

The significance of lifelong follow-up for the ostomate: the nurse's perspective of ileostomy site adenocarcinomas

ABSTRACT

The development of adenocarcinoma at an ileostomy site is an extremely uncommon and late complication that can occur for people living with a permanent ileostomy. Predominantly it is found in individuals who had their stoma surgery for ulcerative colitis, familial adenomatous polyposis or Crohn's disease, at an average time of 27 years after the stoma was created. There have only been 70 reported cases in the literature worldwide, most of these in the last 20 years. The extended latent period for the adenocarcinoma to occur from time of stoma creation could help explain this increase in incidence. The exact cause of this malignancy is not clear but it has been suggested that factors such as chronic mechanical and chemical irritation from stoma appliances, disease predisposition, malignant transformation of adenomas, changes in bacterial flora and Ileitis/backwash ileitis, could contribute to their development.

Primary adenocarcinoma at an ileostomy has been reported in the literature by surgeons and medical practitioners. Despite this, there remains limited information on the care and management from key stakeholders such as stomal therapy nurses, when caring for a people living with a permanent ileostomy. This article provides a different understanding and description from the perspective of a stomal therapy nurse, describing two cases of primary adenocarcinoma at the ileostomy site.

Keywords ileostomy, adenocarcinoma, stomal therapy nurse role

For referencing Vickers KJ. The significance of lifelong follow-up for the ostomate: the nurse's perspective of ileostomy site adenocarcinomas. *WCET® Journal*. 2025;45(1):20-26.

DOI <https://doi.org/10.33235/wcet.45.1.20-26>

Submitted 9 July 2024, Accepted 15 December 2024

INTRODUCTION

Primary adenocarcinoma at an ileostomy site is an extremely uncommon and late complication.¹⁻⁶ Worldwide there have been only 70 cases reported in the literature up until 2020.² The first reported case of a primary adenocarcinoma at an ileostomy site occurred in 1969 in a patient 19 years after a partial colectomy for ulcerative colitis (UC).⁵⁻⁸ The timeframe between stoma creation surgery and developing an adenocarcinoma lesion is varied with cases diagnosed as early as three years and as late as 51 years³ and the average time documented as 27 years.⁵⁻⁷

Primary adenocarcinoma at an ileostomy site is predominantly found in people with an initial diagnosis of UC and familial

adenomatous polyposis (FAP),¹ with some reports in patients with Crohn's disease.² Although occurrence in patients with FAP is rare. Permanent ileostomies are often created during surgeries to treat UC, FAP or Crohn's disease. These conditions, in particular UC and FAP, can require total colectomies, proctocolectomies, ileal pouch, ileoanal anastomosis (restorative) and pan (total) proctocolectomies with permanent ileostomies.^{1,2} Temporary ileostomies can become permanent if the patient decides living with a stoma permanently is the preferred option, or they become medically unfit for further surgery.¹

Pan proctocolectomy with permanent end ileostomy has been performed for individuals with UC or FAP since the 1950s.⁵ It involves removing the entire colon, rectum, anal canal and anal sphincter in one surgery with the formation of an end ileostomy, and is considered to be a curative treatment for FAP and UC.⁹ This was once considered the first line surgical treatment for UC and FAP patients, but today restorative proctocolectomy surgery is considered standard procedure avoiding a permanent ileostomy for the patient.^{3,10}

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Stoma malignancies are not a complication that stomal therapy nurses (STNs) often encounter. Stomal therapy text books will only dedicate a paragraph or up to half a page to the topic, if at all, as it is so uncommon, therefore STN knowledge is lacking in this area. Experienced STNs may have limited exposure throughout their vast careers. This paper provides two case studies with insight into the identification and management of this condition.

Patient A

CASE PRESENTATION (BACKGROUND)

A 54-year-old gentleman with a previous history of total proctocolectomy and formation of an end ileostomy in 2012 for FAP (also reported by Jacob et al⁷). Past medical history of depression, gastric oesophageal reflux disease (GORD), post-traumatic stress disorder (PTSD) and a BMI of 35, obese.

Patient A was lost to follow up due to non-adherence with health care and poor health literacy. He presented to the Emergency Department in January 2022 with a large painful and partially reducible parastomal hernia (PSH), peristomal skin damage and a hyper nodular stoma. An urgent referral to the colorectal team was completed followed by a review by the colorectal consultant and STN in the outpatient department. The patient reported no previous contact with an STN for at least three years.

