

Living with bowel problems following radiotherapy

**A scoping study
commissioned by NACC -
The National Association for
Colitis and Crohn's Disease**

Judy Wilson

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LIVING WITH BOWEL PROBLEMS FOLLOWING RADIOTHERAPY

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EXECUTIVE SUMMARY

This short scoping study carried out in 2005/6 included a literature and website search, conversations and a small qualitative research study interviewing nine people affected. A consultative day brought a number of different organisations together.

Increasingly people survive cancer. Radiotherapy is a common lifesaving treatment for a number of pelvic cancers. Most people experience bowel problems during treatment but these usually stop when the 6 week period is complete. 6,000 individuals a year, however, continue to have problems, or experience them months or even years later. Effects can be permanent so the total number in the UK will be much higher. Efforts are being made to improve radiotherapy techniques but this degree of occurrence is likely to remain. Gynaecological, bladder and rectal cancer patients are most likely to be affected. The figure of 6,000 people a year is not generally known or accepted.

Gaining consent and describing risk, while complex and taking place when patients find it difficult to absorb and process information, appears not to be always done well.

Access to skilled assessment and diagnosis is enormously important for a number of reasons. But most patients do not get referred to a specialist gastroenterologist, of whom there are very few. Perhaps 20% get referred to any gastroenterologist, who may lack confidence and experience in managing such patients. Many constraints affect referrals, in both the professional cancer and gastroenterology worlds and from patients not raising the problem. Some patients can be cured and some treated using a variety of approaches but there is no recommended standard treatment. No agreement on terminology appears to exist. Information on treatment is not routinely provided.

People affected may experience diarrhoea or constipation, urgency, faecal leakage, pain and rectal bleeding: symptoms very like inflammatory bowel disease, (though inflammation is not prominent after radiotherapy has stopped). The patient study showed severe effects on people's quality of life; delays in access to specialist help, or none; and extreme isolation. People felt their needs were not always of interest to cancer specialists or sometimes their family. Family and friends found it embarrassing.

No specific patient organisation exists, except a small Yahoo internet support group. No charities or NHS services have developed detailed information and support for people affected. Some cancer charity information appears to play down the risk of ongoing effects. But incontinence and gastrointestinal charities and a specialist hospital have produced useful general information on managing bowel problems.

This limited study paints a picture of a neglected area of healthcare, falling between two specialisms, neither of which has taken real responsibility for improvement. Not always seen as a legitimate problem, there is no strong patients' voice. But the study also revealed a small number of clinicians, charities and patients working to improve the situation and identifies potential and opportunities for improvement.

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1.0 INTRODUCTION

This scoping study looked at bowel problems following radiotherapy, not at the situation for people during treatment. Most patients experience bowel problems during pelvic radiotherapy, a common radical treatment largely used to cure a number of different cancers, but these usually stop when the normal six weeks' treatment is complete. Bowel problems after radiotherapy may continue after treatment ends but sometimes start months or even years later and can be permanent.

The origins of this report stem from NACC's information work. NACC, the National Association for Colitis and Crohn's Disease, both inflammatory bowel diseases (IBD), found it was being asked for help by a number of people experiencing severe bowel problems, but not affected by IBD. Their symptoms, often severe, were very similar to those encountered by people with IBD and were understood then by NACC to be 'radiation colitis'. NACC was also approached by Dr Jervoise Andreyev, a gastroenterologist with a particular interest in this area, who had become very concerned about this group of patients. He felt they were currently being largely ignored.

A six month project was undertaken aiming to:

- increase knowledge about the needs and numbers of people affected and whether numbers are likely to increase.
- understand more about diagnosis and treatment.
- explore what other organisations know and may be doing already.
- set out options for action by NACC, or in partnership with other organisations.

Originally it was also intended to include other forms of colitis, but it soon became clear that the experience of cancer and its radical treatment made symptoms following radiotherapy a special case. The study was accordingly restricted only to people affected in this way. The original term proposed, 'radiation colitis', was found to be not in common use and the term 'bowel problems after radiotherapy' has normally been adopted. There is no one generally accepted term and a Glossary lists terms used.

A range of methods were used over a five month period in 2005-6. Briefly, they comprised:

- a literature review, giving details of references ⁱ
- conversations with a range of health professionals and charities ⁱⁱ
- a small qualitative set of interviews with people affected ⁱⁱⁱ
- a consultative day in January 2006 attended by twenty people.

Judy Wilson, an independent consultant and researcher led the project, helped by Katie Clarke and John Gray. Dr Andreyev acted as adviser and very many other people and organisations, listed in the Acknowledgements section, also contributed their experience, views and knowledge.

This report is written for the Trustees of NACC. But it is also for those who contributed, those affected and others who wish to know more about the situation for thousands of people, often unidentified and poorly served.

2.0 THE CONTEXT

2.1. Cancer

The background to this issue can be found in both the cancer and the gastrointestinal fields. Cancer is common in the UK. Briefly:

- More than 1 in 3 people will be diagnosed at some point in their lives
- 270,000 new cases are diagnosed a year
- Increasingly people survive cancer - cancer death rates in the UK have fallen by 11% over the last ten years.

Professional care

Enormous resources have been put into NHS cancer services. An emphasis in recent years has been to speed-up and optimise the diagnostic pathway. This has been done by developing the role of the multidisciplinary team (MDT), which is now required to meet and discuss formally the treatment plan for every new patient with cancer. MDTs, made up of a range of professionals, usually including a clinical oncologist or a medical oncologist, surgeons, specialist nurses, dieticians - and sometimes gastroenterologists - meet together in hospitals. Other emphases of cancer services have been on improving treatments which save lives and on palliative care. Significantly for the focus of this study, there has been much less emphasis on quality of life after cancer is cured.

