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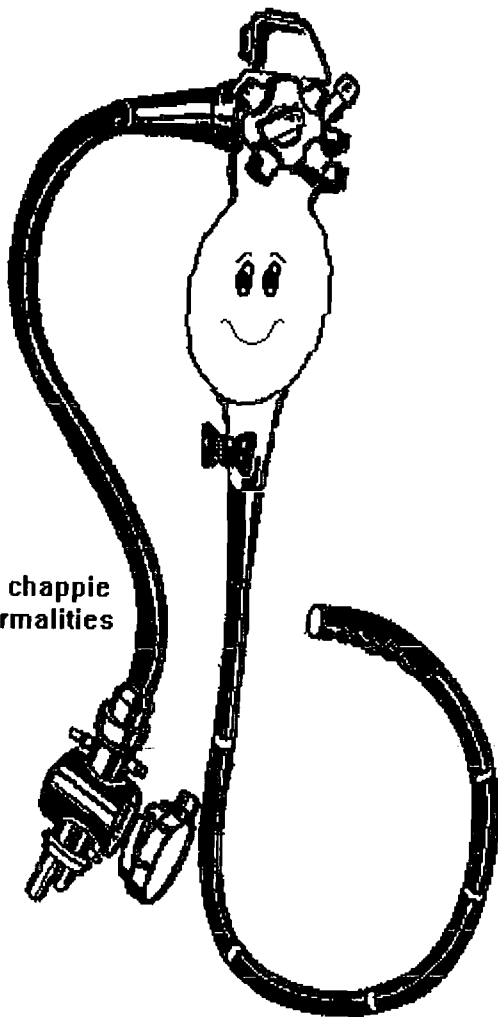
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An Anthropological Approach to Evaluating Patient and General Practitioners'

Experiences with an Open Access Flexible Sigmoidoscopy Service in Teesside, UK.

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"I am a happy chappie when no abnormalities are detected".



19 APR 2002

Table of Contents

	Page Number
Table of contents	i
Abstract	iii
Acknowledgements	iv
Chapter 1. Introduction	1
Chapter 2. Methodology	6
2:1 Participant Observation	8
2:2 Patient Satisfaction Questionnaires	11
2:3 Patient Interviews	12
2:4 Patient Focus Group	14
2:5 General Practitioners' use of Guideline Study	14
2:6 General Practitioners' Interviews	15
Chapter 3. Fieldwork up the Colon	18
3:1 Separation Stage	18
3:2 Liminal Stage	19
3:3 Re-incorporation Stage	21
Chapter 4. Patient Satisfaction with the Open Access Flexible Sigmoidoscopy Service	22
4:1 Introduction	22
4:2 Results of Patient Satisfaction Questionnaires	29
4:3 Results of Patient Interviews	41
4:4 Discussion	51
Chapter 5. General Practitioners' Satisfaction with the Open Access Service	57
5:1 General Practitioners' Responses	57
5:2 Discussion	66
Chapter 6. Patients' and General Practitioners' Perception of why Patients' Delay in Presenting with Rectal Bleeding	70
6:1 Previous Studies	71
6:2 Delay in Presentation: Patients' Perspectives	74
6:3 Delay in Presentation: General Practitioners' Perspectives	77
6:4 Discussion	81

Chapter 7. General Practitioners' Perceptions of Guidelines in General and with those of the Open Access Flexible Sigmoidoscopy Service in Particular.	89
7:1 General Practitioners' Views on Guidelines	93
7:2 General Practitioners' Views on OAFSS Guidelines	98
7:3 General Practitioners' Views on Educational Tutorial	99
7:4 Discussion	100
Chapter 8. Conclusion	106
Appendix 1 Patient Satisfaction Questionnaire	110
Appendix 2 OAFSS Guidelines	111
Appendix 3 Educational Intervention letter	113
Appendix 4 General Practitioners' Questionnaire Schedule	115
Appendix 5 Glossary	118
Bibliography	120

Abstract

The reported high incidence of colo-rectal cancer on Teesside UK has led to the instigation of an Open Access Flexible Sigmoidoscopy Service (OAFSS) in two National Health Service Trust hospitals on Teesside. This thesis reports on the results of my involvement, as an anthropologist, with the evaluation of the service.

The issues addressed are patients' and general practitioners' satisfaction with the service, patients' and general practitioners' perceptions of why patients delay in seeking advice on rectal bleeding, and implementation and adoption by general practitioners of guidelines in general and in particular with those designed for use with the OAFSS. These topics are approached using anthropological methods, such as participant observation, in-depth patient and general practitioner qualitative interviews, a patient-centred focus group meeting, and a standardised questionnaire.

This holistic methodology offers a more realistic evaluation of 'satisfaction' than do those using a standardised questionnaire alone. This also queries the meaning of 'satisfaction' and 'perceptions' in the post-modern health arena, providing a convincing demonstration of the valuable contribution anthropologists can make to evaluations of patients' and general practitioners' perceptions and experiences.

Acknowledgements

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I am immensely grateful to the 612 patients who completed the questionnaire, 64 patients who gave of their time and privacy so willingly and to the 26 general practitioners' who gave of their 'no time' to participate in this study.

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Chapter 1. Introduction

In many Western countries colo-rectal cancer is one of the most common internal malignancies, (Correa et al 1978) yet indicative symptoms such as rectal bleeding appear to be accepted by many as the norm. This perception of 'normality' in Western cultures ("It's just my haemorrhoids, doc") is in many instances the reason for patients' delay in presentation and has been identified as a major factor in delayed diagnosis of colo-rectal cancer. The consequence of presentation delay burdens the financial resources of National Health Service Trusts. At the same time increasing longevity invites greater susceptibility to colo-rectal cancer.

Rectal bleeding is well documented as being an indicative, but by no means singularly diagnostic symptom of colo-rectal cancer or pre-malignant polyp, which, if detected in the early stages via sigmoidoscopy/colonoscopy has the potential for excellent prognosis. Whilst treatment does not eradicate familial predisposition to this cancer, consultant gastro-enterologists are becoming increasingly predisposed to the benefits of screening and as such open access flexible sigmoidoscopy/colonoscopy services are becoming an integral part of National Health Service Trusts.

Colonoscopy is the passing of a fibre optic tube via the anus by which the interior of the rectum up to the caecum can be viewed.

Colonoscopy is viewed by most prospective patients as an experience that will be at best unpleasant, probably quite painful, and possibly excruciating (Hull & Church 1994).

A patient within the National Health Service today, is sometimes referred to as the 'customer'. The auditing of services provided for these customers has become a crucial issue in post-modern medical care. This is evidenced by the £220 million allocation from



the National Health Service Fund between the years 1989-1994 (Power 1997) for auditing purposes. Whilst it can be argued that we have come a long way with the advent of the Patients' Charter, ways continuously need to be devised to measure aspects of outcome, which to-date, have been overlooked.

Innovative practices and procedures give rise to great optimism and continue to grow with the medicalization of society; this Illich (1975) describes as the transformation of natural events in the human life course into medical phenomenon. He uses old age, unhappiness, loneliness, childbirth and menopause as examples to illustrate medicalization which in turn influences health behaviour within cultures and as such creates a mosaic of satisfaction levels for patients as well as general practitioners'.

General practitioner roles have also changed dramatically within the last twenty years with the advent of the 'white paper' following market-model reforms (Secretaries of State for Health, Wales, Northern Ireland and Scotland, 1989; Leavey et al., 1989). For full allocation of monies, general practitioners require high levels of patient attendance at clinics, as well as an acceptance of innovative treatments, such as hormone replacement therapy, immunisation, asthma assessment, and cervical smears. Self-funding has been abolished since the commencement of this thesis, however the 'audit ethos' continues in its wake.

These audits, coupled with the philosophy of evidence based medicine, often invalidate the previously accepted general practitioners' clinical assessment and prescription, replacing, or at best supporting them, with 'scientific' medications and allegedly more accurate and safer tools in the form of guidelines to assist clinicapractice. However whilst hundreds of guidelines have been written, both at local and national level

to assist with diagnosis, treatment and criteria for referral, adoption levels amongst general practitioners vary.

In the case of the Open Access Flexible Sigmoidoscopy Service (OAFSS) on Teesside, the subject of my thesis, evidence based guidelines were compiled at a local level by primary and secondary care physicians; these were designed to offer general practitioners advice on the suitability and criteria for referral. Primary care or general practitioner referral enables patients to have the selected examination at a substantially reduced waiting time, using minimal NHS resources. The philosophy is that the general practitioner will remain in full control of the patients' post colonoscopy care, yet at the same time, secondary care facilities in the form of consultant gastro-enterology advice or treatment is at hand for colonic abnormalities such as malignancy, diverticulitis, irritable bowel syndrome and the numerous other gastro-enterological disorders.

This multidisciplinary study which took place between 1997-1999 encompassed consultant gastroenterologists, general practitioners, economists, health administrators, and anthropologists. The high incidence of colon cancer in Teesside led to the instigation of an open access flexible sigmoidoscopy service in two local hospitals. The rationale was to reduce morbidity and offer a quicker and more efficient service to people presenting with rectal bleeding, and/or altered bowel habit, while at the same time maximising financial resources. *'It is estimated that screening could prevent approximately 5,500 colorectal cancer cases per year and 3,500 deaths in the United Kingdom, thus saving 40,000 years of life'* (Wilmink 1997). Studies also reveal that early polypectomy has a protective effect against colon cancer for ten years after sigmoidoscopy. Whilst sigmoidoscopy (passing to the level of the sigmoid colon) is the

procedure recommended in the guidelines (Appendix 2), this will often, at the discretion of the colonoscopist, lead to a full colonoscopy (passing to the level of the caecum).

My responsibility as medical anthropologist was to look at patients' and general practitioners' satisfaction with the service. General practitioners' responses were assessed by means of an interview schedule (Appendix 4), which incorporated questions about administration, waiting lists, the primary/secondary care interface, and patient feedback. This holistic study also looks at the various components interrelated within the set up of the service, in particular the implementation and distribution of guidelines. This also incorporated a peer instructed educational package, designed for maximum service usage and efficiency.

The reasons patients' delayed in presenting with rectal bleeding was investigated both from patients' and general practitioners' perspectives, and patients' experiences of the service were recorded. This incorporated administration, medical and nursing care, and the general environment of the unit that resulted in perceptions of patient satisfaction or dissatisfaction.

Initially I had planned that this thesis would explore patients and general practitioners satisfaction with the OAFSS. However as I entered my second fieldwork year I decided that if I was to present a holistic perspective of the service I had to look at the wider issues surrounding satisfaction. For example, I felt it essential to examine the reasons patients delayed in presenting with rectal bleeding as well as general practitioners' use of guidelines *per se* and in particular with those implemented for use with the service.

Anonymity has been maintained for both patients and general practitioners throughout; where the general practitioners refer to a particular consultant or surgeon I have replaced the name with a colour pseudonym.

Chapter 2. Methodology

Many studies have concentrated on quantitative methods in assessing patient satisfaction and whilst it is argued that this is a cost-effective method the pitfalls of this methodology are well documented. Survey reports are the most commonly used method of research due to time, finance availability and skill (Baker and Whitfield 1992). A few general instruments have been devised to ascertain levels of satisfaction, one example of this being the Clinical Accountability, Service Planning, and Evaluation (CASPE) closed questionnaire which is widely used within the National Health Service. Fitzpatrick (1991) criticises this methodology arguing that as patient satisfaction is multidimensional, more focused, episodic-specific questions need to be asked, rather than global general questions. He agrees with Baker et al (1992) who submit that by using generally worded standardised questionnaires as a lone methodology, the question of validity arises through their consistently high recordings of satisfaction. Thomas et al (1996) take the debate further by proposing that closed questions generate bland general answers and that they fail to fully address the complex attitudes and opinions held by respondents.

Williams (1994) believes that the original aim of the white paper to investigate patients' perception of experience, has been reduced to the bland measure of 'satisfaction'. He argues that there is not enough qualitative research being done to assess patients' levels of satisfaction with health care provision. Avis et al (1997) agree with this believing that little is known of patient's prior beliefs, experiences and knowledge of the health service that may influence their judgements about satisfaction.

To assess patient satisfaction with the OAFSS, I felt it essential to adopt three different qualitative methods; this would give me the advantage of assessing satisfaction with the service as well as gathering narrative perceptions of experience. My methodology therefore incorporated a) in-depth personal interviews, which were used to access patient's experience in a richer, more complex way than simplistic terms like satisfaction or dissatisfaction, b) participant observation where I could actually observe the procedure of colonoscopy and share something of the private experiences of patients during this examination and c) a patient-centred focus group, which through its spontaneous interaction (Morgan 1988) offered different information to that gained by interviews in that my 'focus' in the latter was to ascertain patients' satisfaction levels with the OAFSS. The focus group, however, allowed a full narrative of the patient's experiences from their first sighting of rectal bleeding and/or any alteration in bowel habit. The focus group also gave the opportunity for follow-up discussions from the individual interviews. For example, one of the patients previously interviewed had gone on to have a large part of his colon removed and a subsequent colostomy performed. It also allowed the other people (from both units) to share experiences remembered, and those experienced which were triggered by the interactive processes as suggested by (Silverman 1993). In addition to the qualitative methods, a quantitatively-based standardised questionnaire was also used.

To assess general practitioners satisfaction with the service, as well as their perceptions of why patients delay in presenting with rectal bleeding, a qualitative method using in-depth semi-structured interviews was utilised.

2:1 Participant Observation

Bronislow Malinowski, one of the founder-fathers of Anthropology discovered during his study of the Trobriand Islanders Malinowski (1922), that it was insufficient merely to sit on the verandah and observe. He decided that it was necessary to 'come off the verandah' and enculturate himself into Trobriand society in order to appreciate the 'whole' functioning society. Huby (1997: 1112) takes this a step further by suggesting *'that the responsibility of the researcher is to capture the expression of experience without removing it from the flow of time'*.

A nursing background proved to be advantageous in that over the years I had been enculturated into the National Health Service, and as such had developed good interactive skills with patients and could both sympathise and empathise with their situation. Yet these nursing skills did not equip me with the 'action knowledge' to do participant observation ...as a nurse I was simply too busy to 'observe' what I perceived at that time to be incidental issues. My lack of 'total awareness' is highlighted in Monsey's demonstration using vending machines, as discussed in Spradley (1980), and this model was adopted during the participant observation stage.

The participant observer records minute details of what he sees, hears, and experiences, yet at the same time both observes and records the various steps taken to reach the goal, for example drugs used during sigmoidoscopy/colonoscopy, where the drugs were stored, which drug and how much was used, putting the drugs in the syringe, pressing the plunger and finally taking the needle from the syringe and disposing of it in the yellow bucket. Finally recording the drugs used in the dangerous drug act book (DDA). Also observing the peoples dress, and the way the patients, nurses,

colonoscopist interacted with others. And of course watching my own actions and the ways people interacted with me.

According to Milgram (1974) complexity of social life in the modern world requires that the ordinary participant excludes much from their conscious awareness; we may overhear a conversation, but generally what goes on around remains outwith our explicit awareness. Milgram's theory suggests that if humans remembered all the incidentals going on around them, then we would go into overload, this he likens to the systems inability to process inputs from the environment because there are simply too many inputs for the system to cope with. So what we watch and listen for remains limited to our immediate purpose. In contrast the participant observer has a heightened awareness and must approach the social life with a wide angled lens observing a broader spectrum. They must become explicitly aware of the incidentals surrounding the situation and overcome years of selective inattention. In other words you must switch on, and discipline yourself to see what was previously unseen.

My research involved shadowing patients from the minute they reported into the unit. This allowed me to observe the different stages the patients went through; how they were separated from their normal society and introduced into an alien hierarchical society; the liminal stage which involved them having to interpret a new language in the form of medical terminology, their disempowerment and estrangement from previous self identity i.e. person to patient, and their reactions to advanced technology and colour stratification of the staff uniforms. And finally how patients were re-incorporated back into their own society. The ordinary participant sees some of what goes on around them, because they are insiders, i.e. being a part of that social situation. In contrast the skilled

participant observer sees life from both angles simultaneously, as an insider and an outsider. Furthermore the participant observer must become introspective, in other words we examine the situation and ascertain how well or how badly we have done, for example after each visit I debriefed on how I felt during particular times. Armed with this new found knowledge, solid theoretical framework, ASA Ethical Guidelines, as well as an advantage of having 'one foot in and one foot out', I felt confident to venture into the field. Following Huby and Malinowski's examples, participant observation has been written up in the ethnographic present; a snapshot picture of 'how it was' at a particular time. I used Van Gennep's 'rites of passage' model to analyse the procedure.

While access might otherwise have been a major headache I was fortunate enough to have been employed in a study commissioned by the National Health Service to evaluate the two new open access units on Teesside. Clearance from the relevant ethics committees had already been arranged so this alleviated any problems I would have undoubtedly encountered had I been doing this work alone. Whilst clearance from the ethics committees had been granted for this research I was constantly aware that these patients were in a vulnerable situation and that I was privy to viewing an area of their body that is culturally perceived as being a taboo, i.e. the anus. Ellen (1984) states that ethnographers should recognise the rights of participants to privacy, confidentiality and anonymity, and also the right to choose not to be studied. However this should be an informed decision and participants should be aware of the methods, aims, anticipated consequences, benefits, risks or disadvantages to the study. I was therefore pedantic in my reiteration to patients that participation was strictly on a voluntary basis. My aim

being to build a rapport with the patients before their colonoscopy, in an endeavour to seek a follow-up interview.

Introductory meetings were set up at North Tees Hospital and South Cleveland Hospital by the team co-ordinator, wherein I could meet the medical, nursing and administration staff. Frances (1992) suggests in her studies that having a gatekeeper or mediator is particularly helpful. The powerful association of the research team was advantageous to me as both Dr. Greg Rubin and Dr. Pali Hungin my gatekeepers, were well-respected in medical and academic circles. Consequently, as a member of this research team I was regarded without threat and accepted quickly as a respected member of that team. During my initial contact with the service providers, nursing sisters gave a tour of the wards and theatres incorporating an introduction to the equipment and drugs used during sigmoidoscopy.

The administration staff offered a concise picture of the referral system, instructions and procedures prior to admission, patient numbers and approximate waiting times for admission. Through participant-observation a clear understanding was obtained of the procedures and organisation of the clinics. Furthermore, by gathering information from both the patient and medical staff perspective I was able to design a questionnaire, which incorporated internal as well as external validation (Bamford et al 1992).

2:2 Patient Satisfaction Questionnaire

The patient satisfaction questionnaire was designed after initial consultation with the medical staff from the OAFSS; their input was invaluable in the planning stage. During the first few months of the study distribution of the questionnaire took place by

the nursing staff at both hospitals. However, due to the heavy demands of nursing duties this was often overlooked so it was decided that all questionnaires would be distributed by post from the research centre. All patients were asked to wait twenty-four hours after their colonoscopy before filling in the questionnaire and returning it in the pre-paid envelope provided (Appendix 1).

2:3 Patient Interviews

The patients who agreed to be interviewed were requested to wait until the following day to complete the questionnaire, but to complete this before my visit. This time span was set to counteract the varying sedative effects of the drugs used during the procedure, also to combat any bias from the personal interviews which were scheduled to take place within a twenty-four hour period. Sixty-four patients took part in this section of the patient satisfaction study.

Whilst all the patients interviewed had their colonoscopy/sigmoidoscopy examination in the OAFSS, thirty two of the patients were directly referred by their general practitioner to the OAFSS, the other thirty two patients were referred to the OAFSS via the outpatient service (comparison of these 'routes' was a major part of the main study and ultimately played a significant factor in the patient satisfaction results). Their names were chosen at random from the colonoscopy lists of the two hospitals, thus eradicating any bias for the more sociable and articulate, age, gender, education levels and previous health problems (Oppenheim (1992: 128); Benjamin (1992)). All patients asked, agreed to take part in the study. However I decided not to visit one male patient because of personal safety issues.

The aim of the interview was to ask patients open-ended questions about their colonoscopy, and through narrative and vignettes to record critical incidents to assess levels of satisfaction. However, the majority of patients had been administered Midazolam, an amnesiac which induces temporary memory loss and this offered a challenging problem for my methodology. How could the patients evaluate a service when they may have been in a state of drug-induced memory loss?! Suffice to say they could not; my data collection in many instances was therefore coloured from the point of intravenous injection by Midazolam until memory retrieval. This drug was used extensively in both units.

