Stories from the bedside
Case study of a young adult with colorectal cancer and formation of a stoma

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ABSTRACT
This is a case study of a young female adult who was promptly diagnosed with adenocarcinoma of the rectum, which resulted in surgery and the formation of a stoma. The postoperative recovery was complicated by an intermittently prolapsing stoma along with a disruption in bladder function that required self-catheterisation. Furthermore, the resected tumour was considered to be at the stage that required adjuvant treatment. The impact of undergoing these dramatic changes can have both physical and psychological consequences, unique to a young adult. Body image, sexuality and relationships can all be influenced. Consideration of the specific needs for this age group is vital for those providing care.

INTRODUCTION
Colorectal cancer is often considered an older adult’s disease, with a peak incidence in the sixth decade of life1. However, colorectal cancer can also occur in young adults. It is of concern that young people are often reluctant to discuss disturbances regarding their bowel habits, let alone consider they may have bowel cancer. This case study highlights a young adult’s perspective on issues arising from a diagnosis of colorectal cancer. This young woman’s long journey includes an unexpected diagnosis, immediate surgery, recovery from surgery, managing a stoma and undergoing adjuvant treatment. Surgery will leave visible physical changes but there are also significant unseen changes to body image, sexuality and relationships.

COLORECTAL CANCER AND YOUNG ADULTS
Statistics
Whilst a large proportion of colorectal cancers occur during the sixth decade of life with 60% of cases aged 65 or older at diagnosis2, it also occurs in the younger adult population. Colorectal cancer rates (CRC) in older adults are thought to be decreasing due to better screening and earlier detection but at the same time the incidence in young adults in the United States has been rising over the past 25 years3. Between 1992 and 2005, CRC increased by 1.5% for young adult men and 1.6% for young adult women4. It is uncertain whether the increase in younger adults diagnosed with colorectal cancer is a result of more aggressive investigation of symptoms than previously performed on younger adults5 or whether poor diet and sedentary lifestyle are contributing factors6. In Australia, diagnosis of colorectal cancer under the age of 40, accounts for 2% of the total incidence of colorectal cancer in New South Wales7. Currently Australia has no significant increase in rates in younger adults; however, it is still important to address their concerns.

How colorectal cancer is different in young adults
The fate of young adults diagnosed with colorectal cancer is unclear. Younger patients are found to have higher rates of mucinous secreting tumours8, with these types of tumours generally resulting in a poorer prognosis. Younger adults tend to present with a more advanced stage of the disease and require a more aggressive treatment approach. A reason for presentation at a later stage of the disease is the delay that is thought to exist between the onset of symptoms and diagnosis9. Young adults presenting with symptoms are not always immediately suspected to have a diagnosis of colorectal cancer. Fortunately, they do have similar or slightly higher survival rates than older adults10.

Impact of diagnosis on young adults
Young adults who require surgery for colorectal cancer undergo numerous life-altering physical and psychological changes. A cancer diagnosis along with the formation of a stoma will cause significant changes to a young adult’s lifestyle and habits. Society today idolises the ideal body as being young and beautiful with vitality and good health. Young adults who feel that their illness means that they now fall short of the ideal body, may struggle with this adjustment. The formation of a stoma for a young adult who previously would never have considered discussing their bowel habits, can cause insecurity and embarrassment. A case study will be used to discuss both the physical and psychological changes that can occur for a young adult with colorectal cancer and formation of a stoma. In the interest of confidentiality, the patient is referred to by the pseudonym Lisa.
CASE STUDY

Initial symptoms and patient presentation
Lisa, a 24-year-old female who lives with her parents, had recently embarked on her first position post-graduation from university. She had just entered a new relationship with her partner. Lisa presented with a two-week history of blood in her stools. At first she was reluctant to see her family doctor but decided to arrange an appointment due to the persistence of her mother. Lisa was generally in good health. There was no family history of colorectal cancer. Fortunately the general practitioner referred Lisa to a gastroenterologist which is not always common practice for someone her age. A colonoscopy was performed and at this stage Lisa was diagnosed with adenocarcinoma of the rectum. Lisa was immediately referred to a colorectal surgeon for discussion regarding treatment options.