On examination by the STN a large PSH was evident. On removing the stoma appliance, a large polypoid lesion was noted on the stoma mucosa, becoming the more concerning feature (Photos 1 & 2). Patient A reported the parastomal hernia had been increasing in size for years, and he experienced discomfort and multiple appliance leakages daily. He had started using Coloplast Mio Concave[®] drainable bag to improve adherence around the large PSH, as this appliance is designed to fit around bulges, hernias, and curves with its star shaped base. However, the opening of the bag was not being cut large enough by Patient A for the both the stoma and polypoid lesion resulting in device failure and persistent friction and irritation at appliance opening. Additionally, the patient cut an opening into the hernia support belt that he was using to accommodate the bag and not surprisingly, found that this worsened.



Photo 1 and 2. Anterior & Lateral view of polypoid lesion & PSH.

MANAGEMENT AND OUTCOMES

Patient A had an urgent elective open parastomal hernia repair and refashioning of stoma. Mesh was not inserted due to unknown pathology of the polypoid lesion. Pathology of the large polypoid lesion that was excised returned as villous tumor with transformation into adenocarcinoma, with superficial focal invasion. Postoperatively, the stoma was irregular in shape and oedematous from being handled during the surgery, which is expected after stoma creation and slowly decreases in the first 4-6 weeks. A parastomal outwards protrusion was still evident and a lateral sutured wound for excess skin extending outwards at 9 o'clock, which further caused the parastomal area to be uneven and undulating (Photos 3 & 4).

He developed cellulitis to the peristomal skin requiring intravenous antibiotic treatment with Ceftriaxone during the recovery period and was discharged four days after his surgery with oral Augmentin Duo antibiotic coverage. On discharge, he was using the Welland Aurum[®] Profile drainable bag. The base of this product is designed to fit around curves, creases, and complex body contours which the patient had acquired post-surgery. It was also felt that the medical-grade Manuka honey infused base could assist with healing and decreasing the inflammation of the peristomal skin cellulitis (Photo 5 & 6).

Post discharge in the community, the patient was changing his bag every two days with no leakages. Stoma care post discharge was complicated by developing a large pseudoverrucous lesion with moist hyperkeratotic tissue below



Photo 3. Anterior view of parastomal topography post operative.



Photo 4. Lateral view of parastomal topography post operative
Photos 1-4 © 2023 Royal Australasian College of Surgeons.

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Photo 5. Peristomal cellulitis.



Photo 6. Parastomal area with appliance in place.

the stoma, causing extreme pain and considerable bleeding (Photo 7). Visible erythema was managed with an extended course of oral antibiotics. The STN focused education on cutting the base to the correct size for his stoma, introducing a Welland Hyperseal® to manage the peristomal skin complication and correct use of support belt for parastomal hernia prevention.



Photo 7. Pseudoverrucous lesion with moist hyperkeratotic tissue.



Photo 8. Ostomy equipment Patient A was using in the community.

Patient B

CASE PRESENTATION (BACKGROUND)

A 52-year-old woman with history of Crohn's disease and a total colectomy with formation of end ileostomy in 1985 when she was 14 years old. She had a complex medical history of pulmonary sarcoidosis, an inflammatory disease in which cells of the immune system cluster together to form tiny noncancerous masses, usually in the lungs and nearby lymph nodes.¹¹ She was immunosuppressed from methotrexate treatment for her sarcoidosis, lung function tests demonstrated a severe obstructive ventilatory defect, mild obstructive sleep apnea (OSA), prednisolone related Type 2 diabetes, depression, and a BMI of 30, obese. This patient reported no follow up by a gastroenterologist, colorectal surgeon or STN following her total colectomy 38 years prior. The patient displayed poor health literacy.

Patient B presented to the Emergency Department in November 2023 with an 18-month history of a progressive polypoid growth to her ileostomy causing pain, bleeding, peristomal skin complications and increased appliance leakages, leading to her to apply Super Glue® to her appliance base as the best management option to counteract leakage. At the time patient B was using a Coloplast Mio® convex drainable appliance, with no additional seals or belt.

On examination a polypoid lesion was to the right side of the stoma mucosa at 9 o'clock and almost twice the size, dwarfing her stoma. Her peristomal skin was significantly eroded from the frequent appliance leakages, and damaged from the use of Super Glue®.



Photo 9. Polypoid lesion at 9 o'clock and eroded peristomal skin.

Pathology of punch biopsies taken in the Emergency Department returned as invasive low-grade mucin producing adenocarcinoma. Patient B underwent further preoperative staging with CT, PET and ileoscopy.