Interviews were conducted in the privacy of patients' homes; confidentiality was established and a commitment given by me that they would be non-attributable. I also assured participants that the research was an independent anthropological exercise and was autonomous from the open access unit. While participants were in full control of the agenda for narration (Bailey 1994) they were prompted to talk about their emotional as well as physical state, their feelings about the staff and their feelings both during and after the procedure. Those who delayed seeking medical attention were encouraged to discuss their reasons. Interviews were either recorded or key words or phrases noted when describing critical events and written up as near to verbatim as possible (Bender & Ewbank 1994).

2:4 Patient Focus Group

Whilst the services offered at North Tees Hospital and South Cleveland Hospital were supposed to be standardised, differences in procedures did come to light during the

personal interview stage. It was therefore decided that in order to highlight and compare experiences, a focus group meeting incorporating patients from both services would be of value. The seven focus group participants were unknown to each other, their commonality being their colonoscopy experiences at the open access services of either North Tees Hospital or South Cleveland Hospital. The patients were invited from the group that I had been studying through participant observation and home interviews. All but one had been previously interviewed within twenty-four hours post-colonoscopy; the focus group allowed them to reflect further on their reasons for delay in visiting their general practitioners. With the permission of patients the focus group meeting was recorded then transcribed at a later date.

2:5 General Practitioners' Use of Guidelines Study

This patient/general practitioner satisfaction study was part of a much wider study of the OAFSS by the National Health Service Executive. The main study involved a database established at both North Tees and South Cleveland Hospitals by the research associate; she gathered information of general practitioner usage, patient diagnosis, type of test performed, for example sigmoidoscopy or colonoscopy, and various other components which were tangential to my own focus in the study. However, two important aspects of the main study, distribution of guidelines and a peer education package were particularly relevant to me in that it was from these general practitioner listings that I randomly chose my participants to interview on their use of guidelines.

260 general practitioner practices were chosen to take part in the main study, 130 from North Tees catchment area and 130 from South Cleveland area. Half of these

practices (65 in each group) were 'subject' practices, to which copies of the guidelines were sent, and half were 'controls', who were not sent copies of the guidelines. All general practices who had access to the service were identified from Health Authority records six months prior to the commencement of the intervention part of the study (April 1st 1997).

2:6 GP Interviews

Between June and August 1998, 10% or 26 general practitioners were selected at random for my study. 13 from North Tees and 13 from South Cleveland area. This ensured a broad spectrum of demographic, cultural and professional characteristics. 13 of the practices were in the subject group and 13 in the control group. The 26 general practitioners were contacted via telephone, and were requested to discuss their perceptions of the OAFSS during an interview. All 13 general practitioners in the subject group had been sent desktop (plastic coated) copies of the summary of the guidelines around six months before the start of the intervention period. As well as written guidelines for the OAFSS, a general practitioner researcher in full-time practice began contacting subject practices offering an education session on the use of the flexi-sigmoidoscopy service. A further copy of the guidelines was sent around a month prior to the educational intervention (Appendix 2), on this occasion accompanied by a letter containing the evidence in support of the guideline and academic detailing (Appendix 3). In contrast the control group were not advised, by the research team, of the OAFSS or the implementation of guidelines for service use. However, contamination was inevitable when one considers how closely the gastro-enterology consultants liaise with general

practitioners in rural practice. Furthermore some general practitioners had become aware of the service throughout their compulsory educational sessions at South Cleveland Hospital and through shared socio-medico relations.

During the interview all 26 participants were asked for their perceptions regarding medical guidelines in general. The 13 general practitioners who received the OAFSS guidelines were asked to comment on individual usage of them to establish whether adoption of these guidelines had taken place. General practitioners were also asked to evaluate the educational intervention session, however, only 6 general practitioners from the subject group had actually taken advantage of the educational support offered. By and large most general practitioners were responsive and enthusiastic. Of the four refusals received, time constraints, holidays, workloads and lack of service use were suggested as the causative reasons for their failure to participate. One interview was declined with a general practitioner who demanded a financial reward as a reciprocal payment for his time. These refusals were replaced by other practices randomly selected but with the same subject/control characteristics.

Interviews were conducted after the guidelines had been in circulation for six months. They took place at the general practitioners' work place and lasted between 20 minutes and 1 hour 20mins. All but one were audiotaped; in this exceptional case, where the doctor preferred not to be tape-recorded key phrases and words were noted and written up as near verbatim as possible. Questions related to the general attributes of guidelines, what made them acceptable to general practitioners, (for example their basis in 'evidence', authorship, dual input, and readability). The subject group, but not the control group, were also asked questions pertaining specifically to the OAFSS guidelines,

(Appendix 2) for example what they liked or disliked about this particular set of guidelines. All general practitioners were also asked questions which pertained to patient delay in presenting with rectal bleeding (Appendix 4)

Chapter 3. Fieldwork Up the Colon

Van Gennep (1908) (1960 in bibliography) describes the change of status which people experience through ritual or initiation ceremonies as rites of passage with three separate components. These are a stage of separation in which the person is removed from everyday society, followed by a liminal or transitional stage, before the final stage of re-incorporation into their 'normal' society. I found this schema useful in analysing the stages a person goes through when attending the OAFSS as a patient.

3:1 The Separation Stage

“We can view medicine as a cultural system, a system of symbolic meanings anchored in particular arrangements of social institutions and patterns of interpersonal interactions” (Kleinman 1980:24)

On arrival at reception the person was requested to take a seat whilst the unit staff were informed of their arrival. A blue or green pyjama-clad nurse (this colour coding symbolically denoting the stratification of seniority in a heavily hierarchical institution) duly arrived and called the person's name; the nurse introduced herself to the person and escorted him/her to their bed/trolley-bed. Various degrees of explanation pertaining to the actual procedure occurred depending on the nurse's interpersonal skills and time dictates. In other words the ritual of entering the National Health Service organisation as a patient had begun; they had entered an alien social system. Patients were given a gown that fastened at the back for use during the procedure, asked questions pertaining to their current health status, previous medical history and, whether their pre-colonoscopy medication had been successful. The rationale for this medication was to ensure bowel cleanliness and consequent visibility of all areas of the colon. The patients entered the

first stage in their rite of passage; they were separated from their own societal mores. Their clothes were placed below the trolley bed, their blood pressure recorded and their private space lost. They did however engage in conversation with the nurse and on many occasions shared jokes, which nearly always pertained to appropriate bodily matters. An example to demonstrate this is highlighted below.

Two doctors opened offices in a small town and put up a sign reading "Dr. Smith and Dr. Jones, Psychiatry and Proctology." The town's fathers were not too happy with that sign, so they changed it to "Hysteria's and Posteriors." This was not acceptable either, so they changed the sign to "Schizoids and Haemorrhoids." No go, so they tried "Catatonics and High Colonics". Thumbs down again, so they tried "Manic-depressives and Anal-retentives." Still not good, so they tried "Minds and Behinds." Unacceptable again, so they tried "Lost Souls and Ass-holes." Still no go. Nor did "Analysis and Anal Cysts", "Nuts and Butts", "Freaks and Cheeks" or "Loons and Moons" work either, so they finally settled on "Dr. Smith and Dr. Jones, Odds and Ends."

Email communication, Dr. Jonathan Skinner (2000)

3:2 The Liminal Stage

In North Tees the patients walked to the theatre, accompanied by the nurse whereas in South Cleveland they were wheeled in their trolley bed. The apprehension mixed with anxiety could be seen through the body language of the patient as almost ceremoniously the person started their journey. Signature for consent of the procedure was obtained immediately before the procedure by the colonoscopist. The patient had become part of the technoenvironmental system. (I was aware of the transition into the liminal stage with the transformation from conscious to unconscious as the patients entered the operating room). Douglas (1970: 81) suggests that "surgical procedures are stylised forms of behaviour with order and structure. They may, in and of themselves, convey unconscious meaning to the participants", particularly if, as Douglas suggests,

ritual in itself is pre-eminently a form of communication. The focal point in both theatres was the diagnostic video monitor wherein geography, normality and abnormality of the various parts of the colon were openly discussed by both colonoscopist and nursing staff as they ventured further into the 'field'!

The patient was asked to turn onto the left lateral position wherein an intravenous injection was administered. Standard medication regimens were used (in all but one patient, who refused sedation) with intravenous injection of 2.5mgs-5mgs of Midazolam or 10mgs-20mgs Diazemuls also 25-50mgs Pethidine (See glossary), was administered as a prophylactic against pain. This was titrated against the colonoscopist's perception of its effect, ensuring that each patient, whilst sedated, was able to co-operate with position changes when required. Midazolam appeared to be more regularly used in South Cleveland than North Tees and would account for the quick turnover of patients due to its non-sedative but amnesiac effect which contrasts with Diazemuls. The colonoscopy tube was lubricated and inserted into the patient's anus. The length of the tube depended on whether the colonoscopist performed a sigmoidoscopy or a full colonoscopy. At a later stage the patient was instructed to turn into the recumbent position and pressure was applied to the abdomen to assist an easy passage of the tube.

During the colonoscopy oxygen saturation levels were recorded by nasal sponge; only one patient whom I observed, experienced reduction in oxygen saturation levels. This lady, who suffered temporary hypoxaemia, was in her late eighties and nearing the last stage in the procedure; she recovered well once given a higher oxygen intake.

The duration of the procedure varied from fifteen to thirty-five minutes. Whilst both hospitals performed polypectomies and biopsies during the procedure, unlike South

Cleveland Hospital, North Tees did not have the facilities (or expertise) to treat haemorrhoids either by injecting or banding.

3:3 The Re-incorporation Stage

The patients were returned to the ward by the theatre nursing staff and again, depending on the hospital, were encouraged either to sleep for a couple of hours, or, particularly in South Cleveland, were encouraged to dress and vacate the bed immediately they felt physically able. These patients were encouraged to sit in the waiting room to recover fully, with the aid of tea or coffee.

The manner in which the patients received their results differed between hospitals. All patients in South Cleveland congregated in a large waiting room before discharge. The doctor on some occasions spoke to the patients and discussed the findings, however, many patients were discharged not knowing their results, despite previous assurances to the contrary by the colonoscopist. Those informed were given their diagnosis, regardless of severity, surrounded by other patients. In North Tees during the first fieldwork year, there was no subsequent consultation with the colonoscopist and all patients were informed that their general practitioner would receive the results in approximately ten days. This practice accorded with pre-examination literature. However, on some occasions the discharge nurse would inform the patient of the diagnosis; again this appeared to depend on the technical acumen or time management of the nurse. During the second fieldwork year, in North Tees Hospital, when the consultants assumed the role of the colonoscopists, things were dramatically different in that many patients were informed of the findings by the colonoscopist/consultant before discharge.

Chapter 4. Patient Satisfaction with the OAFSS

Having familiarised myself with the protocol and procedures of the two services I completed the first section of this tripartite qualitative methodology, fieldwork up the colon, which I analysed using Van Gennepe's model. My next stage involved the collection of questionnaires and patient interviews. But first it was necessary to do a literature search and examine the theoretical models surrounding the concept of patient satisfaction.

4:1 Introduction

What is Patient Satisfaction?

Patient satisfaction is defined by Pascoe (1983) as a health care recipient's positive or negative reaction to salient aspects of the context, process, and result of their service experience. This is a heterogeneous concept that can be related to a vast number of variables including education, age, medical history, and the values of both the individual and the society to which they belong (Carr-Hill 1992).

Hunt (1977) theorises that satisfaction and dissatisfaction are not an emotional reaction, but are based on pre-conceived notions of what is expected to happen. He opens this debate by demonstrating that whilst pleasure is felt, it can still cause dissatisfaction when evaluated if the experience is below the level of a perceived standard. Linder-Pelz's (1982) theory contrasts with Hunt's in suggesting that satisfaction is an affective response. Her theory arose from numerous studies of industrial job satisfaction wherein she used instruments such as proximity to place of

work to evaluate how people's perceived values would determine perception of job satisfaction.

As patient satisfaction is a positive abstraction, any study must ultimately focus on components of negativity or dissatisfaction. Moreover, complexities further arise within these components, as the reasons for dissatisfaction may be interpreted differently by different people at different times, as well as the same people at different times (Rashid et al 1990).

Current Approaches to Patient Satisfaction

In today's health arena patients are increasingly becoming viewed as consumers of a service, yet it is argued by Pascoe (1983) that consumer-orientated research, (assuming this is an appropriate approach to health care evaluation) "does not attend to the conceptual and methodological development of marketing-based models of consumer satisfaction". Fox and Storms (1981) suggest that understanding the central core of patient satisfaction should be the fundamental element rather than the sociodemographic correlates which, they argue most researchers use as their central instruments. Gutek (1978) considers that for this to be done succinctly exploring the cognitive definition of satisfaction for respondents is vital. A solid sociopsychological framework is therefore proposed by him; Locker et al. (1978) also believes this to be the most effective approach.

Linder-Pelz (1982) postulates that satisfaction is related to a positive attitude and uses a framework surrounding an expectancy-value model gauged on attitude. Fishbein and Azjen (1975) also work on this value premise describing satisfaction as a "general

evaluation or feeling of favour toward the object in question.” Stimson and Webb (1975) suggest that satisfaction is related to perception of the outcome of individual care and to the extent to which it meets the patient's expectations. However Owens et al. (1996) disagree with this theory suggesting that there is little evidence to suggest that satisfaction is mainly the result of fulfilled expectations and values.

An alternative model, namely the discrepancy model, is used by Lawler (1973). He argues that a patient's fulfilment of expectation is the most valuable instrument. This he defines as “a function of the amount received from a situation regardless of how much one feels they should want or want to receive.” Most patient satisfaction studies have used a discrepancy approach (Pascoe 1983). This is based on the researcher's personal definition of satisfaction in relation to perceived satisfaction; this is then cross tabulated with expected care to actual care received.

Studies suggest that patients' perceptions of good care are highly emotive with personal qualities of the staff, for example, friendliness and reassuring interpersonal skills taking precedence over technical acumen and medical competence (Fitzpatrick et al 1991). Dissatisfaction is perceived if the doctor treats the consultation as routine and does not recognise the 'person' within the patient's diagnosis. Studies show that a disinterested doctor will have many dissatisfied patients (Meredith 1992). Hall and Dornan (1988) found that patients feel more rapport with trainee-doctors than consultants. Helman (1990) suggests that this is because student doctors are in the early stage of “a process of enculturation whereby they acquire the higher social status due to their socially legitimised role of healer.” This may also be due to a pre-conceived idea

that a 'white coat' consultant requires a ritualistic, revered attitude from his patients, which inevitably cause feelings of inequality and 'ill-ease'.

Physicians will often fail to inform patients of their surgical outcome, particularly concerning any negative prognosis, which further leads to dissatisfaction (Meredith 1992). Failure to take into account patients' comprehension of medical terminology and an unwillingness to become 'culturally aware' further creates a barrier to the easy exchange of information, which McGhee (1991) argues, is the greatest single fault in patient care.

Various explanations have been given for patient dissatisfaction with health care provision. It is suggested by Schutz et al (1994) and Fitzpatrick et al (1993) that patients' differing educational backgrounds initiate different responses to health care. A failure to reassure anxious patients is suggested by Hall et al (1988) as being a further source of dissatisfaction. Furthermore they suggest that patients with a history of ill-health are usually dissatisfied people anyway and because of constant pain their overall outlook to health care is coloured by their ill-health. But Greenley et al (1982) argue that it is not the patients who are to blame for the dissatisfaction; it is the doctor's attitude and reaction to these particular patients which instil low levels of satisfaction. In Nelson and Larson's (1993) opinion patients who receive a perceived positive outcome (or good surprise) to their care and who are pleasantly surprised with this result, are more likely to voice satisfaction than those who receive a negative outcome (or bad surprise). Thomas et al. (1995) suggest that patients in hospital appreciate being given details of the day's itinerary, particularly relating to any surgical procedures, and, that failure to fulfil this requirement induces dissatisfaction with the nursing staff.

Current studies indicate that only the tip of the iceberg has been revealed in the pursuit of explanation for dissatisfaction. A possible reason for this might be that patients need security and the authority of medical staff but questioning satisfaction paradoxically questions this authority and makes dissatisfaction more likely. Dissatisfaction may affect the subsequent prognosis of the patient, due to cessation of medication, possibly because patients fail to attend required follow-up appointments (Fitzpatrick (1991); Williams (1994)). Broader issues of outlook and attitude to illness coupled with actual experiences will also subsequently affect outcome. Shultz et al (1994) found that dissatisfied patients are likely to be less compliant, engage in legal action and 'physician shop', a process in which they move from one doctor to another.

Bruster et al. (1994) believe that the very act of asking patients about nursing care often produces highly positive findings, because patients want to please. The reluctance of patients to criticise health professionals is evidenced by particularly high recorded ratings of patient satisfaction. Therefore, inadequacies experienced by the patient are not always uncovered. Williams (1994) demonstrates this in his study of elderly patients who are using the district nurse service. His findings are that the majority of elderly patients voiced satisfaction when they were actually dissatisfied with some aspects of their care. His findings also suggest that loyalty to the nursing staff is a primary concern to elderly patients. Meredith (1992) on the other hand suggests that older people may judge present health care satisfactorily because they have witnessed poorer health care provision when younger.

Williams (1994) concedes that some patients will critically evaluate their health care. However, the majority of studies show that most service users are uncritical and

will indicate satisfaction with poor quality care. Owens et al (1996) found in their studies that a large majority of health consumers express overall satisfaction and few respond negatively to any specific item. My own studies demonstrate how patients may feel 'let down' by insensitivity, yet at the same time express high levels of satisfaction. If patients do complain at all, it is often about long waiting periods at outpatient clinics, appointments, admission and inadequate information at all levels. Various consumer-type health studies show that on average, patients produce a 77.5% level of satisfaction with their health care.

Owens et al. (1996) suggest that patients should act like consumers when buying services within the National Health Service as they would do in any other marketing arena. They suggest that rejection of passivity by the patient should be encouraged when evaluating any aspect of health service. I would argue like Owens, that patients need to be informed and empowered to act like customers. However I would also suggest that, in emphasising 'satisfaction', we are denying patients the opportunity for their experiences and opinions to be included in the future planning and improvement of health care services (Black 1994).

The elderly have a low status within Western society and as such portray high levels of passivity and satisfaction (Williams 1994). It may be argued that infantilized and disempowered elderly patients manifest high satisfaction ratings (Hockey & James (1993). The American studies of Ware et al (1975) indicate that the doctor's conduct was the most important factor of relevance leading to patient dissatisfaction. American culture is thought to produce patients who feel alienated and dissatisfied because of unrealistic expectations and authoritarian physicians (Mechanic 1976).

Studies carried out in Costa Rica by Low (1983) discovered that patients evidenced high satisfaction levels when their expectations were fulfilled in the form of medication, clinical tests and examinations during consultation. In contrast the dissatisfied patient failed to have their expectations fulfilled. It was also reported that the more articulate, financially advantaged patients recorded higher levels of dissatisfaction; these results arose despite a two-fold increase in physician-time allocation compared to a poorer group.

Williams (1994) argue that insufficient qualitative research is being done to assess patient's levels of satisfaction. Pope and Mays (1993) advocate that for effective research, both qualitative and quantitative approaches need to be used; this accords with Frankenberg's theory, which suggests that:

Surveys, at least in isolation, miss the point of everyone's life. It has taken the determination of women to understand and change their own lives to make this apparent to sociologists. They have begun in a more constructive way than mere phenomenological critiques to drive sociology back to a concern with meaning and process...Public structures are in fact always lived through private processes, for men as well as for women, for managers as well as workers; for doctors as well as patients...Successful research and politics makes clear the connection between the private experience and the collective reality.

(Frankenberg, 1986:89).

I shall explore this argument through comparison of questionnaires and qualitative methods.

4:2 Results of Patient Satisfaction Questionnaires

548 questionnaires were returned to the research centre from a total output of 1200. I collected 64 questionnaires from the patients I visited, making a total of 612. These were analysed using the package Epi info, which was also used for the main database analysis. The following tables show the response to each question asked of patients by questionnaire (Appendix 1). The charts give an overall picture of satisfaction levels between the two referral routes.