From colonoscopy, the lower edge of the tumour was found to be four centimetres above the anorectal junction. The tumour was tethered posteriorly with the central part appearing to be mobile. Surgery was discussed and the proposed procedure was a low anterior resection of the rectum with formation of a temporary loop ileostomy. Lisa was adamant at this stage she did not wish to have a permanent stoma; however, she did consider the idea of having a temporary stoma. Preoperative radiotherapy was also discussed with Lisa at this time. There are conflicting studies about the benefits of preoperative radiotherapy. Whilst research indicates that radiotherapy decreases the risk of local recurrence, the improvement in survival rates is not as well defined. Radiotherapy can affect fertility and also decrease vaginal sexual function. Lisa had to contemplate her position on wanting children much earlier than she would have expected. It was thought that not giving radiotherapy in this instance was a reasonable option.

Surgical intervention
Lisa had a few days at home with her parents considering her options. Whilst it was a difficult decision, Lisa decided against having radiotherapy and was keen to undertake surgical treatment immediately. Lisa underwent the proposed surgery of a low anterior resection of the rectum with a temporary ileostomy on 11 September. During the surgery a glassy area of oedematous presacral tissue was noted. It was observed to be thicker than usual and felt slightly nodular. A central portion of this area was resected and sent for frozen section which showed it to be degenerate cells as seen in myxoid tissue. The pathologist was concerned about the possibility of cancer and the decision was made by the surgeon to resect this glassy mass. This would later prove to be significant.

Initial postoperative course
Postoperatively recovery went straightforward until 11 days after surgery, when Lisa required a further operation for a small bowel obstruction due to adhesions. Lisa recovered quickly from this second surgery and had her indwelling urinary catheter removed around this time. How she failed two trials at voiding her bladder with a catheter. It was thought that the nerves involved in the bladder fullness may have been disturbed during the removal of the previously mentioned glassy material. She was also learning to care for a stoma. Lisa was also referred to a self-catheterise four times a day. Lisa was informed of the possibility of postoperative care may take 12 months to return and arrangements were made for her to undergo urodynamic studies at a later date.

Histopathology showed that the tumour extended be to the outer edge of the muscularis propria and one out of a total of 16 nodes was involved. Using the Tumour, Metastases staging system (which is a way of describing the tumour), the tumour was classified as T3 N1 M0 (which is a way of describing the tumour), the tumour has grown into the bowel lining. Since Lisa's tumour had grown to the muscularis propria, her tumour was staged as a T3. The N represents lymph node involvement, and since Lisa had one positive node, it is a stage N1. M represents any metastasis, or spread of tumour to other regions of the body. In Lisa's case, there was no spread of the tumour to any distant parts of the body beyond the colon or rectum, it was staged as M0 for metastasis. The report on the presacral tissue removed during surgery revealed that it was fat necrosis. Lisa was discharged on 7 October and subsequently underwent an external course of chemotherapy. Regular follow-up visits with her stomal therapist were required due to an intermittent prolapsing stoma. Lisa was readmitted to hospital in April for reversal of ileostomy and at this stage she was continuing with self-catheterisation.

EFFECTS OF COLORECTAL CANCER IN YOUNG ADULTS
It is thought younger adults will suffer greater psychosocial distress following a cancer diagnosis. They will use and rely on different coping mechanisms and resources to deal with cancer diagnosis than the older adult. Young adults often do not have the life experience of the older adult to draw upon. Areas of concern for young adults with colorectal cancer are numerous. This can include health and wellbeing before and after surgery, body image, relationships with partner, friends, undergoing adjuvant treatment with its effects on fertility, and a change in work commitments that can affect financial issues. During her journey, Lisa had adjuster consider in all these areas.

Social, cultural, spiritual and religious beliefs that developed from childhood affect how a young adult responds to dramatic changes to their health. A cancer diagnosis during the early twenties can cause great anxiety during confrontation with mortality, a concept Lisa may not have expected to consider until later in life. Cancer can interfere with the normal development milestones of young adults.
such as leaving home, starting a career, finding a partner and starting a family\textsuperscript{12}. Incessant thoughts regarding how much her life will be altered are reasonable fears prior to surgery.