MANAGEMENT AND OUTCOMES

The patient had an urgent elective local resection and revision of the ileostomy. Pathology of the lesion confirmed prior biopsies of low-grade mucinous adenocarcinoma infiltrated into perintestinal fat. Postoperatively, her stoma was red and protruding with lateral sutured wounds for excess skin extending outwards at 3 and 9 o'clock, which exudated low to moderate amounts of serous fluid (photo 10).



Photo 10. Post operative topography of parastomal area with lateral sutured wounds.

A large Welland® seal was applied to the peristomal skin and lateral wounds to assist in absorbing the wound exudate, with a Dansac Novalife® soft convex drainable bag. Her recovery was complicated with a post operative ileus, but she was eventually discharged seven days after her surgery using a Salts® modulable seal, Dansac Novalife® soft convex drainable bag and Coloplast Brava® elastic tape, and re-educated on using a support belt for parastomal hernia prevention.



Photo 11. Ostomy equipment Patient B was using in the community.

Post discharge in the community, Patient B was self-caring for her stoma and changing her bag every 4–5 days with no leakages. Unfortunately, since being discharged, her stoma care has been further complicated by pyoderma gangrenosum to the peristomal skin and episodes of bowel obstructions from a parastomal hernia requiring inpatient admissions.

Both Patient A and Patient B now receive regular reviews in the stomal therapy outpatient clinic and have an STN service that they can contact at any time as needed.

DISCUSSION

Both case studies presented with a known background diagnosis of either FAP or Crohn's disease, both of which are known and identified in the literature as a precursor to developing primary adenocarcinoma at an ileostomy site. As a known late complication, with an average time of development 27 years from stoma creation⁵⁻⁷, these patients had their primary adenocarcinomas diagnosed at 10 and 38 years, respectively, after their stoma creation. Exhibiting symptoms which include a growing mass at stoma site, painful or uncomfortable lesions/polyps, bleeding, skin irritations and difficulty with appliance adhesion.^{2,3,4,12} Other characteristics can include papules, wound on the peristomal area, bowel obstruction and stenosis of the stoma.^{3,4}

The etiology of primary adenocarcinoma at an ileostomy site is not definitive or clear¹ and there are several possible hypotheses for its cause.

Chronic mechanical and chemical irritation to the mucocutaneous junction

Repetitive peristomal trauma from incorrectly fitted stoma appliances and exposure to chemicals used in the adhesives of these may lead to metaplasia and dysplasia of the ileal mucosa.^{1,3,5,10,12} This irritation usually occurs at the mucocutaneous junction and then invades into the surrounding skin and tissue.⁵ Metaplasia occurs when the normal cells are turned into other less recognisable cells in response to a chronic external stress or injury, and is reversible or benign.¹³ While dysplasia is an abnormal development of tissues or organs altering cell growth.¹³ This metaplasia and dysplasia can eventually lead to malignant changes such as adenocarcinoma.³ Both patients in this case series had been using ill-fitting stoma bags for many years prior to their initial review with the STN.

The hydrocolloid adhesives in stoma appliances commonly contain pectin, carboxymethyl cellulose (CMC) and polyisobutylene (PIB), with some ostomy manufacturers including tackifiers (to increase tack and stickiness), pH buffers and skin friendly additives such as aloe vera, manuka honey and ceramide. Table 1 describes the base ingredients found in most hydrocolloid stoma adhesives.

The literature evidences stoma appliances and accessories can cause or trigger peristomal irritant and allergic dermatitis.¹⁵ Stoma appliances including adhesive removers, barrier wipes and flanges can contain ingredients such as ethanol,

ethyl alcohol, butyl alcohol, hexamethyldisiloxane, acrylate terpolymer and stearic acid.¹⁵ Avallone et al¹⁶ even describe an uncommon cause of PIB urolithiasis believed to be from the use of the patient's ostomy appliance. The long-term exposure to the materials in stoma appliances and accessories on ileal mucosa may not be clear, potentially becoming carcinogenic.¹⁹ There is a paucity of information concerning this that requires further research.

Disease predisposition and malignant transformation of adenomas

Permanent ileostomies are often created during surgeries to treat UC, FAP and Crohn's disease. FAP patients carry the adenomatous polyposis gene and are susceptible to bowel adenomas on their ileostomy leading to carcinoma formation through genetic mutations of K-Ras, β -catenin and p53.¹⁻³ UC and Crohn's Disease are also both known to have an associated

increased risk of bowel cancer¹⁷ and the possible presence of benign adenomas risk adenocarcinoma development.