TABLE 1: LEVEL OF SATISFACTION WITH LAYOUT OF THE UNIT				
Value Label	Out Patients	Out Patients %	Open Access (GP referral)	Open Access % (GP referral)
Very Satisfied	243	65.68%	162	71.37%
Satisfied	118	31.89%	64	28.19%
Slightly Dissatisfied	6	1.62%	1	0.44%
Very Dissatisfied	3	0.81%	0	0.00%
Total	370	100.00%	227	100.00%

TABLE 2: LEVEL OF SATISFACTION WITH ATMOSPHERE OF UNIT				
Value Label	Out Patients	Out Patients %	Open Access (GP referral)	Open Access % (GP referral)
Very Satisfied	254	67.73%	182	78.45%
Satisfied	114	30.40%	47	20.26%
Slightly Dissatisfied	6	1.60%	3	1.29%
Very Dissatisfied	1	0.27%	0	0.00%
Total	375	100.00%	232	100.00%

TABLE 3: LEVEL OF SATISFACTION WITH THE ORGANISATION OF THE VISIT

Value Label	Out Patients	Out Patients %	Open Access (GP referral)	Open Access % (GP referral)
Very Satisfied	241	64.27%	154	66.67%
Satisfied	108	28.80%	71	30.74%
Slightly Dissatisfied	16	4.27%	6	2.60%
Very Dissatisfied	10	2.67%	0	0.00%
Total	375	100.00%	231	100.00%

TABLE 4: LEVEL OF SATISFACTION WITH THE TIME WAITED FOR AN APPOINTMENT

Value Label	Out Patients	Out Patients %	Open Access (GP referral)	Open Access % (GP referral)
Very Satisfied	189	50.81%	94	40.69%
Satisfied	119	31.99%	89	38.53%
Slightly Dissatisfied	44	11.83%	40	17.32%
Very Dissatisfied	20	5.38%	8	3.46%
Total	372	100.00%	231	100.00%

TABLE 5: LEVEL OF SATISFACTON WITH PRIOR POSTAL INFORMATON

Value Label	Out Patients	Out Patients %	Open Access (GP referral)	Open Access % (GP referral)
Very Satisfied	232	62.37%	155	66.81%
Satisfied	115	30.91%	69	29.74%
Slightly Dissatisfied	16	4.30%	6	2.59%
Very Dissatisfied	9	2.42%	2	0.86%
Total	372	100.00%	232	100.00%

TABLE 6: LEVEL OF SATISFACTON WITH HOW THE CLINICAL PROCEDURE WAS CARRIED OUT

Value Label	Out Patients	Out Patients %	Open Access (GP referral)	Open Access % (GP referral)
Very Satisfied	269	72.70%	196	84.48%
Satisfied	90	24.32%	34	14.66%
Slightly Dissatisfied	10	2.70%	1	0.43%
Very Dissatisfied	1	0.27%	1	0.43%
Total	370	100.00%	232	100.00%

TABLE 7: LEVEL OF SATISFACTION WITH PAIN CONTROL

Value Label	Out Patients	Out Patients %	Open Access (GP referral)	Open Access % (GP referral)
Very Satisfied	232	62.87%	188	80.69%
Satisfied	89	24.12%	38	16.31%
Slightly Dissatisfied	30	8.13%	6	2.58%
Very Dissatisfied	18	4.88%	1	0.43%
Total	369	100.00%	233	100.00%

TABLE 8: LEVEL OF SATISFACTION WITH CARE BY WARD STAFF

Value Label	Out Patients	Out Patients %	Open Access (GP referral)	Open Access % (GP referral)
Very Satisfied	296	80.00%	199	86.52%
Satisfied	59	15.95%	30	13.04%
Slightly Dissatisfied	11	2.97%	1	0.43%
Very Dissatisfied	4	1.08%	0	0.00%
Total	370	100.00%	230	100.00%

TABLE 9: LEVEL OF SATISFACTION WITH CARE BY THEATRE STAFF

Value Label	Out Patients	Out Patients %	Open Access (GP referral)	Open Access % (GP referral)
Very Satisfied	304	81.72%	200	88.11%
Satisfied	64	17.20%	26	11.45%
Slightly Dissatisfied	2	0.54%	1	0.44%
Very Dissatisfied	2	0.54%	0	0.00%
Total	372	100.00%	227	100.00%

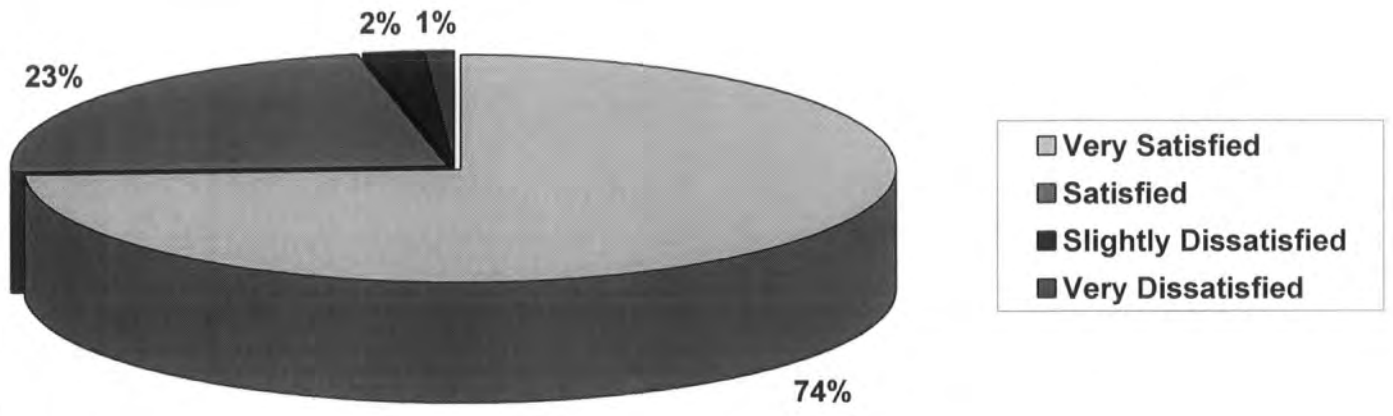
TABLE 10: LEVEL OF SATISFACTION WITH THE MANNER IN WHICH RESULTS WERE GIVEN

Value Label	Out Patients	Out Patients %	Open Access (GP referral)	Open Access % (GP referral)
Very Satisfied	165	46.88%	100	47.85%
Satisfied	101	28.69%	69	33.01%
Slightly Dissatisfied	43	12.22%	35	16.75%
Very Dissatisfied	43	12.22%	5	2.39%
Total	352	100.00%	209	100.00%

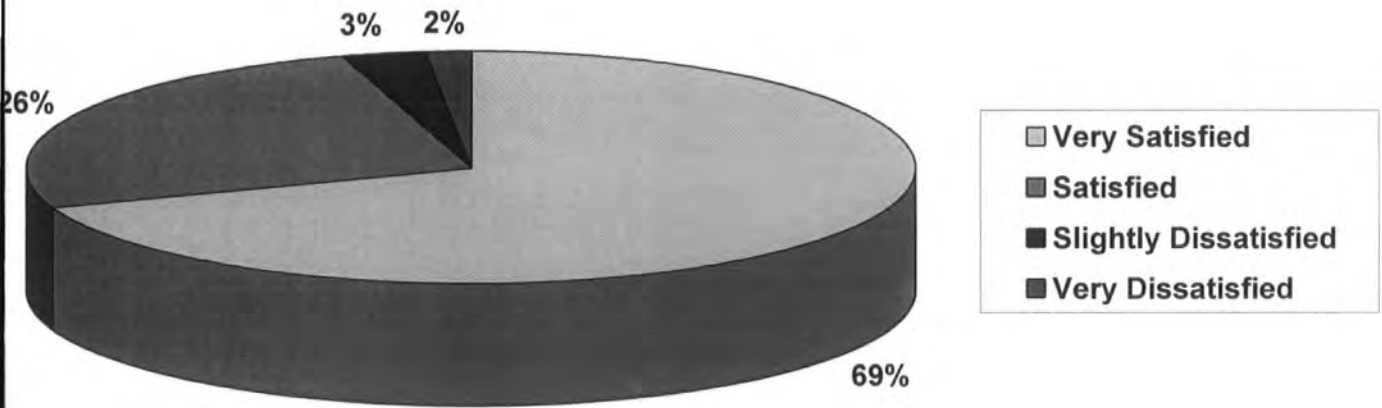
TABLE 11: OVERALL SATISFACTION WITH THE SERVICE

Value Label	Out Patients	Out Patients %	Open Access (GP referral)	Open Access % (GP referral)
Very Satisfied	260	69.33%	188	81.74%
Satisfied	97	25.87%	40	17.39%
Slightly Dissatisfied	12	3.20%	2	0.87%
Very Dissatisfied	6	1.60%	0	0.00%
Total	375	100.00%	230	100.00%

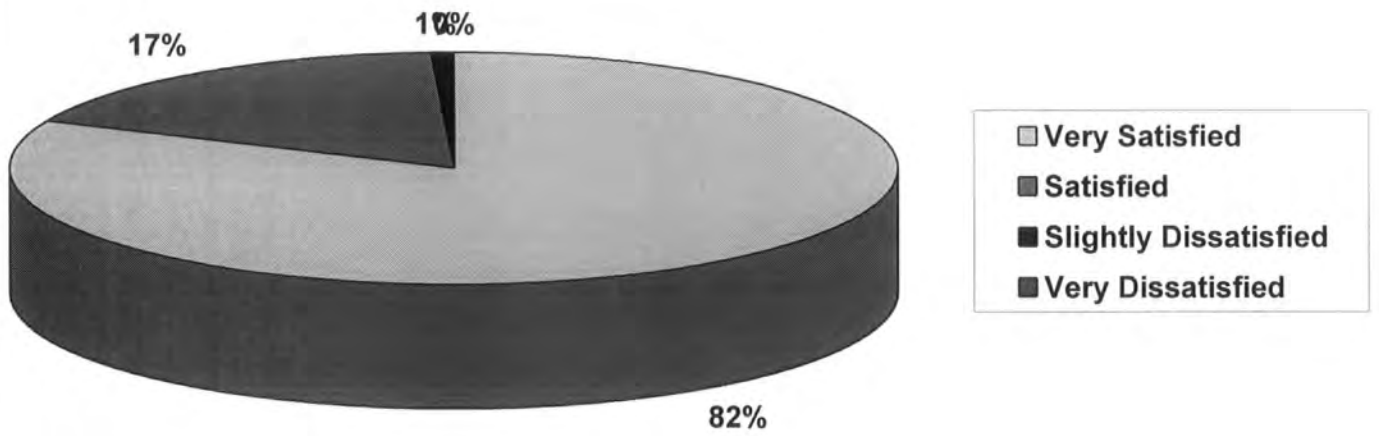
OVERALL PATIENT SATISFACTION LEVELS WITH OPEN ACCESS SERVICE



OVERALL PATIENT SATISFACTION LEVELS WITH THE OPEN ACCESS SERVICE VIA OUTPATIENT ROUTE



OVERALL PATIENT SATISFACTION LEVELS WITH THE OPEN ACCESS SERVICE VIA GP REFERRAL



The results of this section show that of those patients referred to the OAFSS by their general practitioners, 99% were satisfied overall with the service, and 1% expressed slight dissatisfaction. In contrast, 95% of patients who arrived at OAFSS via the outpatient route were satisfied with the service, however 3% expressed slight dissatisfaction and 2% said they were very dissatisfied with some aspect of the service. The average between the two showed a 97% satisfaction rate, with 2% being slightly dissatisfied and 1% being very dissatisfied.

The tables show that the main areas of concern to patients were a) appointment times, with 17.21% from outpatients and 20.78% from GP routes voicing dissatisfaction; b) pain control, with 13.01% of patients voicing dissatisfaction from the outpatient route in contrast 3.01% of patients from the GP route, c) the manner in which their results were given which showed that 24.44% of patients were dissatisfied by the outpatient route and 19.14% were dissatisfied via the GP route.

A few patients added unsolicited comments on various aspects of their care at the foot of the questionnaire. For example in answering question one, three patients indicated that the toilet/changing facilities at South Cleveland hospital were of a poor standard:-

“I was not happy leaving my clothes in a room where people went in to use the toilet”.

“The toilet had faeces on it”.

“The toilet was dirty”.

In response to questions 4 and 5 concerning the waiting times for appointments and information given prior to their visit, 4 patients expressed concern regarding

cancellations and appointment change at the last minute, and four patients indicated that prior information was inadequate.

“I was left around too long before going to theatre”.

“There should be a warning about the strength of the laxative on the information”.

“They should tell you that you should be accompanied”.

“What is clear fluid?”.

“There should be a warning about not feeling up to returning to work”.

Four patients suggested in response to question 7 that their pain tolerance level was challenged during the procedure!

“Medieval torture”.

“Pain intolerable”.

“No sedation given despite letter advising this”.

“The pain was unbelievable”.

The response to question ten highlighted that patients were dissatisfied with how and where the results of the tests were given to them.

“Information given in a public place. I heard one patient receiving unpleasant news; they should have privacy”.

“Took three weeks for the results to reach my doctor”.

“There is a lack of communication between general practitioners and hospital regarding the results; I gave up after three weeks”.

“I was given the information whilst I was still sedated”.

Incidental comments pertained to dissatisfaction with parking fees, the strength of the envelopes in which their medication was posted to them, the wrong positioning of the hospital, and a request for a sound proof booth for the embarrassment-free release of wind. One patient's comments pertaining to his colostomy alerted me to the fact that a degree of contamination had occurred in that he was outwith the parameters for open access referral. One patient, despite reporting an overall satisfaction with the service mentioned that her bowel had been perforated during the procedure.

Quantitative research by definition involves limited depersonalised responses from a wide number of participants. Furthermore as Oppenheim (1992) point out, closed questionnaires may not fully address the complex attitudes and opinions held by respondents. However, in this study, a few patients evidently felt moved to write personal comments pertaining to their experience of the service. These jottings and embellishments to the tick box questionnaire format adds a humanity to the study which would be lost in a computer scored analysis. As Aharony and Strasser (1993) comment, 'virtually no studies have systematically content-analysed the written (qualitative) comments that patients provide on self-administered surveys. But qualitative research by its open-ended unstructured questions adds enrichment to the data, which holistically complexifies both methodologies. Gluckman (1962) comments that case studies impart a sense of concreteness to an otherwise overwhelmingly abstract account, so, by comparing the questionnaire with the qualitative research, I was able to highlight through the following case studies the problems experienced by patients with the service. Moreover they demonstrate the problems with patient satisfaction measures by questionnaire alone.

4:3 Results of Patient Interviews

I interviewed sixty-four patients in their homes the day after their colonoscopy. Their narratives accompanied by body language, facial expression, tears and frustrations produced a holistic picture, which could not have been captured in a group setting (Faraday 1979). I

In successfully identifying and understanding what someone else is doing we always move towards placing a particular episode in the context of a set of narrative histories, histories both of the individuals concerned and of the settings in which they act and suffer (MacIntyre 1981: 197).

Seven case studies have already been published in Social Science and Medicine (Dougall 1999). The different case studies presented here are intended to expand on and amplify the points already made in the published article.

Case Study 1: treated like a king

This seventy seven year old gentleman explained that he had been suffering from tummy trouble for the past two months. He observed blood and mucous in his stool and suggested he had excessive bloating and wind. He also suggested it was probably Irritable Bowel Syndrome. His GP referred him to the open access unit. He waited approximately 6-8 weeks. On arrival in the operating room he said that he might be wasting our time, as he felt better. The consultant explained, in a most compassionate manner, that one does not get IBS over the age of 45years and that it was 'always sensible to have new symptoms checked out'.

A huge growth, resembling coral, was located by the colonoscopist, and an implication made by the colonoscopist that it might be either an adenoma or a large

polyp. The growth, which had a large stalk, was skilfully cauterised by diathermy. It was so large the colonoscopist was unable to extract this via the colonoscope, however he was able to push it as low as possible for the patient to pass later. The patient was returned to his single room and the consultant explained to him that he had removed a large polyp that would have eventually turned cancerous. He congratulated him for coming and assured him that his time was definitely not wasted. The patient, once he was sufficiently awake, was asked to sit on the commode and pass the polyp, this he did and it was sent off to the pathology department for analysis along with the stalk.

“I felt like his majesty, everyone was very welcoming, and I was treated with nothing but kindness. The single room was beautifully set out with a radio. I arrived at the stated time and I appreciate that one cannot guarantee times for these things as the patients before may take longer or shorter. I felt at ease with the doctor. I only felt one pain and that could be likened to an electric shock, a sort of sharp pain. I passed the polyp afterwards in the commode and my son took me home at 5.30 p.m. Yes I was treated like a king”

He and his son suggested that the only criticism they had was that the documentation was not set out particularly well, and could be slightly confusing. This man expressed a high degree of satisfaction throughout the interview as well as on his questionnaire. This man was treated with the rituals congruent with good health care. He was treated in a gentle, caring manner by the nursing staff and with the utmost respect and consideration from his consultant.

His consultant explained the findings of his examination to him, with honest compassion, in a confidential setting, in great detail and with a vocabulary conducive

with his understanding of biomedicine. Whilst he experienced confusion with the documentation, and may not have fathomed this out on his own, this went unmentioned on his questionnaire.

Case Study 2: read it in the Evening Gazette

This forty-year-old man consulted his GP approximately eighteen months ago. His symptoms were mucous filled stools and abdominal pain. A rectal examination proved normal and he was given a prescription for tablets, which he described as helpful. Sixteen months later he noticed his stools now contained blood mixed with mucous. He explained how he read an article in the Evening Gazette pertaining to colo-rectal cancer. At that time the symptoms he was experiencing i.e. rectal bleeding, abdominal pain, mucous in his stool were mentioned in the article as being indicative of bowel cancer. This prompted him to see another GP within the practice who then referred him to the OAFSS. Describing himself as a worrier this man was concerned at the time delay and phoned the unit to request a cancellation appointment. He waited approximately eight weeks.

“Well it was all right, the only problem I felt was there was no information given to me afterwards. The doctor who was doing the procedure told me that if it was urgent she would be there when I woke up. I came to in the recovery area. No one came near me, so eventually I walked to the nurse’s station and she said that they were all too busy to talk to me but that I should contact my doctor for the results in two weeks time.

That’s a laugh, I went back to the doctor in two weeks and they had not heard a thing from the hospital so I went back in another two weeks. This time my doctor had a

letter saying that everything looks fine. Oh yes, I was very satisfied, everything was smashing, maybe they were just busy that day”.

Patient 2 whilst suggesting that everything was ‘smashing’, explained how he was concerned at the time delay in reaching the colonoscope. He admitted to being a ‘worrier’ yet, despite the fact he was offered no information on the findings of his colonoscope, or that the unit failed to send his GP the results within the specified time resulting in a further wait he described his experiences as being ‘smashing’ and subsequently filled out a questionnaire stating he was highly satisfied.

Case Study 3: what a mess I was in

This eighty year old man explained how he is currently suffering from prostate cancer and that he blamed his medication for his persistent diarrhoea which he had endured since April. He suggested that he had been to visit his general practitioner three times in the course of a few weeks and each time was advised to lower the level of his medication. He was also advised to discontinue his anti-inflammatory medication prescribed for arthritis. “I even tried starving for 24 hours but that too made no improvement”. He admitted to a weight loss of approximately one stone.

His doctor then referred him to the open access unit and he waited seven weeks.

“Well I am pleased it’s all over, I’ve had a barium meal which was horrible so this was nothing in comparison to that. I knew nothing about it once they pricked my hand. I had no pain at all, yes no pain at all. The nurse told me to help myself to a drink but there was no tea left and I don’t like coffee. They said they hadn’t found anything and told me to go back to my doctor in two weeks time. What a mess I was in, the doctor

told me to take my teeth out and at the same time she had my hands putting the injection in. Well they didn't explain anything; I don't know what I have had done.

I feel very satisfied with the whole thing”.

This elderly man, having recovered from the invasive procedure was unable to access a drink or offered any explanation as to the findings. He was also subject to humiliation in that he was asked to remove his teeth whilst the colonoscopist was inserting the injection. This frail eighty-year-old man had been subject to purgation and food withdrawal for two days. Yet despite this, coupled with invasive treatment, he was allowed to leave the hospital without a warm drink. He was also intimidated and allowed to feel 'in a mess' because no one had bothered to ask that he remove his false teeth prior to going to theatre. He also suggested that no prior or post procedure information was given and he remained oblivious to this at the time of interview.

This patient epitomised Williams's theory of 'elderly attitude' by manifesting compliance to the authority of the colonoscopist; he too was pleasantly surprised with his comparable experiences of barium meal. His questionnaire states that he was overall very satisfied.

