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"DOCTOR, I WANT MY STOMA REVERSED." A FAMILY PHYSICIAN'S APPROACH TO MANAGEMENT OF NEW "OSTOMATES".

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PATIENT'S REVELATION

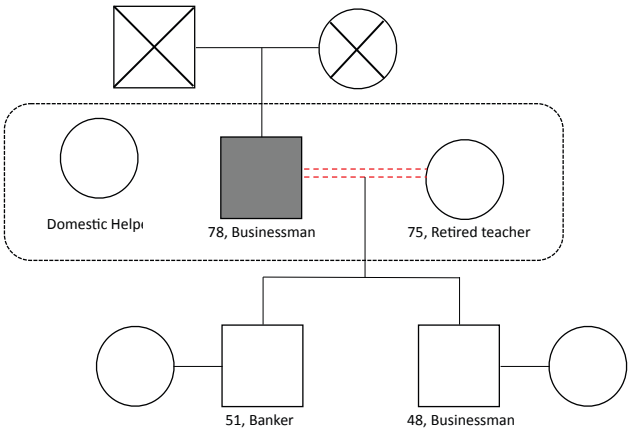
"Doctor, I want my stoma reversed. I'd rather die than have this stoma. If the risks are high, I will gamble."

WHAT HAPPENED?

Patient Demographics and Social History

Mr J is a 78-year-old gentleman who was pre-morbidly independent in all his activities of daily living and ambulant in the community without any aid. He was a retired businessman, married with two children who were living apart from him.

Figure 1: Genogram



Past Medical History

He had a past medical history of ischemic heart disease, hypertension, hyperlipidaemia, and diabetes mellitus (Haemoglobin A1c level: 6.4 percent). He was a non-smoker and a social drinker of alcoholic beverages. He had no family history of cancer.

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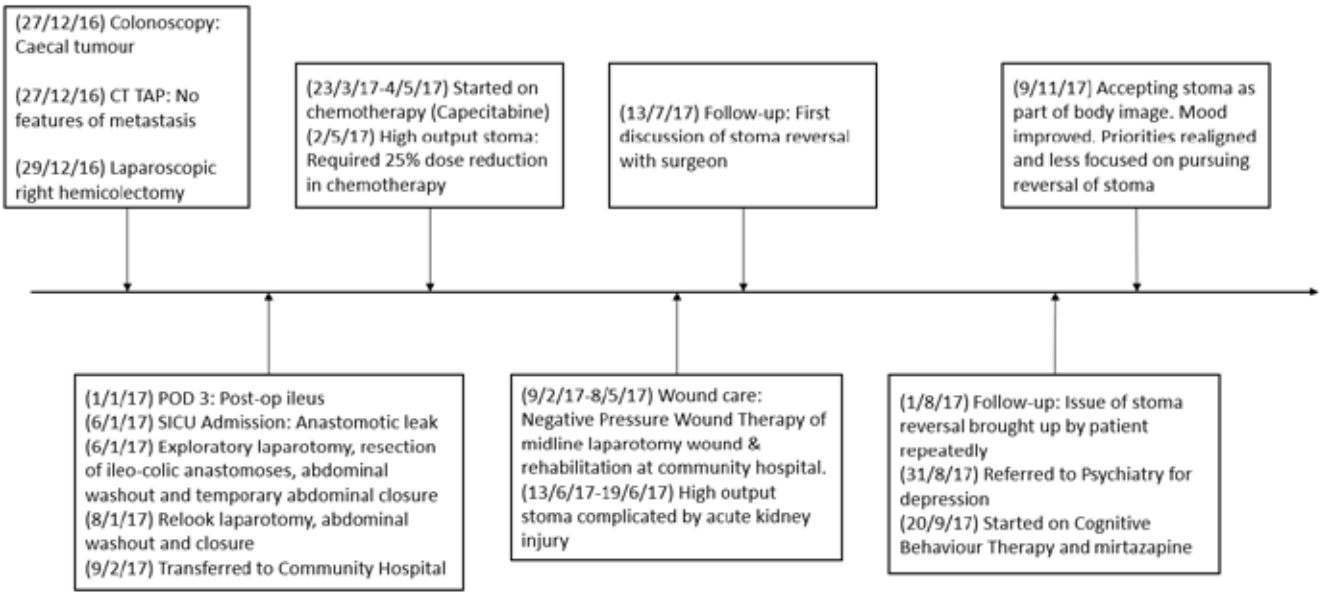
Events Leading Up to Consultation

