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*Experiencing a first surgical consultation : patients' interaction in an outpatient clinic*

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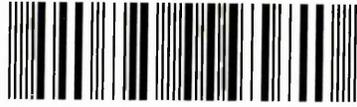
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**Experiencing a First Surgical Consultation:  
Patients' Interaction in an Outpatient Clinic**

Fanny F. Costa-D'Sa

A thesis submitted in partial fulfilment of the requirements of  
Sheffield Hallam University  
for the degree of Doctor of Philosophy



October 2007

*Dedicated to the memory of my parents Peter and Eltrudes Da Costa, who were the beacons of my academic journey and being.*

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## ABSTRACT

Using a grounded theory approach, this study, sets out to explore and elicit the patients' experience during the initial surgical consultation in an outpatient clinic. Its purpose is to derive an analytical understanding of patients' enactment of their role through observation of surgeon/patient interactions, to describe and explain how patients perceive their role during consultation and generate a theoretical framework. It is unique in using 'patient voices' as a means of substantiating theories and observations distilled from data collected.

The research question posed was:

*How do patients describe their experience of the first consultation with a surgeon?*

Following Ethics Committee approval, a sample of thirty patients (following theoretical saturation), not previously seen by the consultant, were recruited from a surgical outpatient's clinic. Theoretical saturation was reached when no further properties or relationships of note were generated by the data captured. Theoretical sampling developed the emerging categories making them more definite and pinpointing the fit and relevance of categories. Three sets of audio-taped patient data, (at pre-consultation, intra-surgeon/patient consultation, and post-consultation interview), were transcribed verbatim. A fourth set of data (surgeon/researcher interview) was obtained on cessation of patient interviews.

Data collection and analysis were managed simultaneously using 'constant comparative analysis' to reveal five categories: *Experiencing crisis*, *Regaining control*, *Seeking engagement*, *Constructing partnership* and *Sensing relief*. The category *Playing the rules of the game* emerged from the surgeon/researcher interview; this tested the hypothesis that interpersonal skills are learnt 'on the job'. The core category, *Seeking peace of mind*, uncovered the essence of the study and represented the concept most significant to patients. An Assessment Triad, a composite of the three categories *experiencing crisis*, *seeking engagement* and/or *regaining control*, which emerged in the initial patient/researcher interview is presented to facilitate this 'search' and to uphold the ethos of patient-centeredness, a dictum embedded in all Government initiatives.

The findings of this study offer grounded evidence of patients' experiences and needs before a surgical consultation in the format of an assessment triad, a tool used to question and prompt clinical practice in order to foster patients' search for peace of mind; and issues pertinent to the role of medicine and professions allied to medicine. These findings can inform future pre-surgical and perioperative protocols and professional education by ensuring that patient empowerment, patient-centredness and their search for peace of mind are incorporated into patient/healthcare professional consultations.

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# CHAPTER 1

## Signposting and structure of the thesis

This section offers the reader a guide and a brief resume of the thesis, which elicits patients' experiences of the first consultation with a surgeon at a hospital's outpatient's clinic.

**Chapter 1** offers the background to the study, its rationale and posits that there exists a substantive gap in the knowledge of the patients' experiences in the first consultation with a surgeon in an outpatient hospital clinic. It concludes that with an understanding of these 'processes' (experiences) medical practitioners and healthcare professionals allied to medicine will offer a patient-centred service to patients. It also recommends a methodology which dissects to understand and not prescribe and evaluate (Salter, 1998), a methodology which listens to the voice of patients and prompts an outcome where the 'needs of the patient not the needs of the institutions are at the heart of the new *NHS*.' (DoH, 1997)

**Chapter 2** Following the researcher's personal interest in pursuing the study, this chapter provides a detailed philosophical justification for the selection, a qualitative approach to the study, the methodological position adopted by the researcher and the assumptions underlying the specific methods of data collection and analysis. It does so by arguing that dominant research methodologies currently used do not elicit the experiences and 'needs' of patients in a surgical consultation, and are not adequate to fully capture the essence of the patient/surgeon consultation process.

The chapter goes on to propose that a grounded theory approach rooted in tenets of symbolic interactionism provides a viable alternative to these earlier approaches.

This chapter also details how the principles underpinning grounded theory are translated into an operational design. These include sampling strategies, data collection, analysis, theoretical sensitivity, coding and ethical considerations and are presented in the form of a decision trail. It also emphasises how my role as the research 'instrument', is challenged as the evolving nature of the study reveals different cultures and possibilities.

**Chapter 3** This chapter introduces the reader to the findings of the study and offers an overview of the patients' story of their experiences of a first surgical consultation from the data collected from audio-taped, unstructured interviews.

It introduces the reader to the 'manner' of presenting results in grounded theory approach by using substantiated support (that is segments of actual data for explanatory power) to allow the reader to make independent judgements as to how the emerging concepts are grounded in the data.

This chapter also offers a brief resume of the study's data collection flow that is the initial patient/researcher interview followed by the patient/surgeon consultation, and the post consultation patient/researcher interview.

**Chapters 4, 5, and 6** present the data and findings from analysis of audiotape recordings of the initial patient/researcher interviews (Pre-consultation). The categories, which emerged from the data are described and labelled (simultaneously) as *Experiencing Crisis*, *Seeking engagement*, and *Regaining Control*.

**Chapter 7** presents the data and findings from analysis of the audiotape recordings of the patient/surgeon interaction (after the patient's personal details are established and noted). This chapter reveals how the surgeon in *constructing a partnership* (the prevailing category) with the patients, offers a sense of collaboration and participation in the consultation.

**Chapter 8** presents data and findings from the analysis of the post-consultation patient/researcher interview, which reveals a complete change in the mood of the patients following their experience of the consultation. It appears that patient satisfaction and compliance was a critical outcome of the category *Sensing relief*.

**Chapter 9** highlights that the data from the researcher/surgeon audio-taped interview revealed that the surgeon's ethos of a consultation was based on his 'early learning' in the clinical arena. Much of this was governed by his reflective practice and the role models he encountered during his 'internship'. The surgeon's effort in *Playing the*

*rules of engagement* fostered a partnership with patients based on trust and empowerment.

**Chapter 10** The core category Seeking peace of mind, which emerged from the culmination of the categories in this study is illustrated by means of an analytic storyline that details how each of the categories, which emerged in the study relate to the central phenomenon seeking peace of mind.

**Chapter 11** This chapter titled *Enabling Peace of Mind: The essence of healthcare professionals' interventions* or Discussion Chapter, draws together the threads of practice and theory which uphold the essence of patient-centeredness within the emergent patient-inspired assessment triad; the tool used by patients in their the ultimate 'intent' for *seeking peace of mind* in a consultation with a surgeon in a hospital's outpatients clinic. This chapter also highlights the study's limitation, offers recommendations for future research and practice and finally provides an insight into the researcher's journey into academia via a reflective account.

# CONTEXT OF THE STUDY

## Introduction

The aim of this study was to elicit and explore the patients' experience of a first surgical consultation, with a consultant surgeon, (to be referred to hereafter as 'surgeon'). This study of a 'case' of the clinic of one consultant was set in a hospital outpatient clinic. This context has been used to generate a theoretical framework that describes and explains how patients perceive their role in a clinical consultation. The overall purpose is intended to provide a hitherto unexplored perspective to surgical consultations by using the 'voice' of the patient, which is in keeping with the policy agenda in formulating the strategic direction of patient-centred healthcare services and the public/patient participation movement. It is anticipated that the findings of this study will contribute to the formation of patient-centred policies in both inpatient and outpatient services in the future.

## Rationale

Traditionally, the National Health Service (NHS) is known to be paternalistic in its approach to its users. Typically the patient's role is perceived as passive in any surgeon/patient interaction, this is seen as being determined by the 'knowledgeable healthcare professionals' (Klein, 1989) as knowledge equates to a position of power. Today however, there is a newer and increasingly more generally held and promoted belief that patient participation makes for better consultations. (DoH, 2004)

This study is therefore significant in that it has both practical and political relevance to today's healthcare climate, which is seen to harness its energy on maintaining the primacy of patients in the healthcare arena.

The World Health Organisation (1978) states that:

**“people have a right and a duty to participate individually and collectively in the planning of their healthcare”**

This is a statement which still resonates in Government initiatives and policies today and reflects two sentiments or dimensions. Firstly, that patients, clients, potential users and carers are involved in the planning of aspects of health services, and secondly, that the role of the users and carers reflects the identification of their needs and their responsibility for choosing the means to meet these.

Presently, Government initiatives are focussed on reshaping the NHS around the needs and aspirations of its patients by ensuring that citizens' and patients' views are listened to and acted upon, thereby giving 'voice' at every level of the NHS. (DoH, 2004; 2001; 2000; 1999a; 1999b; 1997; 1991) 'The New NHS' (1997) for example, in an effort to bring quality and efficiency together, aims to create a powerful alliance between knowledgeable patients and knowledgeable doctors and healthcare professionals. This 'powerful alliance' it suggests will play a role in contributing to an integral part of clinical effectiveness and partnership with healthcare teams, the NHS and the public, and the patient-centred approach as sought of in the 'clinical governance.' (Lugon and Secker-Walker, 1999)

The question arises as to how healthcare professionals will respond to these imperatives while retaining the core values and attention to the constant of basic human needs – a patient's perspective.

The increasing value placed on patient participation reflects a wider societal movement towards beliefs based on consumerism (Brearley, 1990), a government diktat that there is a therapeutic alliance between the patient and healthcare professionals, and accountability in the NHS. Therapeutic alliance in the sense that patients have a significant involvement in decision making, which encourages responsibility, an openness to questioning so that understanding is owned by all and not seen solely to reside with the professionals. (Campling and Haigh, 1999) In other words it avoids unhelpful dependency on professionals.

It is suggested that this alliance must be built on a much deeper understanding of the processes that bring patients to the professional in order that there is better integration of the natural history of illness with the patients' perceptions, understanding and strategies for coping with illness.

This need for a much deeper understanding suggests that healthcare professionals need to move beyond their own 'assumptions' of this alliance and search for that 'patient-centeredness' in their intent to create a therapeutic alliance. This can be achieved by drawing out what exactly patients experience and ask for in a surgical consultation.

Brearley (1990) summarises participation as a collaborative process that should involve the empowerment of patients, clients and potential users. However, although the concept of user participation is seen to be growing increasingly in today's health climate (Jewell 1994), patients' actual level of involvement has been questioned by Naidoo and Willis (1994) who suggest that this can vary and that empowerment is not the norm in a patient-physician encounter.

This territory remains relatively uncharted even today, largely because attention is generally focused on what is offered to the public in the healthcare arena, as opposed to what the patients experience, and really want to receive in a medical encounter. There seems to be a need to move away from this 'ingrown culture' of paternalistic giving, to one which is formed on experiences grounded in the 'voice' of patients; the 'patient need culture.'

However, concerns about lack of choice available to health service 'consumers' (Barnes and Walker, 1996) and championing for the 'voice' of patients in healthcare have contributed to changes in the NHS culture, seeing it move towards more democratic healthcare provision and governance of public services. (Barnes and Warren, 1999)

These changes have influenced research and literature on patient experiences in healthcare focussing mainly on the following: measuring patient satisfaction (Turris, 2005), help-seeking behaviour (Galdas *et al*, 2005; Millar *et al*, 1989; Roberts, 1988), roles which terminally ill patients wish to play in the clinical decision-making process (Degner and Sloan, 1992; Waterworth and Luker, 1990), empowerment of patients in

making healthcare decisions (Olszewski and Jones, 1998; Hope, 1996), patient participation (Tutton, 2005), and patients' preferences for involvement in clinical decision-making within secondary care. (Doherty and Doherty, 2005; Gillespie *et al*, 2002)

Whilst the 'academic race' is on to ensure the studies have a historical value, little is still known about the underlying individual patient experiences or the processes involved within the 'actual' surgeon/patient encounter. There is still an underlying tendency for healthcare professionals to focus on the symptoms rather than the issues from the patients' perspectives. (Turris, 2005)

Assessments of patient satisfaction, health-seeking behaviours, or patient participation in a consultation with doctors or healthcare professionals it is argued, are about the 'interaction' between the two and this is facilitated by and embedded in symbolic interactionism, which believes that people behave and interact based on how they interpret or give meaning to specific symbols in their lives. Therefore, a study which explores the basic social processes in an interaction would focus on the vital aspect of a consultation, which is giving 'voice' to patients and their needs. It is about eliciting how patients interact with the surgeon, take action or engage in a process in response to a 'phenomenon'.

The Government drivers and momentum to shift towards a consumer-related NHS is becoming a reality, therefore it is prudent that research (using grounded evidence) examining the 'processes of access to health service', are executed in order to be able to assess the effectiveness of new healthcare strategies from initiation to implementation. It is argued that without this deeper understanding the proposed 'therapeutic alliance' between healthcare professionals and their patients may remain academic. Furthermore, the overture of 'consumerism' in these government 'drivers' suggests protection or promotion of 'consumers' interest, yet little is known or sought about what it is that patients seek from healthcare professionals whose responsibility it is to deliver the government's health diktat.

There remains then, the potential of violating the Health and Social Care Act of 2001, perceived as being a critical 'building block' for the patient empowerment agenda, as it places a duty on the NHS to involve the public and patients in the planning and development of services, and in making major health promotion decisions.

Policy initiatives such as the Expert Patient Programme (DoH, 2001), which recognises the expertise developed by individuals from their personal experience of chronic 'illness', emphasise patient participation and self-care [through empowerment]. (Wilson, 2002) However, Kennedy *et al* (2004) claim that there is a lack of 'engagement' with this very notion of the 'expert' patient being empowered to guide these policies.

Beresford (2000) indicates that the emergence of the concept of 'user involvement' has made a huge impact in market research and consultation initiatives in social work and social care, thereby increasing the significance of service users' movement in public, political, policy and professional debates. However, he argues that the involvement of service users (which includes mental health service users/survivors) in systematic social work theorizing has yet to be actualised and proffers that service users' knowledge is embedded in their "personal and collective experience and not solely on an intellectual, occupational or political concern." (Beresford, 2000:493)

Further reference was made to this 'user involvement' in the King's Fund Briefing Paper (2005:48) audit, which identified mental health as one of the three Government priorities. 'he paper drew attention to patients within this group who were, in the official language, "hard to engage", and noted the enduring gaps and failures in this area of care. It has urged the Government to "do more to translate their intentions into action" P53 suggesting participation/user involvement/empowerment and its recognition at all levels of healthcare delivery.

This suggestion is embraced by this study, which in the interest of 'servicing' the Government initiatives, and 'actualising' user involvement', sets out to elicit patients' experiences and to offer a grounded theory in a substantive area of the first consultation with a surgeon in a hospital's outpatients clinic.

Consumer-led NHS is therefore about ‘tailored’ interventions and patients’ voices being heard and acted upon if the patient-centeredness enshrined in the ‘new’ ethos of the NHS is to become a reality.

### **Research aim**

The aim of this research study was to build a substantive theory on patients’ experiences during a first consultation with a surgeon in an outpatient’s clinic.

The study was underpinned by a qualitative grounded theory methodology embedded in the tenets of symbolic interactionism (Blumer, 1969 and Mead, 1964) and this philosophy guided the nature of the question to be asked to achieve the aim, which seeks the basic processes that underpin the patient/surgeon interaction in a consultation.

The next section will elaborate how a literature search and review was carried out for this study including the conventions and criteria used to appraise evidence reported in that literature, in order to seek to understand the events, which contributed to the ‘metamorphosis’ of the patient role within the healthcare arena, focusing primarily on the patient’s role within a ‘consultation’ with a physician/surgeon.

Following the definition of ‘consultation’ and its historical application, the context of the study will include concepts such as **medical power, process of seeking professional help, political perspective, and information giving**, and conclude with **today’s consultation**, which appeared to shape the role of a patient within a ‘medical/surgical consultation’ and also offered weight to the NHS ethos of giving ‘voice’ to the patients within the realm of healthcare through patient-centeredness.

### **Literature Review**

In traditional research methodology, a literature review is conducted as a prologue to the study, acting as a foundation upon which subsequent elements of the research process rest. It illuminates for the reader, the background to the problem under surveillance and in doing so makes reference to previous theoretical and research perspectives in the field.

In qualitative research and in particular grounded theory, literature serves a more flexible purpose as a recognised source of data to be utilised throughout the study. Here the literature searching can inform and be informed by theoretical sampling decisions and is regarded as a worthy source of data alongside all other available sources of information that enlighten the subject. Literature will therefore be used as a reference point for comparing, reinforcing or challenging findings in the current study against earlier work.

Glaser and Strauss (1967) advocate delaying the literature review when using grounded theory method until after completing analysis on the premise that the researcher will see the data through the lens of earlier ideas often referred to as 'received theory'. In other words forcing the data into pre-existing categories. Another view is that expressed by Stern (1980) who claims that the purpose of delaying the literature review is to avoid importing preconceived ideas and imposing them on one's work, avoid premature closure of ideas and encourage the researcher to articulate his/her own ideas. More importantly, delaying the literature review until after I had begun data collection ensured that I did not lead the patients during the interviewing process, in the direction of my own beliefs.

Classically Glaser and Strauss however are seen to either overstate or differ on this position. Although Glaser (1992/1998) implies that grounded theorists can and should keep themselves uncontaminated by extant ideas, he admits to having prior knowledge in his discussion of theoretical codes in his book *Theoretical Sensitivity*. (1978) His view creates a dilemma/tension because on the one hand he advocates that grounded theorists should be 'uncontaminated', yet by his own admission recognises that by virtue of the researchers bringing to an inquiry a considerable background in professional and disciplinary literature, there is some degree of prior knowledge.

An initial cursory review of the literature was carried out in this study, which Creswell (2003) suggests helps to focus the study and provide an orienting framework. Creswell suggests use of literature "sparingly in the beginning of the plan [study] in order to convey an inductive design, unless the 'study' requires a substantial literature orientation at the onset" P33.

A selective sampling of the literature was therefore carried out initially to help the researcher to become familiar with the works published on the concepts under study (*see literature search and review in Chapter 2,*) and to identify the deficits in knowledge in the substantive area of patient experience in a consultation with the surgeon in an outpatients clinic, an area of interest to her as a specialist practitioner in perioperative nursing.

As the theory began to develop, further literature review was carried out to learn what had been published about the emerging concepts and to fill in the missing pieces in the emerging theory. In essence, the literature was used as data, which was woven into a matrix consisting of data, category and conceptualisation. (Streubert and Speziale-Carpenter, 2006) This process is addressed later in Chapter 2 - *Method and Design of the Study.*

#### **Sources of data/conventions used**

The Ovid System was accessed via the Athens Access Management System to gain entry to a range of internet-based and bibliographical databases. Electronic databases such as Medline Psyclit and CINAHL (which tend to catalogue mostly UK and American literature and research studies), Cochrane Database of Systematic Reviews (CDSR) and the Database of Abstracts of reviews of Effectiveness (DARE) were trawled and ASSIA was accessed for Social Science journals.

Droogan and Cullum (1998) however, suggest that electronic databases can omit relevant studies and it was felt judicious to manually search for and review library-based literature, which proved productive in harvesting methodological and content work utilised in this study. It also offered tapestry referencing (that is identifying new references through citations in relevant articles) in areas, which sometimes needed a 'jump start' to the search. In addition, documentary evidence consulted included the use of peer-reviewed journals, in social sciences and health psychological fields, Government health policy and Health Reports. (HMIC electronic database)

Key areas of reference were the 'drivers' of this 'metamorphosis' of the patients' role in healthcare, namely Government initiatives, Department of Health White and Green Papers, The King's Fund (important stakeholders in patient advocacy) and medical consultations. The search for medical consultations spanned the 1950s/1960s; the results were sparse and written mainly in Spanish and French (except for the abstracts).

The key words used for literature searching were surgical consultation, referral, physician - patient relations, education, standards, ethics, history and trends. MeSH, is the U.S. National Library of Medicine's controlled vocabulary used for indexing articles (MEDLINE/PubMed) and it provided a consistent means to retrieve information that may use different terminology for the same concepts. Although the literature cited under each heading was fairly intense in that area, it included other more wide ranging research topics. *See Appendix 1 and 1(a) for Scope Note display for: Physician-Patient Relations and Referral and Consultations respectively.*

Much of the evidence based research overlaps and acknowledges the importance of patient-focused communication and 'styles' of communication in medical consultations or doctor/patient relationships.

#### **Criteria for critiquing literature**

All articles or literature on the relevant issues were subjected to a critique of the research process, which included noting the journal in which the articles were published, the editorial board that oversees peer review of published articles (the hallmark of a scholarly journal) the time lapse between the publication of the article and when the study was carried out; considering any external factors that may have influenced the outcome. For example, there was an increase in the number of articles published and books produced on the patient-physician encounters in the wake of the public outcry for 'involvement' in decision-making or the then government's move to encourage self-care. Another point considered was the credibility of the author that is establishing the author's credentials or authority on the subject. (Holm and Llewellyn, 1986)

Studies/articles were assessed for the quality of evidence offered by evaluating the conceptual and methodological decisions the researchers made to produce evidence of the highest possible quality. Quantitative studies were assessed on their '*scientific merit*', (Bryman, 2004), two of the most important criteria being reliability and validity.

Ecological validity, which is concerned with the question of whether social scientific findings are applicable to people's everyday, natural social settings (Bryman, 2004) was at the forefront of this critique as research on 'humans' cannot be totally void of their 'surroundings'. Cicourel (1982:15) asks if our "instruments capture the daily life conditions, opinions, values, attitudes and knowledge of those we study as expressed in their natural habitat?" Qualitative studies, on the other hand, were assessed on the *trustworthiness* of the studies' results. (Referred to in further detail in Chapter 2 - *Method and Design of the Study*)

Each aspect however, of this 'trustworthiness' has a parallel with quantitative studies. For example, *Credibility* in qualitative research parallels internal validity of quantitative research, which asks how believable the findings are. *Transferability*, parallels external validity, which asks if the findings apply to other contexts? *Dependability* parallels reliability in quantitative research and asks if the findings are likely to apply at other times. Finally, *confirmability*, which parallels objectivity in quantitative research, seeks to establish whether the researcher allowed his or her values to intrude on the findings. (Bryman, 2004)

### **Literature review of Consultation**

Following a definition of 'consultation' (the key concept embedded in this search), this 'cursory review' of the literature will explore the historical perspective of this concept and its stance in today's healthcare climate. It is hoped that it will identify deficits in the fuller implications of a 'consultation' *per se* from the patients' perspective.