Case Study 4: incomplete test due to obstruction

This lady explained how she had been incapacitated with constant diarrhoea for three weeks before consulting her GP. He initially diagnosed Irritable Bowel Syndrome and prescribed Imodium. This had little or no effect, so on her General practitioners instructions she cancelled her trip to Canada and awaited an appointment for colonoscope. She was advised that the waiting time was three weeks so when she had

not heard in this time she returned to the surgery. He telephoned the hospital and an appointment was made for six weeks time.

“The day before the scheduled appointment a nurse phoned me from the unit to say that due to an emergency they were cancelling the colonoscopy until the following day. I had already fasted but they said it was an emergency so what can you do. I had received the instructions and medicine about four weeks before the appointment. I was aware and wide-awake throughout. The doctor got so far but it was so painful I asked them to stop. They tried again, but then the doctor said she was not prepared to carry on, as there was an obstruction. I was returned to the ward.

When I left I was given no explanation, the nurse did say that the test was incomplete as there was some kind of obstruction. They told me to return to my doctors in seven to ten days. I was so worried; I said to the nurse what’s going to happen now. She said there were a couple of things but she didn’t know at this stage.

The next morning I phoned my doctor who phoned me back after surgery but said it was now up to the hospital to let me know, and that I would hear from them soon. Two weeks later I still hadn’t heard from the hospital so once again I called my doctor. He said "I’ll phone the hospital and call you back". "I returned to see my doctor five days later. Seemingly the hospital had faxed him with the report which said that obstruction was caused by adhesions from a hysterectomy twenty years ago”.

This lady’s experiences were substantiated during our GP interviews. He did not mention her name, and it was pure coincidence that I chose her name at random from the list. This lady was wrongly advised of the time wait for colonoscopy by her GP, which resulted in cancellation of her holiday. Having waited nine weeks, she followed the pre-

colonoscopy diet, and then received a telephone call postponing the appointment. After the procedure the word obstruction was used by the nurse, which left her, not surprisingly, in a state of fear. She waited the two weeks, as requested by the nurse, before returning to her GP only to find that the unit had not forwarded the results.

This lady completed a questionnaire stating that she was overall satisfied with the unit yet reports that she endured extreme pain during colonoscopy. She explained to me how the health team used the word obstruction and that this instilled worry. Despite voicing this concern to the discharge nurse she left the unit with no explanation as to what was causing the obstruction.

It is good medical practice in the UK for one doctor to be responsible for the overall management of a patient's illness. This system helps to ensure that a patient with a particular complaint is assessed as a whole. (BMA, 1988:10)

This lady was 'let down' by both primary and secondary care teams in that neither would offer an explanation, both suggesting it was the role of the other.

Her completed questionnaire indicates overall satisfaction with the service.

Case Study 5: I thought it was just the drink

This fifty-five year old man discussed how he had observed blood intermittently in his stools for approximately one year. He denied any alteration in bowel habit. He suggested the reason for his delay in seeking advice was that he assumed 'it was just the drink'. He admitted to engaging in heavy bouts of alcohol, thrice weekly, these bouts would involve approximately 18 pints of beer. He also smokes 30 cigarettes daily. His general practitioner examined him rectally but suggested that as he observed no abnormalities it would be wise to refer him for further investigations.

Two large polyps were found and removed by diathermy. The polyps were irretrievable via the colonoscope, and he was encouraged to pass them into a bedpan later.

“The ward was all right, quite satisfactory, and it was very good having the privacy of a single room. The atmosphere was OK, it was organised OK, but in-between seeing the doctor and going to the unit was too long. Two months is a bit too long. The instructions came about a week ago, but the bit that said about clear fluid was very confusing. The Picolax was OK, it did its job. Once I got over the hurdle of saying, I’m bleeding, I wanted it done quick. You always think of the worst, I thought it was cancer. I didn’t lose weight, but I have known people with cancer.

The procedure was good, the only thing I felt was bad was the waiting from one o’clock, and it was two hours wait. The staff were very good, and the doctor explained I’d get pain with the air being pumped in. I was in pain when he was burning the polyps off. They told me I had two big polyps, and I had to pass them into a bedpan for analysis. The just told me not to worry and that they would see me again in 12 months”.

This man thought he had cancer. During participant observation the consultant voiced concern to the nursing staff at the size and shape of the polyps yet this man suggested that the only advice or information given was that he return in one year. He also found the instructions to be confusing, was concerned about his eight-week wait, and had to wait two hours in the unit, yet he suggested in his questionnaire that he was overall very satisfied.

Case study 6: why the huge blood loss?

This forty five year old lady explained how in mid June she observed that the toilet was covered in blood after a bowel movement. This pattern continued for five days when she decided to phone the doctor's surgery and speak to the nurse. The nurse booked her in to see the doctor on-call. The doctor was unknown to her and she suggested that embarrassment inhibited her agreement to rectal examination. He referred her immediately to the OAFSS.

Two weeks went by and an appointment had not been received. On telephoning the unit she was advised, by the receptionist, that they had not received a GP referral for her. She explained how she was very upset about that. She was asked to call again in a few days time. She phoned again to be told that the secretary had gone home. The secretary contacted her the following morning offering an appointment in six weeks.

"I had to read the instructions three times before I could understand it fully. "White" explained that there was no cancer and no polyps and that was a huge relief. But I am still concerned as to why I had such a huge blood loss. It was the getting there that was the problem; I felt I had to push for it once the doctor made the appointment. All the magazines say to go immediately for rectal bleeding but I had to phone up or they would have forgotten about me. The letter got lost so my GP had to fax another one, or I could have been waiting forever. Everything was fine, but the sandwiches made me feel sick. (This lady was given a sandwich and a cup of tea once fully awake). I arrived at 1 p.m. and was given instant attention, and all my questions were answered. The procedure was not what I expected it to be; I fell asleep immediately and woke up in the ward, that was a great relief I was satisfied with it".

This lady had problems understanding the instructions. She admits to being upset that her general practitioner's referral letter got lost, and was concerned at the length of time she waited for an appointment. This lady, it could be argued, expressed satisfaction with the unit because she received a 'good surprise' in her oblivion with the procedure.

4:4 Discussion

Questionnaires vs Qualitative Research

The patient satisfaction study revealed that answers given in tick-box questionnaires are inevitably of a more superficial nature than those given during personal interviews. The case studies delved into participants' private experience of and opinions about the open access flexible sigmoidoscopy service. A lot more dissatisfaction with the service, or grounds for dissatisfaction were uncovered, compared to the 5% of the study group who identified negative concerns on the questionnaire.

The qualitative research evidenced that patients' experiences did not match any specific theory or orientation, rather they produced a mix-match mosaic of theories as was highlighted within the case studies. This might suggest that no single theory works well alone, however, having said that Fitzpatrick's theory (ibid) which is founded on patients' experience of physicians' negativity and lack of interpersonal skills, coupled with a blasé attitude was very much to the fore (witnessed by me) in the first year of fieldwork. Also William's theory of compliance which arose from his numerous studies of elderly patients was evident and seems to be of major concern in this contextually specific field as studies show that colon cancer increases with age (Trichopoulos 1994).

Comparison of Services

Whilst the two services were ostensibly the same it quickly became apparent that their practical protocols were dramatically different.

	North Tees Hospital	South Cleveland Hospital
Site of service	Day case unit (within main building)	Separate consultant working endoscopy unit
Consultant access	Available by phone	Working with the unit
Appointment times	All the same	Individual appointments
Waiting time in unit	1-4 hours	0-30 minutes
Frequency of operation	On call - emergency admissions took precedence	Conveyor-belt system
Ward layout	One large ward	Individual rooms + main ward
Bed allocation	All patients allocated bed and locker	Shared changing room
Entry to procedure clinic	Patients walked	Patients wheeled on trolley

Full colonoscopies were performed at a greater level at South Cleveland than at North Tees. North Tees staff were generally more vigilant in their maintenance of the service guidelines which indicated sigmoidoscopy. The colonoscopist at South Cleveland suggested that the procedural time differential was minimal and that a full colonoscopy prevented incorrect diagnosis. This personal opinion gained from the colonoscopists experience accords with Cataldo (1996) who suggests that five percent of colonic cancers are beyond the reach of the sigmoidoscopy. Whilst the two rectal cancer diagnoses made within the first fieldwork period were from patients who attended South Cleveland Hospital, the actual position of the cancer site remains unknown to me.

The nursing staff in both theatres were congenial and considerate towards their patients. I did however find and assist on more than one occasion at South Cleveland an

elderly person struggling to undress in the confines of their allocated space. The nursing procedures and mode of dress were virtually identical in both units. Protective spectacles were mandatorily worn in North Tees whereas in South Cleveland a more care-free attitude was demonstrated to this practice.

My observations, in the first year of fieldwork at North Tees Hospital noted that the colonoscopists varied in their greeting and body language towards the patients. The patients spoke only when spoken to and the colonoscopist to the patient only when necessary to extract information, in other words a one-sided communication. The two male colonoscopists at North Tees portrayed varying degrees of patriarchal hierarchy and on some occasions displayed both irritation and disdain towards their patients. Through conversation with them I became aware that for them the open access unit was ritualistic surgery performed on patients to fulfil a medical need to justify its financial existence (Bolande 1969). The indicator for this was that some referred patients did not come within the criteria set out in the guidelines; this I felt to be the main factor which initiated intolerance and disdain. In the second fieldwork year atmosphere changed dramatically in that the two colonoscopist resigned and consultants took over their roles. I would suggest that their experience and personal characteristics allowed for ease and rapport building with patients; although this would contrast with Hall and Dornan (1985) who found that patients feel more of a rapport with doctors in training. Hooper et al (1982) suggest in their study that the higher a patients' socio-economic status the more likely they are to be treated by a consultant. In this study no evidence was found pertaining to socio-economic demarcation in that the consultants treated all the patients attending North Tees Hospital within my second fieldwork year. Nor did I find any difference in

the courteous respectful manner and amounts of interaction and information that was given to patients by the colonoscopists/consultants.

The colonoscopist at both hospitals though friendly and relaxed manifested different personal characteristics during the different stages of patient care, for example they chatted and laughed openly with the nursing staff whilst performing the procedure. In fact all colonoscopists manifested what Wall (1996) would call dual-personality characteristics during the pre-sedation and post-sedation periods

No choice was given as to sedation and all but one patient in the study was sedated. The choice to use Midazolam or Diazemuls appeared to be dependent on the colonoscopist's preference. Whilst I have no statistical data it appeared to me that those sedated with a combination of Pethidine and Diazemuls had a deeper level of sedation than those treated with Midazolam. From my observations it would appear that Midazolam was used to a far greater extent in South Cleveland. I can only assume that this corresponded with the display of painful moans that emanated from the many patients during the procedure. Those treated with Diazemuls combined with Pethidine showed little or no intolerance of pain. This contrasted with South Cleveland wherein pain was manifested to varying degrees in nearly all patients; one colonoscopy was aborted as the patient showed great intolerance. Interestingly enough this patient, an elderly gentleman, was administered Midazolam, supposedly an amnesiac, yet the following day he was able to recall in detail the horrors endured during his altered state of consciousness (Dougall et al 2000).

Having compared patients experiences of colonoscopy at North Tees Hospital and South Cleveland Hospital, as well as drawing on literature from a variety of sources, the

one outstanding factor which was revealed in the individual interviews, participant observation studies and the focus group meeting was the patients' unanimous opinion that doctors should not break their 'bond'. When they say they will inform patients of results, they should do so.

To alleviate the problems experienced by patients from both hospitals what is required is a framework providing methods and structures for behaviour and policy change that would be compatible with the needs of the patients and thus lead to higher levels of satisfaction. For example a policy should be implemented in South Cleveland wherein the protocol should be adhered to in that the general practitioner is responsible for giving the patients' post-colonoscopy diagnosis. It would appear that the major inadequacies have come about by failure on behalf of South Cleveland to inform patients of their diagnosis, having made this prior commitment. North Tees Hospital also fails to comply with the protocol in that many patients are informed by the consultants of the findings. Whilst the research evidences that patients are happy with this arrangement problems of inconsistency have been uncovered.

I would therefore recommend that both secondary and primary care services adhere to the guidelines in that the general practitioner has total management of the patient. The general practitioners should ensure that their patients are aware of this 'shift' within the open access service, so that they are in no doubt as to who will be informing them of results. Perhaps general practitioners could be invited to an open day at the clinic.

While the actual procedure is generally adequate (although this study has revealed discrepancies between North Tees Hospital and South Cleveland Hospital over what is

ostensibly a standard procedure) from what patients can remember of it, my research captures the perceptions and experiences of the open access flexible sigmoidoscopy service rather than reducing it to levels of satisfaction. The analysis of patients' experiences either side of this liminal point in the rite of passage indicates a high level of agreement amongst patients in conversation, that there are currently inadequacies with the management of the required rituals through which this service operates.

Patients want efficiency, kindness, understanding, and gentleness; and if they have to go through a major ordeal they want to feel that this is only what the doctors involved would want for themselves and their own families (Brewin 1993).

These deficiencies which contribute to the break in the healing ritual would not have been highlighted using standard questionnaires alone. As anticipated from previous studies, the standardised questionnaire failed to emulate these findings despite the episodic-specific questions.

The participants in this study were by sheer coincidence all British Caucasians, however the diversities of cultures which will inevitably utilise this service, is such, that only by recognising how individual opinions, symbols, and meanings vary enormously from culture to culture, can we really appreciate the crudities of perceptions of patient satisfaction and offer a service congruent with patients' needs.

Chapter 5. General Practitioners' Satisfaction with the Open Access Flexible Sigmoidoscopy Service

The previous chapter explored the reasons patients were satisfied or dissatisfied with their experiences of the OAFSS. This chapter looks at satisfaction from the providers' point of view, the general practitioners who were expected to use the service. In contrast to the patients who had a 'lived experience' of the service, general practitioners were asked if they were utilising the service and, if so, what was their 'occupational' satisfaction. Unlike patients, general practitioners' experiences with the service were 'unfelt' more abstract and hence inevitably emotionally detached. Furthermore unlike all the patients in the study many general practitioners who were asked their opinion of the service had not actually utilised it.

Traditionally general practitioners, when faced with colo-rectal problems which they feel unskilled to manage refer patients to the secondary care sector or consultant gastro-enterologists. The shift from secondary to primary care management has resulted in additional responsibilities being placed on the general practitioner. Many are happy and confident to take on these extra responsibilities, however some are loath to accept the role of amateur specialists preferring to maintain the traditional pathway of referring their patient on to the specialist. Twenty-six general practitioners were interviewed regarding their experiences of the service using an interview schedule in a semi-structured way (Appendix 4).

5:1 General Practitioners' Responses

An overriding theme was the waiting time for appointment. Some general practitioners suggested that the waiting time for OAFSS was significantly less than the

outpatients' route, whereas others suggested it was much quicker to refer to outpatients. There was a clear line of demarcation in that some of the general practitioners who utilised the North Tees outpatient service maintained that the out patient clinic was significantly quicker than OAFSS. However there appeared to be great confusion amongst these general practitioners in that they were referring to one specific 'general surgeon', (unrelated to the gastro-enterology outpatients) who was able to deal with a cross section of minor surgery from varicose veins to anal fissures. Other general practitioners referred to the consultant gastro-enterologists via the outpatient service. In South Cleveland a more standard service operated in that all patients seen via the outpatient route were seen by consultant gastro-enterologists.

"I have never used it. (OAFSS) I always feel there is something else and by the time the management plan works we find that not only colonoscopy is required but other things. The decision is quicker; the workload is less on me. It depends on the patient, if we are talking about colonoscopy for cancer or inflammatory bowel, is it more advanced? Is it due to internal piles? The report would then come back to me, and I would refer to another surgeon to be done. I feel it is more relevant and I choose the consultant as well, if my perception were that it is most probably piles, I refer to someone who would do that. The waiting time for out patients is brilliant, brilliant. The surgery is brilliant. I never send to South Cleveland which has a well-established colonoscopy unit. Everything is sorted out in two weeks and no problems" (North Tees GP)

"I am aware of it. No I refer to the colo-rectal clinic, the waiting list is very small and so I have never actually had to make referral to the open access clinic. If I refer to the colo-rectal clinic the patients are seen within one to two weeks at the most. I have no problems with that, I am happy with the service as provided by North Tees. 'Green' used to run the clinic but then he retired and now 'Blue' has taken over. The service they are providing I feel is quite adequate. No I cannot recall ever using the OAFSS. Colo-rectal appointment times with 'Blue' are one week. (Audrey asked, "is that the time for fast tracking if you are querying a malignancy?) No this is routine outpatient waiting times. The waiting time for the varicose vein clinic is three weeks. If I refer them urgently

they are usually seen within a week and I am quite happy with that. No I have never used the OAFSS. The service I find North Tees to be offering is quite satisfactory from my point of view.

I have no complaints with the colo-rectal clinic at North Tees. (Audrey asked "If you had a patient over 45years with altered bowel habit where would you refer". (GP) 'Blue's" colo-rectal clinic.

(North Tees GP)

"I haven't used it (OAFSS) because I have not had a patient presenting with symptoms that I felt at the time, that that was what I wanted to do. I expect that going to an open access would be cheaper, the numbers of people involved are small fry and you may well end up sending an open access patient on so you are increasing your costs. I try not to worry too much about costs; I try to do what I feel is right for the patients. We currently get such a good service that I don't feel an alternative is needed. It depends on what the problem is, if I examine for rectal bleeding and find a local cause and I am not worried. I refer to outpatients. I suppose it is what I have always done. Rectal bleeding is an essentially worrying area particularly for the patient, and we have such a tremendous service with the local surgeons, people get appointments very quickly and the benefit of their opinion and I think the service is so good that I don't feel we have to change. I refer to "Blue"who sees them usually at the next clinic or the one afterwards; two or three weeks". (North Tees GP)

As previously stated whilst the two services were ostensibly standard, differences in procedures had come to light in that South Cleveland Open Access Service offered the facility of dealing with haemorrhoids during the colonoscopy whereas in North Tees Open Access Service these patients would simply be returned to the management of the GP. The GP would then have to refer these patients to the outpatient service for follow up treatment.

"I find it a good way to differentiate and find the local cause for bleeding. I feel the patients are more extensively checked out, however I do have to say that if I had to justify referrals, I wouldn't use it. (OAFSS) Good for rectal bleeders, not so good for haemorrhoids. They loose interest if the patients' only have haemorrhoids. I feel that it has improved the service in that it is preventative of future carcinomas. No, I no longer refer to the outpatient department. I only use the OAFSS as the waiting times are much shorter". (North Tees GP)

As well as differences in procedures at the two services, the waiting times also varied.

“Very satisfied apart from the fact that waiting times are getting longer. Well that’s my impression anyway. When the waiting lists are short they can be investigated quickly and sometimes you don’t necessarily need an outpatient’s appointment. I am far more likely to refer than I did previously, particularly in older patients with change of bowel habit in case there is anything sinister going on” (South Cleveland GP).

“I think the waiting time is about two months. Yes it does bother me, we are often sending patients with the potential of malignancy, and you get to the stage where you think, is it worth doing an open access sigmoidoscopy or send them straight for a referral. Especially if you strongly suspect a malignancy it is probably better to make a straightforward referral to a surgeon. It is very good, but the only thing is that initially it was a very short waiting time, but now it takes two months” (South Cleveland GP)

Within the subject group (the 13 general practitioners who had received guidelines and had the option of the educational package) eight general practitioners agreed that they were managing patients with rectal bleeding more confidently.

“Well it’s good in that I don’t have to refer to the consultants to act as technicians. I act on the basis of results as long as they are within the parameters. If patients need to be seen quicker I refer to the consultants. I hate writing referral letters, I am far more likely to investigate myself and frankly the patients get a better deal. Any undiagnosed rectal bleeding I refer to the OAFSS. I have no complaints and I am managing more confidently”. (South Cleveland GP)

“Absolutely satisfied. I don’t use it very often. I think it is marvellous, there are patients when you are fairly sure that you are on safe ground but you need to be a bit more sure than that. And if I think I am delving in slightly more suspicious grounds, I send them straight there. Sometimes I go straight to the gastro-enterologists and say, “please will you sort this one out?” Sometimes you don’t actually need a specialist opinion about whether it’s that, or x-rays or anything, and you just want to know the result of the investigation. But if it is something more complicated or the patients got other symptoms e.g. weight loss or whatever then I feel they should go to the gastro-enterologist”. (South Cleveland GP)

“The main thing is it’s actually easier from our point of view, personally speaking anyway, to simply fill in a form and refer. And also that’s it, you simply get what you want, rather than all the other paraphernalia”

“Well first of all it gives me the independence to investigate fully before I make the decision to refer to the specialists and it can curtail my referral rate. It allows me to either to treat myself or request specialist advice”

“I like the open access, and the fact that you bypass the consultants”.