Mr J had a positive faecal immunochemical test and was subsequently diagnosed with moderately differentiated caecal adenocarcinoma in December 2016 after a colonoscopy. Preoperative Computed Tomography of his thorax, abdomen, and pelvis did not reveal any metastasis. He underwent laparoscopic right hemicolectomy for en-bloc oncological resection, which achieved adequate margins. Although there was adjacent invasion into the adherent omental fat, there was no evidence of nodal involvement. Unfortunately, he had a stormy post-operative recovery due to multiple complications as shown in Figure 2.

He was discharged to a community hospital for inpatient rehabilitation, wound management, and stoma care after a two-month stay at a tertiary hospital. At the community hospital, his care was helmed by his family physician. His rehabilitation was impeded initially due to poor wound healing and low motivation during physiotherapy sessions, which were attributed to adjustment disorder. He had persistent high stoma output upon commencement of chemotherapy, which had to be stopped eventually. His mood, appetite, energy, and sleep quality started to decline, and he was diagnosed with depression. Mr J was provided pastoral support and initiated on mirtazapine. This helped to improve his mood, but he was only able to return home with a trained caregiver after two months of inpatient rehabilitation.

Mr J commenced follow-up with his family physician at the community hospital outpatient clinic. He continued to express that he felt depressed due to activity limitations caused by his stoma such as dietary constraints, poor sleep due to frequent night-time emptying of stoma bag, and various restrictions on his lifestyle such as not being able to partake in previous hobbies like golfing due to the outpatient rehabilitation. This was compounded by marital discord, voluntary social isolation stemming from an innate desire to avoid being a burden to his children, and a lack of emotional support from his family. Mr J persisted in his demands for stoma reversal "at all costs" because he'd "rather die than live with the stoma". Despite all its associated risks, he wanted to take a "gamble" and insisted on surgery but was repudiated multiple times by his colorectal surgeon. To address his concerns, his family physician provided counselling and found that this stemmed from significant maladaptation to the changes in his life brought about by his stoma. Mr J's beliefs about stoma and his self-imposed restrictions were challenged by his family physician and he was encouraged to pick up old hobbies such as golfing again. To facilitate this, his stoma output was managed with loperamide and he was provided with an abdominal binder to use during activities.

Figure 2: Mr J's healthcare journey



Mr J was co-managed with a psychiatrist, who provided further assessment into possible common co-morbid psychiatric conditions such as anxiety disorder, stress, and insomnia. He was not found to have any other co-morbid psychiatric issues and was treated with cognitive behavioural therapy and pharmacotherapy. With treatment, Mr J's mood improved and he was able to cope with managing his stoma independently. As he began accepting his condition and developing a stronger sense of responsibility for his health, he was introduced to stoma support groups to help with reintegrating into his previous roles and returning to his hobbies. Mr J was also introduced to marital counselling and advised to involve his family for support. Eventually, he was able to resume his golfing activities, drive, and go for short trips overseas. He began to agree that the gamble of undergoing surgery was not one worth taking and that he needed to "work on self-stoma care, acceptance, and mindset". Mr J's journey through the healthcare system is summarised in Figure 2. His latest PET scan showed that he was in remission.

GAINING INSIGHT: WHAT ARE THE ISSUES?

1. Why was Mr J repeatedly asking for stoma reversal surgery despite its poor risk-to-benefit ratio?
2. How could we have helped Mr J?

Let us address both questions.