The New Shorter Oxford English Dictionary (1993: 490) describes 'consult' as a stem word of *consulere*, which means to take counsel, to deliberate, taken counsel, to confer (with someone about, upon a matter), consider, mediate, plan, contrive. Furthermore 'consultation' is described as having consideration for the interest, feelings, good etc., of a person or persons. A meeting in which parties 'consult' together or one person consults another specialist on a medical or legal matter, having the right to advise but not to decide on an issue

'Consultation' is about asking for advice or seeking counsel or professional opinion from; refer to a (source of information); "seek permission or approval for a proposed

action.” In essence it appears that the concept ‘consultation’ is about two or more persons in an environment, which nurtures respect for each other’s feelings; where one gives advice and allows the other to make a decision to accept or refuse it.

The phrase ‘*seek permission or approval for a proposed action*’ (above) for example seems to encapsulate the whole meaning of a ‘consultation’ and is applicable to either ‘party’ in the consultation, the giver or the recipient of the sought for advice. From the ‘giver’ perspective the permission is sought to initiate the proposed action following the *consulere*; from the ‘recipient’ perspective it seems that following deliberation permission is sought to accept or refute the proposed action. Embedded in this concept it appears is the issue of a ‘dialogue’, a communication between the two parties.

### **Historical perspective**

The patient’s metamorphosis into this ‘new patient’ is best appreciated by reviewing Parson’s thesis for the value of learning from past events (1951). The thesis states that neither the life of an individual nor the history of a society (in this case the role of a patient in healthcare management) can be understood without understanding them both.

As indicated in the Scope Note Display for ‘Physician-Patient Relations’ the search results revealed 38 articles, and the Scope Note Display for ‘Referral and Consultation’ revealed 200 results. Scope Note Display provides additional information about the MeSH, offers interactive query building, and is a useful tool when drawing on controlled vocabularies. Its intent is to clarify the meaning (*see Appendix 1*). The literature on the latter search will be reviewed later in the study as the theory develops. The literature on early ‘medical consultations’ (the former search) was sparse (compounded further by their publication in French or Spanish) with only 8 of 38 articles viewed appearing to offer a historical perspective.

However, the abstracts, which were written in English, offered an interesting insight into the professional instability of the medical practice/consultations and the patient role, in 18<sup>th</sup> century Spain. For example, medical consultation as a specifically structured procedure, served as an “instrument to define the hierarchy of those present.” (Leon, 2002: 1) Pardo and Martinez (2002) suggest that the *consultas* (consultations) and *juntas* (meetings) of physicians in the Novator Movement (1687 -1725) in Spain

represented an area of prime importance for both medical practice and doctrinal discussions about the human body and disease. They do highlight however, that the difference between '*consulas*' and '*juntas*' depended on the person who took the initiative. The '*consulas*' arose from the practical difficulty of the physicians confronted with a case, which they decided to submit to the judgement of other colleagues, whose experience and prestige was greater. This action seems analogous with General Practitioner (GP) patient referrals to hospital consultants of the present time.

The '*juntas*' on the other hand seemed to be the initiative of the patients who were plagued by institutional conflicts, professional expectations and rivalries (Pardo and Martinez, 2002); echoing it is suggested the present 'healthcare bureaucracy', patient expectations and monetary demands which form part of the emotional baggage that patients might or bring to a medical consultation today.

Nevertheless, it appears that no mention is made of the level or the type of patient 'representation' in a consultation even though suggestions are made that the opinions of the patients and their circle of acquaintances were represented in a consultation. This limits one's judgement of the status of these 'medical consultations' in earlier centuries. One would ask if the 'representation' reflected a consultation, which consisted of a physical assessment supported by patient stories of symptoms, which were only required "because they might express in purest form the communication of the pathological lesion itself" (Armstrong, 1984:738), or did it move beyond the 'obvious' to embrace the holistic approach to a human being by taking account of the patient's perspective in the 'encounter'?

The next section will offer further insight into the early consultations and factors which influenced the call for 'change' in these.

### **Early consultations**

Hutchison and Rainy's (1923) interpretation of a medical consultation seemed to focus on observing the "attitude of the patient as he lies in bed (*decubitus*)" and relate it purely to physical diagnosis. They claim that in health for example a patient lies on his back, sometimes on his side without much difficulty and has no hesitation in altering his attitude if he slips from his pillows or feels otherwise uncomfortable. But the stress of

disease they claim “will often confine his [the patient’s] activity in narrow bounds because it has reduced the patient to extreme weakness and dulled his consciousness.” (Hutchinson and Rainy 1923:19) The patient no longer makes any effort to secure a position of comfort.

Therefore the assessment of the ‘attitude’ in a consultation for example centred on the physical ‘status’ of the patient, whilst ignoring how the patient might feel or what s/he is experiencing in the ‘illness’, in essence the consultation lacked a patient’s perspective in the ‘encounter’.

This culture is perpetuated further by Hutchinson and Rainy’s (1923) assertion that history taking from patients is made up of two parts namely, ‘interrogation’ of the patient and the physical examination. The object of the former was to elicit information regarding the patients’ present illness and also their previous health status and that of their family. At the onset the word ‘interrogation’ seems a little threatening and has connotations of ‘power’ and ‘formality’ for the interrogator (the doctor in a consultation). Furthermore, this ‘interrogation’ seems to seek and establish the patient’s environment, the work, surroundings and habits, but no reference is made to the mental health in the ‘consultation’.

Interestingly, the later 10<sup>th</sup> edition of the Hutchinson and Rainy, book published in 1935, continued to emphasise the status of these consultations within the realm of ‘physiology and physical status’, with increasing focus on anatomy and physiology and use of technical resources in patient management.

### **Medical Gaze**

Armstrong’s (1984) paper on the historical journey into medicine and the patient’s view, offers an interesting insight into what the interaction between the doctor and the patient was founded on. He refers to clinical manuals, which provided details of how to go about ‘case-taking’, and refers to the process as “interrogation and the examination.” (Hutchinson, 1935) Such words in themselves bring to mind the power within the formality of the whole doctor-patient relationship.

Later however, these same manuals no longer referred to the term ‘interrogation’ and replaced it with one less threatening such as ‘take history’. It appears that

communication was recognised as being central to this process and that “it was necessarily a two-way business.” (Armstrong, 1984: 739)

This major shift, referred to by Foucault (1963) as the ‘medical gaze’ now perceived the patient as a holistic individual – the *psyche* and the *soma*. (Selye, 1956) “It is no longer a pathological species inserting itself into the body...it is the body itself that has become ill.” (Foucault, 1963:136)

Although this ‘transition’ could be considered a major way forward, in effect these patients had no independent views or autonomy and only existed as good or bad historians. They spoke on behalf of their pathology.

By the 1970’s this medical gaze had begun to engage with a new problem – the patient’s view. It became evident that the patient was not only seen as a sign and symptom of some disease or illness but as a person, whose ‘view’ lay behind the words uttered, “the subjectivity behind the words.” (Armstrong, 1984:742) This raised the issue of perception, the patient’s perception.

Armstrong argues that the patient’s view cannot be described or isolated, because it is bound up by what is heard, not what the patient said; establishing therefore the need for the reality (accuracy) of the patient’s view.

What Armstrong fails to disclose is whether the perception of patient’s reality in the doctor/patient interaction, is verified with the patient for accuracy. What patients need, and what they feel they need, was argued in 1959 by Mills as a quality of mind that will help patients use information and to develop reason in order to achieve “lucid summations of what interventions are proposed, and what may be going on in themselves.” (Mills, 1959: 214)

Therefore for doctors and other healthcare professionals to remain true to the doctrine of the ‘new’ health climate today, they must tailor the consultation to the specific needs of the patient, based on an understanding of their cognitive and emotional experiences during this search for professional help. This ‘reality’ must surely be realised in a study, which seeks to elicit patients’ experiences, for example in consultations with a surgeon in a hospital’s out-patient clinic, (a substantive area with limited information).

### **Calls for change**

There have been several calls for the renovation of clinical medicine/consultations and doctors are increasingly pressed to understand the difference between disease and illness, between organic lesions, patho-physiological processes and the patients' experiences, interpretations and meanings of being sick. (Zaner, 1990)

One of the more successful attempts at a new integrated medicine was by Balint (1956:58) who claimed that the role of a doctor was to organise unorganised illness, by reorganising the patient's problems, symptoms and worries so as to make sense of them, by constructing a "dense web of interconnections between feelings, symptoms, and social context such that the lesion [is] reduced to a single nodal point within a network of more abstract relationships."

Kleinman (1988: 232) argues for the doctor's focus on disease [in a consultation] to "be complemented by an equally needed interpretation of patients' perspectives of themselves while sick." Kleinman (1988), Cassell (1985) and Pellegrino (1982) all suggest that clinical medicine/consultations should be based on a 'phenomenology of illness' whose moral core is an 'existential commitment' to be with the sick person; and that this first and essential step to revamping clinical medicine must occur through "an experiential phenomenology and its acts of *empathic witnessing*." (Kleinman, 1988: 232)

Historically, therefore the medical consultation was being shaped into a more bio-psychosocial model with its emphasis on a consultation, which reflects a patient's perspective, as opposed to the traditional physician-led biomedical model.

### **Bio-psychosocial model**

From a historical perspective, Emery's (2002) work (which is traced back to writings well over 200 years ago) claims that the legacy of the art of consultation in Traditional Chinese medicine is today's healthcare's emphasis on 'holism', a holistic approach to the patient, which is achieved by going beyond the obvious. He suggests that Traditional Chinese medicine emphasised a natural and holistic approach to illness. He refers to the *yang* and *Yin*, which were conceived as two opposing forces, and dominated everything in the world from astronomical phenomena to health and disease;

and though they were opposites, they were not seen as being in conflict but were in fact complimentary. A concept it is suggested, which highlights the importance of the mind and body encapsulation in a medical consultation.

Engel (1980: 120) developed the 'bio-psychosocial' model, which integrated the traditional scientific approach with an equally objective method that was designed to elicit the "nature and history of the patient's experiences." The intent was to integrate "what they meant for the patient" with "what they might mean in terms of other systems of the natural hierarchy, be they biochemical and physiological, or psychological and social" taking on board therein the patient perspective.

Others such as Gadow, (1982), O'Neill, (1982), and Zaner, (1982), whilst not endorsing this proposal, have called for greater attention to what actually transpires in clinical 'encounters', appealing therein to the need to raise awareness that clinical medicine is no longer understood as solely a scientific enterprise but one which embraces the 'person' who is 'ill'.

Yet others remained dubious that any renovation of the biomedical model was required, calling into question therefore what exactly transpired in medical consultations and how far they reflected the patient's voice in the 'encounter.'

### **Medical Education**

Historically, this reluctance to 'change' could be associated with the ethos of medicine and medical education.

Traditionally, since 1910, scientists and researchers increasingly dominated medical education and as such "according to the values and standards of academic specialists," doctors came to be trained as scientists (Clouser, 1977: 5) and this invariably influenced clinical practice.

Physicians were trained almost exclusively in causal-etiological analysis that is, causally connected to some underlying patho-physiological lesion or process. (Cassell, 1985) Such attitude at the price of what the patient experiences and has to say about his/her own illness, being considered irrelevant unless it is demonstrably reducible to physical, chemical, or biological properties. (Engel, 1980)

Zaner (1988) however, urged that the transition to a bio-psychosocial model is made in clinical consultations if the patient's experience is to be rigorously understood and incorporated systematically into clinical methods.

### **Move to a new Paradigm**

Zaner's (1990) concept of a medical consultation seems to be influenced by the views of the sceptics or methodists who staunchly opposed the dogmatic view of traditional medicine. He first introduced the idea of *semeosis* (interpreting bodily, personal, and historical signs), as opposition to the dogmatics' idea of *diagnosis* (interpreting the visible as caused by the invisible). He argued that the dogmatics' idea deliberately ignored the unique sick person, whose body and personal life must be interpreted precisely and only as these are actually and fully presented.

Only then, he contends, can the central and governing purpose of medicine, that is, therapy, be properly conducted. In this context he refers to the term *epilogismos*, a reasoning form of deliberate weighing and considering, which is strictly opposed to the dogmatic's idea of *analogismos* (causal reasoning) as the essence of a patient/physician consultation.

To summarise, it appears that in a medical consultation, medical knowledge and not medical power should arise solely from the physician's therapeutic efforts, which are based on a mode of reasoning that takes into account all the properties and characteristics of each unique person, the *psyche* and the *soma*, 'the story of illness as the patient tells it' in a consultation. Furthermore, this story of illness should form the basis of a 'format', which identifies and addresses patients' needs and experiences of a medical consultation.

### **Historical perspective**

#### **Medical power**

It appears that despite the plethora of policy and professional literature related to participative models of healthcare, collaborative models, which seek to integrate a partnership approach between professionals and patients/clients and the public, are

academic because of obstacles, the most pertinent one being professional dominance (Brownlea, 1987).

The key notion in the literature on participation has been noted in 1976 when Illich challenged the power of medicine suggesting that it has created passive patient populations. However, this notion is not new as in 1975 Webb associated the practice of medicine as being governed by power and control. Confirming it is argued, Sheldon's (1966) suggestion that people's ideas of health and illness are culturally defined. Echoing yet again the early tenets, which dominated a consultation and "served as an instrument to define the hierarchy of those present" [in a consultation] (Leon, 2002:1).

The concept of the power of 'medicine' however, dates as far back as the practice of Shamanism, which is defined by Eliade (1968) as a technique for attaining ecstasy, enabling persons to come into contact with the sacred order of the cosmos. Porterfield (1987) argues however, that whilst one celebrated its liberating and therapeutic effects, its role as an enforcer of social conformity was overlooked. Within the 'mystic' of curing was bred a passive recipient of 'learned' rituals. This shamanic element continues to exist in the world of healing today. For example, in the 20th century, the major focus of healthcare policy was with individual ill health and on provision of measures to cure those suffering from it (Morgan *et al*, 1985), with little mention being made of the role patients played within this gesture.

Yet, in every society and historical era, it seems there is a critical common factor in the 'encounter' between professed healers and patients when they are sick: the 'need for healing', seeking the ordering principle, the universal fact that humans become ill and in that state seek and need help, healing and cure (Pellegrino, 1983).

Pellegrino defines sickness as when a "person experiences some disturbance in his accustomed state of balance between body, psyche and self" P163. An upset to one's health equilibrium and induced vulnerability it could be argued, which creates the need for a consultation with the doctor, and therefore behoves the doctor to restore "wholeness or, if this is not possible, to assist in striking a new balance between what the body imposes and the self aspires to [in other words to restore the balance]" (Pellegrino, 1983: 163).

Therefore action which is both technically right and morally good in cure provision is suggested; the former being based on empirical and scientific facts and adjusted to the 'particularities' of the illness in the patient and the latter to what the patient perceives as worthwhile, and is personally derived and incorporated into his own life (Pellegrino, 1983). A consultation, which in essence focuses on the patient's perspective, identifies needs and adds further weight to the intent of this study.

This concept of 'cure provision' was actualised by the inception of the NHS in 1948, which embraced the ethos that healthcare would be free at the point of use for all citizens, and be based on the core values of universality, comprehensiveness and continuity from 'cradle to grave' (Ham, 1991). The NHS operates a 'command and control' model of care, which has been criticised for its provider-dominated culture where patients have little say in the care they receive and generally do not expect to have it (Klein, 1989).

Parsons (1951) viewed this emergence of the functional importance of health for society with certain reservations, arguing that this state of optimum medical capacity, fostered roles and tasks for which individuals were socialised, creating the 'sick role' which perpetuated patient passivity within the bargaining power of 'healing' in a medical 'consultation'. Illich (1975) an ardent critic of the healthcare 'transition' claimed that medicine had duped society into believing that the medical profession has an effective and valuable body of knowledge and skills, which made society dependent on doctors and took away the individual's ability to self-care or self-regulate, making them succumb to medical paternalism and the power of medicine when seeking help. This in essence was the basis of a medical consultation.

Another aspect of this 'search' is that patients seek 'healing' from non-medicals such as families, friends, ministers and psychologists. Pellegrino (1983:162) suggests that patients who seek non-medical help from these sources do not consider themselves sick but simply 'troubled or anxious'. This is a behaviour that is described as the 'lay referral structure' by Freidson (1960) and is referred to in more detail in the next section.

### **Process of seeking professional help**

Historically patients sought help from anyone who offered 'relief' from their problems. Freidson (1960) referred to this 'help seeking' as the 'lay referral structure' and 'professional referral structure'. He claims that before the doctor and patient are brought together, there is a casual exploration of diagnosis by the patient. Local remedies are tried out and the diagnostic resources of friends, neighbours, relatives and fellow workers are explored. "Discussion of symptoms and their remedies [is considered] as referral as much as prescription until the 'professional' [doctor] is reached" (Freidson, 1960:231). This network of 'consultants' is called the 'lay referral structure' with the doctor positioned at the apex of this structure.

This 'lay referral structure' forms part of the conceptual framework used to underpin this study. It was important to establish the patients' 'referral' structure as it played a significant role in what and probably when patients presented their symptoms, and what triggered the processes manifested in this consultation.

The professional referral structure on the other hand, is comprised of a network of relationships held with colleagues that often extends beyond the local community and tends to converge upon hospitals and medical schools (Freidson, 1960). It is argued that the further into this structure the patient enters, the fewer choices are made available to them and the less control over what is done to them is provided. More importantly, when the General Practitioner, for instance, refers a patient to a hospital consultant, the professional referral structure is activated, as is the 'control' over decision-making.

This latter assertion of loss of control over decision-making offers an early insight into medical paternalism and the inequality of patient participation in decision making in health issues during a consultation with the hospital consultant. It appears that patients seek professional help at the cost of compromising their control on matters that are important to them. Seeking out the processes of how patients cope with this inevitable outcome will help inform healthcare professionals on how best to tailor interventions in healthcare management.

The inherent link of healthcare and paternalism has been accepted as the norm in social thinking per se. To remove this would mean to give back the onus of decision making in healthcare to patients. However, considering the long history of patients' subjection

to paternalism, the psychosocial aspect of patients' experience must be treated with some sensitivity. Interventions discussed and agreed with patients during a consultation must reflect the healthcare professional's moral thinking and understanding of the patients' rights and experience in this new role and their need to seek professional help. Yet this aspect is barely addressed from the patients' perspective in order to truly uphold the inherent moral thinking alluded to here.

### **Ethical Perspective**

From the 'medical consultation' perspective, it appears that other factors such as ethical, legal and social are also seen to shape the professionals' and lay persons beliefs to incorporate the concept of patient participation in healthcare (Avis, 1994 and Barnes, 1994). Avis suggests that the principle of autonomy, humanity and self-determination are embraced by many people, whilst the issue of the legal aspect of informed consent has nurtured the conceptual growth of patient participation in decision-making in healthcare (Barnes, 1994).

Pellegrino (1983:157) had also previously emphasised the 'moral' aspect of medicine by claiming that it is a special moral enterprise because it is grounded in the special personal relationship between "a person who is wounded in specific ways" and one who professes to heal.

Ethicists and moralists however, had already begun to take a stand on issues related to the rights of individuals and claimed that the concept of informed decision making or 'autonomous authorisation' (Faden and Beauchamp, 1976) is the mechanism of ensuring the rights of the individual in the medical context. The opponents of this concept however, claim that it is a myth - that patients do not and cannot understand the information given or they do not wish to be given any information (Thornton, 1992; Tobias, 1988; Meisal et al, 1981). It could be considered that both aspects of this argument hold true and that both need to be taken into account in the doctor/patient encounter. There is however limited information on this aspect of the 'debate', particularly the patients' perspective or 'voice' as to how the issue of patient 'involvement' in a consultation should be developed and resolved.

Ethicists have recognised the value of respecting the 'rights' of individuals in the healthcare arena. Clinical decision making for example, has come to be viewed by them as a 'right' of an individual, whilst the responsibility of nurses and doctors to provide information has come to be seen as a moral obligation (Beauchamp and Childress, 2001).

It is contended however, that with the patients' right to make clinical decisions becomes their responsibility to exercise that right in order to maintain a healthy lifestyle. How patients go about exercising this 'right' and what processes are involved in doing so appear vague, and the available literature offers little enlightenment to healthcare professionals. Respecting the rights of patients must warrant the need to identify a wider perspective of the processes involved in their exercising this right in a physician/patient consultation, an area, which appears to offer a limited insight.

Against the backdrop of promoting patient collaboration/participation as is inherent in the 'right' to clinical decision making, is the moral issue as to whether all patients should become more involved in decisions about their health. Literature and studies on patient involvement in decision making appear to focus mainly on the treatment decisions of terminally ill patients with potentially life-threatening illnesses (Beaver et al, 1996; Degner and Sloan, 1992). There is some reference made to the interaction between the patient and the healthcare professionals in certain publications (Waterworth and Luker, 1990).

Fundamental to this ethos is the incorporation of patients' preferences about treatment and interventions and an understanding of the effects of emotional upheaval. This is a view challenged by Waterworth and Luker (1990) who warn that patient involvement in decision making could create anxiety in some people, and suggests that encouraging patients to participate in treatment decisions is in some way unwittingly coercing patients to comply. Patients they claim viewed collaboration with nurses and other healthcare professionals as simply 'toeing the line'.

Waterworth and Luker on the other hand project their patients in a 'sick role' where they "found out the rules and exhibited the 'right' behaviour", P74. Support for such compliance must surely be an attribute of 'social iatrogenesis' (Illich, 1976), which

conditions patients into this passive role and cements paternalism in a patient/physician encounter.

This inherent presumption that patients generally prefer a passive role in decision making could be contentious. Degner and Sloan's (1992) study for example, revealed that cancer patients wanted a passive role in decision making, whereas those women who never had cancer wanted an active role. Beaver et al (1996) confirm these findings and suggest that 'well' people expressed the wish to play an active role in their healthcare management. From the healthcare professional's perspective an understanding of what it is that keeps well people interested in controlling their healthcare as opposed to the sick people who abdicate this responsibility, will offer a wider perspective to giving voice to patients and ensuring that care is tailored to needs.

Such assurance is gained through research, which seeks to elicit patients' experiences and needs in a 'consultation' with a healthcare professional and not through (as noted in many studies), assumptions of what patients seek.

Whatever the patient stance - 'involvement or non-involvement', there is a need for closer scrutiny of the emotional and cognitive energy expended by patients in seeking professional help in a consultation at the hospital, so that the healthcare professionals' moral stance on issues of respect for the autonomy of the individual become central to the delivery of care.

### **The political perspective**

The NHS and politics however, continue to perpetuate this 'passivity' as they remain inseparable financially. Salter (1998) and Klein (1989) argue that the State which is chronically short of finance, traditionally recognised that the public would trust doctors and not politicians to make decisions on clinical priorities, and therefore offered further clinical freedom to medicine, perpetuating medical autonomy, paternalism and control to include economic and political spheres.