“Well we had a number of patients with various disturbances who needed investigation and we really started using the open access endoscopy units and it’s clearly better for us to do that. I like the philosophy of open access very much”

“Yes, I would say yes, in as much as that if someone comes in over 45 with rectal bleeding and I am not quite sure as to what it is and it is not obvious piles and I am worried about it I don’t need to go to the consultant I just refer”

Some general practitioners suggested, that their management was less stressful to the patient.

“It means that you can refer somebody without scaring him or her to death. You can say “now look, I don’t think you need to see a surgeon but I’d like to send you for a quick telescopic test”. It increases the stress levels in patients by suggesting that they need to see a surgeon. It’s faster and you can get the answers straight back rather than waiting for a consultant. Also you can do it at a lower threshold without having to frighten the patient”.

In contrast some general practitioners said that they had either never used the service, or had reservations about using it.

“Never used it”

“Yes I am aware of its presence. No I have never used it, I refer all my patients to the surgeons, the consultant surgeons at South Tees”

“If I have suspicion of irritable bowel, that’s how things come, you are suspecting Irritable Bowel Disease and when you send it to the consultant, it is sorted out. The patient comes out with the treatment. Not to say that there are dangers I don’t want to put down the open access, but one colonoscopy might be sufficient but if the patient is with the consultant the review appointment comes and a repeat colonoscopy. It tends to be a dangerous tool, if I thought that’s normal, and if the patient is happy.

(Audrey) Happy to have the patient off your hands? (GP) Yes, in things like that, obviously the endoscopy is totally different”

Four of the general practitioners interviewed had practice partners with a speciality in gastro-enterology; these partners operated a rigid sigmoidoscopy clinic at the surgery.

“I have not used it yet, as least I don’t think so, no I haven’t. (Audrey) So why haven’t you used it? (Hoots of laughter) I just haven’t had anyone yet. My partner does rigid sigmoidoscopies here not that I really appreciate that there are many indications for flexible sigmoidoscopy where rigid sigmoidoscopy would not be appropriate. No I don’t think I have used the service, in fact I am pretty sure I have not. No I don’t think I would, the main reason for me not using the service is that since I became aware of it, I have not had anybody appropriate”.

“But I will use it if necessary. We have “Yellow” who does rigid sigmoidoscopies in the practice, and I have not had a patient to-date that fits the bill. I have had a few obvious rectal cancers on examination, but they have just gone straight to the consultants. I would use the service and I have the guidelines”

“I haven’t, I must confess I still use; prior to this we had an open access arrangement with “Blue”, (a general surgeon at North Tees) not for the flexible sigmoidoscopy so I have actually carried on using this for some cases. We have a partner in the practice who also does rigid sigmoidoscopies, which I continue to use. For the same service however this is slow, some of those actually seem to have flexible sigmoidoscopies carried out, rather than a true colonoscopy. I don’t refer to “Blue” for colonoscopies. Four or five years ago we established a rectal bleeding protocol which essentially gave us access to barium enemas. To be honest the colonoscopy has come on and taken over most of the patients you would have referred to the service anyway, but it has been blighted by delays and workload. I have noticed that a significant number have a barium enema anyway to clear out their systems”

“I think I was a bit slow to take it up in the first few months but I have been using it increasingly, I have just sent someone this morning. I was still tending to send referrals via the consultants but I think I had one or two people with bleeding and I thought it would be good to go through this route and it has worked well. Yes I haven’t had any complaints about it. In general it seems to be a reasonable time scale, people are not having to wait too long to get access and have a colonoscopy. Yes the out patients departments are not bad. There are only certain things you would send for OAFSS but for those problems I think it is convenient not having

to bother the surgeons and go through the whole business of out patients and then for the patient to go back for colonoscopy”

Some general practitioners manifested ignorance as to the protocol and procedure of sigmoidoscopy/colonoscopy. For example all patients are sent an oral laxative with instructions on how to take this so that when they arrive for colonoscopy their bowels are clear. Some general practitioners were oblivious to the fact that all but one of the colonoscopists involved in the service were also gastro-enterology consultants, but more importantly, they seemed unaware that if a diagnosis of malignancy was made then the patient was automatically transferred to the secondary care consultants for follow-up treatment.

“I only found out about it 2-3 months ago from my secretary, so up until then I was referring to the consultants. Haven’t used it yet. I tend to send to outpatients because a lot of them are hard to colonoscope as they have difficulty getting around, so I prefer to refer to the surgeons. Perhaps because they have a stricture or they are just not properly relaxed and so they cannot get the colonoscope around. A lot of them get referred on for barium enemas. Also it’s quite nice to get followed up by a consultant, especially if there is a tumour there”. (North Tees GP)

“I usually refer to the general surgeons because I was not involved at the meeting you had and so perhaps I was just not primed up on it. Yes I refer rectal bleeding to the consultants. I think what may be happening is that they may look at the letter and possibly re-direct through to the open access service. I have not noticed a delay in patients going through the general surgeons. The last patient I referred had to wait a few weeks. But that particular patient had been seen before. Yes I am satisfied with outpatients; of course a quicker referral would be favourable. Nobody has really encouraged me at the moment to use the OAFSS. If I had positive feedback encouraging me then obviously I would refer more” (North Tees GP).

“Very satisfied. I feel I can refer easily with symptoms, which I may have been humming and ah-ing, as to whether I would be wasting consultant time in someone, who may have bleeding; but it may just be piles. With the open access you can cut down consultants time in getting your answer if it is just piles. It may be, at the end of the day that the patient is no

better or worse, but you have observed the protocol, and the patient is happy”

“I have heard about it but I wouldn’t say that I’ve actually used it. My understanding is a flexible sigmoidoscopy capable of reaching the top left hand corner of the splenic flexure. I’m not certain that it would provide me with the information I would need to manage a condition. My knowledge of gastro-enterology isn’t particularly brilliant. I would be uncertain as to its use in diagnosing or excluding diagnosis of a malignancy. And if I am looking for that kind of investigation I would probably look for help, so I would use a specialist. Well I suspect it means I’m de-skilling in gastro-enterology because patients are self-selecting in that direction. The patients very fast get a feel for it, they talk to each other and say” ““oh. I’ve been to see so and so, he was really good about my problems””. “And you certainly do seem to see that patients gravitate in that particular directions. Yes, if I’ve got somebody with unexplained rectal bleeding or alteration of bowel habit, or any suspicion of malignancy I would be looking for gastro-enterology help. If I was thinking of a diagnosis of inflammatory bowel disease, I again would be looking for specialist help” (North Tees GP)

Whilst many general practitioners clearly felt that open access was the way forward for many of their patients, the following general practitioner forcefully expresses dissatisfaction with open access services and points out why some patients ‘should’ feel dissatisfied with the open access flexible sigmoidoscopy service; Berlin sets the scene:

Happy are those who live under a discipline which they accept without question, who freely obey the orders of leaders, spiritual or temporal, whose word is fully accepted as unbreakable law; or those who have, by their own methods, arrived at clear and unshakeable convictions about what to do and what to be that can brook no possible doubt. I can only say that those who rest on such comfortable beds of dogma are victims of forms of self-induced myopia, blinkers that may make for contentment, but not for understanding of what it is to be human. Berlin, (1990:14)

“No, I have never used it. Historically, it arrived at a time when I got into open access stuff. In the first five years I became very frustrated by “Blue’s” open access endoscope service for bleeding which involved a Byzantine organisation, especially with regard to letters. Everything went wrong and then the open access sigmoidoscopy came during a time of gross dissatisfaction amongst my GP colleagues. I was frustrated with the gastro-enterology service and “White” in particular. And so I felt it arrived at a time when there was a number of open access forms e.g. breast

open access and I made a decision just to carry on referring as before with an open letter. It was a lot quicker e.g. Dear "White" etc. etc. And I could do this by dictaphone in between seeing patients, it was more convenient, and it also absolved me from making a decision as to what was the most important examination for the patients. I see it as a random fashion of choice, either barium enema or sigmoidoscopy, or a permutations scam as well, so it was a combination of factors. Total inconsistency! I was not educated enough in gastro-enterology to be able to see why those decisions were being made, and so there was not a clear choice of investigation for me.

It went wrong so many times that it was not possible, I mean what the purpose was. I was involved in the original plan and I thought this was to save referral for patients with rectal bleeding, an easier way for us to send patients. I mean if it worked properly the patient should have been for their test and the report would have come back to me, but invariably things went wrong. I cannot remember what it was. All sorts of silly things, either the patient would go and did not have the letter or the report got lost, a complex system. In the early 1990's I was pro-open access. It started in 1993/96 with the open access termination of pregnancy and open access D&C for bleeding. In principle it would have been good, but it all became too complicated.

Yes, it is cheaper to use open access. Yes, there are advantages to carrying on with out-patients, as the disadvantages to the patients are nil, particularly gastro-enterology which is rubbish. The patients wait far too long for their appointment, and then get an arrangement for an investigation. They then go for their investigation, come here for the results, turn up for the results and occasionally they get a follow up about three months after that. And they go there and sometimes are told their results. And I know that I certainly would not accept it, especially for people who find out they have cancer, to wait three months for a follow-up is ridiculous. I am amazed at the British people who sit there and put up with this, a sixties generation. But it is so easy, and we read personal views in the BMJ about three or four months ago by a physician who said the same thing. It would be so easy for them if the results were all available, they could give a letter to the patient with a copy for the GP of the results of each investigation".

Audrey "So if that were a possibility would that influence you in your referrals?"

"Yes, oh yes, what I am saying is it would be more efficient for me to use the open access system, so if what you have just suggested is not logical, then I am opting to give my patients a better service by referring to outpatients. And also in this particular case of the open access sigmoidoscopy is the expertise. I have the expertise to refer people for termination of pregnancy or hernia operations but I do not have the clarity as to why the gastro-enterologists randomly decide on what to do. So that

undermines my consistency, whether to send for this, this, or that". (North Tees GP)

"We do get people with PR bleeding and change of bowel habit, and before we used to have such a long waiting list to see the gastro-enterologist. And really that's all you want really, and really they need a colonoscope. You can say to the patient, it may be irritable bowel but just to be on the safe side I am sending you for a colonoscope. And there you are. And also sometimes you just have that question mark, and you think it would be useful to investigate. Before you would wait ages to be seen, so this does tend to put you off.

5:2 Discussion

This section demonstrates general practitioner ambivalence towards the OAFSS with loyalty to consultants and traditional referring patterns being the major deterrent to its uptake. Lack of gastro-enterology base knowledge was also significant in the determination of the referral path with the more confident general practitioners adopting a managerial position. The most striking differences were in the waiting times suggested by general practitioners. Many of the general practitioners who used the North Tees Service suggested that the outpatients waiting time was only a couple of weeks. There was obviously great confusion amongst the general practitioners in what was actually gastro-enterology outpatients and the rigid sigmoidoscopy outpatient clinic operated by "Blue". As a result the general practitioners who used the latter clinic were delighted with the short waiting times in contrast to those general practitioners who used the gastro-enterologist's outpatient route (at that time six months waiting time). It was therefore not surprising that the general practitioners who used "Blue's" clinic suggested that this was a favourable time scale to the OAFSS, which was eleven weeks at the time of this research.

In South Cleveland the waiting time for OAFSS was then eight weeks, while going through the outpatient route, the time taken to reach colonoscopy was approximately six months. This lengthy delay proved unacceptable to one elderly patient experiencing rectal bleeding. Her family paid £89 for her to be seen privately to prevent the long wait suggested by her GP in reaching consultant opinion. Ironically this lady was seen by the same consultant/colonoscopist working in the OAFSS and after consultation went on to follow the same procedure within the unit as those patients going through the NHS route. She waited two weeks for her private appointment.

Many of the general practitioners were in total ignorance of the pathway patients would undertake before reaching sigmoidoscopy/colonoscopy. Did general practitioners who said it really believe that the patients would undergo a barium enema before colonoscopy? The other extreme could be highlighted by the general practitioner who suggested to me that the procedure of sigmoidoscopy/ colonoscopy was very minor; the preparation he said was merely the administration of two glycerine suppositories! Did he believe that two glycerine suppositories would clear the bowel up to the level of the sigmoid colon, let alone the caecum? Pendleton and Bochner (1980) study suggests doctors may wish not to give information to patients and so maintain a balance of power, but in the case of sigmoidoscopy/ colonoscopy how could they explain the procedure to the patients when their own knowledge of the procedure was non-existent? Was it therefore very surprising that some patients were telling me that they simply did not know what was going to happen to them?

Base knowledge of sigmoidoscopy/colonoscopy also varied amongst general practitioners, for example one general practitioner suggested that he was uncertain as to

its use in diagnosing or excluding diagnosis of malignancy! He also suggested that he was de-skilling in gastro-enterology.

I was led to believe that all patients being diagnosed with a malignancy would be automatically followed up by the consultants, however one general practitioner explained how he had personal experience of patients waiting up to three months after a malignancy diagnosis before being followed up by the consultants. He backed this up with evidence from a paper written in the British Medical Journal. (I have to say that the two cancer diagnosis I witnessed were referred immediately to the consultants and were operated on within the week.) As a result of his experience of 'inefficiencies' with open access services and reading about the problems which patients incur, he made a decision to refer to the secondary care sector in an endeavour to follow the best practice for his patients. However he also mentioned that the gastro-enterology outpatient service was 'rubbish' in that the patients also got a bad deal.---Hobson's choice!

Personal characteristics of the general practitioner were very much to the fore in this study, particularly in what they perceived to be best practice for their patients. For example whilst OAFSS offers no age barrier for rectal bleeders many general practitioners described the inappropriateness of this mode of service for elderly patients, the rationale being that they are at greater risk of colo-rectal cancer and so would benefit from immediate consultant referralthe right approach for the wrong reasons. One particular general practitioner admitted that depending on 'his mood' he would either refer on to secondary level or 'sit on it'. This kind of decision is fraught with dangers as in the case illustrations in Dougall et al's (2000) study of a rectal bleeder with altered bowel habit and weight loss who was stereotyped as suffering from stress and who waited

nine months as the result of his general practitioner's procrastination in referring to OAFSS. The result of OAFSS revealed an advanced colo-rectal cancer.

A few practices within the study had general practitioners whose speciality was gastro-enterology and in fact operated rigid sigmoidoscopy clinics. My findings were that colleagues within these practices would refer their patients for rigid sigmoidoscopy in preference to open access or secondary care referral. In view of the known limitation of rigid sigmoidoscopy, in these instances I was forced to speculate on whose interests took precedence, the amateur specialists' or the patients'.

In comparing satisfaction from the patients' and general practitioners' perspective the one outstanding factor that this section of the research demonstrates is that general practitioners provide clear and formal 'models' of satisfaction, whereas the patients' models were more diffuse and 'muted'. In other words the patients' opinions are expressed but not heard because they do not have a place in the paradigm (Chapman (ed) 1989:130).

Chapter 6. Patients' and General Practitioners' Perceptions of why Patients' Delay in Presenting with Rectal Bleeding

The holistic nature of my research involving questionnaires, interviews and focus group sessions with patients, interviews with general practitioners and participant observation of the service itself, highlighted other aspects of relevance to the goal of the service to reduce the rates of late detection of colo-rectal cancer on Teesside. One of these is the question of why patients delay in presenting with rectal bleeding. I intend to outline my findings in this chapter indicating a possible discrepancy between general practitioners 'occupational experience' and patients 'lived experience'.

I became interested in whether or not both patients' and general practitioner's perceptions of the reasons for delay in presenting with rectal bleeding were the same, since, according to Helman, (1994) despite coming from the same cultural background, patients and general practitioners are believed to perceive physical conditions in different ways. Helman's theory is based on the idea that the general practitioner looks only at the physical symptoms of the patient whereas the patient might view physical symptoms as also having social consequences. For example, Helman discusses the polluting power of blood and the psychological, physical and social manifestations of its potent symbolism. He therefore recommends that clinicians should be aware of the possible symbolism in any lay conceptualisations of blood. Foster and Anderson (1978) point out that in many parts of the world, blood, when lost from the body leaves the victim permanently weakened. Although it may be contradictory in Western culture the idea of 'normality' of rectal bleeding can be seen as a façade to deal with psychological pain, even though the loss of blood is actually physically weakening. The consequence of acknowledging the loss of blood as being anything other than normal would instil emotions which 'stiff

upper lip culture' do not find easy to cope with, such as the fear of cancer, or of 'social exclusion' because of their unclean condition.

6:1 Previous Studies

Although prognosis for colo-rectal cancer is excellent if located at an early stage, studies carried out by Dent et al (1986) found that a large percentage of the general population who experience symptoms such as rectal bleeding, perceive this as normal. Whilst these symptoms may be indicative of colo-rectal cancer, many patients delay in seeking medical advice. Studies carried out in the USA with patients who were subsequently diagnosed with colo-rectal cancer show differences in the length of delay in presentation. For example Hackett et al (1973) reports a delay of 11 weeks, Holliday et al (1979) suggest an average of 22 weeks, while Byles et. al (1992) report a delay of between 13.5 weeks and 31.5 weeks. In contrast studies in the UK by Macadam (1979) maintain that 45% of patients present with rectal bleeding within one month of onset, and a further 28% present within three months of onset of rectal bleeding. Whatever the figures these studies indicate that early presentation for rectal bleeding is unusual.

We can see from the above that patient delay in presenting with rectal bleeding has been well documented, but this delay in reaching sigmoidoscopy/colonoscopy is not always governed by the patients. For example Carter (1998) suggests there is considerable evidence to prove that general practitioners also delay in sending patients with rectal bleeding for investigation, yet he says that many authors dispute this. Carter's (1998) questionnaire study highlights how 60% of general practitioners would refer any patient with a dark red rectal bleeding to the hospital *immediately*. But seven percent of

general practitioners in the study suggested that they would take no *immediate* action for patients presenting with rectal bleeding.

Carter also suggests that delay in investigation may, and does, occur at the hospital or secondary care level. The explanation he gives for the latter is a) current pressure on hospital beds and b) that GP referral letters will often suggest that bleeding is due to haemorrhoids.

Social demographics/age/class/ethnic origins

According to Dent et al's (1990) studies, there was no correlation between the ethnic origin of patients and the time delay of presenting with rectal bleeding. Their findings also show that delay was unrelated to the amount of social support patients had received or to their marital status. They did however find an association between time of delay and education, the less educated having a longer delay span.

Byles et al (1992) suggest that one of the reasons why the majority of patients delay in presenting with rectal bleeding is because they perceive it as being non-serious in nature and that it will heal up by itself. Other reasons given for failure or delay in presentation were that patients believed tests would be unpleasant and embarrassing, that they had little faith in doctors, and they were worried that it might be serious. Some patients even suggested they 'knew' their diagnosis but chose to ignore it.

Even though some patients have a greater predisposition to colo-rectal cancer, such as those with a familial history, or those in the age range of between 45-60 years, Crosland and Jones (1995) point out that they too give their reasons for delay as being due to haemorrhoids/piles or constipation, embarrassment, discomfort of the examination, and fear of confirmation of cancer. Yet Dent et al's (1990) study shows that

embarrassment, denial, fear, and lack of social support did not engender delay except in isolated cases; this contrasts with the findings of the previous authors.

The Relationship of Rectal Bleeding to Colo-rectal Cancer

According to Silman et al (1983) apparently healthy people in Western societies have a high prevalence of non-serious rectal bleeding. This accords with Dent et al (1990) who suggest that most rectal bleeding is caused by anal lesions or from benign colorectal conditions other than colorectal cancer. The guidelines implemented for use with the OAFSS on Teesside recommend sigmoidoscopy for all rectal bleeders whereas Metcalf et al (1996) are opposed to invasive investigation for all patients presenting with rectal bleeding, advocating that only those aged 40 years or over should be subject to sigmoidoscopy/colonoscopy. Eighty per cent of the six hundred general practitioners in Metcalf's study saw between one and five patients per month with rectal bleeding; only one third of these general practitioners felt that rectal examination was necessary for diagnosis. Whilst rectal bleeding is associated with colorectal cancer, according to Douek et al (1998), 90% of patients who present with rectal bleeding have only minor complaints. They suggest that colorectal cancer presents infrequently with rectal bleeding in isolation and that associated abdominal pain, weight loss, and altered bowel habit is more of an indicator for sinister diagnosis.