1. Why Was Mr J Repeatedly Asking for Stoma Reversal Surgery Despite Its Poor Risk-To-Benefit Ratio?

Detecting Underlying Psychosocial Issues

In colorectal cancer survivors with ostomies, unresolved psychosocial issues can eventually lead to psychiatric issues such as depression, which has been found to be prevalent in as high as 53 percent of patients.[1,2] This was evident in Mr J as his depression was likely contributed to by medical issues as well as his physical impairments and resultant lifestyle restrictions. This was compounded by a lack of social and emotional support. Notably, Mr J had not participated in any stoma support group activities. From Mr J's point of view, the surgery and stoma may have seemed to be the "cause" of all his problems and he therefore continuously requested for stoma reversal.

2. How Could We Have Helped Mr J?

Management

The journey of a patient with ostomy, also known as ostomate, should involve a multi-disciplinary team, with his family physician taking on the vital role of coordinating and prioritising medical care according to his needs. This would also involve the care of a surgeon, oncologist, and stoma nurse. We go on to discuss the roles of each individual member in this multi-disciplinary team and highlight a suitable approach to care for stoma patients.

Role of the Stoma Nurse

A newly-created ostomy presents drastic lifestyle and body image changes to ostomates as it affects their quality of life (QOL) and self-esteem.[3,4] One of the greatest challenges of stoma care is the ability to perform a successful pouching application, which maintains seal until the next change. Persistent leakages lead to negative associations towards life with an ostomy due to embarrassment from the smell and effluent from a lack of control over continence. These issues affect ostomates both physically and psychologically.

Furthermore, an ostomy appliance is not a "one size fits all" solution as each stoma is different and unique (Figures 3 & 4 highlight some stoma complications affecting the application of pouches). Lack of stoma siting, changes to stoma and peri-stoma conditions, high stoma output, and challenging body profiles are all contributory factors to a poor seal of the ostomy application, causing leakages.[5] Moreover, it is reported that the majority (21-70 percent) of ostomates will experience some form of complication related to the stoma after surgery.[6] There needs to be a certified ostomy care nurse who is able to provide expert assessment, management, selection, advice, and follow-up on stomal and peristomal complications and stoma pouching, as well as help ostomates adjust and adapt to live well with a stoma.[7,8] Stoma nurses can also provide telephone consults and caregiver training for stoma care. Unfortunately, in reality, there is a lack of emphasis on having a certified ostomy care nurse on board due to a lack of role awareness.[9] As such, some of these ostomates may fall through the cracks and receive inadequate care. The family physician thus has to be poised to lead the patient to the appropriate resources.

Figure 3: Peristomal pseudo-verrucous lesions

(Photos reproduced with patient's permission)

Figure 4: Severely retracted stoma with extensive peristomal skin erosion

(Photos reproduced with patient's permission)

Role of the Surgeon

At follow-up post-operatively, surgeons assist with routine screening of surgical complications and cancer recurrence and address surgical queries like ostomy reversal. Surgeons also oversee Enhanced Recovery After Surgery (ERAS) protocols, which are evidence-based, multi-modal peri-operative care pathways designed to achieve early recovery after surgical procedures. They are protocols designed to standardise medical care, improve outcomes, and lower healthcare costs. Based on data from observational studies and randomised trials, they are associated with reduced hospital length of stay, morbidity, and faster recovery.[10,11]

However, despite widespread application of ERAS in tertiary hospitals and its lauded benefits, limited studies on post-operative QOL did not reveal similar trends of improvement as the clinical outcomes.[12] With expedited processes and less inpatient stay, there are also inadvertent disadvantages such as less caregiver training time and less time for ostomates to learn self-care and adjust to their stomas. This was also reflected in local qualitative studies that identified similar gaps in post-operative care, which includes "inadequate availability of channels to seek help", "calls for integrated care to support psychosocial needs", and "the need for smooth transition".[13]