The late 1980's however, saw the beginning of opposition against this culture of excessive paternalism, lack of respect for patients and their right to make decisions about their care (Ham, 1999). In addition, during this period the 'healthcare' consumer

movement moved the patients and their carers into another dimension away from the patronage of the past (Ham, 1999, Salter, 1998). The then prime minister, the Rt Hon. Margaret Thatcher, (now Baroness Thatcher) was sensitive to the changing public mood and expectations, and it was signalled that patients and the public should come first when it came to delivery of healthcare. Conservative governments responded to these changes by introducing initiatives such as the Patients' Charter (DoH, 1991), in an effort to make services more responsive to patients' needs. They later introduced the Patients' Rights as an endorsement of its support to patients' voices in the NHS. Essentially, these 'voices' should be loudest in a patient/physician consultation but there seems to be little known as to what is articulated in the 'encounter' in order to uphold these 'Rights'.

In 1997 the incoming Labour Government's health manifesto was driven by its attention to the quality of healthcare provision and accountability. Thus 'New Labour', began by introducing Clinical Governance (DoH, 1999b), a framework for ensuring the delivery of high-quality care, based on the philosophy of continuous quality improvements (Reid, 2002), whilst retaining the principles of accountability to patients in their care.

However, the modern consultant finds it hard to admit to 'fallibility and error' (Irvine, 2001), contributing to the demise of the 'soft parts' of medicine, namely communication with patients and relatives and the exoneration of science and scientific research (Klein, 1989). It is suggested that the monopoly of medical knowledge has compounded the passive role of patients in healthcare giving rise to disparate power relationships.

There is a perception however that the present Government has facilitated, via its policy shifts, the conditions necessary for a 'therapeutic alliance' (a basic tenet of today's healthcare), thus providing the potential for an open dialogue and information exchange during doctor/patient consultations.

This 'potential' for an open dialogue and information exchange must however move away from the present 'euphoric overture' of giving patients a 'voice' in the health agenda to a down-to-earth effort to establish and ground the voice in a mutually agreed ownership.

### **Information giving**

The call for an 'open dialogue' is reflected in the directives within the NHS Plan (DoH, 2000), which attempts to put the patient into a more empowered position within the health service, and instructs healthcare professionals to keep patients informed at every stage of their care. The 'Plan' claims that, "too often patients feel talked at, rather than listened to" in contrast with doctors who claim that the knowledge that they command is "too esoteric to be given freely and fully shared with lay persons" (Inglefinger, 1980:21). Hardy (1999) believes however, that such sentiments are a thing of the past as the increased availability of information technology today has demystified much of the medical knowledge available and released those 'vocal cords' of patients, which were once restrained by the knowledge of the medical profession.

The momentum to keep patients informed and to be given a choice in decision making is being 'championed' by the increasingly critical media. The Government continues to be besieged with reports on the NHS inadequacies and failure to respond to the needs of the patient. The media's reports on several high profile inquiries, such as the Bristol Inquiry (Bristol Royal Infirmary, 2001) and the Liverpool's Alder Hey Hospital Inquiry (1999), had highlighted the failure of healthcare professionals to communicate and to offer access to information for patients and their families. They also highlighted the need for an increase in partnership, honesty, transparency and openness with patients (Gillespie et al, 2002). The Bristol inquiry for example, concluded that the exchange and provision of information is at the core of an open and honest relationship between healthcare professionals and patients ([www.bristol-inquiry.org.uk](http://www.bristol-inquiry.org.uk)). (DoH, 2002). Such open and honest relationships can be nurtured in a climate where there is an understanding of the help-seeking behaviour of patients in a consultation with the surgeon at the hospital.

### **Today's consultation**

Studies and literature on more recent accounts of the patient-physician consultations seem to have used quantitative methods and questionnaires to gather data, which in essence are patients' responses to questions posed by researchers. Furthermore, there is the likelihood that the respondents may differ in their reading levels or in their ability to

communicate in writing. These questionnaires have in essence produced findings that are technically valid but reflect little of what happens in people's everyday lives.

There was a sense that some quantitative studies, which used coding systems had embedded values that were appropriate in some settings but not in others. Other studies that relied solely on quantitative measures for analysis of recordings or transcripts seem to have failed to distinguish between what is said from what is actually 'heard'.

Generally, however, models of consultations over the last thirty years could be placed under the rubric that the healing relationship is best conceived as a form of dialogue, in a 'face to face' interaction. This is noted for example in studies on physician telephone consultations that have shown that although the telephone is increasingly being used to provide care, telephone consultations cannot be taken as equivalent to those conducted face-to-face and suggest that more work needs to be done to delineate the features of telephone consultations (Innes et al 2006).

Several studies such as Makoul, (2001), McCool and Morris (1999), Thompson *et al* (1990), Savage and Armstrong (1990) and Stewart, (1984), seem to suggest that doctor/patient communication remains a problematic issue despite the growing rhetoric of developing 'partnership' roles between doctors and patients and encourage a patient-centred emphasis with health services. These studies therefore focused on the styles of consultations, compliance and patient satisfaction in an attempt to address this 'problematic issue'.

Savage and Armstrong (1990) for example, compare the effect of directing and sharing styles of consultation on patient satisfaction. Patients were randomised to receive a directing or sharing style in the part of consultation concerned with giving treatment advice and prognosis. There was a significant attrition rate noted in the patients' responses to the questionnaires a week following the 'consultation'. These questionnaires measured patients' satisfaction with the General Practitioner's (GP) perceived understanding of their problem and expectations. The result showed that the style of consultation did influence patient satisfaction and most noticeably in consultations with patients with physical problems and patients who received prescriptions.

Whilst acknowledging the value of such findings it seemed that the questionnaires in most studies focused on what the researchers thought of as being significant to 'patient satisfaction' as opposed to actually determining what patients themselves thought of as significant contributors.

Stewart's (1984) study conducted in twenty-four family physicians' offices sought to establish what constituted a successful consultation. The video tape recordings of one hundred and twenty-four patient/doctor interactions were analysed using the Bales Interaction Process Analysis (BIPA). The patients were then interviewed at home ten days later to assess patient satisfaction and their reported compliance. The Bivariate analysis indicated that when physicians demonstrated a high frequency of patient-centred behaviour, there was a significantly higher reported compliance and satisfaction.

Stewart's (1983) earlier study however, which looked at patient characteristics in relation to doctor/patient interaction, concluded that different groups of patients may need and implicitly demand different sorts of relationships with their physician. Yet again, while her findings were plausible and valid, there remains that patient 'exclusivity' from actually contributing to what might constitute a patient's view, rather than responding to the category of physician/patient statements in the BIPA.

Studies such as Mahler and Kulik (1991), Krantz *et al.* (1980) on patient 'inclusion' or involvement in healthcare, have shown that patients' desire for information and for behavioural involvement with treatment are reasonably independent orientations to healthcare involvement. The distinctions between these are of interest because explicit efforts to increase patient involvement with healthcare have produced mixed results (Schulman, 1979, Rotter, 1977). It may be that from a motivational standpoint, the patients who desire behavioural involvement with treatment are motivated by the basic desire to exert direct control over the situation, reduce uncertainty and arousal (Mahler and Kulik, 1991). Whatever their 'motivation' for their desire for involvement, there seems to be little reference made to the patient's input into such summation.

In an attempt to improve patient-oriented interventions, studies such as Thompson *et al.* (1990), and Roter (1984) asked randomly selected patients to write down questions to ask the physician during the consultation. These questions were prompted by a list of possible health concerns. The result showed that patients who listed these questions

asked more questions in a consultation and reported to being less anxious. The studies suggested that the effect may be attributed either to thinking one's questions out ahead of time, or to the perception that one's physician is open to questions (Thompson *et al*, 1990).

This seems an interesting outcome as the study asks patients for their input into the consultation. One could ask that if the questions asked by patients were not prompted, then would the researchers be given a different insight into the needs of the patients – a patient's perspective altogether? Why not encourage the patients to ask questions by creating an 'open dialogue' in the encounter?

### **Growth of 'models' of consultations'**

Finally, literature reveals the growth of the models of consultation over the last forty years. There was a dichotomous relationship of art and science in medicine and models evolved to seek a balance between the two. There was a sense of a quiet revolution in thinking and teaching about medical consultation; that is teaching of exclusively disease-based clinical method, and history taking, which was entirely doctor-centred to one that considered the patient perspective, and rapport was more than a polite bedside manner.

The medical approach is primarily associated with disease and diagnosis (McWhinney, 1981); sociology and anthropology (Helman, 1981) and transactional analysis (Berne, 1974) as well as concern about the roles played by doctor and patient. Very early models such as the Balint (1957) and others' (Bryne and Long, 1976) emphasised the dynamics of a consultation, whereas social psychologists were more concerned with the behaviour of the doctor and patient (Becker and Maiman, 1975).

Neighbour (1997:32) claims that present medicine is an enormous 'model-shop' occupying "the common ground between mankind's physical, mental, and spiritual experiences." He associates the evergreen model in the West with the 'dualistic' model of Man, which underpins centuries of scientific and religious debate, with Rene Descartes. This Cartesian dualism holds that the "body is nothing more than a mechanism, obeying physical laws, while the mind is altogether different stuff, God-given and not susceptible to physical explanation" P32.

Another model of relative importance to medical and philosophical thought in this century was the psychoanalytical model of the mind, originating with Freud and endlessly 'revamped' by generations of psychiatrists of different schools. For example, Freud conceived the mind as tripartite, with ego, superego and id, and awareness divisible into conscious, pre-conscious, and unconscious. Berne (1966) on the other hand refers to the structure of personality and interactions between individuals using the three ego states, Parent, Adult, and Child, which in essence is underpinned by Freud's 'tripartite' of the mind.

In medicine however, the most pervasive model was the 'Medical Model', which was taught to medical students who found it 'most attractive because it stretched their intellects, and spared them much involvement of their feelings' (Neighbour, 1997). Its ethos was based on the theory that normal health exists in terms of bodily structure and function, is compatible with comfort and survival, and studied in the disciplines of anatomy, physiology and biochemistry. Within this model therefore, successful therapy restores "diseased processes to, or in the direction of normal, thus curing or improving the patient's illness" (Neighbour, 1997:33). There was however, a distinct absence of the patient's psychological being.

It seemed that the consultation using the medical model served merely as a setting within which the doctor gets on with the job of diagnosing and treating with total disregard for the patient's needs or views.

McWhinney (1981:78) had made the case that this holistic theory of disease, as noted within the concept of the medical model, should be recognised as the scientific basis of Family Medicine, however, acknowledging too the holistic being of illness, by claiming:

*"That it is not a matter of rejecting the reductive (disease) but enlarging its scope to overcome its limitations. The holistic approach recognises that illness is closely related to the personality and experience of the patient, and that man can not be understood in isolation from his environment."*

The 1970s and 1980s began to sense discomfort with the medical model and the traditional doctor/patient roles within a consultation and the mood of the time reflected words such as 'consumerism' 'deprofessionalisation' and 'holistic'. Models emerged

which were either doctor-centred or patient-centred. The former described the aims and behaviour of the doctor and the latter focused on patient's aims or behaviour. The two most prominent models were those of Pendleton et al (2000), doctor-centred and task orientated, and Neighbour, (1997) patient-centred and behaviour orientated.

Neighbour's model draws an interesting analogy with doctors and patients having two heads each in a consultation. One he claims is the 'outer' one between the doctor and the patient, the 'out loud one' which both the patient and doctor know about; the other is the 'inner' consultation, with thoughts that go back and forth between the individual and the 'second head'. Neighbour uses this example to highlight its effect on a doctor during a 'consultation' if distracted by an inner 'overload.' This is a useful analogy from the doctor's perspective but could also be used to elicit the patient's 'inner' consultation in an attempt to fill in the psychological 'gap' and balance of power created by the 'knowledge' of medicine in a doctor/patient encounter.

Exposure of patients' feelings, emotions or needs in a consultation, for example, could be the lynchpin to a patient-centred medical encounter, patient satisfaction and compliance. The strength being that the exercise stems from the patients' perspective and lead.

Neighbour's model like many others focuses on rapport building, recognising minimal cues, the physical signs of mental states and listening and eliciting skills embodied in communication skills. All this in order to find out and to understand why an individual patient has sought help and advice, and together to be able to agree the most appropriate way forward.

A study, which is grounded in patients' experiences in a consultation with a surgeon in an out-patients clinic, would complement this search with needs-related interventions and ultimate patient satisfaction and compliance.

### **Summary**

The ethos of 'integration' of patient and public involvement into the work of the NHS (DoH, 2001) assumes a bigger presence and participation of patients in healthcare decision-making today. However, what this actually means to patients has yet to be

explored. One needs to determine what processes govern this 'transition' of patients into a participatory realm, as this realm remains elusive or uncharted. It is suggested that unless healthcare professionals address this issue, then public involvement and patient voices will remain 'silent' or marginal (Bury, 1997).

The literature review on the historical aspect of the patient role in healthcare has highlighted the 'shift' from medical dominance to patient sovereignty, which embraces a feel of 'medical democracy.' This democracy seems to be intent in the Government's effort to bring quality and efficiency together to create a 'powerful alliance' between the knowledgeable patients and knowledgeable doctors and professionals allied to medicine.

What underpins this suggestion is that there should be an equal role and an open dialogue between the doctor and the patients. The 'open dialogue' includes exploring what Neighbour (1987) refers to as the 'inner consultation' within a 'consultation', which might disclose what each is thinking about during the 'abstract' notion of a consultation. Particularly so, it is argued from the patient's perspective, which may reveal several issues that the patient may need to address in the 'encounter' with the doctor.

The 'lesion speaking through a patient' seems to be a concept of the past and today patients' views have come to be seen as valuable diagnostic and therapeutic tools. It is this that Helman (1978:109) claims is a move from considering the patient's view from "an irrelevance to a theory" towards making 'communication' a two-way process business, which focuses with more intensity on the subjectivity behind the patients' 'spoken and unspoken words.' Such exploration or scrutiny can be realised in studies, which seek out the patients' views; perspectives, which are grounded in their dialogue with the healthcare professional.

Literature on doctor/patient relationships and consultations has revealed useful and interesting findings, which have looked at styles of consultations, physician telephone consultations, patient characteristic in relation to doctor/patient interaction, patient motivation to be involved with treatment decisions, and patient 'inclusion' to improve patient-orientated interventions; all of which should be viewed in relation to patient satisfaction and compliance.

The use of pre-meditated questions in the questionnaires may have however, compromised the true reflection of what patients may have felt or needed. There appeared to be a distinct omission of the patients' 'voice' in what actually contributes to the 'inner' satisfaction within a consultation.

For example, Stewart's (1983) study offered a significant message to healthcare when it identified that different groups of patients may need and implicitly demand different sorts of relationships with their physician. They may choose to seek control of the 'illness' or abdicate the responsibility to the healthcare professional.

From a healthcare professional's perspective, the challenge for achieving this patient involvement also resides in the accommodation of the 'modernised', informed and assertive patient of today. It is contended that effective healthcare is not only the delivery of technically competent care, but also the recognition of the narratives and processes that patients bring to the encounter with the surgeon or healthcare professional at the hospital.

There is a need therefore to elicit and understand fully the processes, which govern the patients' decision to embrace the offer to 'engage' in a dialogue with a healthcare professional (the surgeon in the case of this particular study), or the decision to simply choose to relinquish the responsibility for self-care. This search requires a methodology, which dissects to understand and not prescribe and evaluate (Salter, 1998). It requires a methodology which listens to the voice of patients and prompts an outcome where the 'needs of the patient not the needs of the institutions are at the heart of the new NHS (DoH, 1997).

Therefore a study it is suggested, which uses 'symbolic interactionism', a theoretical perspective that assumes society, reality, and self are constructed through 'interaction' and thus rely on language and communication, will elicit the experiences of patients in a consultation.

This perspective assumes that interaction is inherently dynamic and interpretive and addresses how people create, enact, and change meanings and actions [an insight into that 'inner consultation' referred to by Neighbour] (Blumer, 1969), and will therefore

offer a firm basis for a patient/surgeon interview format, which includes these essential perspectives.

Giving 'voice' to the patients, a concept, which is currently being paid lip service to in the literature on the substantive area of surgical consultations in a hospital's outpatient clinic, is therefore a viable proposition for this study.

## CHAPTER 2

### METHOD AND DESIGN OF THE STUDY

#### Introduction

The literature review in the previous chapter, has highlighted that the patients' identity in a consultation, which was provided by their ability to speak for the otherwise silent pathology (Armstrong, 1984), is no longer embedded in the 'unformed words of the disease.'

Furthermore, in keeping with the policy agenda in formulating the strategic direction of patient-centred healthcare services and the public/patient participation movement, many studies have focused on patient/physician interaction in a consultation. This focus has however, primarily been on the behaviour of the physician and their disregard for patient involvement in the consultation with regard to their communication and information needs. Other studies such as Street (1992, 1993) and Roter (1984) have shown that not only do patients' comments influence the physicians behaviour; they may also be related to the patients' satisfaction, adherence, and health (Kaplan, 1989; Orth et al 1987).

However, although these studies offer a solid body of evidence, linking positively (for example), the amount of information doctors provide patients with in a consultation to the patients' levels of satisfaction with care, adherence to prescribed regimens, understanding of medical conditions, and even health improvement, it is their quantitative methods that may be questioned with regard to their validity and usefulness in understanding the dynamics of physician/patient interactions.

The correlative quantitative measures used by researchers in their studies appear to assume that patients respond to physicians' communication in terms of numbers; "how often?" or "how much?" certain acts occur (Street, 1992; 1993) and Roter (1994). These studies in essence ignore a host of contextual and psychological factors which potentially affect outcomes such as the nature of the visit, the patient's expectations, the physician's responsiveness to the patient's needs and requirements, and the patient's subjective interpretation of the physician's behaviour (Waitzkin, 1990; Stiles, 1989).

It is these assertions that have provided the impetus for the selection of an appropriate method and design for this study. A methodology, which elicits the patients' perspective in a consultation, gives 'voice' to patients' experiences and grounds it in the 'interaction', and while generating theories about social and psychological phenomena, will also embrace the contextual and psychological factors which govern medical 'outcomes.'

This chapter begins by providing the reader with the historical backdrop of the 'moments' within the qualitative and quantitative debate and the philosophical and theoretical 'thinking' in research and methodologies. It suggests that there is a place for both approaches in the search for 'new' knowledge. In order to be able to offer a rationale for the choice of a qualitative research approach to this study and to address the question which sought to elicit patients' experiences in the first consultation with a surgeon, the selection of the grounded theory method and design for this study is critiqued and justified by comparing it to two other qualitative research traditions namely ethnography and case study.

The role of the researcher as the research 'instrument' will also be presented and as the researcher is an integral part of a qualitative study (Streubert-Speziale, and Carpenter, 2003); this section will be presented in the first person. The use of the first person reflects my engagement with the patients and supports Webb's (1992:747) view that the use of the first person is required in keeping with the "epistemologies of the research and in pursuit of reflexivity."

### **The Quantitative/Qualitative debate**

The tradition of science has uniquely been quantitative, an approach which is justified by the rigidity of its methodology and controlled settings. Qualitative research on the other hand is rooted in empiricism, is fundamentally interpretative and emergent and has a long history of use within social sciences (study of human phenomena) and human disciplines. Rossman and Rallis (2003) refer to the characteristics of qualitative research as that of openness, curiosity and respect on the researcher's part. However, the utility of qualitative research as a source of 'knowledge' remains a huge debate.

The quantitative/qualitative debate spans across what Denzin and Lincoln (1998) describe as the five moments, across which moved a successive wave of epistemological theorising. The traditional moment is associated with the positivist paradigm; the modernist or golden age moment and the 'blurred genres moment' are connected to the appearance of post-positivist arguments; the crisis of representation moment which when spurred on by the blurred genres moment, experienced great difficulty with locating themselves and their subjects in reflexive texts. Finally, the post-modern or present moments are characterised by a new sensibility that doubts all previous paradigms (Denzin and Lincoln, 1998). Paradoxically, what underpins all of these 'moments' is a conflict and tension between the schools of social sciences striving for academic dominance in the arena of hard versus soft science research.

By the 1960s however, the traditional moment, which had enjoyed much dominance as an empirical research in social science, and offered little challenge by the moments of the traditionalist period and the modernist phase was being challenged. Scientists had been asked to explain phenomena that defied measurement, and the inability to do so prompted the search for other modes of studying, particularly those concerning human phenomena. This triggered the 'paradigm wars', which Punch (2005) claims was largely due to the increased interest in a group of methods labelled as qualitative research methods.

Proponents of both approaches, the quantitative (traditionalist) and qualitative (naturalist) methods, argued that their 'assumption' was more appropriate to the study of human behaviour. 'Assumption' in this context is defined as a basic principle that is believed to be true without proof or verification (Politt *et al*, 2001). Lincoln and Guba (1985) claim that definitions of the concept of 'truth' are questionable and challenge the assumption held by traditionalists or positivists that truth can be achieved through the scientific pathway. They suggest instead that truth is reality and offer four ontological positions or realities namely objective, perceived, constructed and created to support this assertion, who have underpinnings in the positivist paradigm assume that there is a reality out there to be studied and known. Furthermore, because of their fundamental belief in an objective reality, they pursue knowledge as objectively as possible. This objective reality asserts that there is a tangible reality and that experience of it will

result in knowing it fully (Lincoln and Guba, 1985). This position supports the gestalt of the whole being equal to the parts.

The Naturalist or phenomenologist on the other hand, who emerged as a countermovement to the positivists, (the modernist or golden age moment), claimed that reality was not a fixed entity and that it was a construction by the individuals participating in the research. In addition, reality for them existed within a context where many constructions were possible, therefore holding the position of relativism. This perceived reality is based on the ideological position, which suggests that there is a reality, but one that cannot be understood fully. This reality "can only be known from a certain viewpoint, never be known totally and is only available through one of the parts" (Lincoln and Guba, 1985:23).

### **Philosophical Perspective**

As alluded to earlier, the philosophical arguments that surround the qualitative/quantitative debate appear to feature on the search for truth and the certainty about 'reality.' The whole concept of 'objective knowledge' appears to be a contradiction in terms as it shares, as with any conception of knowledge, the "necessity that [knowledge] appears within the consciousness of an active subject" (Diefenbeck, 1984:8). Diefenbeck's definition of the term 'objective' is that it should "be anything but the active subject who is aware of it", which raises what he calls "curious irony" and which he claims has dominated Western thinking. P8

Furthermore, philosophers such as Plato sought a normative solution to establishing an objective truth, whereas Aristotle sought truth in descriptions of observable forms, "an interest in subject-object relationships" (Diefenbeck, 1984:84). Whatever their leaning, they both sought after truth and certainty about the real world.