There has been increasing but variable provision of support and information and the Coalition for Cancer Information was formed in 2002 to improve this. Clinical nurse specialists are often available to provide support for cancer patients with specific diagnoses and to help them through their treatment. Patients normally return for annual check-ups for 5 years.

Radiotherapy

Radiotherapy is planned and prescribed by consultant clinical oncologists, formerly usually called radiotherapists. It treats cancer by using high-energy x-rays which destroy cancer cells, while doing as little harm as possible to normal cells. It can cure some cancers, help reduce the risk of cancer coming back after surgery, or may also be given to help relieve symptoms.

Cancer charities

A number of cancer charities with some interest in this area were identified. Cancer-BACUP publishes three booklets on radiotherapy treatment, but no cancer organisations have developed detailed advice and support for people with bowel problems after radiotherapy. Charities often make some reference to bowel problems in their literature and on their websites, but some appear to play down the risk of ongoing late effects to an extent that can be misleading. Information published by cancer charities does not reflect how common ongoing bowel problems can be. The approach seems often to be often one of reassurance and to imply any side effects during treatment are likely to pass in time.

Information from a number of cancer charities was drawn on for this study, some concerned with issues across all cancers, others focussing on specific cancers. Information was sought from websites, publications and through conversations with staff when possible.

Broad cancer issues:

- Macmillan Cancer Relief
- CancerBACUP
- Cancer Research UK

Specific cancers:

- Prostate Cancer Charity
- Jo's Trust (cervical cancer)
- Bowel Cancer UK
- Pandora's Box (cancer of the endometrium)

Macmillan's 'late effects' project - late effects including bowel problems after radiotherapy - is working with GPs, patients and 'Connecting for Health'. The project is looking at how best to link patients to timely information, tests and information to support self management and improve their experience.

In conclusion, more people are surviving cancer. The main interest in cancer services remains though in saving lives, not the quality of life after diagnosis and successful treatment. No cancer charities provide detailed information for people with bowel problems following radiotherapy or promote their interests.

2.2 Gastrointestinal illnesses and incontinence

Symptoms of IBD are often very similar to those experienced by people with bowel problems following radiotherapy, though age groups affected are very different. Ulcerative Colitis (UC) and Crohn's Disease (CD) are the most common forms of IBD. The cause or causes have not yet been identified in either illness. Both genetic factors and environmental triggers are likely to be involved. The situation for people living with IBD is also part of the background to this project. Briefly:

- UC and CD affect about 1 person in every 400 in the UK
- 12-18,000 new cases of IBD are diagnosed a year
- They are chronic ongoing conditions
- The most common age for diagnosis is 15-35
- Severity of symptoms fluctuates unpredictably over time
- Flare-ups in between intervals of remission or reduced symptoms are common

IBD is not the only cause of bowel problems, which occur in approximately 1-4% of adults and may be due to a range of reasons. Whatever the cause, they always bring much distress, loss of dignity and are likely to affect the quality of people's lives severely.

Professional care

People affected by UC or CD can expect to be referred to a gastroenterologist in a local hospital and to continue to see them as needed during their life. Assessment and diagnosis is routinely undertaken and a range of treatments and sometimes surgery may be needed. Some trusts employ gastrointestinal (GI) nurses, though this is far from universal. The Association for Continence Advice links professionals in the field together but provides no direct personal advice to patients.

A small number of specialist centres, for example St Mark's Hospital in North London, provide generalist help for people with bowel problems. Provision of services throughout the UK is however very variable. A recent national audit of incontinence care for older people by the Royal College of Physicians, for example, showed widespread failure to diagnose and manage continence problems.

Gastrointestinal and continence charities

A network of charities in this field, the UK Continence Alliance, (UKCA) meets three times a year to share information and provide mutual support. It has also planned awareness events together and a joint project on nurse education. Its members include both generalist and condition-specific organisations, including NACC, The Continence Foundation and InContact.

Generalist continence charities place most emphasis on urinary problems. Enquiries about bowel problems form only 10-20% of enquiries to the Continence Foundation Helpline and by email, for example. Charities produce useful online self care literature on faecal incontinence and some sell publications.

NACC produces a range of booklets on IBD and UC and directs people to publications on managing continence problems, advises people through its helpline and offers support through an evening telephone service and local groups. Only one enquiry was received from someone with symptoms following radiotherapy in a 2 month monitoring period, though it was thought this figure was unusually low. Nearly all people contacting and joining the organisation have Colitis or Crohn's Disease and its focus is on their needs.

In conclusion, in general, while much good work is done, resources for work in the GI and continence fields are limited, in both professional services and charities. Compared to cancer, they have not received anywhere near the same money, political backing or media interest, for a number of reasons: they are not normally life threatening; they are not attractive to the media; and are embarrassing to talk about or to hear about.

3.0 RADIOTHERAPY TREATMENT AND ITS RISK

The aim of giving radiotherapy to a pelvic cancer is to cure the patient. It is occasionally given to reduce symptoms, but in most of these cases, people do not live long enough to develop long-term problems. Considerable efforts are being made to improve radiotherapy services by the Royal College of Radiologists (RCR) and clinical oncologists and some steps taken to identify and develop good practice are discussed below.

Consent

The issues of consent, damage and past legal cases, first, provide further background. There is a legal obligation to gain informed consent from patients for treatment and increasing demand for better information about diseases and their treatment. The use of a written consent form, recommended by the RCR, is not however universal and the impression gained is that the process of gaining consent is still not done particularly well. ^{iv} The RCR recommends that all patients should be made aware of late side-effects "for which there is a recognised body of evidence which defines the likely incidence." There is no standard leaflet for people to be given before treatment on the risk of bowel problems and it is not known how many hospitals have one.