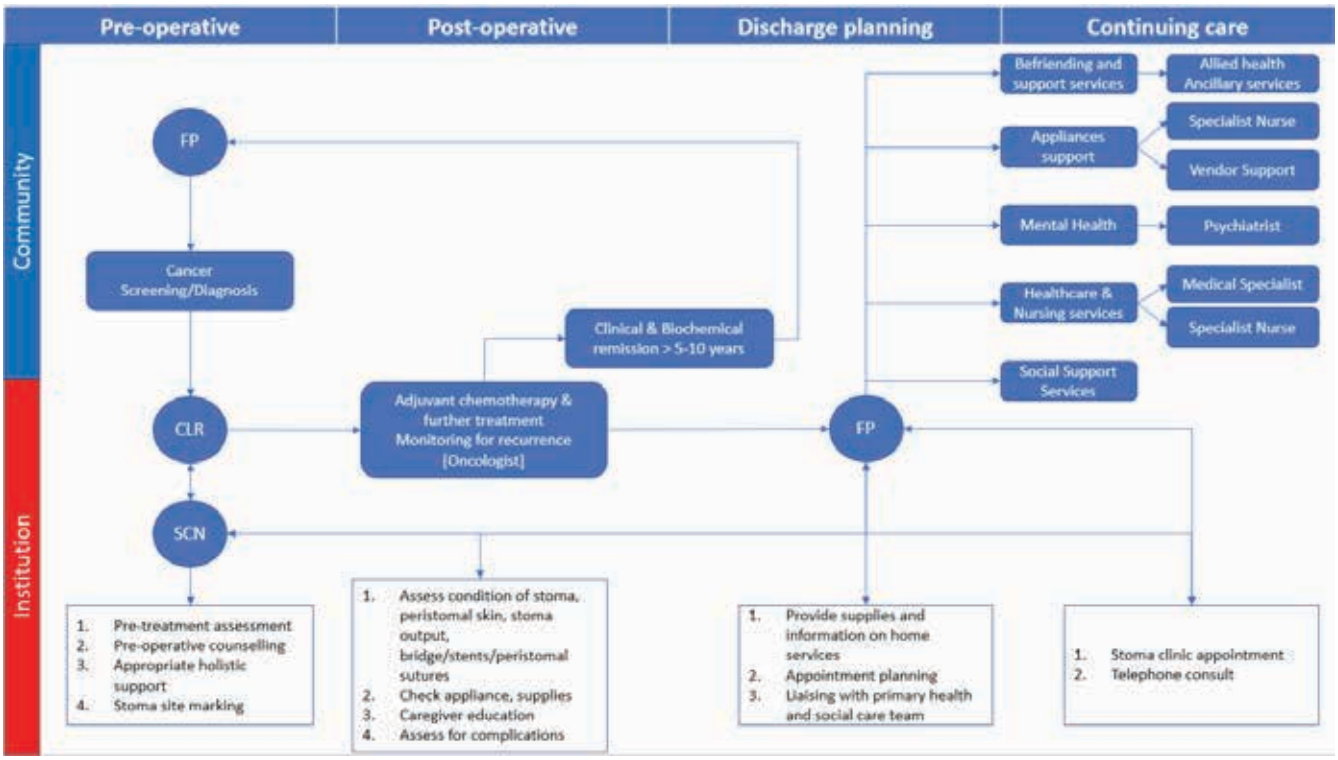
Role of the Oncologist

Oncologists take a leading role in all four phases of cancer survivorship. In the first phase of acute survivorship, including time of diagnosis and treatment, oncologists participate actively in offering discussion and advice to patients regarding initiating chemotherapy and monitoring for associated complications. Following this, there is transitional survivorship when treatment has ended and oncologists engage patients in active surveillance for recurrence of primary and secondary cancers. In subsequent phases of extended and permanent survivorship, where patients' conditions range from being cancer-free to being in remission, oncologists and surgeons may co-operate with family physicians based on a patient-centric approach to propose individualised cancer surveillance and follow-up plans for patients.

Role of the Family Physician

With colorectal cancer being the leading cause of cancer in Singapore, affecting approximately 36 out of every 100,000 people [(14)], family physicians play an important role in cancer screening and in the continuing care of ostomates. This is because with rapid patient turnover, coupled with the wide range of healthcare professionals with whom patients are scheduled for brief "pit-stops" in an attempt for multi-disciplinary care, ostomates can often ironically feel that they suffer from care fragmentation and lack of continuity of care at a time of profound change and immense stress in their lives.[15,16]

Figure 5: Multidisciplinary framework for family physicians managing ostomates



Note: FP = Family physician; CLR = Colorectal surgeon; SCN = Stoma care nurse.