The outlook, which was seen as positivism however was rife amidst this 'intellectual growth.' Socrates for example, saw the need for society to acknowledge that there was a distinction between "what appears to us and what is in reality" (Caton, 1973:67), that is a distinction between opinion and knowledge. This total disregard for the subjective component of any form of 'perception' was reflected in his thinking that there is "a world of objective reality that exists independently of us and that has a determinate nature or essence that we can know" (Bernstein, 1983:9). This notion was later supported by Weber who claimed that science was the "arbiter of values" and that personal bias and standpoints should be separated from any scientific action (cited in Barone, 1990:19). However, Descartes and Kant, the founders of modern scientific thought, challenged this form of 'reality' and introduced a duality to it, i.e. "the subjective knower and objective known to conceptual adulthood" (cited in Barone, 1990:4). Descartes seemed anxious however to establish a universal objective foundation of knowledge, thinking that valued science as the only source of knowledge, and facts as the only possible objects of knowledge (Barone, 1990).

The objectivist perspective stems from the Newtonian ontology of the early inorganic sciences, which had no "intentionality or variation" (Couch, 1987:97). It simply recognises objects and not processes and sees the world as discovered (Jensen and Peshkin, 1992). The positivist notions of "constancy and the existence of permanent regularities" were challenged by Darwin who proposed 'transformations, variations, and highlighted processes rather than objects' (cited in Couch, 1987: 107). Darwin's ontology of change, inherent in organic existence, prompted the "growth of naturalistic procedures and a call that these procedures study people in their natural environment" (cited in Couch, 1987:108).

Subjectivists study processes, people and events and see the world as constructed (Jensen and Peshkin, 1992). The concept of 'practical consciousness' is claimed as "the underlined center of human practical activity" (Giddens, 1986:107), which supports the subjectivist's ethos of human process, wherein it embraces the ability of people to explain their intentions and rationality for the outcome of their actions.

Giddens (1986: 108) argues that the difference between subjectivists' and objectivists' perspectives is not a divide but a logical discussion to investigate truth. He does however propound the richness of subjectivism by suggesting that any account of social activity, which excludes this practical consciousness is "greatly deficient in the rich accounts which human agents display in social life", and concludes that humans be treated as the "conceptual centre for social analysis and that the knowledge gained must be contextual" (Giddens, 1986: 110).

### **Qualitative paradigm**

The variety of definitions of qualitative research indicates that even within qualitative approaches there are differences in emphasis between those who believe that there is a world 'out there' which can be accessed through the use of particular techniques, and those who believe that this world is socially constructed by the researcher and other participants (Kellehear, 1993). Qualitative research and methods are however valuable in generating theories and are extremely important to produce 'thick descriptions of and rich insights about unknown or vaguely known phenomena' (Leininger, 1992) as noted in qualitative approaches including grounded theory.

Qualitative research is based on the belief that there is no one singular universal truth, that the social world is multi-faceted, and that it is the outcome of the interaction of human agents, a world that has no unequivocal reality. (Ashworth, 1997) Furthermore, most qualitative researchers believe that 'truth' lies in understanding the action, beliefs and values of others from within the "participant's frame of reference" (Grbich, 1999:16). However, in the search for truth, qualitative researchers using grounded theory approach, develop hypotheses and test them against emerging concepts through a method of constant comparison analysis and theoretical sampling. These 'hypotheses' however, are grounded in the data being generated rather than in any *a priori* assumptions. Therefore qualitative research is concerned with describing, interpreting, and understanding the meanings which people attribute to their existence and to their world. (Cutcliffe and McKenna, 1999)

The dynamic approach within a qualitative methodology focuses on techniques and the emphasis on paradigms offer two aspects of the qualitative spectrum within which the researcher's position can be seen to vary. The researchers for example, may see their role as separate from the reality under exploration, and then later see their role as

integral to, and impacting on the construction of processes, meanings and outcomes of the research investigation. This assertion was evident in the grounded theory methodology adopted for this study where the researcher let the participants' voices (data) do the 'talking' and then moved in to construct processes, and develop meanings through theoretical sampling (discussed in the section regarding Data Collection).

Qualitative approaches also have the capacity to allow assessment of researcher's experiences and impact on the setting (Grbich, 1999). Streubert-Speziale and Carpenter (2003) argue that qualitative researchers who are orientated toward the natural world try to understand how people make sense of their worlds, and capture this in their entirety, through multiple methods that are interactive and humanistic. Therefore this calls for recognition of patterns in phenomena rather than explication of facts that will be controllable and generalisable as in the quantitative method. Morse (1994) offers three key perspectives which facilitate this 'recognition' in phenomena, namely the emic, holistic and inductive and interactive process of inquiry.

The emic perspective elicits meaning, experience or perspective from the participant's point of view rather than the researcher's perspective (the etic or world's view). This clearly expects that the researcher refrains, (unlike the traditionalist who provides a theory to direct inquiry), from imposing their beliefs and theoretical perspectives on the data. The holistic perspective emphasises the inclusion of the values and beliefs of the participant to enrich the contextual interpretation of research findings.

Finally, the process of inquiry is interactive as the objective of such research may change as the researcher gains insight and understanding about the research 'topic.' These three key perspectives were a significant *aide memoir* to the use of grounded theory methodology in this study.

Schutz (1970) highlights that the focus of qualitatively grounded social science is that our subjective experience of the world is filtered through unquestioning acceptance of its form and content, and that the researchers view constructs that people use in order to render the world meaningful and intelligible to them. In other words "phenomenological reduction" which Schutz (1970:56) claims asks the researcher to "bracket the thicket of prior understandings in order to grasp the subjective experience in its true form"; or "setting aside prior assumptions about the nature of the experience

being studied" (Ashworth, 1996:15). Therefore from a researcher's perspective, social action has to be examined in terms of the actor's own interpretation of his or her action and its motivational background (Bryman, 1996).

The holistic perspective of qualitative research considers and includes the underlying values and beliefs and the context as part of the phenomenon. This is described as the "holistic injunction" where the researcher needs to "learn all, take all into account and tell all" (Noblit and Engel, 1992:45). In other words the researcher is seen as being instrumental in the progression of a fruitful inquiry (Appleton and King, 1997).

### **Researcher as an instrument**

Qualitative research expects that the 'human investigator' is both proactive and responsive and able to be flexible to the demands of the inquiry process (Appleton and King, 1997) by combining the observer, interviewer, or the interpreter of various aspects of the inquiry roles of the researcher. Streubert-Speziale and Carpenter (2003) indicate that objectivity serves no purpose in qualitative studies, which seek 'intimacy' that is shared between the researcher and the participant in order to uncover the worldview of the participant. In a sense this human instrument is expected to fine tune the inquiry process in order to "generate the most fertile array of data" (Erlandson et al, 1993:114). Researchers construct the worlds they research and therefore the 'knower' is inseparable from whatever can be known within the overall construction of a particular reality (Annells, 1996).

In this research, the instrumental role was actualised through my interpersonal skills, which included an empathetic understanding of and profound respect for the perspectives of the patients, which Marshall and Rossman (2006) suggest are fundamental to the success of qualitative studies. Gorden (1987) indicates that the skills of active listening, attentiveness and hearing the inner voice of participants are the basics essential to the art of interviewing (the data collection tool used in this study). The researcher however, is expected to be receptive to contextual cues and have the ability to interpret and respond to these cues in order to guide the study forward.

I found this aspect difficult, as I was overwhelmed initially at the speed with which patients related their stories. Whilst I had the capability to establish a genuine trust and respect in the 'encounter', I was inexperienced in 'grasping' the 'richness of the data'

from the in-depth interviews with the patients. The process of *constant comparative analysis* afforded by grounded theory method offered me some sense of 'stability' in critical thought and verbal interaction, which culminated later in reporting findings in a literary style through inclusion of quotations and commentaries to add to the richness of the report. This also offers other researchers or readers a "decision trail making the findings auditable and a criterion of rigor or merit relating to the consistency of qualitative findings" (Guba and Lincoln, 1981:31). However, all of my creativity (Cutcliffe and McKenna,2002), tacit knowledge (Altheide and Johnson,1994) and intellectual entrepreneurship (Cutcliffe and McKenna,2003), are a necessary and conscious choice to bring to this study, hence an 'auditor' should be able to detect the bias present in this study and not consider it as a limitation of the study.

### **Selection of an appropriate method and methodology**

In this section comparisons are drawn with traditional qualitative research methods of grounded theory, ethnography, and case study approach in order to support the selection of an appropriate approach to this study.

Crotty (1998) suggests that justification of choice and method and methodology used in a study is governed by its purpose, in other words with the research question that the piece of enquiry is seeking an answer to. He therefore asserts that the process a researcher engages with must be capable of "fulfilling those purposes and answering that question" (P2) and suggests that method, methodology, theoretical perspective and epistemology are used as a framework of reference.

In a similar vein Norton (1999) indicates that the research approach taken in any study is based on the researcher's view or stance on ontology, epistemology, and research methodology and suggests that they are related. Guba and Lincoln (1994), claim that ontology refers to assumptions made about the form and nature of reality; the study of being.

Blaikie (1993) expands on this notion by claiming two broad ontological approaches to social enquiry; the realist and constructivist. The former assumes that social reality exists independently of the observer and the activities of science, that it is observable, and can explain uniformities within it. The researcher and the 'subject' are independent.

In the constructivist paradigm of 'reality' on the other hand, mental constructions are formed by individuals, and assume, as in grounded theory, that social reality is produced and reproduced by social actors, (patients in the case of this study), thus suggesting that there may be several constructions of a single reality. Since researchers in essence construct the worlds they research (Annells, 1996), social realities cannot be separated from the researchers.

The assumption underpinning grounded theory is that it is rooted in symbolic interactionism, that people make sense and order of their social worlds. Essentially, common perceptions are shared within particular social groups and theoretical constructs are described through grounded theory (McCann and Clarke 2003). In essence grounded theory explores basic processes.

In comparison, in ethnography, social scientists and anthropologists are committed to the discovery of cultural knowledge; the study of nuances of people who live together and share similar experiences (Streubert-Speziale and Carpenter, 2007). There is much debate about the historical beginnings of ethnography, how it always has contained within it a variety of perspectives such as aesthetic and interpretive standpoints (Atkinson, 1999: Streubert-Speziale and Carpenter, 2007). But essential to this is the quest to discover cultures and behaviours different from the researcher's, which drives the use of ethnography.

In case study methodology on the other hand, researchers attempt to analyse and understand issues that are important to the history, development or circumstances of the person or entity under study. (Polit and Becker, 2006) In other words determining why an individual thinks, behaves or develops in a particular manner rather than on what his/her status, progress and actions are.

It is however, the epistemology, which refers to how knowledge of this 'reality' may be gained, that influences the selection of the methodology and methods used to conduct a

study. When knowledge is perceived as hard, objective, and tangible the method of choice will be quantitative or positivist; and when one looks for the personal, subjective and unique knowledge, the method of choice rests within a qualitative or interpretivist approach.

Crotty too asserts that justification of 'choice', with regard to the method and methodology is reliant or dependent on what the researcher perceives as human knowledge and what status is ascribed to. In essence it asks what kind of knowledge the study will offer and its characteristics.

### **Research methods**

The concept 'selection' asks about the method, that is the technique or procedure used to gather and analyse data related to the research question. Crotty asserts that it is not adequate to simply claim for example, that interviews will be carried out to justify the research process, instead we must give detailed information on what kind of interviews were used and in what setting they were conducted. Again, it is not just about talking about the themes identified but showing how the themes emerge, how they are identified and what is done with them when they are identified.

In grounded theory unstructured interviews are used to gather data, whereas in ethnography for example, data is gathered primarily from observations and interviews with additional artefacts during extended time in the field. Case study method on the other hand includes multiple sources such as documents, archival records, interviews, observations, and physical artefacts.

### **Research methodology**

Research methodology is the research design which shapes the choice and use of particular methods. This process accounts for the rationale for the methodology, which sets out the strategy, plan of action, process or design underpinning the choice and the use of a particular method, therefore linking choice and use of method to desired outcomes. (Crotty, 1998) For example, grounded theory method seeks to develop a theory, which is 'grounded' in data from the field. In this approach the researcher strives to see things from the patients' perspective, thereby justifying the use of unstructured interviews as a means of collecting data.

In ethnography where the researcher describes and interprets a cultural and social group, observation and verifying interviews would be the tools of choice, whereas in case study methodology the researcher develops an in-depth analysis of a single case or multiple cases and therefore uses multiple research 'tools' and resources.

The literature on patient/doctor relationship/interaction has revealed a lack of theoretical framework to guide or elicit patients' experiences or needs in a surgical consultation. Therefore a methodology, which helps to understand the nature of human behaviour by generating theories about social and psychological phenomena, will be the grounded theory approach.

### **Theoretical perspective**

The theoretical perspective is the philosophical stance, which informs the methodology, provides a context for the process and grounds its logic and criteria. Researchers inevitably bring a number of assumptions to the selected methodology and are justified by expounding the researcher's theoretical perspective that is his/her view of the "human world and social life within that world, wherein such assumptions are grounded" (Crotty, 1998: 7).

Symbolic interactionism, as a theoretical perspective for example, appears to 'ground' these assumptions and deals with issues of language, communication, interrelationships and community.

Ethnography on the other hand has its genesis in cultural anthropology and although the various anthropologists took the natural sciences as a model for research, they differed from traditional scientific approaches through the first-hand collection of data existing in 'primitive' cultures. (Atkinson and Hammersley, 1994) Later it expanded to include schools or subtypes of ethnography with different theoretical orientations, creating a distinct lack of orthodoxy in ethnography as a general approach (Creswell, 2003). However, an eclectic combination of the sociological approach of Hammersley and Atkinson (1995) and the educational anthropology of Wolcott (1994) and Fetterman (1989), finds the ethnographer beginning the study by looking at people interaction in

ordinary settings and attempting to discern pervasive patterns such as lifecycles, events, and cultural themes. (Wolcott, cited in Creswell, 2003)

## **Epistemology**

Finally, Crotty refers to epistemology, the theory of knowledge, which he claims is “embedded in the theoretical perspective and thereby in the methodology” (P3). Epistemology deals with the “nature of knowledge, its possibility, scope and general basis”(Hamlyn, 1995:242) and is concerned with providing a philosophical grounding for deciding “what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate”(Maynard, 1994:10).

In my study for example, its epistemology ‘constructivism’ suggests that there is no objective truth waiting to be discovered, and that instead truth and meaning exists both in and out of my engagement with the realities of the study. Meaning, in this context therefore is not discovered but constructed and different people may construct meaning in different ways even in relation to the same phenomenon (Crotty, 1998).

In essence it is the very inquiry into human experience and action that sets me on the journey, which arises from an awareness on my part that at every point of the study, I will impose several assumptions in my observations, my interpretations, my reporting and in everything else that I do as a researcher. These are assumptions “about human knowledge and realities encountered in our human world” (Crotty, 1998).

This study began with an interest in exploring patients’ information needs at the consultation with the consultant surgeon (referred to as the surgeon hereafter) in a hospital outpatient clinic. It was prompted by my current knowledge as a specialist lecturer in perioperative nursing and previous practice experience as a theatre sister, which made me aware of the patient’s vulnerability during their perioperative journey taking them into the complex environments of anaesthesia, surgery, and recovery in theatre suites. Furthermore, as an academic I questioned the level to which patients were informed about this journey and how much control they had of the process.

In keeping with the tenets of grounded theory method, once the study commenced its focus evolved towards an uncovering of the experiences and the processes that patients

undergo to arrive at the decision to see the surgeon at an outpatient clinic, how these 'processes' were actualised in their interaction with the surgeon, and where and what they led to, from the patients' perspective. Hutchinson (1993) suggests that an accurate research question is impossible to ask before starting any grounded theory study because it depends largely on the data generated.

The intention was to take into account the total context of the patients' lives by *eliciting* the experiences of 'new'<sup>1</sup> patients during a consultation with a surgeon; and exploring the social processes enacted during the patient and surgeon encounter at a surgical clinic. In order to understand this I was required to locate the actions and perceptions of patients and to grasp the meanings they communicate to the surgeon in the 'encounter.'

The research question posed identifies the phenomenon to be studied and lends focus and clarity about what the phenomenon of interest is (Strauss and Corbin 1990), yet is broad enough to enable a thorough exploration of all the various aspects of this phenomenon (Smith 1997) and asks:

*How do patients describe their experience of the first surgical consultation with a surgeon in a hospital's outpatient clinic?*

This study seeks to elicit patients' personal experiences and therefore warrants a methodology based in the qualitative realm, and a method, which will generate and manage data produced from loosely structured in-depth interviews as found in the interpretivist approach of grounded theory methodology.

### **Justification for selection of grounded theory methodology**

Justification for the selection of grounded theory methodology for this study will be presented by comparing the five dimensions of research traditions in qualitative research namely focus of study, discipline origin, data collection, data analysis, and narrative form, to ethnography and case study methodology as offered by Creswell (2004) in this section.

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<sup>1</sup> \* Patients who have not been seen by the surgeon previously

The focus of grounded theory, whose discipline originates in sociology, is to develop a theory grounded in data from the 'field' focussing on dominant social processes that present within human interactions and is achieved by understanding the nature of human behaviour.

In Ethnography, whose discipline originates in anthropology and sociology, the focus relates to the culture of individuals and describes and interprets a cultural and social group.

Case studies on the other hand, originate in political science, sociology, evaluation and other social studies and focus on in-depth investigations of a single entity or a small number of entities (Polit and Beck, 2006), and a searching insight about specific phenomenon developing an in-depth analysis of single or multiple cases. (Moch and Gates, 2000)

The focus of grounded theory is more amenable to this study's research question, which seeks to elicit the experiences (the processes) of patients in the substantive area of a surgical consultation in a hospital outpatient clinic.

The data collection in grounded theory would depend on the 'saturation' of categories, following open, axial, selective coding and conditional matrix, and finally be presented as a theory or theoretical model.

In ethnography, data collection is primarily observation and interviews with additional artefacts during an extended period in the 'field'. Analysis, which would be presented as a description of behaviour of a group or an individual would follow a process of description, analysis and interpretation.

Case study methodology's data collection is extensive drawing on multiple sources, which include observations, interviews documents and audio-visual material. This can itself pose a challenge as to what bounded system to include, recognising that several might be possible candidates.

This process would prove difficult in my study, as there is the need for a 'purposeful sampling' that is first referrals (patients) who have the potential of offering rich data to the search for patients' experiences and needs in this consultation with the hospital

surgeon. Had my study sought to explore the behaviour of the particular surgeon who participated in the study, then the case study methodology would be the methodology of choice. However, the study's intent is to elicit the patients experiences in the surgical consultation in a hospital outpatient clinic and to offer a theoretical framework to this substantive area of clinical practice - this need is met by the grounded theory approach.

In summary therefore the grounded theory approach is selected for this study as it is grounded in reality, the *patients' reality* and provides explanations of events as they occur (Field and Morse 1985). The 'grounded' approach to grounded theory was also appealing for its natural approach to handling data and the fluency of presentation style that it appears to support. Furthermore, it offered me the opportunity to explore rich data in 'relatively uncharted waters' (Stein 1985) and allows for interpretive understanding of what is going on in the consultation. Wimpenny and Gass (2000:1486) suggest this is facilitated by the grounded theory methodology's process of constant comparison and reduction, which aims to "establish tight, well-integrated theory built from well-defined concepts arising directly from the empirical research in hand." Most importantly, grounded theory approach whose theoretical underpinnings focus on the meanings of events to people in natural settings, helps to understand the nature of human behaviour by generating theories about social and social psychological phenomena, thereby creating a new perspective on and understanding of common behaviour. (Chenitz and Swanson 1986)

Finally, grounded theory with the positivistic elements (that are so often criticised), embraces multiple realities and provides an eclectic view of 'truth', something that is clearly needed for a discipline of medicine and professions allied to medicine, where reality is at the interface between humanity and technology. (Kirby and Slevin, 1992) It is suggested therefore that the intent of my study to elicit patients' experience in the surgical consultation, will be best met by the grounded theory approach and its theoretical basis and this is discussed more fully in the next section

### **Grounded Theory**

The philosophical basis of grounded theory is pragmatic and phenomenological (Strauss and Corbin, 1990) and accepts the major parameters of the symbolic interactionist school of psychology, which emphasises the uniqueness of humanity, and claims that interactions are the fundamental basis of human society. The ethos of grounded theory

therefore lends itself as the method of choice for my study, which explores (from the patients' perspectives), an 'uncharted' substantive area of the patient experience of a first consultation with a surgeon at an outpatient clinic. Stern (1980: 20) indicates that the strongest case for using this method is in investigations of "relatively uncharted waters, or to gain a fresh perspective in a familiar situation."

Glaser and Strauss (1967) developed grounded theory as a means to enable the systematic discovery of theory from the data of social research. Glaser particularly felt the need for a specific systematic process of generating theory that was grounded in the reality of the social world rather than in interpretation (Smith, 1997). The object of the grounded theory is therefore to create new theory that is "directly tied to the reality of individuals" (Rennie et al, 1988: 147) and the methodology was therefore structured in an attempt to develop scientific respectability for qualitative research.

The grounded theory seeks to develop a theory about the dominant processes that emerge in the data rather than to describe a particular phenomenon (Streubert-Speziale and Carpenter, 2003). This differentiates it from all other qualitative methods. Furthermore, it is the method used to explain a given situation by identifying the core and subsidiary processes operating in it. It allows researchers to "discover what is going on" (Glaser, 1978:21). For example *seeking peace of mind* was identified as the core category in this study, which embraced all other sub-categories identified in the study (*See Chapter 8, Figure 10*).

Essentially, grounded theory methodology incorporates a system of analytic steps; simple descriptions of events or situations are replaced by theoretical conceptualisations (Munhall, 1989) that endeavour to generate sociological theory.

### **Theoretical basis of grounded theory**

Grounded theory is rooted in symbolic interactionism, which focuses on the meanings of events to people and the symbols they use to convey that meaning. It is both a theory about human behaviour and an approach to inquiring about human conduct and group behaviour (Tourigny, 1994) which provides the theoretical underpinnings of grounded theory method. For symbolic interactionists, meaning guides behaviour, and a stage of deliberation or definition of the situation precedes action. (Morris, 1977)

Mead (1964) postulates that a biological organism develops a mind and a self and becomes, through social integration and society, a rational being. It is in social interaction that an individual achieves a sense of self and the capacity to look back at self (a distinctly human capacity); and it is the seeing of self from the capacity of others, which enables the individual to hold a concept of self (Mead, 1964).