In the first year of fieldwork, (Dougall 1999) of two patients in the study who were diagnosed with colon cancer, one patient experienced weight loss and altered bowel habit, yet, the second patient had only one symptom, that of rectal bleeding.

6:2 Delay in Presentation: Patients' Perspectives

Within a focus group setting seven patients were asked to explain if they had in fact delayed in going to their doctors after their first experience of rectal bleeding, and if so, were asked to explain their reasons. Qualitative patient interviews unveiled that delay extended from a couple of months to twenty years, and that this bleeding was often kept secret from close family members. Patient explanations varied from embarrassment to fear of cancer, as well as fear of the unknown.

“Yes I did, I put up with it for about two years. I don’t know, I think it was embarrassment a lot of it and then you just think it’s going to be all right after a week or two. It just got worse and worse and in the end I could not put up with it any more and I went to see the doctor. Yes you ask yourself what can be done about it”.

“Twenty years I’ve had it and it was not until the open access finally came about that the doctor said” “there is this thing on the go and we’ll send you for that”.

“I think it’s partly that you don’t like to go to the doctors unless it’s really serious, you don’t immediately rush to the doctors every time you feel unwell. You just get used to it and feel it’s normal”.

Many patients' said they perceived their rectal bleeding was normal and made comments such as:

‘It’s just my piles’

Weller and Wells (1991) define pile as a haemorrhoid, which is then further described as locally dilated rectal vein. Piles may be either external or internal to the anal sphincter. Pain is caused on defecation, and bleeding may occur”.

Rectal bleeding has different meanings for different people. For example it could signify normality in the form of bleeding piles or abnormality in the form of 'the unknown'. When we consider Anthony Synnott's (1993) symbolic approach to the body,

not just as a physical blob, but also a social body full of social meanings and messages, and Douglas's (1973) theory that the body provides a common symbolic frame of reference in human thought, it becomes apparent that symbolism for the following patient was indicative of abnormality.

“Yes I think it is embarrassment. I watched a television programme last summer about colon cancer and found it very interesting, as it's one of the best cancers to cure. So not long after that I had rectal bleeding, not a lot and it only happened once. I spoke to my family, they had not had this, but they had piles and told me not to worry but I don't know why, but something told me that it was not quite right and when I went to the GP I was completely amazed at how quickly I went into hospital”.

Some bodily functions we accept as socially acceptable and others as morally unclean and socially embarrassing. These opinions vary, and are dependent on the amount of social rapport between people. We need look no further than the incidence of releasing flatus. In the company of people we feel at 'one with' the release of flatus is perceived as socially acceptable by some, yet in the presence of others, this release is often regarded as socially taboo. Similarly in the case of rectal bleeding, it has been evidenced that a degree of social familiarity needs to be in place before people will share such information.

“People find this embarrassing. I didn't, I went straight away but I suppose it depends on your relationship with the doctor”.

“Well, my mother died from cancer and I really felt sure I had that, but could not go to the doctors. If it was not for my husband pushing me into it I would never have gone by myself”

“I thought it was just my excess weight I was carrying and some days it was worse than others but I did not associate it with anything else. It was the difficulty of going [*passing faeces*] and nothing happening and I think it was just not coming away, it was just staying in there and I thought it was the residue of the flu I had

about eighteen months ago. I had an awful bout of flu then. It was only the restriction there was only a little rectal bleeding”

Poole (1994) in his studies of the Wimbun people of Cameroon indicates similarities in the perception of rectal bleeding with those of the British culture in that rectal bleeding is thought to be caused by changes in bowel habit i.e. diarrhoea, followed by constipation and the hardening of the faeces causing fissures in the anus. Interestingly enough the prescription of cure for diarrhoea offered by the Wimbun soothsayers is meat and eggs. The soothsayer in diagnosing the alteration in bowel habit, for example constipation, would believe this condition is the result of eating food from the ‘cold’ category and as such would prescribe foods from the ‘hot’ category, such as red meat, to re-balance the system. However Teesside consultant gastro-enterologist “White” suggests there is a correlation between eating red meat and the incidence of colo-rectal cancers.

According to Shirley Lindenbaum, the ethnographer of the Fore (1917: 148)

"Despite early anthropological reports to the contrary (R Berndt 1962: 271) the catch phrase "ritual cannibalism as a rite of mourning and respect for the dead kinsmen" continues in medical and popular literature, a close to Western rather than Fore thought on the matter". Fore took it up as animals disappeared, in the first instance by women and children who were denied animal meat by the male hunters. (pp 22-25).

By analysing the eating habits of various peoples it has been found that many foods have a social meaning as well as a nutritional value. For example the Fore People of Papua New Guinea believe that by practising cannibalism they take into their own bodies the souls of their dead ancestors (Harris 1977). At the same time they might actually have a physical need for the protein that the dead bodies provide.

6:3 Delay in Presentation: General Practitioners' Perspectives

The 26 general practitioners who took part in the study were asked if they had experienced any patient delay in presenting with rectal bleeding, and if so what they thought would account for this. Some General practitioners reported that delay had taken place and for various reasons.

“Patients with rectal bleeding put up with it for a considerable length of time, often, and come in and say “when I am here doctor can I have some stuff for my piles”. And you say, “What do you mean?” and they then say “Well I have been getting a bit of bleeding for a year or so” but have never sought medical attention. Lots of people don’t seek medical attention for rectal bleeding because they just think, ‘oh it’s my piles’. I think if we want to take rectal bleeding more seriously it has to come from before surgery. I think they are more likely to present if they have a family history. The ones that ignore it are the ones that have no first hand experience”

“Because bleeding is seen as normal, especially piles”.

“I think especially the old people they say ‘well I thought I had bowel cancer and there wasn’t anything that could be done for it”

The reason for delay in presentation could be because the British culture as a whole is inhibited from discussing, showing or touching their anus. In fact the very act of scratching ones body three inches below the level of the umbilicus, (anteriorly as well as posteriorly) in public, is seen as behaving with impropriety. Not surprising therefore that to bare one’s anus, albeit to a medical physician, is still fraught with perceived embarrassments and taboos. James (1998) suggests that acceptable areas of ‘touch’ are

culturally and socially constructed in childhood. Ennew (1986) agrees with this, identifying how British culture demands the reprimand of children touching inappropriate parts of their bodies.

“There was one very tragic case last year, an elderly woman was bleeding and I wanted to examine her. She would not let me so I gave her some medication and told her to see me in the next week or two. The following week she had a huge bleed and was admitted to hospital; apparently she had cancer. She went on to have a resection, complications arose and she died”.

I wouldn't say there was a long delay but usually there is a delay. That's much more of a problem in the younger males who are less likely to have colo-rectal cancer”

Anderson (1990) found in his narrative research that ‘where there is risk of embarrassment real life events are dramatised within contexts that obscure them from easy recognition’. Most patients will happily, and often proudly discuss their appendectomy or cholecystectomy; a cardio-bypass operation offers elevated status to an individual because of the hierarchy of the body parts. Yet in contrast operations that entail bodily waste material, for example colostomy, are often considered taboo subjects and are therefore embarrassing to some people. Douglas (1970) discusses how the social relevance of bodily products, such as blood and faeces are looked upon as having a polluting influence when found outside the physical body.

Several general practitioners reported that there was more of a delay in presentation by the elderly and male patients and they accepted that embarrassment might have been the cause of this.

“Not so much delay. It's usually the elderly who are embarrassed but you do still get it in the 20 age groups”.

“Yes embarrassment does cause delay, especially in males”

Some doctors did not accept embarrassment as being a major factor in late presentation of rectal bleeding.

“Well I think some of them might think about serious causes and are frightened to find out that they have got such a cause and others put up with the symptoms longer than others. That’s the nature of it. generally not embarrassment, but once they have actually decided to come not many people voice or show it, at least from what I have seen with reluctance to have a rectal examination. Yes it happens that some people mention it when they are going out the door. It does happen, but I wouldn’t say or perhaps it may be me not perceiving it. But once they realise it is just part of the examination they just accept it”

“I think most of the patients I see present early. I think it’s the change of bowel habit that one tends to look for. One patient with anaemia has had rectal bleeding for a long time but not bothered to tell anyone Well he has a malignancy. So yes there are a couple of examples. Probably just fear, yes, fear more than embarrassment”

“I don’t think it is embarrassment, I don’t know, I never thought of that, because I don’t think they would expect PR examination. I think they think of this problem as here (pointing to abdomen) not down there. They think it is their tummy. I get presentation early, often through the other members of the family, the wider families even will say “ I am worried about my father.”

“Most people tend to be tolerant of major symptoms. Weight loss etc. May be to do with embarrassment or education”

'The world of pain becomes a special world, a world largely unshared and unsharable' Byron Good (1992:47). He suggests that the individual is isolated by virtue of an experience that defies articulation. In the West, illness more than alienates the self from the body, it alienates the self from its community by its capacity to stigmatise and isolate the self.

In recent years, with the increased availability of health education, it is assumed that people should have more understanding about physical conditions although this has not always proved true.

“Somebody came with a 6 months history of about 10-12 stools per day and I couldn’t think how someone could not think that was not right. He was sent for an urgent appointment and he had rectal carcinoma. I think people do not come because they think it is something nasty. And I say to them “why did you not come to me”, and they say, “ I knew about it but I did not want to know. It is dependent on the personality”.

Although general practitioners gave several reasons for delay in presentation, some believed that patients regarded rectal bleeding as a natural state.

“When you take a proper history you find these sort of symptoms were going on for a while but not sufficiently to annoy patients, or to make them feel, I must see my doctor. With colon especially because most of them regard it as natural type of symptoms, diarrhoea, passing a bit of blood in stool or piles. The main thing really is there is no pain, no urgent pressing need to come and see the doctor. It is something they can put up with. They are happy that they are losing weight, most of them, and bowel changes they regard as natural. It is multifactorial, no pain, social class, something to do with the club, for example my friend had this, and it is nothing to worry about. A couple of lagers might clear it”.

Two general practitioners remarked on how geographical culture influences the way patients impart information

Well, they are backwards in coming forwards. They will put up with something partially because they are frightened and they would rather not know. And partially because certainly out in this area they tend to be quite stoic, and they put up with things rather than do anything about them. I don’t know if they are embarrassed.

In contrast a general practitioner who consults in a densely populated area of Middlesbrough said that patients present late:

“Because they are embarrassed. I think that it is a social class thing. I think you will find that social class one and two folk waltz in and discuss their sex lives without batting an eyelid, whereas a lot of the more elderly males are very reticent. They come in and tell you that they have got a cough. They have got a cough, and on their

way out they say, “I have had some blood doctor”. I do think even the really really thick ones and the poorly educated ones know that you should not bleed from your back passage, and if you do, it is not right and you ought to go and tell your doctor about it. Sometimes it is fear”.

6:4 Discussion

During the focus group meeting patients were encouraged to reflect on what rectal bleeding had meant for them in an attempt to identify what, if anything, had inhibited them from seeking immediate medical advice. The advantages of this qualitative method of research offered greater sensitivity to patient concerns and misunderstandings, and also turned the face of research from the customer ‘patient’ back to the person. Furthermore as evidenced it unearthed the unexpected in that general practitioners' perceptions are as ‘individual’ and varied as that of patients’. In many instances the discussion reached the heart and soul of patient experience in that for some patients rectal bleeding and the subsequent examination was merely a ‘been there, done it’ experience. Whereas for others it was literally the beginning of the end of their lives (Dougall et al 2000), in that two patients were diagnosed with rectal cancer, and their prognosis maximised five years. In contrast to the quantitative part of the study the focus group participants engaged in anecdotal laughter and in some instances black humour (from those diagnosed with cancer) which I felt offered a psychotherapeutic revitalisation. The focus group allowed me to hear patient’s discussion of their personal values, indicating what was ‘initially’ normal and acceptable to them and the subsequent catalysts to their decision to consult their general practitioners.

The overall themes running through both patient and professional responses for the reasons for delay varied from embarrassment and fear, to perceptions of normality. However there was a clear division in that while all patients suggested they had experienced some level of embarrassment, in contrast the majority of professionals suggested that embarrassment was not something they considered as a reason for delay in patients' presentation. Many patients discussed other reasons for delay, such as fear. Fear was due to both genetically acknowledged family histories of cancer and fear of the unknown, or perhaps it would be more appropriate to say fear of the 'known' as they all voiced fears of cancer. My feeling is that cancer with its metaphoric trappings and stigma might have inhibited these people from seeking medical assistance early enough, and from insisting on clinical examinations. Sontag (1991), whose book, *Illness as Metaphor*, was written because she had cancer, is of the opinion "cancer should be seen just as a disease, a very serious one, but just a disease. Not a curse, not a punishment, not an embarrassment".

Goffman (1963: 34) suggests that the stigma of cancer today initiates a psychological response of disgrace, similar to the body marks of leprosy during the historical period. Colon cancer however because of its association with colostomy and external abdominal excretion of faeces further stigmatises by instilling a cultural meaning onto the sick person. This stigma may invoke cultural meanings of polluting, ugly, deformed and even inhuman, which can result in the patients' withdrawal from everyday society. These feelings are further exaggerated when health professionals treat patients with a lack of sensitivity as has been evidenced in some of the case studies.

Two general practitioners were adamant that they experienced no patient delay in presentation, yet one of these general practitioners suggested that his patient had in fact put up with diarrhoea for six months before consulting him. The other GP maintained that his patients also present early with rectal bleeding, yet at the same time he indicated that he had been treating a patient with undiagnosed chronic anaemia who hadn't throughout that time mentioned his rectal bleeding. It appeared in some instances, patient perceptions were subjugated to general practitioner perceptions. For example one general practitioner who came from an ethnic minority background generalised that he experienced no patient delay as he knew and socialised with the wider family network, thus removing any inhibitions about particular subject matter. He suggested that members of extended families were comfortable discussing particular relatives and their ailments, denoting a way of life, which dates back to pre-bureaucratic society wherein communal life predominated. Jan Broger's (1992) ethnography of the Nazarenos explains how people in such societies were less emotionally restrained and played their life in public view contrasting with today's dyadic relationships and orientation towards 'holding' within the nuclear family. The general practitioner, who consulted in the rural area, found a much tighter knit community and neighbour infrastructure. For example when I visited a patient from this area, many of the neighbours were in the street chatting and nodded in acknowledgement of my arrival. The patient confirmed that the neighbours knew of my imminent visit. Becker (1995) suggests that public disclosure is not necessary to the cure, simply the removal of the secret from the individual; a theory well evidenced throughout the case studies.

If we consider Katz's (1981) studies of 'Ritual in the Operating Room' we can see how medical doctors are trained to view patients' bodies in a dispassionate manner. For example within an operation setting they will touch internal organs and their accompanying secretions, whether this be blood, pus or faeces in a blasé cavalier manner. They are conditioned into believing that 'disgust' or 'embarrassment' is not an emotion that they should feel within a medical setting. Similarly general practitioner consulting rooms with their focus on precise rituals and questions, which lead to 'diagnosis' and subsequent prescription, instil emotional boundaries between general practitioner and patient. Perhaps it is these rituals and boundaries which Gluckman (1962) suggests are what gives licence for behavioural change in that the patient can divulge concerns to doctors (but apparently not always rectal bleeding) which they are prohibited from discussing in every day communication.

Human perceptions are believed to be socially constructed within the family and are rarely singular or simple, they also have the capability of being altered by education. The general practitioners' perceptions of the reasons for delay may have evolved from the biomedical training prevalent in the West; theories that change as medical knowledge develops different solutions or prophylactics for illness. The patient's perceptions in contrast would be subject to personal experience, possibly based on cultural learning.

An example to illuminate this would be the traditional cultural belief that a 'clean bowel' is necessary for good health. (The researcher remembers the boarding school queue every second Saturday night for the dreaded Syrup of Figs!). As one lady respondent suggested a weekly dose of laxative was part of the cultural norm, a symbolic

meaning deeply embedded within her generation. Yet it was this practice of bowel cleansing, her consultant suggested, which had led to 'a lazy bowel' and her subsequent constipation was the reason given for her rectal bleeding. This epitomises the swing of medical discourse in that once, that which was regarded as 'beneficial' to good health is now often perceived as 'harmful'. For example we in the West are now encouraged to eat a high fibre diet in order to maintain regular bowel habit, whereas in the past, high fibre diets were considered 'bad' for us.

Because we in the UK perceive anal touching as disgusting, as previously mentioned by James (1998) British cultural learning encourages us to look after our bowel by controlling what we take in to our bodies through the oral route i.e. food and medication. Yet, not all European countries perceive the anus as culturally 'untouchable'. For example French physicians orientate towards the anus as the 'preferred route' for drug administration, with 72% of all medications being in suppository form. The rationale for this preferred route is that because French culture views the liver as the organ most likely to incite ailments and as all oral medications are initially absorbed in the liver, bypass via the rectal route is favoured. They also favour the body temperature being recorded from the anus, since this method is more accurate; a procedure practised in Britain but only in young children. In Britain medication tends to be administered orally; we have a very low prescription rate for rectal medications in the form of suppositories, and those prescribed are generally because the patient is unable to absorb via the oral route (Payer 1990)

In recent years illness patterns throughout the world are changing with the development of industrialisation, which has led to significant alterations in human

habitat, and way of life. These have heralded dramatic decrease in infectious diseases replacing them with conditions, such as multiple cancer mutations, which are often associated with poor diet and high levels of stress. According to Ludwig Feuerbach 'Man is what he eats'; this everyday amorphism is fundamental to understanding perceptions of normality within the context of rectal bleeding. Whilst it is axiomatic that humans need food and water to survive, it is not always quite so obvious which foods may offer immunity against illness and disease. Furthermore the constant swinging of the pendulum leaves the non-scientific individual in a state of quandary, as to what one should eat to reduce the risk of colo-rectal cancer. Red meat containing Bovine Spongiform Encephalitis with its alleged zoonosis in the form of Creutzfeldt Jacob Disease, salmonella in eggs, toxicity from organophosphates sprayed on vegetables, to name but a few 20th Century produced illnesses may have led to Freudian desires for high fat low fibre foods, and 'living for today' attitudes, now inherent in post-modern societies.

The change in family infrastructure and the dual role of women has led to an almost proselytising zeal for ready-made meals. This almost instant food has risen like a phoenix from women gatherers and offers temporary satiated comfort, in what is often regarded as a specious, multi-cultural, post-modern existence.

Amidst the myriad of multi-cultural and innovative foods, healthy longevity features minimally. This section looks at perceptions of 'food waste', in the form of faeces and suggests 'why' large numbers of people, straight across the occupational spectrum, perceive blood as a 'non-abnormal' secretion within this 'food waste'. This

occupational spectrum includes general practitioners who will on occasions delay in investigating the reasons for rectal bleeding.

During its passage through the alimentary tract, ingested food is transferred altering dramatically visual and sensory dynamics of almost Jekyll and Hyde proportions. As the journey commences, visual sighting of the food incites salivation by the salivary glands in the oral orifice, the entrance to the alimentary tract, the sensual mouth consumes through mastication, further instilling feelings of warmth and satisfaction, yet, at the journey's completion the same food in its waste state is regarded with cold repulsion. It is therefore not surprising that fragmentation of the anus from the body occurs inherently within British culture and as such rectal bleeding is generally regarded as taboo conversation. Because of this, our perceptions from hopes and fears is a more convenient attitude to have, given the fear of abnormality.

Fragmentation of the body imbues social and cultural hierarchy within the body, the central nervous and cardio-thoracic systems taking precedence over the digestive system. These perceptions are further divided into laypersons' and general practitioners' ideas of the body and can be observed through the medical and lay model of health, in particular how the general practitioner has been enculturated into the biomedical model of health. This dictates scientific examinations to establish ailments, (routine blood testing being one example) and a decision made within the allotted 'white paper' six minutes, necessitating the 'conveyor belt' diagnosis.

Whereas formerly doctors were able to provide comfort and support to patients but not always much in the way of effective therapy, the general practitioner now offers a more comprehensive service, but with a consequent diminution in the time available for lengthy discussion. (Murray and Shepherd, 1988: 512-13)

The average lay person whose knowledge of anatomy and physiology is at best limited and often viewed within personal experience, views the general practitioner as a healer who will rid him or her of ailments, predominantly by the writing of prescriptions. Perceived illness or abnormality is categorised by the person into acute illness, which requires immediate general practitioner advice, or chronic illness/abnormality, which is an on-going process, and will either continue or disappear through time. Rectal bleeding is one abnormality viewed by many people in Western society as belonging to the latter category and despite public health campaigns suggesting that rectal bleeding may be a sign of colo-rectal cancer, studies suggest that a large percentage of the population do not regard this as a 'symptom', merely a 'normality'. An example to demonstrate this is the high turnout at accident and emergency departments, of people with various forms of anatomical haemorrhaging. Yet few, if any will present with rectal bleeding.