Cancer patients have to absorb a large amount of information at a difficult time, when they are likely to be in a state of shock. Communicating risk is very complex and information may be uncertain. Clinicians may be reluctant to describe the risk too forcefully if this could lead to a decision by a patient to refuse life saving treatment.

Damage

Bowel problems after radiotherapy are seen as an 'acceptable risk' in legal terms. Some oncologists feel problems should not be described as 'bowel damage' but rather as a 'late effect'. Damage implies something which is avoidable or that there has been an error, from wrong treatment or faulty equipment. But the term 'Radiotherapy Damage' is the name adopted by an online patient support network formed three years ago. This may be an area where patient and professional perspectives are different. The question of terminology remains a difficult one.

Medico-legal claims

A number of high profile cases arose in the 1990's when patients who had been very severely damaged through radiotherapy took legal action. Cases usually fall into two categories: a misdiagnosis of the original cancer, making the radiation unnecessary; or radiotherapy incorrectly given e.g. an overdose, a machine wrongly calibrated, or treatment regime resulting in too high an exposure for the timeframe.

In some cases there were devastating consequences and some women died. Reading their experiences is heart rending. RAGE, (Radiotherapy Action Group Exposure), took the lead at that time but is now only concerned with damage following breast cancer treatment. This past history may have led to some defensiveness by oncologists.

Action taken to improve practice

Action did follow. Between 1995 & 1998, The Department of Health and the RCR set up two working groups. The process uncovered common issues e.g.:

- difficulties in obtaining a firm diagnosis, consistent information or prognosis
- lack of structured management plans
- patients described a reluctance amongst health care professionals to engage with them, either through fear of involvement in a litigation process or a sense of failure.

As a result a number of steps were taken, including the production of guidelines for managing late effects associated with pelvic radiation therapy for cervix cancer and a Cochrane review on the literature. ^v The review process revealed significant differences between patient and health care professional priorities:

- patients were concerned about diagnosis & self management; symptom control, particularly pain and urgency; and psychosexual and mental health problems.
- health care professionals generated issues around damage scoring systems; and evaluation of specific medical and surgical interventions.

The process of developing the guidelines highlighted the level of misunderstanding, among both patients and in health care professionals from outside the field of radiation therapy, about risks and benefits of radiotherapy and the implications of late radiation changes. The guidelines are to be recirculated this year. ^{vi}

New techniques described at the consultative day, are being developed and include moving the bowel out of the way and getting a neater beam.

In conclusion, current problems should be seen against a background of past mistakes, horrific legal cases and attempts to learn from them and change practice. There is evidence of efforts to improve techniques, though these may be costly, and to

identify good practice, but difficulty in sharing it effectively. The process of gaining consent and describing risk is complex and takes place at a time when patients find it difficult to absorb and process information.

4.0 BOWEL PROBLEMS AFTER RADIOTHERAPY: AN OVERVIEW

4.1 How many people are affected

6,000 people a year in the UK are affected by bowel problems following radiotherapy. About 12,000 people are treated with radical radiotherapy for pelvic cancer and most of these are left with a permanent change in bowel habit. 50% of the 12,000 are affected by problems following treatment, to varying degrees. The literature review showed that while an absolutely firm figure cannot yet be given, this is the best estimate to date for the UK and should be used. ^{vii} This is not a problem restricted to this country. Worldwide up to 300,000 patients a year undergo pelvic radiotherapy and studies suggest a similar proportion are affected.

The problem of bowel symptoms after radiotherapy is not going to go away, even if techniques are improved. The incidence will stay the same or even increase. A recent review invited by the journal Clinical Oncology gives more detail about patients in the UK. ^{viii} The review summarises current knowledge as follows:

Results following pelvic radiotherapy	% of the 6,000 patients affected
Permanent changes in bowel habit developed	9 out of 10
Patients say change affected their quality of life	5 out of 10
Patients say effect on QoL is moderate or severe	Between 2 & 3 out of 10
Very serious complications developed within first 10 years after treatment	Between 1 in 10 and 1 in 20
Very serious complications developed within 20 years after treatment	2 out of 10

A number of cancers are treated by pelvic radiotherapy.

People affected	Cancer Type	People affected	Cancer Type
Women	Vulva	Men & women	Rectum
	Vagina		Bladder
	Endometrium		Lymphoma (a relatively small number)
	Cervix		Anus
	Ovary (rarely)	Men	Prostate
			Testicular (a relatively small number)

The proportion of people affected with bowel problems after treatment varies depending on the cancer: the frequency of significant problems appears to be higher in gynaecological, bladder and rectal cancer patients, than in prostate patients. ^{ix} An age range of 31-87, with a median of 67 for women and 65 for men, took part in one recent study and this would seem to be fairly typical. ^x Twice as many women as men in the same study had been affected and this too is likely to be common. Nothing is known about incidence in different ethnic communities or social classes.

How do these figures compare with IBD and some other conditions? While up to three times as many people become affected by IBD, both problems are much less common than cancer generally, and other common conditions, say, for example, diabetes. Nonetheless, IBD and bowel problems following radiotherapy are more common than really rare conditions affecting only a very small number of people. Some examples are given below.

Condition	Approx. number of cases in UK
Cancer	270,000 people diagnosed pa
Behcet's Syndrome	2000 people living in the UK
Gaucher's Disease	Less than 100 in the UK
Ulcerative colitis and Crohn's disease (IBD)	12- 18,000 people diagnosed pa
Bowel problems following radiotherapy	6,000 people pa develop problems

Not everyone who contributed to the scoping study felt the scale of bowel problems following radiotherapy was significant. A number of conversations with eleven health professionals in eight different institutions were undertaken:

Gastroenterologists	3
Clinical oncologists	5
Nurses	3

In no way could this be described as a survey but conversations allowed some tentative conclusions to be drawn from the conversations.