Before surgery

A sudden disruption to health can be difficult for a young adult who has relied on their resilient body to perform daily tasks. Lisa had never previously undergone any surgical procedures. She had to contend with a new environment and the great unknown of surgery. Lisa had many questions during this preoperative period. The most prominent was: “What is going to happen to me?” Lisa was also dealing with a prompt diagnosis of cancer with little time to comprehend the full extent of the surgery she required. She appeared to be overwhelmed by the amount of information given to her and fearful at the thought of what would happen next. A speedy diagnosis of cancer requiring surgery can be difficult to accept, especially as Lisa had been feeling well. Her reaction was less positive compared to someone who has been suffering from illness for an extended period of time\textsuperscript{15}.

Another major issue before surgery was the need for a stoma. Lisa had questions about whether others would be able to smell the bag, whether anyone would be able to see the bag through her clothes, whether she would still be able to work and how she would cope with changing the bag? These are normal concerns\textsuperscript{13}. During this pre-surgery period, Lisa made it clear that she did not want a permanent stoma. When asked what made her fearful of this, she indicated that she felt she would never be able to manage to look after it herself because she would be "repulsed by it" and it made her "feel disgusting". Often the diagnosis and treatment of cancer are given more importance than the impact a formation of stoma and loss of body function can have on an individual\textsuperscript{15}. In Lisa’s case, whilst she was scared about the surgery and what her future may hold, her immediate concern was the need for a stoma and how she would cope postoperatively.

Postoperative recovery and stoma care

Recovering from major surgery places the young adult in a position they are dependent on others, something they may not have experienced since they were a child. Lisa felt that she was no longer the expert about her own body and difficulties can arise when it appears that the medical profession have now taken over that role. This can have a huge disruption on the construction of sense of self when one no longer understands the workings of their body. Lisa was observed to be quiet during this initial postoperative stage and was reluctant to converse with the nursing staff. At this point, Lisa did not wish to acknowledge the stoma and would turn away during appliance changes. It is important that even when patients are not interested in stoma care that regular contact is maintained\textsuperscript{16}. Given time and gentle persistence by the stomal therapist to slowly include Lisa in the appliance changes, Lisa started to take interest. Small steps to achieving self-care were also assisted by her prolonged hospital stay. There were days, however, when Lisa was just “over it” and wanted nothing to do with changing the appliance and this was considered a norma reaction.

The formation of a stoma affects the whole person\textsuperscript{17}. It is important to consider that the creation of a stoma is happening within the world of a young adult and all the influences that make this person a unique individual will impact on their ability to cope. Lisa was not only experiencing alterations in faecal elimination but also urinary elimination, requiring her to self-catheterise. While attending to the physical tasks required for self-care, Lisa was constantly reminded of her cancer diagnosis and was unable to escape from this. These constant reminders can cause great anxiety\textsuperscript{15}. For Lisa, it was not just about applying a bag and performing the physical task of inserting a catheter. They had greater meaning for her in relation to her sexuality, body image and socialisation. Lisa was given the opportunity to voice her fears and concerns. Often this was carried out separately to the physical component of caring for the stoma. Lisa had a few misconceptions about the stoma that were making her worried. Addressing these issues in a quiet environment alleviated some of her concerns.

Psychological considerations

There were dramatic changes that had taken place in Lisa’s life that will have psychological effects. The initial cancer diagnosis, the need for a stoma and the requirement to self-catheterise all had an impact and affected her quality of life. The manner in which Lisa reacted was unpredictable and it was important to consider the stage of lifespan development she was at when addressing her psychological needs\textsuperscript{16}. The full range of psychosocial concerns may not have become evident until Lisa was discharged home and she had to rely on her own resources to manage. Due to her lengthy hospital stay, there was also the concern she could have become attached to the security of the hospital environment\textsuperscript{15}. Psychological adjustment is thought to be more difficult in patients who require temporary stomas\textsuperscript{15}. This is because they delay adapting, telling themselves that “it will soon be gone”.

A crucial area to address for a young adult experiencing colorectal cancer and the need for a stoma is the impact this has on body image and sexuality.