Changes in bacterial flora

Changes in bacterial flora have been linked with cancer occurrence.^{1,3} Changes in the flora of the faecal output at the ileostomy and surrounding peristomal skin can start to resemble that of colonic flora, which thrive in a different pH, oxygen level and nutrient environment, promoting colonic metaplasia and influencing cancer development.^{12,18} Additionally, it has been suggested that the constant exposure and irritation of the faecal output on the mucocutaneous junction (MCJ) and peristomal skin can cause metaplasia like that in Barrett's oesophagus.^{4,19}

Ileitis or backwash ileitis

Ileitis is the inflammation of the ileum, seen in patients with

Table 1. Base ingredients in hydrocolloid adhesives. Dansac Glossary; <https://www.dansac.com.au/en-au/glossary>

Pectin	A polysaccharide extracted from lemons, apples, oranges, or grapes. Pectin absorbs moisture and forms a gel and is used in food, cosmetics, drugs, and stoma skin barriers and pastes.
CMC	Carboxymethylcellulose, a polysaccharide extracted from plant fibres that absorbs moisture and forms a gel. It is a constituent of the stoma skin barrier and can also be found in food and drugs.
PIB	Polyisobutylene, a hydrophobic polymer that is a clear/yellowish soft rubber-like substance. It is very sticky and has high viscosity. It does not absorb water and will not dissolve in it. PIB binds/gives inner strength to the skin barrier and helps the skin barrier to adhere on dry skin. It is also used in chewing gum.

Table 2. Reported cases of adenocarcinoma at ileostomy site in the literature

Author	Year	Reported number of cases	Source
Morada, et al ²	2022	70 adenocarcinomas <ul style="list-style-type: none"> • 18 FAP • 50 IBD • 2 Other 	Literature review to November 2020
James, et al ³	2018	57 diagnosed with ileostomy adenocarcinomas <ul style="list-style-type: none"> • 42 UC (1st case 1969) • 15 FAP (1st case 1982) 	Literature review 1975–2016
Quah HM, et al ¹²	2005	44 case reports 40 adenocarcinomas <ul style="list-style-type: none"> • 31 UC • 2 Crohn's • 11 FAP 	Literature review Medline January 1966–September 2004 Embase January 1974–2004
Iizuka T, et al ²¹	2002	36 cases reported <ul style="list-style-type: none"> • 25 UC • 9 FAP • 2 Crohn's 	Previous reported cases and one new clinical case
Toshiki M ²²	1999	30 cases reported <ul style="list-style-type: none"> • 9 FAP • 20 UC • 2 Crohn's 	Previous reported cases and one new clinical case
Suarez V, et al ²³	1988	8 cases reported	

Crohn's disease,¹³ while backwash ileitis is the inflammation of the terminal ileum usually only in patients with UC.²⁰ UC disease usually only involves the colon and rectum, not the ileum, but it has been suggested that inflammation can cause a malfunction at the ileocaecal valve allowing reflux of colonic material into the ileum, leading to terminal ileitis.²⁰ There is a reported association between ileitis or backwash ileitis and mucosal dysplasia leading to the formation of cancer.^{1,2,3,5} According to Quah et al, "Adenocarcinomas are known to develop in the terminal ileum of patients with ulcerative colitis who have chronic 'backwash' ileitis."¹²

The core principle that underlies all these hypotheses is there is a source of irritation causing inflammation, leading to metaplasia and dysplasia, and finally resulting in cancer formation.

Since 1969, when the first case of primary adenocarcinoma at an ileostomy site was reported, there have been 70 reported cases in the literature worldwide, most of these in the last 20 years. Table 2 outlines the increase of reported adenocarcinomas at an ileostomy site in the literature.

The increase in reported cases over recent years would suggest a rise in the incidence of adenocarcinoma at the ileostomy site.³ This rise in incidence could be related to the long length of time it takes for the adenocarcinoma to occur from time of stoma creation.^{3,6} The average time between stoma creation surgery and developing an adenocarcinoma lesion has been documented as 27 years.⁵⁻⁷ Professor Brooke in 1952, first introduced the technique of everting the ileostomy which transformed treatment for UC in particular and was known as the Brooke (end) ileostomy.^{3,6,12} It could therefore be logical to suggest that with an aging population of patients who had the Brooke (end) ileostomy many years ago, they are reaching the time period where ileostomy adenocarcinoma would be occurring.³ Today restorative proctocolectomy surgery is instead considered standard procedure avoiding a permanent ileostomy for the patient.^{3,10} This may change the incidence of ileostomy adenocarcinoma going forward. As this is such an uncommon complication, it is possible that it has been under diagnosed and/or under reported with medical practitioners now being better at identifying and reporting these cases in academic journals.

