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The Patient Experience of Traversing the Complex Rectal Cancer Pathway

This pathway is not straight forward in that each person from rural Northland, New Zealand, may have as many as 12 different groups of health professionals involved in their care. In this article I will focus on the treatment journey and the patient experience, and hope to impart some understanding of how confusing it can be for patients setting out on this pathway, 200 km or more away from home. In this article I plan to:

1. Discuss the Standards of Service Provision for Patients with Bowel Cancer in New Zealand
2. Consider the NZ Health and Disability Commission Vision
3. Consider the question, 'Have we met the needs of the consumer?'

In the latter part of this article, I examine the consumer perspective by talking to a patient and share these findings in order to assist with the planning of future services.

So, why is rectal cancer so important?

Associate Professor Diana Sarfati from the Department of Public Health, University of Otago, Wellington, summarised the data at the Rectal Cancer summit held in Wellington in August 2013. Rectal cancer is a major health issue for New Zealand: 3000 colorectal cancers are diagnosed every year and 1/3 are rectal cancers. New Zealand death rates from colorectal cancer rank among the highest in the world: in 2009 there were 300 deaths from rectal cancer [1, 6].

She also identified inequities in outcome for New Zealanders. Maori are more likely to develop cancer and die from cancer than non-Maori across all NZ deprivation deciles: between 1981 and 2004 the incidence of colorectal cancer remained stable for non-Maori but increased significantly for Maori. Maori also have a 33% poorer survival from colorectal cancer than non-Maori, are less likely to receive adjuvant chemotherapy, and experience lower quality of care [2, 5].

In order to address some of these issues, the National Tumour Standards for Bowel Cancer in New Zealand were born. The standards were developed by the National Bowel Tumour Standards working group chaired by Professor Frank Frizelle, a

colorectal surgeon with the Canterbury DHB. The group consisted of a multidisciplinary team of professionals working in the area of colorectal cancer in N.Z. The final draft was published in December 2013 by the Ministry of Health: it can be found on the Ministry website www.health.govt.nz or through the Northern Cancer Network at www.northerncancernetwork.org.nz

The new standards describe the care and services a person with colorectal cancer should have access to, no matter where they live in NZ. Their aim is to improve consistency of care for people with colorectal cancer across all NZ District Health Boards, in particular improving outcomes for those living away from the main centres. The standards are built around the person's journey rather than traditional "silos" of hospital oncology care.

The standards recognise the need for evidence-based practice, and were initially developed by referring to established national and international guidelines, particularly the UK Department of Health Guidelines. The working group had access to expert advisors, including Maori and consumer health experts, and there was wide consultation with key stakeholders and relevant professional organisations.

The standards document has a list of contents as below, but I will enlarge upon only two areas for consideration [3].

1. **Timely access to services**
2. Referral and communication
3. Investigations, diagnosis and staging
4. Multidisciplinary care
5. Supportive care
6. **Care coordination**
7. Treatment
8. Follow up and surveillance
9. Clinical performance monitoring and research.

Timely access to services:

A suspicion of cancer or a cancer diagnosis is very stressful for the patient and family. It is really important that patients are given timeframes and that they know how quickly they are going to receive treatment, are managed through the pathway and that they experience well coordinated service delivery.

1. New patients referred urgently with a high suspicion of cancer are required to have their first specialist assessment or colonoscopy within 14 days.
2. Patients with a confirmed diagnosis of bowel cancer must receive their first cancer treatment within 31 days of the decision to treat.
3. Patients needing radiotherapy or chemotherapy must receive their first treatment within four weeks of the decision to treat.
4. Patients referred urgently with a high suspicion of bowel cancer must receive their first cancer treatment within 62 days [4].

Care coordination:

In order to support patients through this pathway of care, each patient has a nominated single point of contact, in the form of a Clinical Nurse Specialist, to accompany them throughout the care trajectory which for many traverses different departments, two or three hospitals and numerous health professionals. So one of the key messages here is that the standards are developed around the 'person's journey' through the continuum of care.

The New Zealand Health and Disability Commission Vision

In 2013 Anthony Hill, the N.Z. Health and Disability Commissioner, visited Northland, New Zealand, and spoke to us about his vision for health and disability services in N.Z. He also shared with us some of the findings of the Mid-Staffordshire report that was released in the UK in 2012 and the learning points arising from the report. I want to consider his vision as we review the complex rectal cancer pathway.

That vision is a consumer-centred system, a system built on the concepts of seamless service, consumer engagement, transparency and an empowering culture, which promotes and protects the rights of health and disability services consumers, as set out in the Code of Health and Disability Services Consumers' Rights.

A consumer-centred system is about engagement: an engaged consumer is an empowered consumer. The opposite, as was found in the Mid-Staffordshire report, is not listening to patients' stories.



A consumer-centred system is about seamless service: the complexities of modern medicine demand that clinicians no longer work as 'cowboys', working alone in their specialist field, but work within teams. We need to be more like pit-crews at the V8 races where the crew know their roles and work together as a team to get those tyres changed.

A consumer-centred system is about transparency: sharing information and being open to criticism and to new ideas. In Mid-Staffordshire there was a failure to share information and a defensive approach to criticism.

A consumer-centred system is about culture: a culture of taking responsibility for the care you deliver and always taking notice of the patient's concerns and feelings of isolation.