It seems to me that most general practices now offer well woman/well man clinic appointments which provide atmospheres conducive to discuss, for example, breast or testicular concerns. These appointments are generally less stressful in that the patients perceive this time for merely having their 'bodies serviced'. I would therefore suggest that these appointments would be an ideal opportunity to discuss genetic predisposition to colon cancer as well as any incidence of rectal bleeding. In my experience patients will admit to rectal bleeding once asked but because of embarrassment will not volunteer this information. Within the well man/woman clinic setting, we need to bring the bottom to the top!

Another issue, which arose from the diverse elements of the main study was the question of general practitioners use of guidelines, and in particular for those used with

the OAFSS, the subject of my next chapter. Unlike the patient satisfaction study wherein I had total control over the decision to use the tripartite qualitative methodology, the methodology for this section, i.e. personal interviews was defined in the main study remit.

Chapter 7. General Practitioners' Perceptions of Guidelines in General and with those of the Open Access Flexible Sigmoidoscopy Service in Particular.

According to the National Health Service Executive (1996) the use of evidence based guidelines is crucial to a more efficient clinical effectiveness in general practice. It was within this ethos that guidelines were compiled in association with the open access service, in an endeavour to change general practitioners' referral patterns. The guidelines were systematically developed by a representative group of local general practitioners and hospital specialists in gastroenterology, radiology and surgery, using a graded synthesis of the existing literature.

Coupled with the guidelines a peer education package using illustrative case studies was set in motion to instruct and encourage adoption of guidelines by general practitioners through the delivery of educational outreach visits. The idea of a dual strategy emanated from previous studies in Leeds University (Effective Health Care Bulletin 1994) which suggest the importance of a mixed methodology to ensure maximum uptake. Whilst many general practitioners' agree with the concept of using evidence based guidelines there are those who fail to comply with this in clinical practice, leaving them open to criticism in their failure to provide effective treatment (Ketley et al 1993). The overall rationale for the OAFSS guidelines was to encourage general practitioners to 'manage and refer' rectal bleeders in all age groups, coupled with those patients over forty five years who have experienced an altered bowel habit to the service. Contra-indications for use of the service included the elderly, infirm and those patients with a cardiovascular or diabetic concern.

This section of the research looks at perceptions of guidelines in general but in particular with those designed to be used in conjunction with the OAFSS. Previous

studies appear to have been written up from a medical perspective (McColl et al (1998) i.e., by general practitioners or consultants. However this qualitative study offers a different slant on compliance and failure to comply with the use of guidelines in that it looks at culture and power structures.

Field and Lohr (1992) define clinical guidelines as 'systematically developed statements to assist decisions about appropriate care for specific clinical circumstances'. On the face of it, this innocuous definition would suggest an additional clinical hand being offered to the generalist, a hand which would be grasped and utilised within the heavy workload of the primary care sector. But how do general practitioners really perceive these statements?

Marshall (1998) suggests that general practitioners' key role as the patients' advocate has been enshrined in legislation, (for example the Patients' Charter) and the influence they have as purchasers of hospital services has resulted in a power shift within the profession. Newton et al (1994) maintain that this shift has initiated communication problems at the interface between primary and secondary care providers. However Marshall's (1998) research contradicts with this demonstrating (despite what the literature or anecdotal stories might suggest) that there is a good level of understanding and mutual respect between general practitioners and specialists. Furthermore he suggests that individuals give a high priority to a friendly, respectful, personal relationship, established over years of working together. It is this consultant/GP working relationship, which Grimshaw (1995) maintains is the preferred authorship of guidelines.

Grimshaw et al (1994) demonstrate in their studies that a significant increase in guideline use can result when general practitioners produce their own guidelines.

However Hungin (1998) indicates many available guidelines tend to be from outside general practice, e.g. pharmaceutical companies, and despite sometimes representing consensus from mixed groups he cautions that they risk interpretation as products of self-perpetuation or unwelcome advice.

Sudlow (1997) agrees with Hungin proposing the need for more quality guidelines, pointing out that many are of impoverished quality, some even lacking the basics of both reference and systemic literature reviews. Grol et al (1998) maintain that many guidelines do not remain in regular use; not surprising as graphically illustrated by Hibble et al (1998) that wading through 855 guidelines, the equivalent to 28Kg per annum is simply not compatible with general practitioners' reading time at five hours a week (ibid)

Grimshaw et al (1995) indicates that educational intervention is likely to lead to implementation, correlating with Grol's (1992) research which demonstrates that face to face peer instruction was particularly effective; an historical teaching method dating back to the hunter gatherer. Grol (1992) suggests that practice dynamics play a major role in educational uptake suggesting that soloists have less information and resist change more than those collaborating closely with other care providers, possibly due to professional interaction.

According to Grimshaw et al, if the Bolam test, which sets the criterion for professional adoption, has been passed, then failure to adhere to a particular guideline, which has been well established in a clinical setting, may indeed have medico-legal repercussions. The "Bolam test" states that if a medical practitioner follows a practice common to a responsible section of the medical profession, he cannot be held guilty of

professional negligence. This test has been used to ascertain civil liability and is, or should be, no more than that. Chalmers (1993) argue that evidence based practice may in the future overrule the Bolam test. Dixon et al (1997) argue that evidence based medicine is merely a combination of both individual clinical expertise and the best available external evidence. This practice of using both evidence based guidelines and clinical expertise will culminate in protecting general practitioners from lawsuits, as well as supplying patients with the best possible medical care. However, general practitioners may resent the increasing pervasive role of medico-legal issues in their practice.

Sweeney (1998) infers that values and attitudes of general practitioners towards guidelines derive largely from their training and occupational subculture. A Western physiological dogma often used amongst general practitioners delving in gastroenterology is 'put your finger in, or your foot in'. Such a doctrine ironically may incite alleged embarrassments and subsequent delay for patients' seeking advice on rectal bleeding.

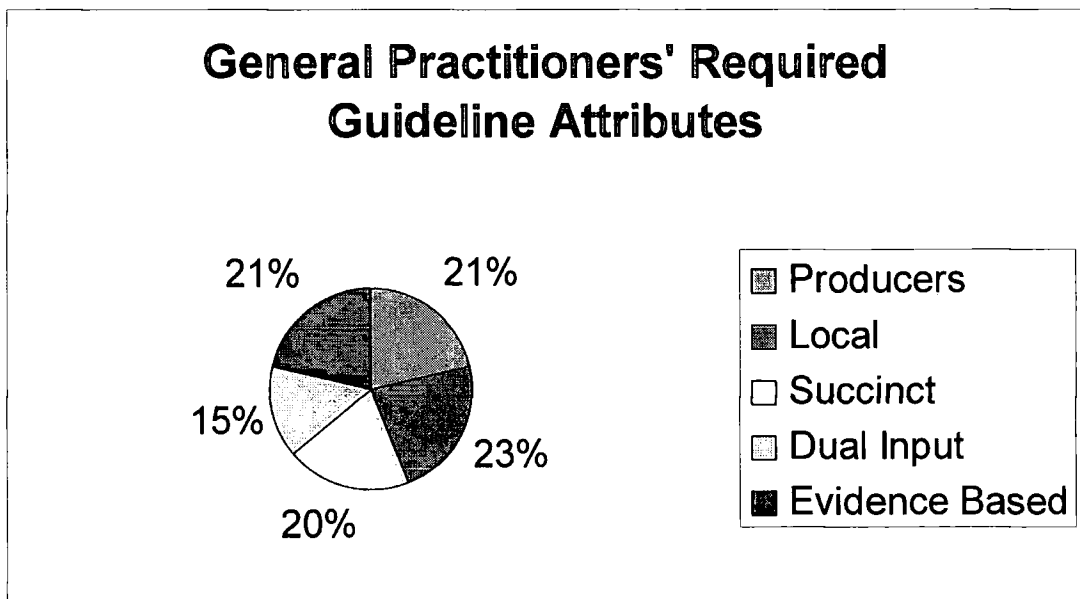
Woloshynowych et al (1998) argue that patients' beliefs about their illness should take precedence over guidelines, as illness for one patient, or indeed one culture, may be regarded as the norm to another and vice versa. Hungin (1998) advocates that the management of patients with dyspepsia must be based on patients' beliefs and fears of what they perceive to be the cause of their ailments.

Patients in our post-modern world are becoming informed consumers of health care, due partly to the Internet, which is redefining the once fragmented form of society. Lomas et al's (1997) study for example found that patients are now more familiar with the biomedical model and that they possess an elementary understanding of anatomy and

physiology which has increased awareness and demand for services from their general practitioners. As a result of this new-found patient knowledge, coupled with the new 'litigation society' guidelines are being produced for almost every ailment known to society.

7:1 General Practitioners' views on Guidelines in General

16 general practitioners' commented that authorship of guidelines was important in their decision to adopt them; 11 of those suggesting a preferred dual input from consultants and general practitioners. 17 suggested the need for local geographical medical input. 15 posited that guidelines should be succinct and easily memorised and 16 indicated a requisite for evidence based guidelines.



Use of Guidelines

The frequency in which general practitioners admitted to guideline use ranged from never referring to them to actually living by guidelines.

“I live by guidelines. We don’t adhere to them rigidly; it’s a matter of best practice for the patient”

“I use guidelines when I feel I really need to, which is about 50% of the times”

“I use them as little as possible”.

General practitioners said that they preferred guidelines that they could memorise, felt familiar with or saw the relevance.

“You are in surgery and there is a patient in front of you, you have very little time, you have your six or seven minutes with that patient and you have to make up your mind. You don’t have time to say I shall look at my guidelines and whatever, you tend to memorise them”

“I adhere to guidelines in the strict formal sense I would say about one a week. It depends on whether I am operating a guideline and recalling memory. If I am familiar with a set of guidelines I think I would probably operate them regularly”.

“I am married to a hospital specialist so we discuss poor communication between hospitals and general practitioners over breakfast, dinner and tea; with the best will in the world we cannot read and memorise all of them”.

“I don’t consult the ones I don’t value. If I haven’t grasped the relevance or value of them the first time round then I reject them by default”.

Difficulties Experienced with Guidelines

“I think loss of autonomy is one of the aspects of primary care groups; some doctors may feel unhappy about them. A conformity, or merging, or some sort of loss of clinical autonomy because of pressures at national or legal level”.

Field and Lohr's (1990) definition and rationale for using guidelines is epitomised in this general practitioner's words

"I think guidelines are there certainly to help but if you are going to stick to guidelines absolutely rigidly then a monkey could sit in this chair. Couldn't they? I see them as a helping hand of expertise".

"They do not undermine autonomy they just martial thoughts better".

"We can choose to ignore guidelines if we want. They are not for instructions, they are there to guide you"

"Sometimes they are rationing, difficult, and can sometimes conflict with patient care. For example take the requirement for gynaecological examination before going on the pill. An internal is not necessary; postnatal examinations are a shining example of this. Often they are just administrative. Thou shalt do it"

"Some are over complex. I think one of the things that always concerns me is that you go two steps down and they say refer. I think as I say some of them that have not had primary care input are consultant led and they don't trust you to look after them. Partly autonomy, but partly lack of guidance and lack of trust, it's do this, do that, and if you cannot cope, refer them".

The majority of general practitioners complained about the relevance and verbosity of guidelines, some indicating that despite being aimed at general practitioners, their input was lacking. From the following comments it was evident that doctors preferred guidelines which involved them as part of development and networking within both primary and secondary care providers.

"Ones produced without a lot of consultation with general practitioners can be counterproductive and those tend to be the ones produced by smaller groups".

"Imperative that they are a mix of secondary and primary care in the development of the guidelines. I would disregard them if they have come from consultants in ivory towers whose work is not applicable to us".

“I keep the ones I think might be useful, the things I do not feel confident about. I think in general, hospital based practitioners are a bit more adept at doing it, and so I wouldn't go along with the argument that we are in general practice and they are in hospitals, and therefore they cannot tell us what is best to do. If we have a case and we are stuck it is the hospital that we refer to”.

General practitioners also suggested that whilst guidelines were useful in certain situations, sometimes they were limiting and inhibited diagnosis. An overriding theme was the quantity of guidelines received and where these should be stored.

“The problem with guidelines is really that we are absolutely inundated with them so I don't refer to guidelines terribly often. I'm afraid I chuck a lot in the bin”.

“There are that many flaming guidelines. I try to keep them all, I just never know where I have kept them”.

“I keep them all. I have piles everywhere”.

“I keep guidelines in my head; when they are paper based it is often difficult to keep up to date. I am inhibited from using guidelines largely as a result of irrelevance. If local and agreed in policy and of course if evidence based facilitates these I use them”.

“Well, I think they have got to be practical and sensible. Most of them are quite good. I don't think there's a great difference between local and national especially in the areas I deal with. I am very much in favour of guidelines; it makes our life much easier”.

General practitioners said that they more likely to comply with them if they were part of the referral form.

Ownership

“The respect comes from knowing the people who have produced them. I think you always end up with a bit more ownership of them if they are locally produced and they are often more relevant to the local population. The guidelines being on the referral form and an explanation why is the best combination”.

“Well the classic one is ownership, lack of respect for the original source; for example the hypertension guidelines produced in 1988-9 were produced by an old teacher of mine. I respect those because I know where they have come from. I have a hard core that I keep in a file and the rest I keep in various places”.

Local Vs National

“I refer to guidelines. I don’t particularly like local guidelines. I have little experience in this field and to be frank with you the local guidelines are usually national. I am nervous of altering national guidelines in that I suspect the amount of research that goes into locally produced don’t have either time or the expertise of the academics that do national guidelines. They have the time to sit and go through all the literature and sometimes they don’t have the clinical spin offs, and what tends to happen is the academic ones tend to be broadly correct, but not presented soon enough or, presented unrealistically”.

“Certainly local ones I’d keep. National ones I wouldn’t bother to keep. However national ones taking on board a local policy I would keep. Yes, if the guidelines have been written by people we are referring to, you take more notice of and keep them”.

“I look for GP input; I always look to see who produced the guidelines and if they are locally produced”.

“Local involvement, local consultant involvement, that’s quite important, and conflict of interest, because they are often sponsored by some drug rep at the bottom and that makes me dubious”.

General practitioners who had an overall negative attitude to guidelines expressed their opinions very strongly.

“I never refer to guidelines. I tend to assess the situation individually and take into consideration lots of factors; guidelines put you in a straight jacket. They are useful as an outline for general things, but not to look and say those are best care. They are too stiff, and do not allow for training and experience to come into play. You can really misdiagnose with guidelines, or be too eager to investigate. Weight loss and other factors must be looked at, medicine as you know is not just mathematics, the formula is not either right or wrong, lots of areas

of grey. Cookbook medicine is a good analogy. Otherwise we would be all the same; all doctors would consult guidelines and would be automatons. If they are legally minded they will apply the guideline and never go wrong and never take a risk”.

One general practitioner suggested that he had ‘no’ guidelines:

“I don’t have any guidelines, oh yes; I do have some in the nursing room”

“I am not inhibited at all by guidelines; most of them are local guidelines. I don’t see why I should not take them out in front of patients. I know where they are and I can just get them out if I need to use them”.

“You have got to look at what the clinical situation is, you don’t have time to think “there is a guideline for this, now where is the guideline?” When I read them, I do not think they would help my day to day work, and so would make the decision on what I thought was in front of me, rather than take out a form, and think; “do they fit into that?” (GP)

“I keep all the guidelines. I don’t tend to take them out during consultation at this practice; we are just too busy. Apparently in court guidelines don’t stand up. It’s medical practice that stands up; guidelines are not legally binding. So the bottom line is guidelines are simply that, guidelines”.

7:2 General Practitioners' views on OAFSS Guidelines

I was keen to ascertain if the OAFSS guidelines had succeeded in acting as the intended additional tool, or as Lomas (1989) posits, whether they changed clinical behaviour. The overwhelming positive point about the OAFSS guidelines, as expressed by all participants, was that they were written on the referral form.

“We take the referral forms out and start filling them in and this has got the guidelines on, so you don’t have to remember them”.

“I like this very much because generally speaking you are discussing it with the patient and thinking about it as well. It’s just a way of refreshing your memory as to, have I got it right? The guidelines being on the referral form and an explanation why is the best combination”.

“They were really useful to make sure that you were not tempted to refer everybody. Because it is a very good service, I look at the

guidelines to see what patients would benefit and also the patients I would not refer, that is useful”.

“Got to accept the local ones. Take Teesside the health is worse than half the national average”.

“Guidelines are simplistic for GP’s to understand”

“OAFSS guidelines are fairly brief, really that’s the main thing. Brief and straightforward”

7:3 General Practitioners' Views on Educational Tutorial

The six general practitioners opting for the educational package were asked if they found the session beneficial, and what effect if any it had on their service use. This elicited a mixed range of responses.

“It was a pleasant way to spend an hour at lunchtime and it’s nice to be stimulated from another colleague. But whether it actually influenced my practice was less clear”.

“I started using it immediately after the training session with Jim. Approximately six months ago I was prompted by the speed of the service over a longer waiting time. Very satisfied, I have no complaints; I like the speed.”

“Probably James Larcombe coming along to speak increased our usage, and certainly my usage has increased dramatically, because effectively what they were saying was they wanted it used as much as possible. This is because the colonoscopy is one of the most valuable tools they have got. There is a low pick up rate with endoscopy but a very high pick up rate of cancer with colonoscopy”

7:4 DISCUSSION

By changing nothing we hang on to what we understand, even if it is the bars of our own jail--John Le Carre (1990)

The bars of the general practitioners' jail may be the beginning of termination of patients' lives as was evidenced from Dougall et al's (2000) pilot study. Can general practitioners afford to "*never take a risk*", as was advocated by one general practitioner? The following is a case study, (already published) epitomising the horror, which can develop when a general practitioner takes a risk.

Case Study 7: private anguish: public mortification

This forty-six year old gentleman had been visiting his general practitioner for nine months. "You see I have been off work for nine months with this diarrhoea and the stomach pains have been bad. My doctor thought it was stress related and has been treating me with beta-blockers. Prior to this I haven't been to the doctor for years, and you know what it's like you just accept that they know best so when he said it was stress I just accepted his diagnosis"

This man was referred to the open access service nine months after his first visit to his general practitioner. His diagnosis is colo-rectal cancer.

A respect for local consultants working in consultation with general practitioners reverberated throughout the interviews with many general practitioners advocating the need of their involvement if guidelines are to be used as a daily tool in general practice. A loyalty and respect so highly regarded that I would venture to argue that this shift from ritualistic consultant referral to the post-modern general practitioner referral would hinge ultimately on consultant stamp of approval to alleviate any general practitioner dis-ease. This is evidenced by the general practitioner who suggested that if he had positive feedback encouraging him to use the service, he would refer more patients.



Post-modern medicine is paradoxically enshrined in symbolic workings and symbolism, from the colour coding of the white shirt (replacing the white coat in training) to the myriad of military metaphors, which emanated throughout the interviews. It has also invoked a juxtaposition of traditions in that general practitioners are becoming the generalist/specialist; Shanks et al (1997) identify that 28% of all general practitioners have a specialism and in fact hold clinical assistantships at hospital clinics. From the twenty-six general practitioners interviewed many were specialists or training as practice specialists in fields such as paediatrics, orthopaedics, rheumatology, gastroenterology, and urology. It was also of interest to note that three general practitioners with a gastroenterology interest offered their patients' a rigid sigmoidoscopy service and were rather complacent about both the OAFSS and the associated guidelines. Yet as was evident in the former chapter the findings of a rigid sigmoidoscopy test due to its limitations, are not conclusive in eradicating sinister diagnosis.

General practitioner vintage (although I have no statistical data) proved indicative and congruent with traditional patterns of referral, rather than using the OAFSS as recommended by the guidelines. The older and soloist general practitioners tending to 'have one finger only on the pulse' and to favour the traditional secondary care route. Grol's theory of soloists having less information was evident in that this study unveiled the advantage of the 'grapevine effect' which through its social and professional bonding ensured that six general practitioners within the control group manifested familiarity with the OAFSS guidelines.

The six participants who experienced the educational package voiced enjoyment; it also appeared that these sessions initiated an element of change in individual practice.