This concept is elaborated further by Blumer (1969) who claims that people act towards things on the basis of the meanings that things have for them; that meanings of such things are derived from or arise from social interaction with one's fellows; and that these meanings are handled and modified through an interpretive process used by the person in dealing with the things encountered. This premise however is based on the belief that:

***"The human being is not a mere responding organism, only responding to the play of factors from his world or from himself; he is an acting organism who has to cope with and handle such factors and who in doing so has to forge and direct his line of action."*** (Blumer 1969: 65)

The basic tenets of symbolic interactionism therefore underpinned the interviewing process in this study and relied on my interpersonal skills.

In summary grounded theory is a qualitative approach, which incorporates distinct features such as specific sampling and data collection techniques and processes ensuring rigour and comprehensiveness. These include the making of constant comparisons and the use of a Glaserian coding paradigm to ensure conceptual development and density. (Glaser and Strauss 1967) The formation of theory occurs around a core category and explains basic patterns in social life. (Chenitz and Swanson, 1986)

This is achieved by the systematic collection of data via the use of semi-structured interviews, and by means of constant comparative analysis, writing memos, open categorising, sorting memos, determining a core category, theoretical sampling, and writing up the theory. This process in grounded theory is referred to as "hierarchical and recursive because researchers must systematically categorise data and limit theorising until patterns emerge from the categorising operation." (Morse and Field, 1995: 157) This concept will be discussed in the next section.

## **RESEARCH DESIGN**

The research design offers specific techniques of data collection and analysis available to the researcher (Norton, 1999) and is influenced by the research methodology which refers to how researchers go about finding out whatever it is they think can be known (Blaikie, 1993). Furthermore, it also provides guiding principles that help inform decisions about procedure and research strategy (Holloway and Wheeler, 1996).

The dynamic psychosocial and social processes that are the focus of grounded theory method may be inferred from observing social interactions (as in the surgeon and patient encounter in this study), from listening to patients relating stories of their illness (as in the patient and researcher interviews in this study), and may be inferred from their past experiences of illness (McCann and Clark, 2003).

### **Literature review**

As alluded to in the last chapter, literature is used in grounded theory as part of the process of discovery by providing (initial) sensitising concepts as sources of data and finally for comparing emerging with extant theory. Benton (1993) and Chenitz (1986) suggests that literature review is ongoing, taking place during and after data collection rather than prior to it; the primary purpose being to relate literature to the emerging theory through the integration of ideas (Glaser, 1992).

Glaser (1978) further claims that in order to promote theoretical sensitivity, only literature in a substantive field different from the research should be read prior to commencing the study. Furthermore he argues that preconceptions often mean little or nothing when derived from grand theory concepts (Glaser,2002), and runs the risk of clouding the researcher's ability to remain open to the emergence of a completely new core category that has not figured prominently in the research to date thereby 'thwarting' the theoretical sensitivity. (Glaser, 2004) As with professional experience, knowledge of the technical literature was used to sensitise me to the subtle nuances within the data during constant comparison analysis, on condition that primacy was given to what can be inductively derived from the data. (Wuest, 2000)

In grounded theory literature is used to compare emerging with extant theory by making comparisons with previously posited analytic concepts and relationships between them and those present within the developing theory. (Chenitz, 1986) Once the category has emerged as pertinent, the technical literature is re-visited to determine if the category is there and if so what other researchers have said about it. Morse and Field (1995) suggest that this research is examined for its explicit and implicit assumptions or unsubstantiated conclusions. Furthermore, Miller and Fredricks (1999) argue that if the generated theory is totally consistent with existing theory then its uniqueness as a grounded theory is compromised.

### **Sampling strategies**

Unlike the quantitative researcher the grounded theorist does not determine the size of the sample population before commencing the study as representativeness in qualitative research relates to the data and not the sampling units. (Sandelwoski, 1986) Grounded theory therefore uses non-probability sampling procedures. There were two sets of samples namely the patients and the surgeon. The 'new' patients attending the outpatient clinic following referral by their General Practitioners (GPs) were considered to be best placed to meet the informational needs of the study. This 'purposeful sampling' (Patton, 1990), that is sampling where the phenomenon is known to exist, was used to obtain maximum information and a full array of responses.

Streubert-Speziale and Carpenter (2003: 113) suggest that the basis of participation is their experience with the social process under investigation, and that the sample size is determined by the data generated and its analysis. In other words data is collected until they "achieve saturation of conceptual information and no new codes emerge" through the process of constant comparative analysis and theoretical sampling (discussed in the section on Data Collection). Hutchison (1993) indicates that the researcher can gain closure by constant questioning and re-examination of the data.

An eventual sample of thirty patients was recruited (there were no refusals or attrition once recruited). Selection criteria ensured that the sample was chosen for its representativeness in providing the patients' 'fresh' experience of the phenomenon under scrutiny (Smith, 1997), and eliminating the chance of 'pre-empted' or contaminated information from previous consultations with the surgeon.

The sample consisted of twelve males and eighteen females with an age range of between twenty-four and sixty -seven years with the majority being within the fifty years band. They were also taken from a variety of social classes, and ethnic groups. Stern (1980) suggests that this process is appropriate in grounded theory where the focus is on processes rather than on a unit.

Two key guiding principles in sample selection in this study were the designated time of the patient's clinic appointment in relation to the interview schedule with the researcher, and the use of 'new' patient referrals. I was particularly sensitive to "not disturbing the natural context of the phenomenon of interest" (Streubert-Speziale and Carpenter, 2003:16) and therefore did not want to cause undue stress to the patients or distraction, by the possibility of missing their allocated appointment slot with the consultant. I therefore allowed sufficient time by 'selecting' patients whose appointments were not due for thirty-five to forty minutes after they consented to participate in the study.

This decision was accommodated by default too by the over-running clinic schedules. As the clinic nurse escorted the patients to the interviewing room for their second interview with the researcher, there was a tangible link between the clinic process and the data collection process of the study, minimising further disruption of the natural context of the phenomena of interest.

I approached the patients in the clinic's designated area. Following the usual greeting and introduction to the researcher's role in the environment, the patients were introduced to the intended study. The patients were given full information of the study's data collection format and how this collection would proceed during their time at the clinic (*see Appendix 2*). Patients were informed that data collection was in three stages – all to be completed during their clinic attendance on the day. Data collection would include an initial audiotape recorded interview with the researcher followed by an audiotape recording of their interaction with the surgeon.

It was stressed that this recording would not include their initial exchanges, which focused on their personal or private details and assurance was given that the recording would commence after the surgeon had given/offered them tentative diagnosis or

proposed treatment. The final stage of data collection was a second interview with the researcher, which would follow the same format as the first.

Patients were given a written resume of the data collection process (*see Appendix 2*) and allowed time to read and 'digest' its contents before signing the consent form (*see Appendix 3*) and were reminded that participation was entirely on a voluntary basis. They were reminded too of the use of an audiotape recorder in the interview, and were asked permission to do so each time it was used.

### **Access to the Sample**

Permission to approach the patients at the surgical clinics was achieved in the following manner. Consultant surgeons at the hospital were approached collectively at one of their monthly 'Surgical Meetings.' I presented a brief resume of the intended study and requested access to their patients in the clinics.

The response was very favourable and access was granted from their perspective to any clinic that was thought relevant to the study. This was endorsed formally by the head of the surgical division (*see Appendix 4* - identification details have been removed to maintain confidentiality and anonymity), and informally by several consultants in the 'hospitals corridor conversations' or via the telephone.

Following this response, ethical approval was sought from the hospital's Ethics Committee. A copy of the research proposal was enclosed in order to offer a background to the study (*see Appendix 5 and 6*) - identification details have been obliterated to maintain confidentiality and anonymity).

I then visited the clinics at various times to familiarise myself with the environment, the workings of outpatient's clinics and most importantly to meet and work with the nursing and support staff of the clinics. This was found to be particularly useful as it developed a rapport with them and also established a relationship of trust and support. For example, a member of the trained staff who attended the patient during the surgeon/patient consultation participated by taking responsibility for audiotape recording the 'patient-surgeon interaction' following the examination of the patient.

The patient-surgeon consultation is in three tiers: tier 1 relates to the surgeon taking and charting the patient's personal and 'illness' history; tier 2 relates to the physical examination, and tier 3 relates to the patient-surgeon dialogue post examination. The staff nurse was asked to ensure that NO personal details or disclosures during the 1<sup>st</sup> and 2<sup>nd</sup> tiers of the surgical consultation were recorded. On completion of the surgical consultation, the staff nurse escorted the patient back to the 'interview room' for their 3<sup>rd</sup> and final interview.

## **DATA COLLECTION**

### **Grounded Theory Interviews**

Qualitative researchers rely quite extensively on in-depth interviews for their data and are generally referred to as "conversations with a purpose" (Kahn and Cannell, 1957: 149 cited by Marshall and Rossman, 2006). The researcher explores a few general topics to help uncover the participant's views but otherwise respects how the participant frames and structures the responses. This supports the ethos of qualitative research interviews, which is based on the assumption that the participant's perspective on the phenomenon of interest should unfold as the participant views it (the emic perspective) not as the researcher views it (the etic perspective).

The most important aspect of these interviews however, was my approach in conveying the message that the participant's views are both valuable and useful. In addition I was aware that my success would depend on how well I anticipated and practised my role in ethical issues related to the study (Marshall and Rossman, 2006).

The two most frequently used data collection strategies in qualitative research are participant observation and interviewing (Gerson and Horowitz, 2002; May, 1991; Hammersley and Atkinson, 1983), both of these strategies have been used in this study.

The processes of grounded theory interviews are similar to that of qualitative interviews. They are concerned with eliciting, as in the case of this study, a patients (participants') worldview or experiences, and gathering in-depth information through loosely

structured interviews. It is about [my] engaging in the patients' 'world' in order to see this 'world' as the [patients] see it. (Chenitz and Swanson, 1986)

### **Initial Preparation**

My professional background in nursing and nurse education enabled me to carry out all the interviews and transcribed them verbatim. This was helped by my previous research that had involved qualitative interviews with qualified nurses, which offered me an insight into the processes and management of unstructured interviews. However, I felt that I needed to sharpen my skills in managing an unstructured interview lest I 'lost' some vital cues en route to uncovering patients' stories/experiences of their illness.

I practised my interviewing skills on a selection of Perioperative Nursing course students. Six students who were aware of my intentions volunteered to be the practise 'patients.' They were asked the hypothetical question, "What are your expectations in the consultation with the surgeon in the outpatient clinic?"

This 'pseudo-pilot' study of interviews offered me invaluable insight into my shortcomings, particularly that of drawing conclusions prematurely, not allowing the data to speak for itself and at times curtailing the nurses from speaking. I was 'interrupting' their flow of thought. I noted my discomfort with long pauses during an interaction. In reality, these practice sessions helped me to cope with managing the audiotape recorder, writing-up memos and most importantly 'listening' to the message that the participants were delivering. Practicing interviewing also helped me to discipline my thoughts, contain my enthusiasm, and balance the researcher/student interaction so that I would be mentally prepared to attend to the data from the patient interviews.

Not only did these practice interviews allow me to rehearse the interviewing process but they also gave me the opportunity to test out environmental issues pertinent to conducting interviews. These included the preparation of the interview room to ensure privacy and to avoid being interrupted, checking that the audiotape recorder was in working order and that back-up batteries were available, and selecting the optimum location of the tape recorder so that it was not intrusive but nevertheless allowed for conversations to be recorded clearly and in total.

## **The 'Interviews'**

The interviews conducted in this study were loosely structured, in depth and of thirty to thirty-five minutes in duration. These interviews set out to see what was out there and what was going on bio-psychosocially in the individual who was consulting with the surgeon.

I therefore asked a broad question which allowed for a wide response from the patients:

*Tell me what are you expecting to hear from the surgeon today?*

However, the interviews were not entirely unstructured in the sense that I did not conduct the interviews without some initial focus. Initially, the interviews focused around the concept of being informed about their illness and what it meant to them to be informed. Gradually during the course of the study my questions became 'funnelled' becoming more focused and specific, (Lincoln and Guba, 1985) which is a reflection of the essence of the emerging concepts and processes. However, the interviews remained conversation-like and both the patient and I remained relaxed in each other's company. This was a useful stance to the 'encounter', as patients did not have to rehearse their responses or how to articulate them or feel that the researcher was looking for correct or acceptable answers.

Following the usual conventional openings or greeting to any social encounter, the patient who accepted the invitation to participate in the study was escorted to the interview room by me where we exchanged a few thoughts on their journey to the hospital. This social exchange was essential for rapport building and often helped to set the 'tone' for the encounter and release the tension created by the pending 'interview.' My accent also contributed to this 'release of tension' as many patients seemed keen to locate its origin.

The 'openness' of the interviews and patient-researcher rapport prompted the patients to disclose personal information and their emotional experiences, thus I became privy to a rich source of data. However I was concerned about the ethics of using my naturally 'friendly' self to gather this data (discussed in the section Ethical Issues later on in this chapter). Constant reflection on this concern led me to believe that I too gave

something of myself in the encounter in order to create 'mutuality' and trust. All thirty patients seemed relaxed with the pre-consultation interview and were keen to return for the post-consultation interview. For the 'flow' of data collection in this study *see Figure 1 overleaf*.

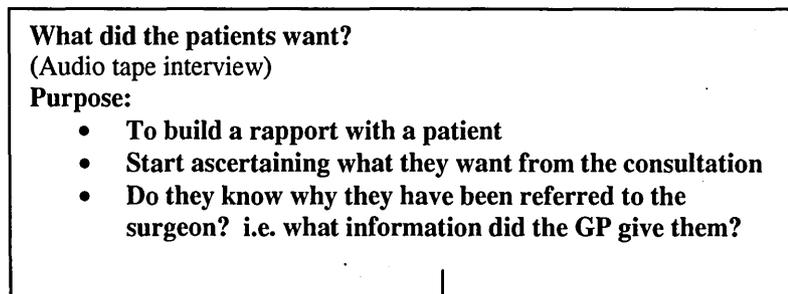
## Figure 1 - FLOW CHART DIAGRAM OF DATA COLLECTION

The aim of this study was to explore the information needs of a patient undergoing a hospital consultation with a surgeon (Consultant). Following a few interviews and in keeping with grounded theory approaches, further aims were developed concerning the experiences of these patients.

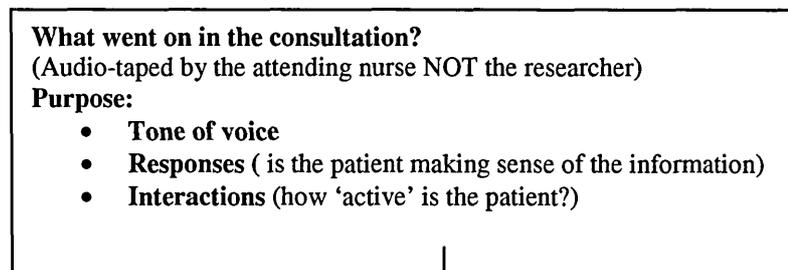
The aims were as follows:

- What do patients want from the consultation?
- What goes on during the consultation?
- How do the patients describe what went on?

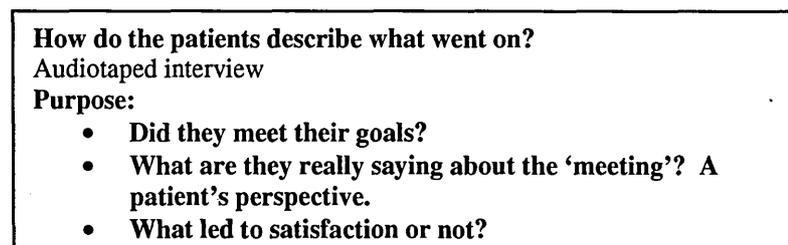
### **Initial interview –researcher/patient (pre-consultation)**



### **Observation of Surgeon/patient interaction**



### **Interview 2 of researcher/patient (post-consultation)**



## ANALYSIS

As an open, generative and emergent methodology, analysis in grounded theory lets the natural organisation of substantive life emerge. Its mandate is to be open to what is actually happening and not to start filtering data through preconceived hypotheses and biases, to listen and observe and thereby 'discover' the [patients'] main concern [in illness] and how they resolve it (Glaser, 2004). This facilitates the goal of data analysis, which is the generation of a set of categories and properties and described by Glaser (2002) as emergent conceptualisations into integrated patterns, which are denoted by categories and their properties and the combination of these into theory.

Therefore the process of data analysis involved constantly coding emerging data and following concept leads and themes through the literature or in subsequent interviews. This helped to refine explanations and to generate further reflections or thoughts on the data. This cyclical action involved the process of inductive-deductive thinking as verifying or disconfirming emerging evidence so that "patterns and processes, commonalities and differences, can be identified." (Miles and Huberman, 1994:9)

The goal is achieved via the constant comparative method, which consists of the comparison of incidents with categories, the integration of categories, delimitation of the theory and finally writing up of the theory.

This section will therefore describe and discuss the various stages of grounded theory building namely: Constant comparative analysis, theoretical sensitivity, coding, memos and diagrams, and theoretical sampling. Finally, this section will discuss the 'generic' theory building perspective in qualitative research and conclude with that of grounded theory building.

### **Constant comparative analysis**

Constant comparative analysis is considered the principal approach to data analysis in the development of grounded theory (Benton, 1993, Hutchinson, 1993). This approach required that I tease out the categories and their related properties (elements) by comparing incidents applicable to each category asking: 'What is this data saying? What is happening here? It was about examining processes and then attempting to

integrate categories and their properties. The early interviews in my case had more memos and questions than any sense of perception about the data.

Glaser and Strauss (1967) maintain that there are three general approaches to qualitative research. In the first approach, researchers 'code data and crudely quantify the codes in an attempt to prove a theoretical proposition.' In the second approach researchers are only interested in creating theories. They inspect data to 'detect new properties of theoretical categories'. In the third approach, which entails Glaser and Strauss's constant comparative method, "the first two approaches are combined." (Rennie *et al*, 1988: 141) Therefore this meant that I systematically categorised data and limited theorising until patterns in the data emerged from the categorising operation.

This comparative analysis method involved data collection, open coding, writing-up memos and moving towards identifying the core category and its relationship with other categories in the study, offering a new theory embedded in and facilitated by theoretical sampling. (Glaser, 1978) The constant matrix of comparison between concepts and categories is illustrated in *Figure 2* on the next page.

Figure 2

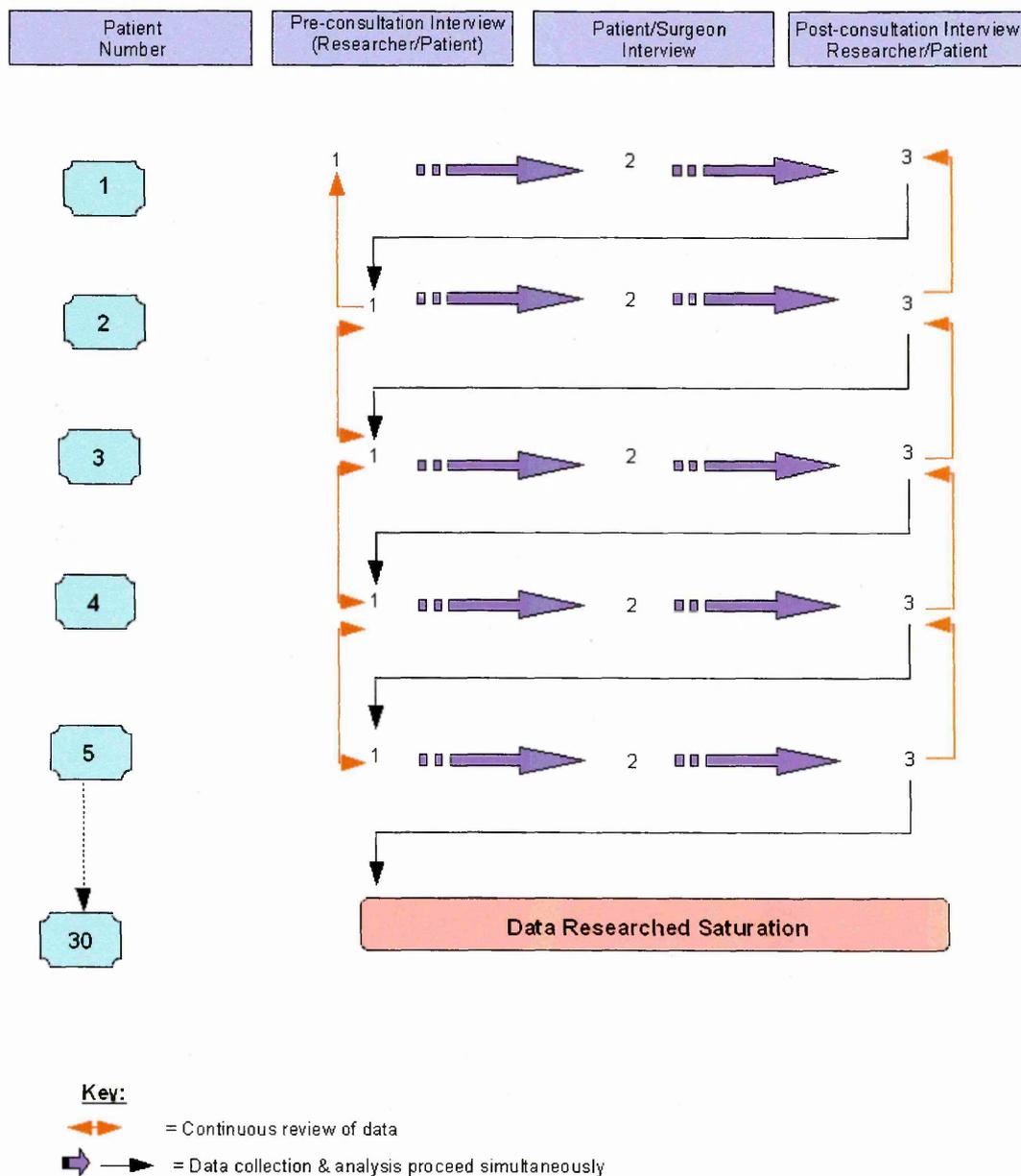


Figure 2: **Constant Comparative Analysis**

Analysis occurs as a matrix rather than as a linear process and is supported by detailed memos and notes about the researchers thinking processes.

### **Theoretical sensitivity**

The concept of theoretical sampling was initially a daunting task for me because I did not move into the theoretical sensitivity mode and hung on to what I knew best, the descriptive mode of quantitative thinking. I realised that as the process of open and theoretically coding began I was soon considering the data in a descriptive sense and not actually interpreting it. Glaser (1978) indicates that theoretical sensitivity or entering the field with an awareness of the subtleties of the data sensitises the researcher. It is the ability to have insight, understand and give meaning to data, and to detach the relevant from the irrelevant (Strauss and Corbin, 1998).