Recurring themes in the Mid-Staffordshire Report are lessons for each of us:

- Get the basics right
- Read the notes
- Ask the questions
- Talk to the patient
- Listen to the patient and the patient's family
- Ensure continuity of care
- Take responsibility for the care you deliver

So, for those with a new diagnosis of rectal cancer, do we provide a service

built around the person's journey and is it a consumer-centred service?

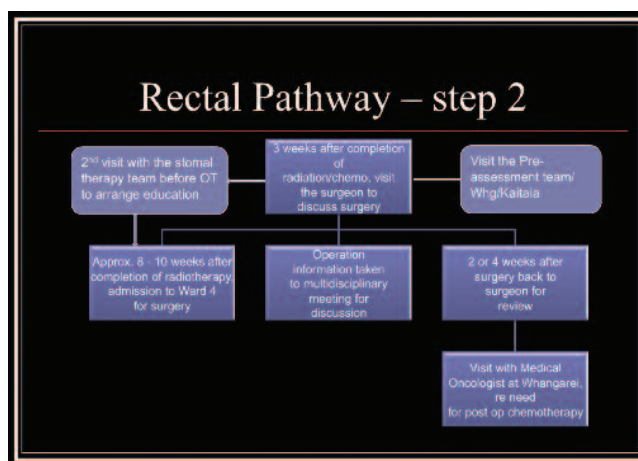
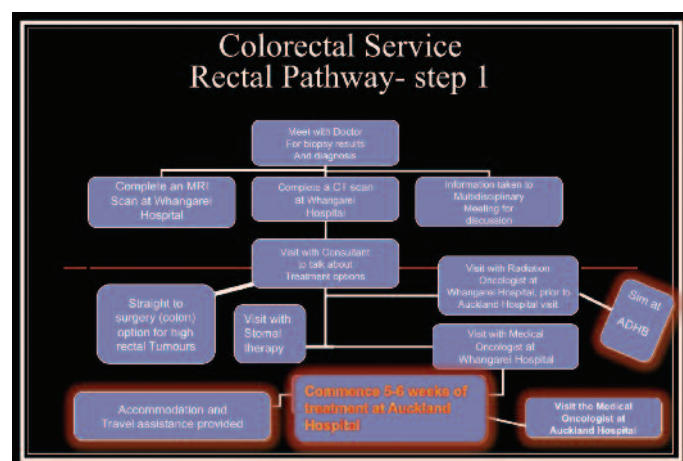
Let's look at the rectal cancer pathway, and the multiple people and places encountered over the course of investigation, diagnosis and treatment.

- Referral to secondary services
- Surgical clinic team
- Endoscopy team
- Colorectal team including the stoma therapy team
- Radiology team
- Northland DHB Radiation and Medical Oncology team
- Transport and accommodation team
- Auckland DHB Radiation and Medical Oncology team
- Pre-assessment team
- Surgical ward team

The diagrams overleaf demonstrate the pathways of care that each rectal cancer patient receiving neo-adjuvant radiotherapy and chemotherapy is required to progress through to ensure the best possible outcome.

Rectal Cancer Pathway – Part 1 and Part 2

Have we met the needs of the consumer? Have we directed our care at the person's journey and provided seamless care as recommended in the Standards of Service Provision and by the Health and Disability Commission? I asked Sarah, a patient with rectal cancer, about her experiences.



How do you feel you coped with this complex pathway of care?

I feel I coped well considering the side effects of treatment and the fact I was three hours from home for a period of nearly six weeks. I would like to say it was the people around me who helped me to cope – the staff in both hospitals who explained everything so clearly for me, and my family and friends who were with me all the way.

Can you take your mind back to the time when you were given the diagnosis and comment on the attitudes and support of the health professionals around you at that time?

I felt supported and respected by all the health professionals, the nurses, the doctors. I did have one area of concern though, and that was when I was at the end of my treatment and a nurse spent time with me explaining about the use of vaginal dilators and the need to continue this at home. I was totally unprepared for this as none of the written information or the verbal discussions I had had with staff had mentioned this at all. I do think a paragraph about this needs to be added to the information booklet.

Did you feel your concerns were listened to?

Generally, yes, especially when I had concerns around transport and accommodation at the treatment centre. However, I experienced terrible diarrhoea and dehydration from the treatment and needed to be admitted to the oncology ward. I tried many times to describe how ill I felt, but there seemed to be a real delay in getting a bed in hospital.

What support services were you given access to?

I was referred to the cancer liaison nurse from the Cancer Society and she visited me at home and helped me come to terms with the cancer, and she also helped me to explain the treatment to my family who live overseas.

Thinking now about your 6 weeks of combined chemotherapy and radiotherapy treatment in Auckland – how did you feel about the coordination of that part of the journey?

It was very well coordinated, with appointments and accommodation and travel.

So, would you use the word seamless?

Yes, I was informed each step of the way, and given written information to help me. When I was in the ward, I found it difficult to cope as my family really thought I was dying, and that was upsetting. At the same time my brother was admitted to the ward on the floor below, so I had extra concerns.

Talking to patients like Sarah has helped us to recognise the impact of this complex rectal cancer pathway on the person and family undertaking the journey through treatment and beyond. She shared with us her experience of a well coordinated pathway of care and her feelings of great support from the team around her. I'd like to take this opportunity to thank the team who deliver this consumer centred care to those people with colorectal cancer from Northland NZ.

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