- There was no unanimity on how many people were affected - while some agreed with the figures above, others, quoting personal very limited experience of seeing patients, implied this was not a great problem.
- Helpline nurses in charities had a variety of experience of how frequent requests for help were, one saying they were uncommon, another not surprised to get calls.
- Some implied that this was a minority problem: people whose lives had been completely destroyed and who were very vocal.
- Clinical oncologists put forward differing opinions on whether numbers were increasing or decreasing, but on balance felt that this would remain about the same.

The literature review revealed a number of reasons why there is such uncertainty and lack of consensus over incidence of these problems, including actions and beliefs of patients. A research nurse reported from her clinical experience:

"If this group of patients is not specifically questioned about their bowels then they will not volunteer this information due to embarrassment, not wanting to waste anyone's time and because some feel that they should be grateful having been cured of cancer and now accept this is their new way of life" ^{xi}

Other constraints on patients reporting problems and asking for help included:

- many patients fail to report symptoms to oncologists until severe complications occur
- patients may believe that symptoms are the inevitable consequences of treatment, being old, and nothing can be done
- patients may feel there are more important issues to discuss in limited time available
- unwillingness to complain and lack of awareness that any further help was available
- men may be more reluctant to report than women

4.2 Referral rates

Most patients never get referred to a specialist gastroenterologist, of whom there are very few, and only a small minority - perhaps 20% - get referred to any gastroenterologist. Reasons for this include constraints from patients, such as those outlined above, but also arise from the following reasons:

- lack of systems and diagnostic tools for determining problems
- lack of information on where to refer people
- lack of confidence in managing patients
- symptoms starting more than 5 years after treatment, by which time the patient has normally been discharged from follow-up by the oncologist
- GPs coming across patients very rarely. One GP can expect on average to see one affected patient every 6 years and there is no system of coding them
- some professional beliefs about patients, particularly older people.

The conversations revealed a range of opinions. One clinical oncologist commented that if there is no likely source of help or treatment, oncologists were less likely to enquire if patients had problems. They also felt it was unrealistic to expect oncologists to do all the tests needed. Another oncologist, however, saw it as part of care by oncologists and always asked patients if they have any problems; if they have bleeding they may be sent to a gastroenterologist, who will also check there is no other cancer.

There were varying attitudes to patients, particularly older ones. One oncologist was very sure he would know if there was a problem and seemed to dismiss the problem as one that older men were prepared to live with. A nurse, unhappy with such attitudes, felt that people were being patted on the head and told to get on with their life.

4.3 Diagnoses, symptoms and treatment

Bowel symptoms following radiotherapy is a complex situation. Access to skilled assessment and diagnosis is enormously important for a number of reasons, not just quality of life for patients. They include the facts that new bowel symptoms may be triggered for many reasons, not just radiotherapy, and including further cancer; radiotherapy can induce cancer; and some symptoms may predate the treatment.

Distressing symptoms, described by people affected in a later section, are summarised here with their expected incidence. Diarrhoea often leads to urgency and many people may also be affected by emotional and psychiatric problems.

Problem	Incidence
Diarrhoea or constipation	1:2
Faecal leakage	1:5
Pain	1:10
Rectal bleeding	1:20

The degree of distress varies according to symptoms and the cancer. ^{xii}

Causing moderate/much distress	Bladder	Prostate	Cervix	Rectum
Frequency	11%	-	-	46%
Urgency	15%	17%	43%	78%
Loose stool	11%	10%	38%	29%
Faecal incontinence	10%	14%	15%	17%

Treatment, when offered varies, and is not the same as treatment for IBD. A range of different forms are touched on in the literature:

- Pelvic floor training
- Dietary advice
- Medication
- Laser therapy
- Surgical interventions
- Complementary therapies
- Hyperbaric oxygen treatment
- Self-management advice

This study does not attempt to go into details of treatment, but the view of a specialist gastroenterologist speaking at the consultative day was that some patients can be cured, some treated and for some nothing can be done. Most patients, a paper quoted in the literature review suggested, can be managed conservatively but occasional surgical interventions may be needed. The Cochrane Review concluded that currently there is no recommended standard treatment because the quality of the few studies which have been performed is generally inadequate. More research needs to be done.

As mentioned above, access to services, even if referrals were done better is very limited. A survey of members of the British Society of Gastroenterology suggests that few clinicians see sufficient patients with bowel problems following radiotherapy to feel confident in managing their symptoms effectively.

4.4 Information and support

People need information about risk before receiving radiotherapy, about appropriate investigations and treatment when bowel problems develop and self care information to help them cope on a daily basis. To what extent is information available?

As outlined above, it does not seem routine for people to receive information about risk and the whole question of risk communication is complex. Nonetheless, the experience of patients affected is that they would have coped much better if they had known beforehand about the risk. Some think they might have declined treatment if they had known more, though concede this is with the benefit of hindsight and appreciate it is a complex issue to put over.

Virtually no patient information is available on treatment options and what can be expected. Two booklets published by CancerBACUP include extremely brief details on drugs, diet, treatment and hyperbaric oxygen, but do not provide enough information to be of much use and their suggestions are not always supported by scientific evidence.

No information on managing long-term effects on the bowel specifically arising from radiation treatment was found, though some members of Radiotherapy Damage, the small online Support Group, share experiences of treatment and management.

There is however useful general information on managing bowel problems, for example:

- An excellent book providing detailed advice and information, though cost and access might well put it out of reach of many people ^{xiii}
- Advice on the website of The Continence Foundation and a system for ordering a range of useful publications by post

- Downloadable publications on managing bowel problems produced by InContact but no apparent system for patients to purchase hard copies.
- Publications by NACC, though written for people with IBD and their families.

