy. Intraoperatively, an inverted Y-shaped fistula was identified with the help of a thin infant feeding tube connecting abdominal skin with the uterus and to the dome of the bladder. Fistulous tract excised out and the specimen was sent to the pathology department. Left salpingectomy was done in view of hydrosalpinx, and as bladder dome had some swelling attached to the fistulous tract, sleeve resection of the bladder with repair was done in single continuous layer. Uterus was also closed in two layers.

Histopathology of the excised tract confirmed endometriosis. The patient's postoperative course was uneventful and her pain subsided. There was no bleeding and discharge from scar afterward. She conceived spontaneously in May 2014, she was a booked pregnancy in our hospital, and her antenatal period was uneventful. She underwent emergency lower segment cesarean section in view of fetal distress and preterm premature rupture of membranes at 34 weeks 2 days of gestation. She delivered a healthy male baby of birth weight 2.42 kg. The patient's postoperative period was uneventful.

6) Caesarean Scar Endometriosis:

Scar endometriosis, also called as incisional endometrioma, is a rare form of extra pelvic endometriosis, that occurs in those incisions where the endometrial tissue might come into contact [2]. The cesarean section scar is the most common site of scar endometriosis [3]. The prevalence of surgically proven endometriosis in the scar is 0.03 %–1 % [4]. Among those, 0.03 %–0.04 % occurs in the post-cesarean section scars [2]. The diagnosis of this condition is confirmed by histopathology.

Patients typically present with cyclical pain and swelling at the surgical scar, often years after the index surgery. Due to lack of awareness and its resemblance to other surgical conditions such as stitch granuloma, incisional hernia, or abscess, diagnosis is frequently delayed. This case series aims to highlight the clinical profile, diagnostic approach, and management outcomes of 16 patients with cesarean scar endometriosis.

Case Selection: A total of 16 patients were included in the study.

Inclusion criteria:

- Women with a history of cesarean section
- Clinical suspicion of scar endometriosis
- Histopathological confirmation following excision

Exclusion Criteria

- Endometriosis at sites other than cesarean scar
- Incomplete medical records

Table 4: Summary of clinical presentations of patients

Symptoms	Number of patients (n=16)
1. Cyclical pain at scar site	16 (100%)
2. Palpable mass	13 (81.2%)
3. Skin discoloration	3 (18.7%)
4. Non-cyclical pain	2 (12.5%)

Investigations: Ultrasonography revealed a hypoechoic heterogeneous mass in the subcutaneous plane or rectus sheath in all cases. Size ranged from 2 to 5 cm. MRI was performed in selected cases to assess depth and muscle involvement.

Management: All patients underwent wide local excision with at least 1 cm healthy margins. Fascial repair was required in 7 cases. No patient required mesh repair.

Histopathological examination confirmed the presence of endometrial glands and stroma with hemosiderin-laden macrophages in all cases.

Patients were followed up for 3–6 months. No recurrence or malignant transformation was observed.

2. Discussion

This case series highlights the diverse and often under-recognised atypical and extra-pelvic manifestations of endometriosis, including scar, cutaneous, intestinal, umbilical, and fistulous involvement. Delayed diagnosis was common due to nonspecific symptoms and low clinical suspicion, consistent with previously published literature.

Surgical excision with histopathological confirmation remained the cornerstone of diagnosis and treatment, with favourable outcomes and low recurrence rates. Increased awareness among gynaecologists and surgeons is essential to enable early diagnosis and prevent prolonged morbidity in affected women.

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Declarations

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Conflict of interest: None Declared

Ethical approval: Approved by the Institutional Ethics Committee

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