Family physicians are uniquely poised to provide comprehensive care as we have extensive knowledge across medical disciplines as well as access to a wide range of healthcare resources to meet the needs of the individual. Anecdotally, Mr J's case illustrates the impact of common ostomy-related technical problems and negative effects of ostomy on quality of life, and further underlines the importance of follow-up and long-term care.

However, it is our current understanding that there are no locally published guidelines for family physicians managing ostomates post-operatively. Hence, we propose a framework of care (Figure 5) to showcase how the family physician can be involved in the entire healthcare journey of the ostomate. Figure 5 highlights the family physician's role at the time of diagnosis as well as during discharge planning in order to facilitate holistic and individualised patient care.

A basic multi-disciplinary team framework, as shown in Figure 5, involves a family physician, oncologist, surgeon, and a stoma nurse.[17] As illustrated above, family physicians may be closely involved in all phases of cancer survivorship and co-manage patients as an integral part of the multi-disciplinary team. In the acute and transitional phases of survivorship, family physicians may assist in coordination of care between surgical, medical, and radiation oncologists. They may also facilitate discussion regarding benefits and risks of therapy as well as co-management of side effects of treatment. In the later phases of survivorship, family physicians may adopt a shared care model for long-term follow-up, cancer surveillance, and end-of-life issues.

Family physicians can assist ostomates with stoma education, dietary counselling, and pharmacotherapy for stoma output management, while stoma nurses assist with more specific complaints such as gas and odour management as well as device troubleshooting.[7] Building on this framework, family physicians may coordinate and involve allied health and medical specialists as well as community resources to provide better care for the patient.

Family physicians should pay particular attention to monitor for psychosocial issues after surgery, especially since depression typically presents surreptitiously. Many studies have shown that stoma surgery is associated with multiple psychosocial challenges, which have been shown to negatively affect QOL even after accounting for the physical presence of a stoma.[18,19] Family physicians can assist to integrate the patient's family into the care process to provide emotional and physical support at a time of crisis.[20] Mr J was seen to experience the five stages of grief based on the Kübler-Ross model, culminating in acceptance as his family physician journeyed with him. As with this case, psychiatrists provide an important avenue for support in terms of assessment and treatment when multiple psychiatric co-morbidities are present or when complex psychosocial situations abound.

Family physicians are also trained in "social prescription", which involves drawing from a myriad of community resources to support patients. Consideration can be given to ostomates who have mobility or access issues to clinics or communal support groups. In these cases, home care and community services such as Home Nursing Foundation and

Tzu Chi Home Care can fill the gap in care. With the trust that a longitudinal relationship provides, more intimate discussions into topics such as sexual health can also be explored by the family physician. Alternative avenues for care are also available in the community in the form of patient rehabilitation and support programs.

Stoma support groups in Singapore (such as Ostomy Day and Colorectal Support Group Meetings) can be recommended to help patients draw on the experience of peers and reintegrate them into society. These interactions help provide peer support and normalisation of their experience. It is also important for the physician to be aware of the appropriate timing and circumstances to introduce specific interventions.

The path towards accepting their stomas is often fraught with challenges. Based on qualitative studies, ostomates commonly report facing difficulty accepting and dealing with self-care of stoma, their physical limitations, and psychosocial issues that arise. Common psychological reactions that arise include feelings of frustration towards the presence of a stoma, helplessness, and fear of being a burden to their families.[21] Armed with insight into the mentation and concerns of patients, a family physician will be better able to dissect into psychosocial issues. We will be able to provide much needed advice and comfort in times of distress, allaying fears and concerns towards the future, as well as provide readily available support in the community as mentioned.

In summary, a family physician is poised to coordinate the efforts of a multi-disciplinary team and formulate treatment plans according to biopsychosocial needs, harness community resources, and even provide family interventions to support ostomates in their journey to recovery.

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LEARNING POINTS

- **Stoma patients are at risk of post-operative psychological problems. Family physicians play a key role in early detection and intervention.**
- **Longitudinal care of the stoma patient is necessary to understand the psychosocial dynamics for effective management.**
- **Understanding the patient's insight and expectations of his illness allows for collaborative goal-setting and decision-making.**