The supervisor for this study constantly reminded me to let go of the 'chains' of quantitative thinking, which inhibit grounded theory thinking. When finally this happened, I was able to enjoy the stories that the data was telling and I acquired an analytical eye for data analysis. My research behaviour at the onset seems to have stemmed from the 'aura' that surrounds the tenets of grounded theory and was redressed by actually carrying out the method. This theoretical sensitivity assisted the coding process and was to be the bedrock of theoretical sampling in this study.

### **Coding**

The function of coding in the grounded theory method was to conceptualise the data by analysing and identifying patterns or events in the data (McCann and Clark, 2003). Charmaz (2000) suggests that coding initiates the process of theory development. Glaser and Strauss (1967) indicate three types of coding namely open, axial and selective. These initially appear in a linear structure but as the study progressed the 'coding' seemed to follow my matrix of analytical thinking. It seemed like a 'cyclical' process where my thinking was shifting from one mode of coding to another simultaneously.

Soon after the first interview was carried out, recorded and transcribed, I started with the open coding of the data and memos of the interview. This was the process of breaking down the data into discrete parts in order to conceptualise and categorise them. The patterns, which emerged in the raw data, were then coded or given a conceptual label and in this context the code was merely a 'label' with a subjective thought.

Consistent with Glaser's (1978) guidelines, Charmaz (2006:136) suggests using gerunds in coding and memo-writing as this fosters theoretical sensitivity because the "words nudge [researchers] out of static topics and into enacted processes."

Initially, I was afraid of missing clues in the data and therefore started off coding line-by-line but I soon learnt that I was so engrossed in this exercise that I was missing the whole picture by breaking it down so intensely, and Glaser (2002) describes as 'conceptual foppery.'

Glaser (1992: 40) indicates that breaking down and conceptualising data does not mean taking apart a single observation, sentence or paragraph and giving each a conceptual name, and warns that this approach if implemented "would end up in an over-conceptualization of a single incident." However, this exercise taught me to concentrate on the essence of the data and not force or influence concepts by preconceived beliefs about patients' experiences in a consultation with a surgeon. There was a risk of this being so because of my concurrent role as a healthcare professional in conjunction with the academic role. Charmaz (1990) considers that the line-by-line coding during the initial period of data collection prevents the researcher from influencing the data with preconceived beliefs about the field of enquiry.

### **Open coding**

The open coding in the study consisted of asking questions of the text such as 'who?', 'when?', 'where?' and so on, which aided abstraction and the search for theoretical issue and *in vivo* and sociological codes. The former were directly related to the language of the patients (data) which Holloway and Wheeler (1996) consider as having imagery because they give sufficient meaning to the data. The latter were derived from a combination of substantive data from the interviews and from my theoretical sensitivity. The whole process and effectiveness of 'coding' was anchored to the process of memos writing and diagrammatic illustration (to be discussed later in this section), which captured the thoughts that floated in the matrix of mini constructs in the constant comparative analysis. For an example of this please refer to *Figure 3*.

### Figure 3 - Example of the use of Grounded Theory

James: *"In my mother's time they were afraid to ask questions, they simply accepted what was thrown at them. I was like that too you know never changed much with the times, and believe me I should. Gosh, I am ancient aren't I, how embarrassing?"*

Gary: *"It's so shameful when you think that you just accepted what [the doctors] said take their word as gospel and do as they say"*

Dave: *"You are just being a vehicle for the doctor to practice his skill and you do nothing, it is just shameful"*

Rose: *"Gosh, I feel so stupid that I can not assert myself when I come to see the doctor, it's about this old thing that we just accept everything the doctor says, I can not bear to think of it."*

Nick: *"I am of that generation, the doctor is always right, no questions asked and I am ashamed to say I haven't done much about it"*

Do I sense a feeling of guilt or embarrassment? Is it something to do with feeling guilty you think? Guess what? They are mumbling something like feeling ashamed. They seem to use the word embarrassing. I seem to feel that somewhere they have picked up vibes suggesting that they are proactive and not passive in self-management I am NOT sure what is going on. Let's wait and see yeah?

Joseph: *"The old days when doctors sat upon pedestals and dished out information, we just accepted what they wanted us to hear, we did not offer any resistance"*

*Do I note a sense/ a tone of resentments there? Is someone opposing something? Why? Is Joseph making excuses? I wonder why?*

#### Memo

Patients seem to be saying something about not doing their part in the interaction with the doctor. I am not sure but they appear embarrassed because it is unacceptable in today's health climate. Are they kind of ashamed by the doctor inflicted bondage to sort of submission? Are they recognising that they need to be more involved? What is going on here? I am all over the place with this one. Watch out for their emotions on this one, May be? Not sure? Are they 'knocking' blind acceptance? I am not sure what is going on but there is something I feel about wanting to get out of the 'situation.' What situation? Do you think they want to be more active/assertive? They are seeking or experiencing something here, maybe?

### **Axial coding**

Axial coding was undertaken simultaneously with open coding during which I tried to elevate the concepts or elements to a meaningful provisional sub-categories and categories. Aided by the constant comparative analysis I was able then to group or cluster the concepts in a "higher order, a more abstract concept" (Holloway and Wheeler, 1996:61), by using my inductive and deductive thinking and questioning of the data and making comparisons with the 'characteristics' of other categories aided this process. In a sense this process also informed further data collection and hence led to selective coding.

### **Selective coding**

The selective coding or the integrative component of coding continues until each identified concept is saturated and a conceptual framework is developed by further data collection. It comprises of an attempt made at re-assembling data into a meaningful and explanatory framework. Therefore selective coding came into play at the identification of the core category when I attempted to establish the links between the core and overarching category with other categories in the study, ( and supported throughout the data analysis by the memos and diagrams, which captured the conceptual structure and the essence of the emerging theory). It was at this stage that I commenced or confirmed the theoretical coding and saw the data as theoretical piece and not descriptive. In addition I was able to link knowledge from the literature (used as data in the study) as a means of saturating the core category of *seeking peace of mind*.

Eaves (2001) suggests that by identifying linkages between categories, a core category with sub-categories will emerge and make it possible to relate and validate data into a substantive theory.

The core category *seeking peace of mind* seemed broad enough to integrate and explain the relationship between the other categories in the study. (see *Figure 10*)

### **Memos and Diagrams**

Memos and diagrams were used as part of the analytical process in this study. The diagrams offered a visual representation of the conceptual relationship between the concepts and the category and also the categories with other categories.(*illustrated after*

*each category analysis chapter*). In addition, they also helped identify the consistency of these relationships (McCann and Clark, 2003).

Memos on the other hand were the notes or aide memoir, which I made following each interview or even during and throughout the research study in order to keep me in the 'loop' of the study's theoretical growth (see **Figure 3a**). Rennie *et al* (1988: 144) capture this sentiment by suggesting that memos help the researchers to "preserve ideas that have potential value but may be premature."

These memos were mostly thoughts, which captured ideas about a category or the whole study. Charmaz (2000) and Stern (1985) indicate that memos are essential tools for capturing ideas, for abstraction and theory development, and for presenting hypotheses about connections between categories (Grbich, 1999). They played an inductive role when I was looking at the codes or elements and conceptualising them and deductive when I proceeded to link and inter-link the categories and identifying the core or overarching category (Hutchinson 1993). In essence memos reflect the researcher's "dialogue with the data at a point in time" (McCann and Clark, 2003: 15). **Figure 3b** overleaf provides further detail regarding this point.

### Figure 3b: Seeking Peace of Mind

#### Memos and Reflection

##### Initial Interview:

They seem to be 'restless', seems like something is 'bugging' them for want of a better word. Am I hearing something like they want something from this visit to see the surgeon? A lot of deep sighs here, is it anxiety? I don't know but it feels like they want to be put at ease; one of them said something like "peace in the head." Too early yet, just something is happening, some action seeking.

Yes, I am sure they are seeking engagement with the surgeon; they seem to be looking for some dialogue so that they can understand their illness. Some are actually saying something about wanting peace of mind. Watch this, maybe something here or it may be something about being released or something. Not sure but something is brewing here I feel some looking for rest or ease.

Again, there are some patients who appear more assertive. Heard one say it is her right to know, and be in control. Patients want to regain their control? Yes, it seems that control for them is about seeking some relief from the bondage of not knowing what is wrong with them, they want to end all this not knowing so that they can have peace of mind. Remember uncertainty? I must watch this thought because it is early yet; Frances is constantly reminding me of my hastiness. Ok, I will simply watch. But something is telling me that they are here because they want to put their minds at rest. Remember those emotions of uncertainty, fear and worry? They seem to be seeking an outlet, re-assurance, and a solution.

The surgeon/patient interaction seems so amazing. There is a sense of harmony and there is so much chat and 'exchange' between the two. He certainly is a well-mannered gentleman and so patient-centred. I like the belated 'birthday wish' to one of his patients. Clever move, he has transcended formality and has fostered a sense of empowerment. Is he asking patients to tell him what is worrying them? Not sure but he seems to think that they have come to him for some solution, peace of mind. "You tell me what you want first, although I think I have an idea"; He has used words or phrases like 'want relief', Ok, I'll put your mind at rest, that is what I am here for"; mind at rest? I wonder where this is going? Is it back to my earlier thought about patients seeking something like peace of mind? They used this phrase? Don't know but may be? Let us see what patients have to say at the post-consultation interview. Watch closely, it may be something else. My feeling seems to go back to that peace thing.

Gosh, is it real? First they were miserable, now post consultation there is an air of sensing relief. They are muttering something like "what a relief", "such a peace of mind." Hey, look at the number of times that word/words peace or easing my mind has cropped up in the context of the emotions experienced. I am sensing that the process that I am looking for is something like peace of mind. Hey, they used the phrase want peace of mind so many times. Yup, I feel it is their response to their crisis, their loss of control.

This chat between the surgeon and I was very relaxed and I was able to ask specific questions which emerged from my hypothesis that the surgeon's therapeutic behaviour was learnt in the clinical area. He said something about the value of being honest with patients so that they have peace of mind. He refers to his 'formative years'; he observed that patients who were 'involved' in their healthcare or 'participated in decision-making' were at ease, happy and appeared in control; had peace of mind. "I did not have to get out of bed each night to talk with patients who lay anxious and 'helpless' in their beds because they seemed in control of the event." Gosh, he sounds so thoughtful; patients' peace of mind seemed to evolve round the surgeon *playing the rules of engagement*

It feels comfortable now, I feel that patients' seeking peace of mind has evolved from the turmoil of uncertainty and *experiencing of crisis,* and actualised in *constructing a partnership* with the surgeon and witnessed in fulfilment, in *sensing relief.* I think patients were seeking peace of mind in the consultation. This must be the key or core category? Is it manifested throughout.

### **Theoretical sampling**

Closely embedded in the process of coding *per se* is the concept of theoretical sampling, which (Glaser, 2004) suggests is the ability of the researcher to generate concepts from data and to relate them to “normal models of theory in general, and theory development in sociology in particular.” This generating of a theory means therefore that most hypotheses and concepts not only emerge from the data but are systematically thought through in relation to the data during the course of the study. I had initially made sampling decisions about recruiting ‘new’ patients from the clinic appointments list in an outpatient surgical clinic. (‘New’ in this context is taken to mean that the patient had not consulted this surgeon before). As the initial data was collected and analysed, further ‘selected’ data was collected based on the emerging themes or ‘story’ to compare emerging categories and to establish conceptual boundaries that were related to the evolving theory (Charmaz, 2000). This meant that I was constantly moving around in the ‘matrix’ of emerging theories to form patterns, links and experiencing a sense of a new story – a new theory using theoretical sampling.

This sampling continued until there was a sense of theoretical saturation. This is when no new data emerged that was relevant to particular categories and sub-categories, and when there was a conceptual density and all variations in the categories could be explained (from both the patients’ and my perspective). (Smith and Biley, 1997)

The later interviews with patients were in a sense more meaningful as I was constantly testing out ‘mini’ hypotheses from my theoretical thinking mode. For example early data revealed that patients wished to hear the truth in an ‘encounter’ with healthcare professionals - a hypothesis that was ‘tested’ in the interviews that followed as and when the researcher saw fit. This theoretical sampling revealed that patients who were experiencing ‘crisis’ due to the uncertainty of their illness needed to hear the truth (regardless of its content) in order to regain control and to maintain an ‘equilibrium’ in their search for peace of mind in the consultation.

Further theoretical sampling to test the hypothesis that the surgeon’s ‘engaging persona, empowering disposition and empathy’ (*as identified in Chapter 8 - Sensing Relief*) was a culmination of his training and day-to-day practice was confirmed in the researcher/surgeon interview, which revealed that much of his formative ‘learning’ was from ‘role models and reflection on action during clinical practice.

## **Developing Theory**

This section repeats the underpinnings of the qualitative/quantitative debate discussed in Chapter 1, for which I apologise; however, it felt right to juxtapose these two approaches of research in order to bring to bear the type of theory which supports the essence of this study and clinical practice.

It appears that regardless of whether the position of research is considered to be in the 'testing' or 'discovery' of theory, there seems to be a general view that research and theory are intimately linked. Therefore it is not surprising to appreciate that philosophical beliefs and epistemological assumptions appear influential in determining views about theory as about research (Slife and Williams, 1995), and that this belief influences the usage, form and purpose of theory.

Silverman (2000: 78) considers the role of theory as providing a "footing for considering the world, separate from, yet about that world." Chinn and Kramer (2004:9) look beyond this assertion by suggesting that a theory is a "creative and rigorous structuring of ideas that projects a tentative, purposeful and systematic view of phenomena." The 'tentativeness' is echoed perhaps in Slife and Williams's (1995) claim that all theories explain some things about people, how they act or why they act, but they can never explain everything. In this context then, the nature of the subject under 'review' seems important, as different routes to theory appear to be suitable for alternative areas of interest.

However, by provoking ideas about the unknown (i.e. patients' experience of a first consultation with a surgeon in a hospital's outpatient clinic), theories provide the impetus for research. Theories as living entities are also developed and modified by good research (Charmaz, 2006). Therefore the next section will look at the different 'routes/patterns' of theory, partly to give some indication of the form that the findings of this study will eventually take, and also to indicate why alternative routes seemed less applicable.

As in debates on the qualitative and quantitative paradigms, criticisms and opposition abound, and objections appear to stem from a failure either to recognise, or to accept,

the way that features vary within each pattern of theory. (Schwandt, 2000;Crotty, 1998) Aspects of grounded theory for example, are criticised for not showing features that seem generally associated with a deductively derived theory (Bryman, 2004). Academic commentators Schwandt (2000), Lincoln and Guba, (2000), Crotty (1998), Glaser, (1979) and Blumer (1969) have referred to features like the philosophy, view of explanation, specification, identities, questions, concepts, framework, role of research and claim to objectivity, which differentiate the ‘ethos’ of each, the deductive and inductive theories. These will underpin the discussion on each ‘pattern’ of theory and therefore influence the approach taken to address the ‘intent’ of a research study.

The deductive theory identifies the ‘why’ of a phenomenon in order to explain it and this is derived from the logico-deductive route, which usually subscribes to the main parameters of a positivist philosophy. In the deductive ‘mode’ explanation is known to be directly concerned with causal processes and the rationale for such processes is to establish a way of finding out whether something is responsible for something and if so which factors lead to change or lack of it. Therefore these theories in their search for attributive causes and effects factors will enquire about quantity or amount, and features which allow an accurate assessment of probabilities. (Neuman, 2000; Kemmis and Wilkinson, 1998)

In addition, the concepts and relationships between them are required to be definitive; in the sense of outcomes being exact measures of variability or significance, are tentative and can be subjected to rigorous testing. The framework within which testing takes place, is usually fixed beforehand.

However, as the framework in deductive theory is fixed prior to testing, any assumptions built into that framework can become obscured and skew the eventual form of the theory (Neuman, 2000). Such assumptions therefore are part of the fabric of the theory and in some areas such as medicine, a deductively derived theory or logico-deductive theory may be essential or beneficial in the ‘technical’ aspects of treatment per se.

This study is concerned with eliciting the processes embedded in patients’ experiences of a first consultation with a surgeon in a hospital’s outpatient clinic, hence an

approach, which is underpinned by such assumptions as those of deductive theory would seem untenable.

In addition, it does not seem realistic that this 'route to theory' building would embrace a theory, which would account for possible situations or people behaviours or emotions in the substantive area of patient/surgeon consultation. Many nursing theorists have for example questioned the use of logico-deductive thinking as the only and best route to nursing theory (Lincoln and Guba, 2000;Leininger, 1985; Benner, 1984; Stern, 1980). In nursing, a discipline committed to human interaction as well as scientific knowledge, there is and must be many ways to arrive at theory. (Chenitz and Swanson, 1996:36)

Inductive theories (interpretive) are seen to address areas in which uncertainty, complexity, intuition and human 'variability' exist (Lincoln and Guba, 2000; Neuman, 2000) and these could contribute to both the social sciences and nursing/medical knowledge, which Carper (1978) identifies as the aesthetic, personal and ethical knowledge. These theories are inductively derived, they concentrate on the 'how' factors, and the phenomenological belief that supports inductive theory 'patterns' is that explanation and interpretation can be achieved by unravelling the complexities in a phenomenon. (Schwandt, 2000; Miles and Huberman, 1994)

Meaning and clarity within inductive theory is sought by articulating processes, possibilities and features of the field under review. Guba and Lincoln, (1989) suggest that questions in inductive theory approach are not usually concerned with quantities or probabilities but with establishing how a construct fits together or how a phenomenon works, that is the concepts which are sought are expected to be 'sensitising' and seeking as many aspects or features of the variable under consideration as possible.

As 'probabilities' are not being sought, the inductive theory does not require concepts to be precise and definitive and the conceptual framework, which is integral to the theory serves primarily to specify dimensions or to unify diverse fragments of phenomena into a single, holistic entity. (Lincoln and Guba, 2000; Chenitz and Swanson, 1986)

Rigorous research is essential for discovering the theory and including the theoretical framework, as 'objectivity' is claimed because the processes of formulation can be

examined and assessed. In view of this, it is not considered necessary to test the results, or to formulate the theory as a series of propositions, although both are possible if required. More importantly, this pattern of inductive theory can include and encompass other theories, not by confronting or disproving other views but by integrating or transcending them. (Chenitz and Swanson, 1996)

The shortcoming of the inductive theory approach is that it does not offer a statistical prediction of probabilities; however, it can contribute to areas usually covered by deductively derived theories. For example, the 'technical' literature review in this study revealed that the deductively derived theories in the medical research either 'prompted patient responses' in their questionnaires and/or failed to capture the 'essence' of patients' healthcare needs. The inductive underpinnings of grounded theory approach as used in this study for example, will capture this 'patient-centred' touch, often compromised in the deductive theory approach and will complement the emerging theory.

Again, this inductive theory pattern can be used to enhance the potential of deductively-derived theories by explaining how they can be incorporated or operationalised into practice and bringing them together as a "nursing [medical] gestalt or an expert intuition." (Benner, 1984:43) Thus it highlights the 'transcending' nature of the inductive theory approach into a 'patient-centred' ethos in clinical practice. Wimpenny (1993) points to difficulties in changing to a new humanistic paradigm from the traditional dominance of a natural science, for example within the educational framework in nursing. However, he acknowledges the opportunities that exist within this assertion for enhancing nursing theory development and practice.

My proposed study needed a 'route', which would incorporate the complexity of human 'individuality', the dynamism of changing and variable situations. The intent is to elicit patients' experiences, which would involve uncovering hidden processes, allow embedded assumptions to surface and enable "incipient or invisible meanings to be made visible." (Schwandt, 2000) The ethos of grounded theory offers these possibilities in developing/building theory within the realm of the inductive route, and is discussed next.

## **Theory building in grounded theory**

The primary purpose of grounded theory method is to develop an explanatory theory concerning common social life patterns from a 'precise' methodological data generation. In other words "generating grounded theory is a way of arriving at theory suited to its supposed uses" (Glaser and Strauss, 1967:3) Furthermore, when defending the method of grounded theory generation, Glaser (1992:30) emphasised that the systematic generation of grounded theory "should be seen [as] sequential" to verificational research with the ultimate aim of both being the "building up of scientific facts."

The 'precision' in the steps are the outcome of the merging of two contrasting and competing disciplinary traditions and field research, introduced by the originators Glaser and Strauss of grounded theory, who rejected the postulation of the deductive approach that research was only necessary for assessing probabilities and causal relationships between variables. They emphasised instead that the goal of grounded theory research was to generate rather than to test theory.

Glaser's quantitative training at Columbia University is reflected in grounded theory's epistemological assumptions, logic and systematic approach. Glaser also advocates building purposeful 'middle range' theories, which consist of abstract renderings of "specific social phenomena that are grounded in data" (Charmaz, 2006:7). True to his research 'upbringing' Glaser imbued grounded theory with rigorous coding methods, emphasis on emergent discoveries, and its (particularly to a neophyte researcher) ambiguous specialised language, which displayed characteristics of quantitative methods.

Strauss's Chicago school pragmatism and field research however, also pervades the grounded theory method. He viewed humans as active agents in their lives and in their worlds rather than as passive recipients of larger social forces (Charmaz, 2006). Strauss assumed that process, not structure was fundamental to human existence, that human beings "created structures through engaging in processes" and that subjective and social meanings relied on the use of "language and emerged through action." (Charmaz,2006:7) Strauss embraced the theoretical underpinnings of symbolic interactionism as described by Mead (1964) and Blumer (1969).

Both Glaser and Strauss however, shared a keen interest in studying fundamental social or social psychological processes within a social setting or a particular 'experience' (as in the case of patients' experience of a first consultation with a surgeon in a hospital's outpatient clinic, in my study). For them a 'finished' grounded theory explains the studied process in new theoretical terms, "explicates the properties of the theoretical categories, and often demonstrates the causes and conditions under which the process emerges and varies, and delineates its consequences." (Charmaz, 2006:7) Glaser and Strauss list 'canons' for assessing the adequacy of a theory namely, logical consistency, clarity, parsimony, density, scope, integration, fit and ability to work, and claim that development of theory was inhibited by undue "emphasis on testing, and the sense of awe inspired by established grand theories." (Chenitz and Swanson, 1984:49)

Presently, there are essentially two accounts of grounded theory methodology, the Glaserian and the Straussian; the former having been adopted for my study. Although the approaches differ in some aspects of their philosophical underpinnings, both share the 'precise' procedural steps, which include constant comparative analysis, theoretical sensitivity, coding and categorising data, theoretical sampling, and literature as a data source, integration of theory and theoretical memos [and diagrams]. (McCann and Clark, 2003) These steps are by no means linear as constant comparative analysis a fundamental characteristic of grounded theory, guides data generation and treatment. The researcher, for example, who attempts to discover dominant processes in the social scene of the study, may modify data collection according to the advancing theory.