There is no evidence that patients are systematically told about these publications and websites by health professionals. Few see nurses, traditionally better at providing coping information than doctors and cancer nurses are not normally trained in dealing with bowel problems. Some cancer charities give links to continence organisations in publications but do not make it easy for people to follow a trail.

What support is available? Almost none, apart from families, but where there was, immensely appreciated:

- Patients referred to a specialist clinic spoke warmly of the support they felt they gained, just through getting an appropriate referral to a supportive doctor.
- Members of the online support group often post messages about how they feel better supported just through knowing they are not alone.
- Support from families was often crucial, but sometimes complex.

But some patients affected were told they were alone in having this condition, so did not even try to find other people and few people affected will see a nurse. While not everyone wants support, the experience of people with other devastating conditions suggests that many will. There is now substantial experience in the professional and charity world on how support can be provided in many different ways.

In conclusion, a significant number of people are affected, but this is not generally known and accepted. Many constraints affect referrals, but even if made, there are not enough gastroenterologists sufficiently experienced and confident in this specialist area to meet the need. Distressing symptoms are very like those experienced by people with IBD. There is no easy route for patients to find information and little support.

5.0 BOWEL PROBLEMS AFTER RADIOTHERAPY: PERSONAL EXPERIENCES

Nine people affected by bowel problems following radiotherapy contributed their personal experience to this report through a short qualitative study. There were eight women and one man, aged between 31 and 70, with a median age of 54, so younger than the average age of people affected. Seven were interviewed by telephone in their homes and two provided written accounts with a short follow up phone call. Two participants were recruited from a patient support web site and seven from a specialist clinic. Further details and the limitations of the study are discussed in working papers 3.

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Symptoms

Symptoms described in these interviews included constipation, flatulence, pain, diarrhoea and lack of bowel control.

'Over the years that has not got any better (since 1989). I still suffer from protracted bouts of vomiting and pain' (Alice, 64, Endometrial cancer patient)

People were open in discussing the nature and severity of their symptoms. Severity varied from individual to individual. Those living with severe pain and diarrhoea found their symptoms hardest to manage, with these symptoms having more of an effect on their ability to carry on.

'Very frightening experiences of being out and having some very close calls when needing to get to a loo fast. I couldn't leave the house without codeine phosphate that I have needed, to this date!' (Bette, 57, cervical cancer patient)

It is hard to gauge the severity of symptoms from interviews. One person said that they were aware that there were far worse things to be living with, but then went on to describe bouts of diarrhoea and pain lasting many hours through the night.

'I do get a lot of pain, my insides twist it feels like. The scans don't show anything. Physically sick with the pain, but its always bile not food, I get in a cold sweat, it can last hours, I work through it and that's it.' (Bette, 57, cervical cancer patient)

Another said that these were the most severe symptoms they had ever experienced but they continued to live their life as they previously had done, managing their symptoms in the home and workplace with great success. This may say something about people's individual perception of severity, an individual's ability to cope with the situation or the nature of the symptoms. Severe flatulence may be easier to manage than severe diarrhoea for example. Six people had symptoms on a daily basis; two on a regular basis throughout an average week; the remaining one now had rare symptoms.

'Every month and then every three weeks, I was having a week off and that got worse.'
(Alice, 64, Endometrial cancer patient)

Some symptoms were associated with particular times of the day, most commonly the middle of the night and first thing in the morning. This was true for five out of the nine people. Obviously symptoms throughout the night had consequences for fatigue and ability to complete their daily routine, though fatigue may also be an issue in its own right.

Specialist medical support for patients and their healthcare providers

The majority of people interviewed experienced a delay in obtaining specialist help for this problem. This was not through lack of trying, both by the patient and those already caring for their health. Some GP's and oncologists actively sought a diagnosis and specialist support for their patients but even most professionals did not know where to turn for help for those living with radiation induced bowel problems.

'I wasn't treated until (specialist) came to the (hospital), they just said it was piles and thrush; they didn't ignore it they just didn't know what to do with me.' (Tim, 53, prostate cancer)

This process was not postponed in this case by a delay in reporting symptoms. With frequent visits to both oncologists and their own general practitioner there was adequate opportunity to raise concerns. Six people highlighted lack of embarrassment, having been through the diagnosis and treatment procedures of a gynaecological

cancer. This meant that when they experienced the onset of bowel symptoms they were able to discuss this openly with their doctors.

While six people received adequate support from their existing doctors, three were left with no support from oncologists, for various perceived reasons.

'I still see my oncologist and my surgeon twice a year and neither of them are able to help. The surgeon could suggest the treatment for nappy rash.' (Tim, 53, prostate cancer)

Around half of the patients felt that their oncologists were under the impression that treating the cancer was their role. As treatment had been successful there was no major cause for concern. Some people also felt that their doctors were unaware of bowel induced radiation damage as a complication of radiotherapy.

'I have been told for the last five years that I am unique and the only one to have these symptoms' (Tim, 53, prostate cancer)

One person hypothesised that it was not so much that doctors were unaware of the problems but more that they were unaware of the severity and extent of the problem.

Quality of life

Symptoms can have a very detrimental impact on quality of life.

'I was worried all the time, wherever I went I had to know where all the loos were, it caused me a lot of problems physically and psychologically but the (treatment) is a security really, knowing I can go out with it.' (Alice, 64, endometrial cancer patient)

For many if not all people interviewed, every aspect of this illness affected their quality of life: from onset of symptoms; through diagnosis; facing the reality of symptoms affecting one's life; lack of a treatment plan; and the long-term nature of the illness. It had a total effect on people's lives, affecting every aspect of their lives.