The STN can play an important role in the identification and management of a primary adenocarcinoma at a stoma site. The STN is often the first medical professional ostomates present to with any changes to their stoma or ill-fitting and leaking appliances.²⁴ It is recommended that longstanding ostomates with an ileostomy for more than 9–15 years, are reviewed annually by the STN to check for any malignant changes and allow early detection.^{1,3,4,7,12} Best practice and evidenced-based models already support that people living with a stoma should be reviewed by a qualified STN at least every 1–2 years and ongoing for the life of the stoma to ensure that they are using the most appropriate appliances and practices.²⁵ This has long been considered the gold standard of practice by STNs. STNs

need to be aware of this late complication and observant to any abnormal growths, lesions or non-healing wounds that do not respond to usual treatments.^{1,19} These should be referred for biopsy and treatment options may include excision of the affected area and refashioning or relocation of stoma.²⁶ While managing the lesion within the patient's stoma care, the STN can initiate the use of highly absorbent seals and barriers for the mucin created by the nodules, revise any templates or precut appliances to accommodate the size of the nodules and educate the patient on how to protect any peristomal skin that has become exposed.⁹

The role of the STN is often complex, involving early detection and preventative actions to stop adverse events and an ability to identify and respond to patient changes or deterioration.⁹ As a clinical specialist, the STN is an expert practitioner in this clinical field, delivering necessary knowledge, research-based practice, excellence in clinical practice and patient-centered care to ostomy patients.⁴ The STN should be mindful with their provision of information and education to improve overall health literacy for the patient and significant others. Health literacy refers to "the skills, knowledge, motivation and capacity of a person to gain access to, understand, appraise and apply information to make effective decisions about health and health care, and take appropriate action".²⁷

The health literacy of both the patients in this case series, impeded them from contacting a STN for assistance with stoma issues. Both patients lacked the knowledge and motivation to seek assistance earlier. One patient delaying their surgery by two years a result of keeping a Category 1 surgical booking form at home for this period without contacting the hospital, and another applying Super Glue® to the stoma site to prevent leakages. These decisions may have delayed access to appropriate and timely healthcare, and the assessment, identification, diagnosis, and treatment of their adenocarcinoma. Low health literacy can be a common yet under reported issue within stomal therapy. Approximately 60% of Australian adults have a low level of health literacy required for daily life.²⁷ The STN role was key in optimising care once the patients presented at the hospital, providing simple and clear visual and written stoma education to these patients. They were further supported in their health care management by close outpatient stoma care with regular appointments, surveillance, and individualised easy-to-understand education on how and when to seek STN assistance.

CONCLUSION

The substantially late onset of a primary adenocarcinoma at an ileostomy highlights the incredibly significant role the stomal therapy nurse plays in the lifelong care of an ostomate. Primary adenocarcinoma at a permanent ileostomy is a rare complication, however the number of reported cases in the last 20 years have almost doubled. This reported case series describes two patients who presented to the same hospital with this complication less than two years apart. Both had not been reviewed by an STN for a substantial amount of time and were not aware that the changes to their stoma were abnormal.

The exact cause of primary adenocarcinoma is not conclusive but it has been suggested that factors such as chronic mechanical and chemical irritation, disease predisposition, malignant transformation of adenomas, changes in bacterial flora and Ileitis/backwash ileitis, could contribute to their development. Medical practitioners and STNs should be vigilant when caring for persons with a longstanding permanent ileostomy. Careful examination of the stoma should be performed at each review. An annual review with an STN to detect any growths or abnormalities early is recommended, for as long as the ostomate lives with their stoma.

LIMITATIONS

As this clinical case study is a retrospective chart review, education specific to stoma care was difficult to ascertain. However, evidence of management of stoma appliances and support belt is noted in the text.

ACKNOWLEDGMENTS

Thanks to Dr Julie Tucker, Clinical Research Nurse Consultant, Division Surgical Specialties and Anaesthetics, Northern Adelaide Local Health Network for proofreading and editing this article.

CONFLICTS OF INTEREST

The author declares no conflict of interest.

ETHICS

Central Adelaide Local Health Network Human Research Ethics Committee Ref 19710.

FUNDING

The author received no funding for this article.

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