However in looking at these particular results we must take into account the ratio of general practitioners involved, six out of two hundred and sixty. This leads me to suggest that had I interviewed another sample of six doctors, different opinions may have been offered.

Cultural interpretations and power structures were evident in attitude to guideline usage through, for example, assumptions that secondary care is superior to primary care or vice versa, and general practitioners' own socialisation and perceptions which ultimately provide motivation for adoption.

The autonomous man may do what another tells him, but not because he has been told to do it...by accepting as final the commands of the others, he forfeits his autonomy (Wolff, 1970)

What motivates or inhibits general practitioners from guideline usage? In attempting to answer this question I will look to Nietzsche's (1982) theory of 'felt obligation' for a theoretical framework. His famous aphorism "*being moral means being highly accessible to fear*" may initiate general practitioner compliance. Moral, for Nietzsche means, the moral order and specific obligations of a society. For example in Britain we mourn our dead and accord with the demand-generating principles of duty, rights, and prayer that supports this. The idioms used for commitment he suggests may vary across cultures, yet the experiential core is recognisable by the feeling of being under the command of God or some greater force than the self; the experience of guilt and/or fear.

My theory is that general practitioners' in similar vein to teachers or other professionals have to cope with various external pressures generated by government initiatives, such as the Patients' Charter. In modern societies an increasing number of

professionals are employed in large-scale organisations, examples being the National Health Service or University of Durham. As Barritone et al (1994) suggests we can no longer assume that the ideal-type professional is the independent autonomous practitioner practising his/her entrepreneurial role. The professional of today is mostly salaried, performing his activities within hierarchical settings, and often plays two roles within his organisation. For example the general practitioner is expected to be the generalist as well as an amateur specialist. Each of these roles demands different tasks, but the primary role of professionalism in values and standards remain the same.

These professional initiatives are changing the spirit of medicine as a 'community' or fraternity. This community spirit offers a sense of belonging in small-scale societies; the National Health Service has a weighty small-scale cultural tradition in the form of values, modes of conduct, symbolic meanings and traditional social relationships, within a complex social organisation. This cultural experience of community as a bounded cultural whole is universally found in non-industrial and industrial societies. Furthermore this ideology transcends social spectrums and is oblivious to capitalistic ways of life.

Have guidelines destroyed *communitas* or are they a reflection of declining *communitas*, or effort to create larger *communitas*? Ferdinand Tonnies refers to this way of life as a *gemeinschaft*, a face to face contract wherein reciprocity occurs. Where once general practitioners would choose the surgeon or consultant of their personal choice to whom they would refer patients, they are now forced because of new technological advances and guideline introduction to change to the *gesellschaft* model. This contrasts with the *gemeinschaft* model in that the general practitioner is referring patients to a

service wherein they may have had no personal affiliation with the specialist. Furthermore this shift has moved their patients into this gessellschaft model in that there is no prior face to face consultation, they merely arrive at the clinic and the colonoscopist introduces himself immediately prior to the procedure. This allows no time for human contact, which initiates bonding and trust, the reciprocal rewards for the colonoscopist.

General practitioners' life events also cannot be disregarded in the rationale to guideline referral or service use, for example one practitioner who failed to refer a subsequent diagnosed malignancy says he now uses guidelines more frequently. D'Andrade (1992) explains how self-understandings are prone to acquire motivational force and they do so in interaction with personal experience. One could therefore suggest that his compliance to guideline referral is a result of 'guilt', emotional intelligence and felt obligation; emotions or senses being the essence of our actions that evolution has instilled into us (Goleman 1996), or as Nietzsche so aptly submits

And what magnificent instruments of observation we possess in our senses. Today we possess science precisely to the extent to which we have decided to accept the testimony of the senses ---to the extent to which we sharpen them further, arm them and have learned to think them through. The rest is miscarriage and not-yet-science --in other words, metaphysics, theology, psychology, epistemology - or formal science, a doctrine of signs such as logic and that applied logic, which is called mathematics. In them reality is not encountered at all, not even as a problem.

However these emotional actions deter from the rationale of guidelines which is of course to reduce inappropriate variations in practice (Siriwardena 1995)

Evidence suggests contrasting opinions about guidelines, from those who dislike and disregard guidelines in general, to others who regarded them as an additional tool in which to make a clinical diagnosis, and those who suggested that they 'live' by them. In

contrast to the diversities of opinions about general guidelines, the OAFSS guidelines manifested overall a positive and favourable regard with eight of the general practitioners in the subject group suggesting that they now felt more confident in their management of rectal bleeding.

This research, correlating with Grimshaw, indicates that general practitioners are more likely to comply with those guidelines encompassing local dual input, peer instructions, succinctness, on basis of evidence and systemic literature review, as well as easily internalised data and emulation on referral forms. As evidenced by the interviews, participants were appreciative of their personal input to the testing and viability of guidelines suggesting that OAFSS guidelines have reached the parts beyond the reach of the 'scope' of others in that they have imbued *communitas* in their development, content, implementation and dissemination. However, despite general practitioner commendations of OAFSS guidelines, this anthropological research evidences that human individualism and emotion act as the fundamental inhibitor for guideline uptake. The 'paper chase' of guidelines is insufficient alone to change general practitioner behaviour.

Chapter 8. Conclusion

Doing ethnography is like trying to read (in the sense of “construct a reading of”) a manuscript – foreign, faded, full of ellipses, incoherences, suspicious emendations, and tendentious commentaries, but written not in conventional graphs of sound but in transient examples of shaped behaviour. (Geertz 1993:10)

This study has allowed me to see 'new' practices as 'familiar' performances within the health arena. I was intrigued at the once unseen transformation from person to patient as their rite of passage began and similarly when re-incorporation had taken place. This transformation occurred under the auspices of the medical terminology, superiority of doctors, subordination of patients, the ritual performance of signing the medical consent contract, theatre gowns, white coats, nurses uniforms, the mores of Western society and the technoenvironmental system in which modern medicine has now become encapsulated.

I was re-awakened to the fact that regardless of whether it's shamanic healing, Ayurveda, Chinese or Western medicine, all forms of medical treatment are so deeply entrenched in ritual and symbolism that it is the breaking of any one of these healing rituals which cause the patient to be dissatisfied (Wall 1996). The rituals which are perceived to occur in this location vary from building a rapport and trust with the doctor, the one-to-one confidentiality of diagnosis, compassion and honesty, consideration to both parties, and generally the efficient manner in which the ritual is performed. The evidence from separation to re-incorporation in many instances would suggest that these rituals did not occur in a manner that was conducive with patient satisfaction.

Yet despite the 'fractured rituals', the quantitative part of this research indicates that 97% of patients were satisfied overall with the OAFSS. The areas of dissatisfaction

identified by patients were, pain during the procedure, waiting times, and how and where the results of the sigmoidoscopy/colonoscopy were given to them.

General practitioners' also manifested overall satisfaction with the service; dissatisfaction for them focused around the lengthy waiting times. My major findings in this section was that many general practitioners were oblivious to the protocol and procedure of sigmoidoscopy/colonoscopy and were actually giving patients false information (a minor procedure requiring the administration of two glycerine suppositories!).

The reasons for delay in presenting with rectal bleeding as suggested by the patients varied from embarrassment to fear of the known as well as fear of the unknown. All patients said they were embarrassed to some degree, in contrast many general practitioners' said embarrassment was not an issue they had identified with patients' delay in presentation.

Overall general practitioners were positive about the OAFSS guidelines suggesting that they contained all the attributes required for adoption; lack of these attributes being the reasons many general practitioners did not adopt guidelines *per se*.

I suggest that if all general practitioners are to adopt the guidelines then the consultant stamp of approval is necessary. I feel that this would encourage OAFSS usage, as general practitioners require assurance that referral to the open access service is the required pathway. I firmly agree with the general practitioner who suggested that all patients be given a discharge letter informing their general practitioner of the findings. This would be an excellent way forward for both general practitioners and patients and would help in alleviating the psychological trauma for patients and irritation for general practitioners, which this study has unveiled.

Although waiting times were unacceptable to both parties the major concerns identified in this study surrounded communication. For patients these communication problems were two-fold in that a) patients were embarrassed to communicate their problem of rectal bleeding to their general practitioner and b) communication was felt to be inadequate between patients and the consultants/colonoscopists. General practitioners' also inadvertently/advertently suggested a lack of communication with consultants in that they were unaware of the protocol of the procedure and whether consultants were in favour of the shift from secondary to primary care management. One general practitioner was dogmatic in his suggestion that communication problems exist between consultants and general practitioners.

“When told, (life histories) create an emotional bond between the listener and teller” (Denzin 1989:44)

One general practitioner suggested that he was often used as a counsellor during medical consultation when patients' unloaded their problems of stress, domestic problems, occupational problems etc. Giddens (1991) believes that many individuals lack psychological support and the sense of security provided by the more traditional societies. Dr. James Larcombe who gave the academic instruction on the use of the OAFSS also suggested that his peers, i.e. local general practitioners, used him to unload their problems of both domestic and occupational stress. I also felt that the patients regarded me as someone with whom they could share the trials and tribulations of life, for which they had no other outlet in these days of modernity.

In spite of my preparation, prior to the onset of the research, I was not prepared for the emotional bond the case studies demanded, in that many patients through the severity of their diagnosis required that my role change to that of 'listener'. It very

quickly became clear that this bonding process was the trigger mechanism that unveiled the complexities, richness and ambivalence of patient experiences, which emanated from the case studies and participant observation. I was also able to 'anthropologize' or relate to Loizos's (1985) Tales of the Yanomami, as in many instances I was tormented, albeit momentarily, by the problems and sights encountered within the research.





This research has proved salutary in terms of reinforcing the need for qualitative research in patient satisfaction studies. It also provides a convincing demonstration of the valuable contribution anthropologists can make to audits on perception of experience by patients within our post-modern health arena. Yet while this thesis aimed at a holistic approach to perceptions of satisfaction with the open access flexible sigmoidoscopy service, I appreciate the 'unattainability' of this in that many people associated with the service remain silent because of the limitations of this thesis.

Sigmoidoscopy/colonoscopy is an innovative health technology that has come into use only in the past ten years or so. Each year, 15% of the adult population of the UK make risk judgements about the symptom of rectal bleeding that, medically speaking, is indicative of the need for this procedure. Opinions vary as to the appropriateness of the procedure for 'open access' format, and how it should be carried out, yet little cognisance has been made of what patients themselves think of this highly invasive procedure and how their experience of it impacts on their perceptions of rectal bleeding and the possibility of future investigations-----perhaps a doctoral thesis!

Appendix 1. Open Access Sigmoidoscopy Service: Patient Satisfaction Questionnaire

We would like to know how satisfied patients are with their care in the sigmoidoscopy unit. This information, which will be treated in strict confidence, will be used in a study which aims to improve our service. Please help us by completing this questionnaire; additional comments can be written overleaf if you wish, or you may be prepared to discuss your experiences further with an interviewer. If so, please complete your name and address in the space below and return to us in the envelope provided.

Instructions: Look for the box under the face which describes your views and tick.

				
	Very Satisfied	Satisfied	Slightly Dissatisfied	Very Dissatisfied
What is your experience of the following?				
general layout (ward size, bed, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Atmosphere of unit (bright, warm etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How your visit was organised	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How long you had to wait for an appointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information you were given by post prior to your visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How the clinical procedure was carried out	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The control of pain during the procedure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your care by the ward staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your care by the theatre staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How and when the results of your clinical procedure were given to you afterwards	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, how satisfied were you with the open access unit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you would be willing to take part in further discussions about your experience, either in your home or my office, please fill in your name and address below. An interviewer will contact you shortly.

Thank you for your help!

Name _____
 Address _____

Telephone
 (if available)

Appendix 2: Guidelines for Open Access Flexible Sigmoidoscopy

1. Type of Service

The service will consist of lower GI endoscopy, the 1st step management of any identified pathology, a report and a recommendation for further management if this is necessary. Responsibility for the overall care of the patient lies with the GP unless specifically transferred to the specialist.

2. Limitations and Yields

Flexible lower GI endoscopy is the most appropriate option for the type of service envisaged.

3. Potential Demand

On current estimates an open access Flexible Sigmoidoscopy service should have capacity for 120 referrals per 100,000 population per annum with the ability to easily expand to accommodate increased activity.

4. Operational Issues

The service will be provided in units that conform to BSG guidelines and will include lower GI endoscopy as far as the splenic flexure for rectal bleeding and full colonoscopy for altered bowel habit.

5. Indications - the symptomatic patient

The indications for referral are rectal bleeding in an adult, and recent alteration in bowel habit in patients aged > 45. Patients with worrying symptoms should be referred direct to a consultant clinic.

6. Indications -screening

Screening of the general population for colorectal cancer using Flexible Sigmoidoscopy has not yet shown to be of benefit.

7. Patient related factors

Most patients are suitable candidates for the service. Contraindications are:

- severely limited mobility
- inability to understand the procedure
- insulin dependent diabetes
- on anticoagulant therapy
- inability to clear the descending colon of faeces prior to investigation on previous occasions.

Written and verbal information for the patient is of paramount importance and should be provided both before and after the procedure.

Rectal Bleeding - Key Points

1. Rectal bleeding is a common symptom affecting 15% of the adult population each year.
2. Although the cause is often benign, associated features which raise the possibility of serious disease include:

Age > 40

Alteration in bowel habit

Passage of altered blood pr

Blood mixed with the stool

3. There are 24,000 new cases of colo-rectal cancer each year, and 17,000 deaths.
4. Most colorectal cancers evolve from adenomatous polyps. A 2cm polyp carries a 50% risk of malignant change.
(NoRen 1996)

Appendix 3: Educational Intervention Letter

Dear

Guidelines for Open Access Flexible Sigmoidoscopy

You will be aware that an open access flexible sigmoidoscopy service for General practitioners is provided by North Tees Health NHS Trust and South Tees Acute NHS Trust. The specification for this service is based on guidelines, which were developed by a group of General practitioners and specialists under the auspices of NoReN, the Northern Primary Care Research Network. The full literature review on which they are based is available for the NoReN office, Tel 789026.

A short version of the guideline is enclosed, together with a laminated desk top aide memoir, which I hope you, will find useful in your clinical practice. The guideline is intended to help you identify patients for whom OAFS would be appropriate, and to give you essential information about the nature of the service provided.

Lower GI symptoms such as alteration in bowel habit or rectal bleeding are common but can sometimes indicate serious disease. The OAFS service was set up, largely in response to requests by General practitioners, in order that these symptoms be investigated more promptly. These guidelines will help you to make best use of the service.

Dr. James Larcombe has put together an educational package on the management of rectal bleeding and the open access service with PGEA approval for 1 hour. He will be in

touch with your practice soon to see if you and you partner (s) are interested in the education session or require other information on the service.

If you have any comments or queries relating to these guidelines please contact Greg Rubin or Jane Ling at NoReN, Primary Care Resource and Development Centre, Grey Towers Court (Tel 01642 304127)

Yours sincerely

Greg Rubin

Peter Kelly

Andrew Russell

NoReN Research Fellow

Director, CHMR

Anthropology Dept

University of Newcastle

University of Teesside

University of Durham

Appendix 4: General Practitioners Interview Schedule.

GP's perceptions of the OAFS and Guidelines

Preamble

“The aims of this survey are to see how the initiation of the Open Access Flexible Sigmoidoscopy has affected your practice, how it affects you on a day-to-day basis in terms of your management of patients and clinical practice, and your use of Guidelines for the use of the Open Access Flexible Sigmoidoscopy Service. It should take no more than 30 minutes of your time and is entirely confidential”.

1. How did you first become aware of the presence of this new service?
2. Do you use the service?
3. When did you first start using the service?
4. What prompted you to start using it? (Any critical incidents?)
5. Overall, how satisfied are you with this new service?
6. What do you like about the service?
7. Have you had any problems in your use of the service?
8. Are you aware of any resource implications (either positive or negative) in your use of the service?
9. How has the presence of the service affected your management of patients with rectal bleeding?
10. Do you still refer patients to outpatients? [If so, why?]
11. What factors are significant in your decision about whether to send patients to OAFSS or outpatients? [E.g. waiting times, patient management perceived severity]. How are they significant?
12. What do you think is the current waiting time for OAFS in your area?
13. Has the availability of OAFSS influenced you in doing rectal exams, or in any other aspect of your clinical management? [If so, how?]
14. Whose responsibility is it to explain to patients what is going to happen to them when they attend the service?

15. Whose responsibility is it to give results to patients?
16. Are you satisfied with the way results are managed and given to patients?
17. How would you rate patient satisfaction with the new service?
18. Have you had any experience of patient non-compliance with the service/guidelines (e.g. delay in seeking help; patients not showing up for appointments in surgery or at OAFSS; patients refusing service even when indicated; patients insisting on service even though fall outwith parameters of guidelines; patients not following treatment)?
19. Do you feel you are managing patients with rectal bleeding more confidently as a result of the new service?

A. Guidelines

1. How often do you refer to guidelines in your clinical work?
20. What other sources of information do you regularly consult?
21. What medical journals do you regularly read? Do you or your practice subscribe to them?
22. Where do you keep your guidelines?
23. What factors are important in your decision to use guidelines? (E.g. size, readability; evidence-based; patient-centred; locally produced; reputable group; mixture of primary and secondary care; gives sources)
24. What factors prevent/inhibit your use of guidelines? (e.g. financial/time constraints; distrust of clinical trials; don't like being told what to do - autonomy; disregards art/craft aspects of medicine)
25. Were you sent clinical guidelines to enable you to use the OAFSS effectively?
26. If yes, follow on. If no, go to 3.
27. Can you summarise the guidelines for the use of the OAFSS service?
28. Have you used them? If so, when?
29. What do you like about them?
30. Have you found any problems in using these guidelines?

31. Are you aware of any resource implications (positive or negative) as a result of using these guidelines?
32. Did you accept the educational session provided by James Larcombe after the guidelines came out? [if not, why not?]
33. If so, did you find this useful?
34. Have you ever been aware of not following guidelines? If so, why? [e.g. patient insistence; financial implications; 'hunch']
35. Is there anything, which you think, would improve these guidelines?
36. (Go to 4.)
37. What are the things, which would have helped you, pick up on and use the OAFSS?
38. Have you been aware of any uncertainty in your management of patients with rectal bleeding and your use of Out-Patients/OAFSS? If so, when?
39. Teesside has a high rate of colo-rectal cancer. To what do you attribute this?
40. What other ways do you think would be effective in reducing the rates of colo-rectal cancer on Teesside?

Appendix 5:Glossary

Colonoscopy	The procedure of passing a fiberoptic instrument, through the anus, for examination of the interior of the colon.
Colonoscopist	The person performing the colonoscopy
Colostomy	An artificial opening (stoma) in the large intestine which is brought to the surface of the abdominal wall for excretion of faeces.
Diazemuls	A proprietary anxiolytic drug available only on prescription used to treat anxiety in the short or long term, to relieve insomnia, and to assist in the treatment of alcohol withdrawal symptoms and migraine. It may be used additionally to provide sedation for very minor surgery or as a premedication prior to surgical procedures and because it also has some skeletal muscle relaxant properties, to treat the spasm of tetanus or poisoning, or to relieve the bronchospasms of severe conditions of asthma. Diazemuls is a preparation of the Benzodiazepine diazepam.
Fissure	A crack in the mucous membrane of the anus.
Haemorrhoids	Dilated rectal vein.
Hypoxia	Abnormally low amount of oxygen in the tissues.
Laxative	Medicine which loosens the bowel contents and aid evacuation.
Lesion	A broad term for a pathological condition including tumours.
Lumen	The space inside a tube.
Midazolam	An anxiolytic drug, one of the Benzodiazepines, used primarily to provide sedation for minor surgery such as dental operations or as a premedication prior to surgical procedures and, because it also has some skeletal muscle relaxant properties, to treat some forms of spasm.
Pethidine	A narcotic analgesic used primarily for the relief of moderate to severe pain, especially in labour and childbirth. Its effect is rapid and short-lasting, so its sedative properties are made use of only as a premedication prior to surgery or to enhance the effects of other anaesthetics during or following surgery. Dosage should be reduced for the elderly or debilitated.

Polyp	A pedunculated tumour of the mucous membrane.
Polypectomy	Removal of a polyp.
Prostatectomy	Surgical removal of the prostate gland.
Pruritus Anus	Great irritation of the skin surrounding the anus.
Sigmoidoscopy	The procedure of passing an instrument for viewing the interior of the sigmoid colon

(Weller & Wells 1991)

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