'It had a total effect on my life and what I could do; If I make an appointment then I can't keep it, it controls my life completely. I can't plan anything, holidays are a pain in the neck.' (Tina, 50, cervical cancer patient)

'You have to plan your life around the loo, I don't wander far from home now, I don't stay at anyone's house or go on holiday' (Bette, 57, cervical cancer patient)

For some it restricted day-to-day activities, some on a regular basis and others only when they were feeling particularly unwell. Two people were under constant demand from their illness, with very little respite.

'I often can't make it to the loo. I wash my hands and myself and my clothes then sit down again and the same thing happens again.' (Bette, 57, cervical cancer patient)

Some participants described disruption to essential activities such as work, either regularly or on an unpredictable basis. Some have not returned to work since they took a period of absence for cancer treatment, with severe financial results.

'My gas and electricity are no cheaper (than they used to be); I went from £16,000 a year 10 years ago to £50 a week (now)! It's a change in lifestyle, I've not been able to go back to work - I would have done after the cancer but this stopped me.' (Bette, 57, cervical cancer patient)

Others have entered into new careers that fit in with their health and energy levels, or adapted their current working life to accommodate their illness.

'I have had a lot of time off work. I do go to work but I often have to come home again. I commute on the train from (home) to (work) (about a 90 minute journey), but often don't make it that far.' (Tim, 53, prostate cancer patient)

'I had to come to an arrangement with my boss that they didn't pay me when I wasn't there in order to preserve my employment.' (Alice, 64, endometrial cancer patient)

For other participants extra activities such as social occasions or holidays cannot be planned in advance and for some they have been abandoned.

'You can't have a social life, you have to tell friends that you might be there but you can't promise, I can't eat well so I can't go out to restaurants like I used to.' (Tina, 50, cervical cancer patient)

Quality of life is a self-perceived issue. But people who receive inadequate care and support and perceive low control over their health are unlikely to be happy with the quality of their life.

Embarrassment

Interviewees described many symptoms as highly embarrassing. Participants were quick to acknowledge however that their previous medical experiences (e.g. the diagnosis and treatment of cancer) facilitated much easier conversations with health professionals than they had envisaged when discussing this new series of symptoms.

The main area of embarrassment was communicating symptoms to those with no professional training: partners, family, friends and colleagues. Living with their symptoms over a period of time alleviated the embarrassment that they experienced themselves when disclosing or discussing their symptoms with non-medics. However, the embarrassment felt by those friends and family whom the 'ill' person was talking to was a constant battle for those living with these symptoms. This is only the perception of those people interviewed - a one sided view of the scenario - and they were only able to describe how they believe other people are reacting to them when discussing their illness. It appears from the nine accounts reviewed here that this is as much of an emotional struggle for these people as the embarrassment they themselves feel.

'People don't want to hear about it. People don't talk about bowels do they!?'
(Kate, 57, ovarian cancer patient),

Treatment decisions

There were mixed opinions as to treatment decisions people had made within those who had been warned of risks before treatment. None imagined that symptoms would be so severe, but even having lived with the symptoms some believed that they would still have undertaken the lifesaving treatment as they feel life is too important to risk.

'I would choose the same, I like life too much.' (Alice, 64, endometrial cancer patient)

However, having experienced the consequences that these symptoms have had on their life, three people interviewed would possibly have refused the lifesaving treatment because what they have now is no life to speak of.

'If I didn't have the treatment I would be dead, but if I had the choice again I wouldn't have it.'
(Tim, 53, prostate cancer patient)

All interviewees who expressed these feelings were fully aware that they were speaking with the benefit of hindsight. It is easy to discuss this when you have survived the immediate threat to life.

'Life is very precious even though we take a lot of risks, although during the increasingly painful and unpleasant bouts I have thought and thought increasingly about it maybe not being worth it. These attacks were very painful and I thought that maybe I would have been better off... well...this was before it was controlled. No one can possibly know that until they have experienced the pain! And then I questioned it but of course afterwards I was ready to pick my life back up until the next time!' (Bette, 57, cervical cancer patient)

Risk communication

'Risks explained? No not really, But I can't really remember, I was more concerned about losing my hair.' (Jenny, 40, ovarian cancer patient)

The majority of interviewees recalled to some extent a conversation regarding the risk of undergoing radiation treatment. Most found it hard to recall what was communicated to them, some found it hard to recall what they felt when this was communicated to them. None recalled receiving written information about the risks involved. Three people did not recall having any warning about the risks of the treatment being offered.

'Were the risks of having radiotherapy outlined to you beforehand? No, no they weren't, that's a very significant point actually, no they were not. Although it was either that or certain and very painful death.' (Alice, 64, endometrial cancer patient)

A number of people could recall that they did not imagine the symptoms to be so severe as they are, however they do not believe it would be easy to articulate the severity of the symptoms when communicating the risk to patients. This communication can have significant effects on one's decision-making process. Participants were aware that at a time when their life was at threat their ability to process information and make decisions was affected.

They offered many suggestions to improve communication of risk:

- Written communications
- Taking someone with you to consultation where the risk is communicated
- Making detailed notes at consultations
- Talking to people who had been through the experience, with both negative and positive experiences.

Who takes responsibility for this issue?

Communicating risk is a responsibility; it was unclear to participants where this responsibility lies. Some people, too, who reported the effects of radiation felt that these symptoms were not of concern to the oncologists who were caring for them.

'People don't seem to have much interest in the situation; they are there when you are having the cancer treatment but no one has any interest in the damage and the people living with the damage, even the cancer charities.' (Alice, 64, endometrial cancer patient)

On a larger scale, people were aware of the need for research focused in this area and the lack of attention it receives even in comparison to cancer.