Body image and sexuality

Body image is defined as the thoughts and feelings that make up the attitude we have towards our physical function and appearance\textsuperscript{16}. This importantly also includes how we believe others see us. The media, culture, education and socialisation will have an impact on how our own body image is created\textsuperscript{15}. Lisa underwent changes in the feelings and attitudes towards her own body. Lisa was self-conscious and voice that she was embarrassed about the changes to her body. She struggled with these changes and looked away whenever he wounds or stoma were exposed. Lisa often adjusted her face...
expression to demonstrate her displeasure when discussing the stoma. She was tearful and spent periods in her room with the door and curtains closed. This dramatic change in body image can impact negatively as the body she thought she knew had become foreign to her. Body image provides a basis for individual identity and Lisa felt as though part of her identity had been lost.

Lisa at this stage was overwhelmed by the numerous changes that had occurred to her body. This included the stoma, surgical scars and self-catheterising. Acquiring a stoma will change the way someone perceives themselves. Lisa viewed herself as being different to her friends and this could have led to social isolation. A loss of control over bodily functions can leave an individual feeling vulnerable and with a diminished self-worth. Lisa also had to adjust to the stoma prolapsing. Initially she was frightened as she was not expecting this to occur. She then felt disgraced for having this "thing" unnaturally appearing with no warning. There was also the discomfort caused by the prolapse.

Lisa felt she was now at a greater restriction in her daily life by concurrently managing the prolapse with the need to self-catheterise. Lisa was challenged by considering new methods in wearing clothes to disguise the bag and prolapse. The requirement to self-catheterise along with managing the stoma can be a threat to femininity. When Lisa returned for her reversal of ileostomy she disclosed that she felt bowel cancer was an "unsexy disease". Body image and sexuality are intertwined and sexuality issues for a young adult should be taken into account.

Sexuality is more than just the physical act of sexual expression. Due to the often personal and sensitive nature of sexuality, young adults can find it difficult to raise sexual issues or ask about the impact surgery will have on their sex lives. Lisa had just entered a relationship and did not wish to disclose to her partner she had a stoma. Lisa expressed that she did not want to get physically "too close". Even though discussion of sexual issues is considered an important part of supporting patients there is research to suggest that this is not happening. It was important to allow time for Lisa to discuss any concerns she had regarding sexuality. It is thought that patients often find their own answers during meaningful discussions. Lisa was informed that following stoma surgery sexual dysfunction is a possibility and can include dyspareunia and vaginal dryness.

Lisa's immediate social situation and life experiences impacted on how she coped with a change in body image. Lisa had a very supportive family; however, she did not have friends or a new partner to visit her whilst in hospital and she was reluctant to reveal to her friends that she had a stoma. At first Lisa was unable to discuss her surgery with close friends. Friends and family can provide emotional support and can provide an opportunity to discuss their feelings, which can help cope with the illness. Subsequent visit, Lisa revealed that she had started opening up to her close friends and she appeared to be more receptive in discussing the stoma.

ADJUVANT THERAPY

Similarly to older adults, young adults are often treated with chemotherapy; however, there is little data or effectiveness of treatment for colorectal cancer in the age group. Lisa found the side effects of chemotherapy to be demanding and stated she would never undergo this treatment which she would "let the cancer come back". It is important to underestimate the toll having adjuvant treatment has on a young person who may assume it will be worse for them. Lisa encountered interruptions with attending work while undergoing treatment and felt that her life was being held whilst she was undergoing treatment. Following completion of chemotherapy, Lisa returned to have her ileostomy reversed. Since then, Lisa has married and has been involved in the launch of a bowel cancer campaign, encouraging young adults talking about bowel cancer.

CONCLUSION

Colorectal cancer and its consequences can be life-threatening for a young adult. Surgery may result in dramatic physical changes but the psychological impact can be even more serious during this stage of an individual's life. Gainin insight into the young adult's world whilst experiential treatment for colorectal cancer, including the formation of a support stoma, allows us to better understand how this can impact on their lives. Viewing these changes from their perspective
helps to reveal the thoughts and experiences of a young adult whilst they are in hospital recovering from surgery and the areas of support they will require then and when returning home.

REFERENCES