The processes of induction, deduction and verification are the other characteristics of grounded theory. Induction requires that I use a practice to theory approach in my study, and that I enter the 'field' with no pre-conceived hypotheses from the literature or elsewhere, being open-minded and flexible, so that theory emerges from the data. (Charmaz, 2006; Streubert-Speziale and Carpenter, 2006; McCann and Clark, 2003) The process of 'deduction' per se is activated only after the initial data collection and coding have commenced and hypotheses are formed and empirical verification of the hypotheses is undertaken through further data collection (constant comparative method and theoretical sampling). Stern (1980) suggests that the theory can be 'tested' by allowing predictions to be developed deductively from general principles.

Theory building therefore begins with ‘theoretical sampling’, which involves the concurrent collection, coding and analysis of data. Coding lays the foundation to theory building in grounded theory and the evolving codes/concepts are the labels or ‘potential indicators of phenomena’ (Pandit, 1996), which capture the essence/message of the story related by the data during the early stages of analysis. This process is often referred to as the ‘fracturing of raw data.’

Through the process of constant comparative method, which is an analytic method in which segments of data are compared within and between ‘groups’ in order to generate categories or hypotheses relevant to the study (Streubert-Speziale and Carpenter, 2006), the first stage of theory building moves from the isolation or labelling factors (codes) to depicting the relationship between them. This is an early move towards reconstructing the ‘fractured data’ and it is during this phase of reconstructing data that categories or hypotheses are generated.

Categories, within the ‘hierarchical theory building block’ are higher in level, are more abstract than the concepts they represent and are generated through the same analytic process of making comparisons. They are the “cornerstones of developing theory and provide the means by which theory can be integrated” (Strauss and Corbin, 1990:7), making it possible to progress (within the aegis of theory building) to the third level, in which predictions can be made by relating factors in the theory.

This level is facilitated by propositions, which involve conceptual relationships and indicate generalised relationships between a category and its concepts and between discrete categories (Pandit, 1996). It is generally around this stage that collection ceases as no new information is forthcoming about a category, and ‘a theoretical saturation’ is reached.

The final stage of theory development or the highest level of development, (when the core or overarching category emerges), a prescriptive, or situation-producing theory (substantive theory) should be able to guide and inform clinical practice in the domains of medicine and professions allied to medicine.

Although data collection, analysis and integration of the theory all take place concurrently, the emphasis within and between each part varies in depth throughout the study. There is ‘concordance’ in analytical thinking and syntheses but since the study proceeds as a matrix, rather than through clear or discrete stages, it is almost ‘tortuous’ if not difficult, to write simultaneously about the three separate strands of data collection, analysis and integration of the theory.

Therefore each chapter will explain the course of that action from start to finish, ‘cross referencing’ to other concepts or categories when seen fit, and conclude with a diagrammatic illustration of how the strands of concepts, propositions and category/categories are eventually woven together.

My ‘intent’ as a qualitative researcher using grounded theory is to offer transparency of its precise procedural steps and theory building, and avoid pitfalls in theory building, which Glaser (2002) calls ‘incident tripping’ and ‘conceptual foppery.’ The former happens when the rigor of line-by-line analysis of the interview data, and careful comparing of incident to incident, and then to concept, and constant theoretical sampling are abdicated because the “impression source of a concept can be so grabbing” that it takes over (Glaser, 2002). Conceptual foppery, which is closely related to conceptual description or incident tripping is at the other end of the continuum and is noted when every incident in sight is conceptualised with no theoretical meaning deriving from a clear focus analysis of a main concern (Glaser, 2002). This ‘transparency’ is presented in the exemplars of theory building (*see Figures 3c and 3d below and a further two in the ‘Limitations’ section in Chapter 11*). It is also illustrated diagrammatically, following each category in Chapters 4 to 10.

**Figure 3c: An exemplar of theory building analytic operations of *Worrying***

Narrative Exemplars	Conceptual label	Sub-Category	Category	Theory
<p>an: I followed all instructions from the GP's), but as the diet and increased fluids and things has changed. After a few months later, you know nothing has changed for me, I am worried, I need to see the expert (hospital)</p> <p>rah:"I will wait for the tests and worry. The only thing I find worrying about from this is waiting for the results...it is worrying. You worry sick waiting for the results"</p> <p>ry: "yes, I do worry about anything I do with hospitals and doctors...about what they will do if you will have a say in the management of my needs and my needs"</p>	<p>Unmet expectations</p> <p>Worrying ?fearing</p> <p>(Watch out here is worrying and fearing used interchangeably?)</p> <p>Functional? worrying (in vivo code)</p> <p>Worrying about the powerful others?</p> <p>Worrying about unknown</p> <p>Worrying ?sensing loss of control? helplessness</p>	<p><i>Worrying</i></p> <p>The sense of unpredictability of patients' symptoms and of traumatic events and therefore the unpredictability of safety breeds feelings of worrying(Seligman,1975)</p> <p>Sense of functional worrying in that she has taken steps to recall previous experience of 'waiting for results'</p> <p>Worrying about the inequality of power in the surgeon/patient 'encounter' is comparable with Lanceley (1985) who claims that unequal power distribution between [surgeon] and patient promotes worrying.</p> <p>? dysfunctional worrying is noted in helplessness and frustration (Breznitz, (1971).</p>	<p><i>Experiencing crisis</i></p> <p>Worrying compounds crisis. There is a sense of helplessness and loss of control in worrying and the unpredictability of outcomes intensifies emotional 'crisis'</p>	<p><i>Seeking peace of mind</i> to return to normality and have control of life events, in order to maintain a 'status quo'</p>

**Figure 3d:** An exemplar of theory building analytic operations of *Uncertainty*

Narrative Exemplars	Conceptual label	Sub-Category	Category	Theory
<p><b>Gary:</b> "I just want to know what the problem really is; whether it [the rectal bleed] is going to happen again each time I visit the toilet, will the pain come each time. You know I just do not know where it is all going, where it all started, what is wrong with me?"</p> <p><b>Sam:</b> Well, I don't know what is happening, I just hope this bleeding down below is haemorrhoids and nothing else. You know it is this not knowing what it is. I never worried about it much until you read all sorts of things in the press about bleeding down there. This is terrible, this suspense of not knowing what will be told to me today"</p> <p><b>Sam:</b> "Not knowing which way my problem is going. Is it The big 'C'? You know cancer I mean? The papers write about these things being bad. Oh, I do worry about this not knowing. I feel I am losing control over my life just now. I simply want to know, whatever it is for my peace of mind"</p>	<p>Not knowing Wanting to know</p> <p>Feeling insecure <i>Fearing pain</i></p> <p>(<i>Seeking some control?</i>)</p> <p>Expressing fear of 'vagueness' (Both intrinsic and extrinsic contributors)</p> <p>Feeling of 'indefinites' Going no-where</p> <p>Seeking certainty</p> <p>Worrying about what 'papers say'</p> <p>Seeking peace of mind (<i>an in vivo code</i>)</p> <p>Expressing anxiety about suspense</p> <p>Uncertainty of diagnosis Worry of losing control Wanting peace of mind</p>	<p>These elements resonate a sense of <i>uncertainty</i></p> <p>There is a loss of identity in illness. Patients seem anxious about the imbalance of their <i>status quo</i>, their 'equilibrium' or loss of control. A sentiment consistent with Mishel (1998) and Staub <i>et al</i> (1971) who claim that the inherent unpredictability in illness tends to have the psychological effect of lack of control and the inability to form a cognitive schema.</p> <p>There is a sense that worrying is an emotional response to <i>uncertainty</i> too in order to seek peace of mind? a response</p>	<p>The emotions of <i>uncertainty, worrying, fearing, accepting blame and feeling shame</i> identified in the data gathered from the initial patient/researcher interview seem to resonate in a higher category of <i>Experiencing Crisis</i> therefore its building blocks.</p>	<p><i>Seeking peace of mind</i> (the core category) is patients' response to <b>uncertainty</b>; they seek relief from the personal 'turmoil' of not knowing, lack of a 'cognitive schema', an imbalanced 'status quo' or personal equilibrium</p>

## **Ethical Issues**

The ethical issues inherent in this study centre on the use of data collection methods such as interviews and observing participants/patients, which are about patients' personal disclosures given on trust, during the 'encounter.' (Orb *et al* (2001), Behi and Nolan (1995), and May (1991) indicate that personal disclosure, whilst being the essence of the research, is also given on trust and as such must not be defiled; alluding to the importance of confidentiality particularly in qualitative research where samples are small and 'thick descriptions' are presented. "Guaranteeing confidentiality implies that the research subject's data will be used in such a way that no-one else but the researcher knows the source." (Behi and Nolan, 1995:713) I ensured that the patients and the surgeon were aware of each other's participation in the study and that I was therefore not infringing confidentiality. I also asked if I might use direct quotes from their conversation with me in order to support my analysis.

May (1991) cautions too, that some qualitative research involves the researcher developing a relationship with participants over a period of time and that provision must be made for the closure of this relationship.

Interviews in this study involved two sets of participants, the patients and the surgeon, all of whom had been approached for permission to record their interviews and on completion of these, closure was facilitated in the form of 'debriefing the participants.' On completion of the post-consultation patient-researcher interview for example, I escorted the patient to the relevant departments for further appointments, to the bookings desk to make appointments for investigations or to the pharmacy if prescribed/ordered by the surgeon. Others were escorted out of the hospital building and were thanked for their support with the study. This offered 'closure' or an exit strategy to the patients' involvement in the data collection process for the study.

The surgeon (the same surgeon was used for the whole study) was thanked at the end of each clinic session and reminded that the researcher would return on his next surgical clinic day. On completion of the data collection, (that is when the theoretical sampling had ensured 'saturation' in the identified core and sub categories), the surgeon and clinic staff were thanked personally with an assurance that they would be kept informed of the study's outcome. I still remain in contact with the surgeon who has shown particular interest in the results and conclusion of this study.

It was important that I reminded the surgeon of my claim to maintain confidentiality. His patients were aware that the consultation was being audiotape recorded (minus recording of personal and private details) and that this included the recording of his 'interaction' with them. I offered assurance to both parties that they would not be identified and that neither would be privy to the audiotape recordings of the other.

The three ethical dictates of this study were that patients were fully informed, that they had consented to participate in the study and that patients were expected to emerge unharmed from the experience. This includes any psychological harm induced by not being told the truth or being 'duped' into accepting to participate in the study.

As detailed in the Sampling section above, I approached the 'selected' new patients at the clinic where I introduced myself and my role as a researcher, and declared the intent of my study. Patients were given a written resume of the research interviews and a consent form (*see Appendix 2*). I then allowed the patients' time to reflect on the demands of my request and repeatedly but casually assured them that participation was not compulsory and that refusal would by no means jeopardise any of their care or privileges at the clinic or in the hospital *per se*.

Although, the recruitment process attended to the needs of the study, I remained sensitive to the context within which the patient was operating and appreciated that they were in a vulnerable position within the hospital environment and that they would perhaps be obliged to participate in the study. I therefore asked the patients to consider the request and called back after a few minutes to hear their decision. The patient was asked to sign a consent form and their willingness to participate was reaffirmed by the opening statement at the start of the interview as shown below:

***"Thank you for helping me with this study and for allowing me to record our conversation"***

The patient was assured of confidentiality, which was not only confined to the identity, but also to the data generated. Patients were assured that the data would only be used for the intent of the study and that the audiotape recordings and transcripts would be stored safely and destroyed on completion of the study.

The issue of anonymity of patients was also addressed by informing them that a pseudonym would be adopted for the purposes of reporting the data in this study and that all audio tapes would be labelled numerically with the overall list of audiotape recordings being held solely by me.

In the case of the consultant, confidentiality was maintained by protecting his privacy by ensuring that his name was not recorded or transcribed. His identity was not threatened even by the elimination technique because there were three colorectal surgeons employed at the hospital at the time of the study, all male and with equal clinical seniority. This in principle made identification of the surgeon a little more difficult. Had it been a risky proposition then I would have omitted the patients' symptoms in the transcripts, to ensure that the 'speciality' was not identified.

The rationale for the researcher and surgeon interview was not totally disclosed to the surgeon for fear of inducing a *Hawthorne effect*. Denzin (1989) asserts that researchers should not reveal all, as the search for truth permits some non-disclosure, whereas Yow (1994) strongly opposes this assertion and claims that researchers should not misrepresent themselves when seeking to gain access to the private domain. One would argue that in qualitative research it is not always possible to predict the developing interests of the study or there may be practical reasons for not disclosing some elements of the study. I felt that my decision was justified because in essence I had informed the surgeon of the need to establish the origins of some of his practice ethic from him.

As this interview was an add-on to the data collection approach detailed to the Ethics Committee, a further application was made to explain the rationale for expanding the data collection to include an interview with the surgeon and this was subsequently granted.

### **Trustworthiness**

The philosophical argument which surrounds the credibility of qualitative research findings has been addressed from three positions namely: qualitative studies should be judged using the same criteria as those used in quantitative studies; set criteria will not

offer a meaningful judgement of qualitative studies; and criteria should be tailored to fit the qualitative paradigm. (Hammersley, 1992)

Guba and Lincoln (1981) claim that qualitative researchers pursue multiple perspectives of some phenomena in the search for truths and believe that 'reality' is an interpretive phenomenon constructed by the respondents. In keeping with this perspective, my role as the researcher was to render the patients' stories of their 'illness' as honestly, truthfully and fully as possible in order to uphold the goal of rigour in this qualitative study. Furthermore, Guba and Lincoln (1981) also suggest that four major concerns relating to trustworthiness exist which are typically labelled within the rationalist paradigm, and are described by them as truth-value, applicability, consistency and neutrality.

The conventional (quantitative) criteria for trustworthiness are internal validity, external validity, reliability and objectivity and the naturalist (qualitative) alternative to the claimed objectivity of quantitative research is credibility, transferability, dependability and confirmability.

My first step towards ensuring the study's trustworthiness was the presentation of its conceptual framework and systematic inquiry, which offered clarity of documentation and explanation of the process, providing a sense of an "audit trail." (Lincoln and Guba 1985) This was done in order that "others may see and understand the research decisions and assess their adequacy and trustworthiness" (Rossman and Rallis, 2003:122); and also to contain and control my often distracting trend towards quantitative thinking.

Credibility of the findings was sought by sharing my interpretations, the "phenomenon recognition" which involved presenting my 'reality' to those who live it, by asking them whether it indeed reflected their common and shared experience. (Guba and Lincoln, 1981:186) In addition to feedback elicited from the patients interviewed for this study, I was also encouraged by the responses received from two colleagues (both of whom had experienced a long-term illness), who had read 'my story' and identified with the behavioural processes displayed by patients in the consultation. Finally, using my supervisor as a critical 'eye' strengthened the value of what I had reported and concluded from the data collected.

Transferability, (the concept analogous to the rationalistic paradigm external validity) is dependent upon the degree of similarity of 'fitting' between two concepts. Guba and Lincoln (1981:81) suggest that the naturalist does not attempt to generalise findings but forms a working hypothesis "that may be transferred from one context to another depending upon the degree of 'fit' between the contexts." The study's findings are grounded in the patients' experiences and therefore make findings contextual and situational and transferability will 'happen' when there is a similarity in the 'situation.' The finding for example of the 'triad' of assessment in this study (following the presentation of the "thick description" (Geertz, 1973:43) of each of the processes within it), could in essence be 'transferable' to patient/healthcare professional consultations, as the 'fit' or similarity applies to any interaction between these two particular entities.

The dependability of the findings in this study are shown by their transparency, for example, the use of the patients' voices' (thick descriptions) to assume my thinking or interpretation which was checked with the patients through 'constant comparative analysis.' The findings however, are presented on the assumption that the reader could also offer a variation in the interpretation of the readings and that the findings are contextual to the 'specific' setting and participations.

'Confirmability' is addressed on the grounds that humans present with multiple realities including multiple value systems, and that my role as the 'instrument' of data collection could potentially introduce additional 'predispositions' on the analysis based on my own personal viewpoint. The reflective account, which included my personal biography with its interests, potential biases and strengths, offered readers the opportunity to explore how and in what ways I might have shaped or potentially influenced the project and the findings reported. (Rossman and Rallis, 2003)

It is worthy of note that this confirmability in grounded theory is also evident in the presentation of an 'audit trail' (Lincoln and Guba 1985), which Cutcliffe and McKenna (2004:129) suggest is some qualitative researchers' response to the "paradigmatic struggle" and therefore an attempt to "convince their quantitatively-orientated peers of the value of qualitative methods."

To conclude, the trustworthiness of this study has been attempted in two ways; firstly via the adherence to the tenets of qualitative research and secondly via the presentation of data - by 'telling it as it is' and offering transparency in the presentation and analysis of the data.

The role of this 'transparency' is to show the emerging theory's fit, relevance, workability and modifiability and to negate the expectations of validity of the findings of the study. 'Transparency' allows the reader to assess how closely concepts fit with the incidents they are representing and reflects how thoroughly the constant comparison of incidents to concepts was carried out. Glaser and Strauss (1967:238/239) claim that theory fits when it is induced from observation and therefore "faithful to everyday realities."

Dey (1999) in a similar vein suggests that if theory is faithful to the everyday reality of the substantive 'area' and carefully induced from diverse data, then it should fit that substantive area, because it represents that 'reality.' He warns however, that it should also be comprehensible and make sense both to the [patients] who are studied and to those practicing in that area.

Relevance or a relevant study captures the attention of the real concern of participants, in a sense it evokes "grab" (Glaser and Strauss 1967:34). As theory however is applied to an ever changing, everyday reality Glaser and Strauss warn that it is important that it 'fits' that reality, rather than "reflecting the researcher's own values as embodied in a formal theory, which is applied to the situation (through logical deduction) without regard to its relevance." (P 239)

The task therefore of determining the 'relevance' is relegated to those who want to apply the theory by making the necessary "corrections, adjustments, invalidations in applications, when thinking about or using the theory" (Glaser and Strauss 1967: 232); thus making the theory fit as well as work.

The workability of the theory, which emerged in this study, was noted in how it explained the patients' experience of crisis in illness and being solved with much variation such as adaptive processes and the surgeon constructing a partnership with the patients.

Finally, the modifiability (as alluded to earlier) is an asset of grounded theory because the theory can be altered when new relevant data is compared to existing data suggesting that grounded theory is never right or wrong: it just has more or less fit, relevance, workability and modifiability.

In summary this chapter has provided insight into the rationale for the selection of grounded theory methodology to address the question:

*How do patients describe their experience of the first surgical consultation with a consultant surgeon?*

Constant comparative analysis a principal approach of grounded theory to data analysis, theoretical sensitivity, theoretical sampling, memos and diagrams underpinned the search for the processes, which are identified in the chapters that are to follow. In addition, the role of 'transparency' to show that the emerging theoretical fit, relevance, workability and modifiability are offered and have secured the trustworthiness of the study.

## CHAPTER 3

### INTRODUCTION TO THE FINDINGS

This chapter introduces the reader to the findings of the study and offers an overview of the patients' story of their experiences of a first surgical consultation from the data collected from audio-taped, unstructured, in-depth interviews.

Rossmann and Rallis (2003:290) suggest that writing about qualitative data cannot be separated from the analytic process because in the choice of particular words to summarise and reflect the complexity of the data, "the researcher is engaging in the interpretive act, lending shape and bringing meaning to massive amounts of raw data."

Streubert-Speziale and Carpenter (2006) claim that results of a study, which uses a grounded theory approach, are presented by using substantiated supportive data. May (2002) concurs with this concept by suggesting that when writing-up grounded theory the researcher includes segments of the actual data for explanatory power and to allow the reader to make independent judgements as to how well the emerging concepts are grounded in the data.

Data collected during the execution of this study is derived from interviews which were transcribed verbatim and supplemented by field notes of memos and reflections ("hunches") recorded during the interviews and which raised the data to a level of conceptualisation, to develop the properties of each category and to present hypotheses about connections between categories. (Grbich, 1999) In addition, the memos were reminders of what [I felt] was happening in the data. (Miles and Huberman, 1994) These were presented in order to allow the reader to grasp the story or emerging theory. This included the laughter, pauses and intonations evident in the consultations.

I have however, made a few alterations to the scripts where my questions were less than grammatically articulated or where I felt that some data was irrelevant. The latter were depicted by (.....) indicating omission of words or redundant sentences.

In order to maintain confidentiality and anonymity all patients in this study were given pseudonyms. The designated surgeon was simply identified as the 'surgeon.' FcD indicates the name or presence of the researcher (me).

Each category in this study is presented with elements, which act as its building blocks, and are linked and cross-linked with other categories in the study and the supportive literature or data, which augments, supports, and highlights the emergent theoretical concept. A diagrammatic illustration of the categories and the conceptual linkages is also provided in the text. Examples from the transcripts are used in more than one place, this may appear to be repetitive but this is not the intention. Similar sentiments expressed in one context may also be applicable or have a bearing on another. Also a constant use of data from some patients more than others only reflects that they were better 'historians' than others in expressing their thoughts.

A brief resume of the study's proceedings will help the reader to visualise the entire 'flow' presented in the findings chapter.

The patients are initially interviewed by myself (prior to the consultation) in order to seek answers to the question: *What did patients want?*

The patients' consultation with the surgeon asks: *What goes on?* (Observational data)

The post consultation interview the patient/and I ask: *How do patients describe what went on?*

**See Figure 1 in Chapter 2 for the flow chart of data collection**

Although the findings chapter is presented in a linear fashion, it must be pointed out that in essence the entire picture is one of a 'matrix' of interrelated happenings. Each category is written in bold capitals and the elements or sub-categories are written in italics in the lower case.

## **EXPERIENCING CRISIS**

The chapter *Experiencing Crisis* offers an account of the emotions experienced by patients prior to the consultation with the surgeon and highlights their role in triggering adaptive or restorative behaviours. The elements of this category are: *uncertainty, fearing, worrying, feeling shame* and *accepting blame*.

## **SEEKING ENGAGEMENT**

*Seeking Engagement* is a chapter, which highlights patients' adaptive responses to the 'crisis' triggered by the disruption to their 'status quo' and their sense of inquiry and seeking 'mutuality' or 'parleying.' The elements that this category is comprised of are: *acknowledging expertise, trusting expertise, expecting an exchange, appreciating individualised information, hoping for answers* and *seeking truth*.

## **REGAINING CONTROL**

*Regaining Control* is one of the two adaptive/restorative processes identified in the chapter *Experiencing Crisis*. This response resonates with a sense of 'proactiveness' as well as an invocation of patients' rights in *regaining control* of issues related to their own healthcare. The elements of this category are divided into those which provide a more defined effort towards 'assertion' such as *weighing-up options, exercising rights*, and *asserting one's terms*, and those which seek control such as *seeking involvement* (also an element of *seeking engagement*) and *wanting to be heard*.