'This came a poor second to research regarding cancer, the medical profession was concerned with the cancer and dealing with the cancer.' (Tina, 50, cervical cancer patient)

Interviewees expressed a need for practical support from professionals who can offer treatment and advice for symptoms. People who are now receiving specialist care were keen to emphasise the huge benefit this had brought to them, even those who had seen no clinical improvement yet. Just the knowledge that someone may be able to help them is very powerful.

Family support

Sources of emotional and practical support were limited. Family was the main means of support. They were mostly praised for their support; one spouse was even instrumental in setting up an online support group.

'The manifestation of his caring nature came out more, in fact sometimes he feels pushed out by the nursing team.' (Alice, 64, endometrial cancer patient)

Some people found it an experience they felt they needed to go through alone. This may be the result of this illness coming along after a cancer experience, where people may have relied heavily upon friends and family.

'I don't like to burden family, they are always there but I don't want to worry them with my problems.' (Bette, 57, cervical cancer patient)

'Its not always their (interviewee's adult children) fault but they are not around, they don't know what it's like now, they assume the cancer drama is over so mum is better now. I can't tell them the new reality, there's not much they can do anyway' (Alice, 64, endometrial cancer patient)

However four interviewees reported more negative experiences of family members who assumed that once the threat of the cancer was no more the individual with the cancer should be 'better'. The term cancer and the very real threat of mortality lead to a feeling described by our interviewees as a sense of relief when the process was over.

However for these patients, the struggle was far from over with this new challenge to face. Family found this hard to understand. Interviewees suggested that this may be because of embarrassment, and consequently people's reluctance to discuss with friends and family what they are going through. Others believed that their friends and families knew that they were not completely better and that they were now living with new symptoms. However these friends and family believed then that any consequential symptoms experienced should be tolerated because people had survived cancer.

'They don't understand that this is as bad as the cancer if not worse, I know I won't die now but sometimes it is worse than the cancer. At least I had hope then but no-one understands that, they think I should be better now' (Dana, 57, cervical cancer patient)

Isolation

Individuals living with this illness find it very isolating. Many people believe they are alone in their fight, both against the symptoms and in finding support.

'For many years I felt very isolated. I knew no one else who had this problem' (Alice, 64, endometrial cancer patient)

In conclusion, people interviewed experienced symptoms very like IBD, but without the support and information people with IBD can expect to receive, and affected by the context of having survived cancer. There were severe effects on their quality of life; limited communication of risk; and delays in access to specialist diagnosis and treatment, or none. People felt that their needs were not always of interest to cancer specialists or sometimes to their family and often felt very alone. A number of issues, touched on elsewhere in this report, such as the need for agreed terminology and better risk communication are confirmed by this part of the study.

6.0 CONCLUSIONS

This study paints a picture of a neglected area of healthcare, falling between two specialisms neither of which has taken real responsibility for improvement. It does not seem to be seen as a legitimate problem. But the study also reveals a small number of clinicians, charities and patients working to improve the situation, identifies potential for improvement and opportunities to bring it about. Various conclusions may be drawn.

Numbers of people affected

There is enough evidence to be sure that about 6,000 people a year in the UK are affected. It is difficult to measure but this significant number of people are affected by bowel problems following radiotherapy. This is not generally known or accepted however. This incidence is likely to continue and most people affected will go on having problems, though some may be cured, so the total number living with the problem will be much higher. Patients are unaware of how many other people have similar problems, which contributes to their sense of isolation.

The patient journey

Cancer patients are increasingly being cured through improved services, but people with bowel problems following treatment are likely to get a poor deal at all stages of their journey.

At stage one, pre-radiotherapy treatment, risk information is not generally provided in writing or always done as well as it could be. The challenges of doing this appropriately and accurately must be acknowledged and it is an acceptable risk for many. Good practice advice does not appear to be always followed however and there appears to be no standard written information generally provided. Patients say that they would have liked to have known more beforehand and feel they would have coped better having been warned. Some of course may well have been told but not recall this, making written information important.

At stage two, the end of a course of radiotherapy, no information seems to be provided on what might happen long-term and what to do, though plans are being developed to publish a standard exit pack.

During stage three, the following five years, when patients return to see their oncologist for check-ups, there appears to be no systematic way for checking for problems and dealing with them. Some oncologists initiate this routinely and for a few, specialist gastroenterology services are available. But a number of significant constraints have been identified, among both patients and clinicians, in both oncology and gastroenterology worlds. Some problems will need costly, long-term solutions, bigger investment in research on treatments for example and more specialist posts. But some constraints could be overcome through changes of attitude and greater awareness and knowledge among both professionals and patients; through improving systems for diagnosing the problem; by providing information; and by identifying routes to other help and information.

In the fourth and final stage, after regular check-ups stop, people may get support from their GP. Few GPs however will see enough patients in their lifetime to be familiar with the problems and there is no coding system for referral from general practice.

Lack of agreed terminology

There is no consensus on terminology. Patients may be described as having radiation proctitis, enteritis or colitis, but this terminology is wrong. Inflammation, implied by the "-itis", is not a prominent feature after radiotherapy. Other terms, for example, radiation enteropathy and radiation induced bowel damage may be used. The fact that there are a number of different bowel symptoms following radiotherapy may make terminology more difficult but still lack of generally agreed terms is an underlying problem, for both clinicians and patients. This needs to be tackled.

Problems for patients

People are often left with a poor quality of life. Problems include isolation; poor access to specialist assessment, diagnosis and treatment; lack of information; difficulty in communicating their situation to family and friends; and little support in coping with highly embarrassing problems through self care. While a few get appropriate help and others resourcefully find ways to manage, for most people there is still a huge effect on the quality of their lives and that of their families.

There is no strong patients' voice. No organisation exists to raise problems and only a handful use a web-based support network. Both the condition and attitudes towards it mean there are significant constraints in making people's voices heard. These constraints though are not insuperable. Experience in other fields could be used to help patients be heard and to help each other and current systems could be drawn on, helplines and advocacy networks for example. In a patient focussed NHS enabling the patient's voice to be heard could be an important step towards improvements in services.

Strengths and constraints for charities

A strength for charities is their focus on a particular group of people and their needs, but this is also a constraint on meeting the identified needs of people with bowel problems following radiotherapy. Condition specific charities, both cancer and gastrointestinal, have to focus on that condition and priorities for people with it.

Subsequent bowel problems for cancer patients are unlikely to come high on their list, though some charities may well have useful experience and expertise that could be used for the benefit of people with bowel problems following radiotherapy. NACC for example, knows a lot about managing urgency. Most charities concerned with a particular cancer are unlikely to be aware that this is also a problem identified in other organisations based on different cancers.

Charities with more of an overview may well have either relevant expertise or resources and systems to expand their services. There are opportunities to improve the situation through existing services and systems. Willingness to collaborate has already been seen and joint action, as well as working individually is likely to be both an effective way forward, and feasible.

Strengths and constraints for health professionals

Similarly, a strength for health professionals is their immense skill and experience in one speciality. In this case it also seems to be a constraint. There is a black hole. Patients who are being seen by one speciality have a condition which is the concern of another, but routes for referral are hidden and blocked or simply not available.

Other constraints include the legacy of past litigation; perhaps a sense of failure by some health professionals; a focus on saving lives rather than quality of life; attitudes to elderly people; and perhaps, sometimes, concern about coping with demanding patients. There is also, however, some indication of desire and energy for change, and opportunities for improvement through joint working here too.

This theme of opportunity seems to override the problems, great though they are. This scoping study has not only identified facts but also willingness to work together: oncologists and gastroenterologists; specialist and generalist charities, in both fields; and patients and clinicians.

7.0 OPTIONS FOR NACC

NACC is now better informed about the situation for people living with bowel problems following radiotherapy but needed to look at what might be appropriate as its future role. A number of options were set out to help Trustees to come to a decision on any future action, guided by some questions.

These were discussed by the Board of Trustees of NACC at their meeting on March 16th 2006. Further thought is being given both to the use of existing channels and how action might be initiated through a collaborative approach with other organisations interested in the topic. In the meantime, this report is being distributed to all who helped with it and to other interested bodies.

Any organisations interested in helping take work forward in the future should initially contact the Director of NACC, Richard Driscoll, Richard.Driscoll@NACC.org.uk

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GLOSSARY

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The Royal College of Radiologists www.rcr.ac.uk/index.asp?PageID=489

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British Society of Gastroenterology

The mission of the British Society of Gastroenterology is to maintain and promote high standards of patient care in gastroenterology and to enhance the capacity of its members and associate members to discover, disseminate and apply new knowledge to the benefit of patients with digestive disorders.

Clinical oncologist

A doctor trained in the diagnosis and treatment of cancer using radiotherapy and/or chemotherapy. They work closely with surgeons, clinical radiologists, pathologists, and medical oncologists deciding and defining the best treatments for a patient's cancer. They plan and prescribe radiation and other therapy and liaise with psychologists, complementary therapy specialists, etc in the wider treatment of cancer and its effects. They also ensure that patients who cannot be cured are kept symptom free.

Crohn's Disease

A disease of the bowel where patches of the bowel become inflamed from time to time.

Inflammatory Bowel Disease (IBD)

Common name for ulcerative colitis and Crohn's Disease.

Late effects

A term used for a variety of problems after a treatment is completed, also called delayed complications.

Medical oncologist

A doctor who treats patients with cancer using drugs i.e. with chemotherapy.

NICE

National Institute for Health and Clinical Excellence. NICE is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

Palliative care

Palliative care is the active holistic care of patients with advanced progressive illness. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Proctitis

Literally inflammation of the rectum. It can cause constant feeling of wanting to have the bowels open and a feeling of complete evacuation.

Radiation enteritis

Literally means inflammatory changes to any part of the bowel caused by radiotherapy. So, in reality it really only happens during the six or so weeks of radiotherapy treatment and then

settles. However, the term has come to mean patients with visible or presumed damage to the bowel (usually the small and not the large bowel), from previous radiotherapy usually months or years earlier.

Radiation enteropathy

Damage from radiotherapy to any part of the bowel. Not used much in the British or American published literature

Radiation proctitis

Literally means inflammatory changes to the rectum caused by radiotherapy. In reality radiation proctitis only happens during the six weeks or so of radiotherapy treatment and then settles. However, it has come to be used for patients with visible or presumed damage because of rectal symptoms following previous radiotherapy. Some doctors use it to mean specific damage to blood vessels in the rectum after radiotherapy, which then bleed.

Radiation proctopathy

Damage from radiotherapy to the rectum. Not used much in the British or American published literature.

Radiographer

A professional trained to operate equipment concerned with the production and detection of radiation. Radiographers work in multidisciplinary teams led by radiologists to achieve diagnosis and treatment.

Radiotherapists

A term that is rarely used these days. Doctors trained in the delivery of radiation in the treatment of cancer. Most radiotherapists are now Clinical Oncologists.

Radiologist

A doctor who specialises in taking and interpreting Xrays

Radiotherapy

The branch of medicine originating from the use of radiation, usually x-rays, to kill cancer cells now called Clinical Oncology.

The Royal College of Radiologists (RCR)

All RCR members and Fellows of the College are registered medical or dental practitioners. The role of the College is to advance the science and practice of radiology and oncology, further public education and promote study and research through setting professional standards of practice.

Ulcerative Colitis

An inflammatory disease of the colon.

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About the researchers

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