## **CONSTRUCTING PARTNERSHIP**

This chapter *Constructing Partnership* demonstrates that the surgeon's ethos of patient care focused on constructing a partnership with the patients by engaging with them. There was a sense that the surgeon was seeking congruency in meeting the needs of his patients by allowing them to play out their role as experts of their illness. This was evident in the elements of this category, which included: *rapid engaging, transcending formality, sharing information, fulfilling expectations, inspiring confidence* and *empowering*.

## **SENSING RELIEF**

*Sensing Relief* highlighted the fact that whilst patients recognised and valued medical diagnosis and treatment with the use of sophisticated technologies, they still sought good interpersonal skills. In addition patients appeared keen to let the surgeon lead in the arena of medical expertise so long as they were actively involved in any decision making. This post-consultation interview with the patients revealed a sense of relief, the 'feel good factor' brought about by the fact that they had made the decision to seek surgical expertise and that in doing so had gained some peace of mind. The elements, which act as the building blocks to this category are: *engaging persona, genuineness, approachability, empathy, tailored explanation, unrushed manner, and empowering.*

## **PLAYING THE RULES OF ENGAGEMENT**

*Playing the Rules of Engagement* was a chapter which set out to test the researcher's hypothesis that the surgeon's interpersonal skills were learnt on the 'job' in the clinical area. This theoretical sampling seemed to reveal that the surgeon was playing the rules of engagement by using a template of 'early learning', which culminated in offering 'patient satisfaction and compliance.' The interview was more focused because in essence it followed the theoretical sampling mode and tested the researcher's hunches about the surgeon's persona and work ethic. The process was a retrospective exploration of patient satisfaction with the surgical consultation and was consistent with the views of Buller and Buller (1987), Roter *et al* (1987), and Stewart (1983) amongst others who all suggest that certain aspects of the doctor-patient communication influence patient behaviour in a positive manner - for example a display of satisfaction, with their care and adherence to treatment, plus improved recall and understanding of medical information. The elements in this category are: *role models, communication, tailored/individualised information, patient-centred ethos and surgeon-led input.*

## **SEEKING PEACE OF MIND**

*Seeking Peace of Mind* reflects the experiences of the patients who seek peace of mind in order to maintain a 'status quo'- an equilibrium that has been upset by illness. The emotions experienced act as triggers of health-seeking behaviours and the surgeon's ethos seems to focus on offering this peace of mind. There is 'mutuality' and congruence in the meeting of the patient and surgeon and fulfilment, satisfaction and peace of mind is a welcomed outcome. The elements in this category are the culmination of all the elements and categories identified in this study and are reflected in the core category *seeking peace of mind*.

## **ENABLING PEACE OF MIND: THE ESSENCE OF HEALTHCARE PROFESSIONALS' INTERVENTIONS – A Discussion**

This concluding discussion of the findings chapter is presented against the backdrop of the 'metamorphosis' of the patient's traditional role from passive to active. It highlights the bi-partite responsibility of the healthcare professional and the patient in maintaining and sustaining healthcare measures.

The chapter focuses on three key aspects namely the value of linking 'informing theory' to current practice in order to challenge practices, questioning of some hitherto uncontested theoretical assertions in current practice, and finally the use of the study's findings to inform and to offer a format for the education of both patients and healthcare professionals both now and in the future. The patients' search for peace of mind in a healthcare consultation, patient-centeredness and the bipartite responsibility identified by government initiatives remain the overriding themes in the discussion.

# CHAPTER 4

## EXPERIENCING CRISIS

### Introduction

The theme or category of "*Experiencing Crisis*" has been derived as a result of the grouping together of a number of key emotions or feelings that were prevalent in the patient-researcher interviews prior to the surgical consultation. Patients when interviewed used language that described their emotional state; feelings of *uncertainty*, *worry*, *fear*, *accepting blame* and *feeling shame* for their current condition were identified during the writing of the transcripts. It is the intention of this chapter to explore in more detail each of these emotions as experienced by the patients and describe the over-arching theme of "*Experiencing Crisis*" as a culmination of all of these emotions.

Emotions are seen as internal factors, which energize, direct, and sustain behaviour (Lewis and Haviland-Jones, 2000), and are also considered as subjective with negative and positive feelings for individuals. (Stratton and Hayes, 1993) Emotional reactions to illness however, are considered as 'normal' because they are healthy reactions to 'a survival threat' and hold clues for us as to an individual's capacity for adaptation. (Bowman, 2001)

Understanding emotions in terms of the relationship between cognition and emotion is however met by an age-old debate. For example, one could argue on the effects of emotion on cognitive processes or the role of cognitive processes in the "genesis of emotional states." (Williams *et al*, 1988) Whatever the argument for or against the position of emotion versus cognition, these processes are not considered in isolation as "all cognitions are emotionally coloured which gives a sense of urgency to the cognition." (Robinson, 1996:79)

The following sections provide a detailed analysis and exploration of the elements of emotion identified from the patient interviews, in the category experiencing *crisis*.

## Uncertainty

Patients arrived at the clinic for their consultations each with a story to tell. An overwhelming theme running through these experiences appeared to be '*uncertainty*'. There was a definite sense that these patients were experiencing a crisis, triggered by '*uncertainty*', which was manifested in the show of varying degrees and types of emotions. This seems consistent with Perod (2007:660) who suggests that uncertainty is 'rooted in the individual's perception of outcomes or meaning of a situation.' These perceptions she argues challenge patients' sense of confidence and/or control to yield varied types and modes of uncertainty. Generally, patients appeared unable to assign probabilities for outcomes and as such prompted various emotions.

There was a sense that patients initially accepted that the reason for the referral by their General Practitioner (GP) to the surgeon was underpinned by the '*uncertainty*' of their initial diagnosis. This is shown clearly in the statement from one patient below:

**Tim:** "You see my GP he did not know what was going on, he tried everything, and so that is why I am here to see the surgeon. My GP he was not sure what to do now."

However, the *uncertainty* appeared to be intensified by the patients' feelings of frustration of 'not knowing' or not being able to make sense of their symptoms. Gary for example was able to articulate his symptoms but yet could not make sense of them:

**Gary:** "I just want to know what the problem really is: whether it [the rectal bleed] is going to happen again each time I visit the toilet, will the pain come each time. You know I just do not know where it is all going, where it all started, what is wrong with me?"

Sam's (female) experience of 'uncertainty' seemed to be affecting her control over her body, which appears to have triggered a secondary emotion - one of 'worrying' (to be discussed later in this chapter), because she has read something about her 'problem' in the media:

**Sam:** "Well, I don't know what is happening, I just hope that this bleeding down below is haemorrhoids and nothing else. You know it is this not knowing what it is, I never worried about it much until you read all sorts of things in the press about bleeding down there. This is terrible, this suspense of not knowing what will be told to me today"

**FCD:** *Knowing what Sam?*

**Sam:** "Not knowing which way my problem is going. Is it the big 'C'? You know cancer I mean? The papers write about these things being bad. Oh, I do worry about this not knowing, I feel I am losing control over my life just now. I simply want to know, whatever it is for my peace of mind."

The comments made by both Gary and Sam appear to reflect the general emotional upheaval experienced by patients interviewed in this study and seem to express the need to regain control over what is happening to them. This is consistent with Staub *et al* (1971:157) who have recognised this 'state' and claim that the inherent unpredictability in illness tends to have the psychological effect of lack of control, and suggest that "predictability is usually a precondition for control, and that unpredictability may have a similar psychological effect to lack of control."

This desire to 'know' and to have some control is expressed by many of the patients in this study and is a prevalent theme throughout the interview transcripts. This 'need to know' is key to the two additional categories that have been derived from the data collected - *Regaining control* and *Seeking engagement*. Both of these categories will be discussed in subsequent chapters.

Whilst some patients appeared unable to make sense of their symptoms or illness, others appeared to be attempting to understand them in order to address their 'uncertainty.' In the following example we hear from Rose, who like many other patients in the study, seems to be dealing with her 'uncertainty' by seeking out a pattern in order that she can attempt to make sense of her 'illness.' Only when she finally fails to master it does she then appear to take the necessary steps to address it:

**Rose:** "You see first I had this pain in my side [she points to her left side] then when I had nearly finished with the tablets I felt that the pain only came on at nights, may be late evening. During the day it was gone, not there. Maybe a slight ache, I don't know. I think it was not what I ate; honestly, it is so annoying, because I do not know what to make of it, to improve my 'condition.' I am thinking is it my diet or something else? My aches and pains do not exactly add up, I haven't got a clue now."

**FcD:** *A clue?*

**Rose:** "Yeah, I haven't got a clue, I thought I did, that is why I am here to see the consultant, and he is the 'expert.' "

The general pattern that was observed from the patient interviews appears to reveal that the experience of '*uncertainty*' is caused by patients being unable to make sense of their 'ailment', and as such the uncertainty seems to have triggered some emotional unrest. There was also a very definite sense of frustration resonating in the patients' experience of their 'illness', which in turn seemed to elude any rational thinking or 'mastery' over it.

This type of behaviour is discussed by Mishel (1998) who claims that patients face uncertainty when they are unable to form a 'cognitive schema' of their illness, which she argues, is the patient's subjective interpretation of illness events and its treatment.

In Rose's case, as in many others in this study, *uncertainty* seems to be triggered by the absence of what Mishel describes as 'event congruence.' This is the inconsistency between the expected and the experienced in illness-related events, which in essence facilitates 'reliability and stability.' This corresponds with Antonovsky's (1993) concept that a patient's sense of coherence is facilitated by comprehensibility, manageability, and meaningfulness. There is a sense in the accounts of those interviewed, that a lack of these factors has triggered incoherence and feelings of *worry* and *fear*, which seem to further compound the *experiencing of crisis* for a patient.

## Worrying

The feeling of worry or act of worrying or rumination seemed to resonate in all of the interviews and was itself an *in vivo* code. Patients used the word to relay the emotion they were experiencing. There was a sense too that the emotions of *uncertainty* and *anxiety* gave rise to successive emotions of *worry* and *fear*. The feelings of *worry* and *fear* seem related in that they are born from *anxiety* and *uncertainty* - the longer the period of *anxiety* or *uncertainty* experienced by the patient the greater the degree of emotion felt.

Observational data captured during the patient interviews also seemed to reveal that patients were experiencing feelings of anxiety, which were manifested, in their physical behaviour or manner. This behaviour seems akin to Dorland's (1985) claim that the behavioural manifestations being displayed were those of apprehension and difficulty in concentrating. (Dorland's, 1985)

James for example, like most in this study appeared to express emotions of *fear* and *worry* about the outcome of the consultation with the surgeon. These two emotions were expressed synonymously, yet contextually they were relaying different messages. More importantly these feelings were relayed in a non-verbal manner - James repeatedly opened and closed his empty spectacle case throughout the interview with the researcher and conveyed succinctly his apprehension, worry and fear. As with most patients in the study, James appeared to be completely unaware of this non-verbal behaviour. This behaviour is described by Neighbour (1987) in his reference to physical signs of 'speech censoring', which represent a "cluster" of verbal and non-verbal cues. James' non-verbal behaviour was represented by changes in voice quality, a loss of eye contact and a shift in physical position.

Conversely another patient, John, appeared to cope with the anxiety inherent in *worrying* by evading any probing questions from the researcher. He seemed to hold to his own agenda and appeared to deny any cause for concern about his symptoms:

**John:** "Oh, well it's speculative really, I was being treated for something else, and it all stems from my high blood pressure. Umm."

**FcD:** *Yes... but what about the symptoms you are presenting with John?*

**John:** "Oh, well the bleed in the bottom end, I suppose it will stop when I stop taking the tablets, the beta-blockers. I am symptom free; I mean just a little bleed, whatever, because I have severe constipation. I am sure it is my blood pressure tablets causing all this bleeding, no pain you must know with it, just bleeding."

**FcD:** *Do you feel that your GP saw the need for this visit?*

**John:** "Well, it's .. umm, for the mere formality of sending me here, I am all right you know."

The patients' behaviour and language shown above appear to be evasive; the patient is to some degree in a state of denial about the potential seriousness of the symptoms, which he is experiencing. This type of behaviour is analogous with Bruhn's (1990) view as being associated with feelings of control. Worrying about something it seems is seen to ensure that things will work out well; it is as if the individual is extending some control over the *uncertainty* of the situation. This seems consistent with Neighbour's (1987:93) assertion that speech censoring as in verbal cues such as 'non-sequiturs' is a way of avoiding being frank so that you do not talk your way "into an unpleasant treatment or find yourself getting upset, or having to worry about a possible serious diagnosis, or revealing something you feel ashamed of."

The feelings of anxiety also seemed to manifest in patients forgetting to return to the researcher after seeing the consultant as agreed and the researcher having to rush up to them to remind them of the post-consultation interview. The 'escort' nurse may have been distracted too for a moment whilst this 'loss' of concentration prevailed.

Chris for example, like a few others, apologised for not returning to the researcher immediately following the consultation by claiming that he had completely forgotten about it because his anxiety had blanked it all out:

**Chris:** "Oh, I am so sorry, I was not thinking about anything, I forgot because I was so anxious before I went in [to see the surgeon] that I was in another world, I blanked out you see."

**FcD:** *Blanked out Chris?*

**Chris:** "You know I was so anxious and also worried about what he [the surgeon] would tell me, I completely forgot that I had to come to you; so sorry, how can I help you?"

This evasive behaviour or symptom of 'blinking out' is consistent with Borkovec *et al* (1983) who suggest that the focus of attention on inner events appear to be disruptive at times to the engagement of other environmental tasks. What John and Chris appeared to be doing was coping with their feelings of *worry* by 'blinking out' the event, which elicited them. This coping action of 'blinking out' corresponds to Husserl's (1969) view that the behaviour of 'blinking out' or 'bracketing' is the setting apart of the offending event by putting a frame around it and treating it (as both Chris and John seemed to do), as something far removed from what is going on presently. Chris and John's behaviour as with so many others in this study also appeared to be that of 'self-preservation' which is consistent with Charmaz (1997:41), who suggests that this action of 'bracketing' is a means of preserving the self, "aspects of a self known and valued in the past", against the threats of illness. Charmaz noted this trait to be particularly prevalent in men.

The feelings of *worry* seemed to set in when the patients realised that in spite of adhering to their GPs instructions and medications there was no change in their health status.

Jean an articulate individual appeared to be *worrying* because her goals were unmet and was therefore seeking a solution to her problem by *seeking expertise* and *hoping for answers* (to be discussed in later chapters) from the surgeon:

**Jean:** "I kept feeling uncomfortable with my bowels; they were really difficult to move because I had these tags down below. So I went to my GP who asked me about my diet, the fluids I drink and all those questions. He then asked me to apply a cream after each bowel movement. I followed all his instructions, plus the diet and increased fluids and nothing has changed. Six months later nothing you know has changed for me; I am so worried about it because it has gone on for so long. I thought I would be cured but no, I am worried now I need to see the expert and get some answers."

Kady, like Jean too, seems to have had unmet expectations of a cure, when she consulted her GP, triggering the feelings of *worry* with what appeared to be traces of negativity about his (the GP's), treatment regime. Kady sought the help of her friend who recommended her to seek out the expertise of a hospital surgeon:

**FcD:** *May I ask if you were referred to the surgeon by your GP?*

**Kady:** "Oh, no by a friend. I was feeling so bad, yes, because I was pregnant and I felt bad because it was a miscarriage. I went to see my GP because I was feeling sick all the time. He said it was because I had a miscarriage and I was thinking about the baby I lost. So he said take a rest and all will be ok. But I still felt sick and I was so worried. I was worrying all the time and crying what could it be. So my friend she told me to see this French doctor and he told me that I had some stones in my... how do you say it (she points to her right upper abdomen) bladder?"

**FcD:** *Gall bladder?*

**Kady:** "Yes, that's it, he examined me and said that I had another problem not the baby one and that is why I am here to see the surgeon, and he is the expert on this, he will cure me."

Patients' *worrying* caused by the unpredictability of their symptoms seems to be congruent with Seligman's (1975) claim that it is the unpredictability of traumatic events and therefore the unpredictability of safety, which breeds feelings of *worry*. By *worrying*, patients it seems seek a safety signal to tell them whether a trauma will occur or not and when to relax.

There is a sense too that the act of *worrying* prompted both Jean and Kady (and many others in this study) to seek a solution to their problems. This move to action is highlighted by Borkovec *et al's* (1983) and Bruhn's (1990) claim that *worrying* is an instrument, which triggers problem solving and has both a functional and dysfunctional role.

*Worrying* (in this study), seems to be functional in the sense that patients took the necessary steps in coping with a threatening situation (Brenzitz, 1971) and dysfunctional in that they experienced a sense of helplessness and frustration (Bruhn 1990) when their expectations were not met, and therefore were unable to make decisions relating to their health. (Brenzitz , 1971)

Patients' past experiences of being ill also seemed to trigger feelings of *worry*. They appeared to recall for example the worry of having to wait 'so long' for the results of various tests or procedures that were carried out by the doctor. In the example shown below Sarah, like many others worried about the repeat of this waiting experience at this visit to the hospital clinic:

**FcD:** *Why do you say 'I worry' Sarah?*

**Sarah:** "I will wait for tests and worry, the only thing I do find most worrying apart from this is waiting for the results. You wait so long 'for ever' you know. It's a terrible long time and may be three months, the last time I had an endoscopy I had to wait for three months, it is so worrying, you worry sick waiting for them."

**FcD:** *This waiting must be difficult, please tell me more about it.*

**Sarah:** "At first you are worried in case it is something seriously wrong. I mean you worry if it is cancer, and then you want the surgeon to give you the results and again it takes so long and again you worry what the results may be. You see what I mean you want to hear the results but then you worry about what the results might be."

This 'recall' of a past experience as a preparation for the events to follow such as the worry of waiting for the results of tests and procedures is described by Bruhn (1990:577) as the "defensive function of the ego." This is further supported by Janis (1958) who states that the role of *worrying* is to mentally rehearse anticipated losses and to develop reassuring cognitions that can go some way to partially alleviate *fear* and other intense emotions.

The patients' notion of being at the bottom rung of the hierarchical ladder in hospitals seemed to trigger feelings of *worry* too. Patients appeared helpless because they perceived this to be their position and felt that the disparity in their knowledge to be such as to have the potential for curbing their control over issues relating to their health when in the hospital. For example, Gary seems to reflect the views of many in this study when he felt that the disparity of knowledge between him and the 'expert,' (the surgeon), combined with the aura of a hospital, would mean that the surgeon would hold his own agenda and not be concerned about his.

There is a sense that Gary and others were worried about the lack of control and power imbalance in the consultation with the surgeon as is shown below:

**Gary:** "Yes, I do worry about anything to do with hospitals and doctors. Going to see doctors you worry not only about what they will disclose about your problem but also about how much of a say you will have in the management of the illness and my needs."

**FcD:** *But why do you worry about coming to hospitals Gary?*

**Gary:** "Oh, dear you do not want to know. It is the feeling of having no power, no control. They [the hospital doctors] know the answers, you do not matter...your story is another thing. It is like going to someone else's house isn't it? You have to conform to their rules, these hospitals guys [the doctors] can be so controlling by their very attitude towards you, and it worries me that I will not be heard just listened too. I worry about coming to these places, these hospitals. Your story does not matter they ignore it, but it matters to me you see, and worries me. So you see I worry for a good reason."

**FcD:** *That is so interesting, your story does not matter, what do you mean?*

**Gary:** "I mean they will only listen to the things I say about the problem and symptoms not how I really feel. They want to get their diagnosis right... Well I hope so too... but I worry if they will understand me."

This worrying about the 'inequality' of power in the patient-surgeon encounter appears comparable with Shirley and Mander's (1996: 298) assertion that this disparity contributes to the "asymmetry of power and therefore to the controlling nature of language." Lanceley (1985) also concurs with this view and claims that there is an unequal power distribution between professionals and their clients, which promotes the ability of the most powerful to control and dominate. Doctors, it is suggested, hold the right to talk in a consultation and in claiming expertise have the power to 'control those ignorant of such discourses.' (Duranti and Goodman, 1992: 563)

There appeared to be another dimension to the worry over the inequality in knowledge between the patient and the doctor during a consultation. Patients seemed worried that the 'expert' would focus on just the physical aspect of their problem and not on how they felt 'inside.' They seemed to think that the doctor would not have a sense of empathy and were therefore *expecting an exchange* with the surgeon with *appreciating individualised information* to make it a reality (**discussed in Chapter 5 - Seeking Engagement**). There was a sense too that patients *acknowledging expertise* of the surgeon (**discussed in Chapter 5 - Seeking Engagement**) was done so as a means of

coping with the emotion of *worrying*. Although James seems to acknowledge the 'expertise' of the surgeon he appears to worry that the surgeon may not offer an individualised consultation:

**James:** "Yes, I know he [the surgeon] knows all about my condition, the GP informed me that he [the surgeon] knows all there is to know about my kind of problems and that he was the 'expert' who would sort out my problem. But I still worry, will he understand my feelings and how I feel about it all? It is not just that I want to have a say that I do indeed, but I would also want to know if he realises that I am at the centre of this problem."

**FcD:** *That is a very interesting thought, tell me a little more, this centre of problem bit please*

**James:** "Yes, I am the problem and not the symptoms I present to the 'expert', how I feel about them and how I cope with what is prescribed by the 'expert' is important to me. I need a more individualised information, take stock of the whole me not just the symptom treatment."

But as the above exchange shows James' worry appeared to be anticipatory, based entirely on what might happen. Conversely Mary's worry in the excerpt below was concerned with the recurrence of her past experience of meeting with the surgeon who she felt had a 'brash' manner:

**Mary:** "I had a very bad experience when I first came to this clinic. I saw a Dr. X. and I left this place crying. I went straight back to my GP and said I did not want to return to the ...hospital. He [the registrar] was very rude and very rough. I simply wanted to know if my operation could be delayed until my mother was here from South America to look after my daughter. You see my husband and I are separated. He said it was entirely up to me and that tomorrow if I woke up with cancer in my liver or in my brain, don't return to him for help. I was so shocked. Honestly, I worry so much about such behaviours from doctors."

This type of *worrying* evident in many patients' interviews is consistent with Gross and Munoz's (1996) 'mind-body dualism', which they claim occurs when the doctor focuses on identifying physical abnormalities while ignoring the patient and their attributes as a person, as a human being.

Patients appeared to cope with *worry* by not only *seeking expertise, acknowledging expertise and trusting expertise* but in *seeking truth* (**discussed in Chapter 5 - Seeking Engagement**). There was a sense in some of the accounts, where at the onset of the initial patient/researcher interview, the patients worried that they could not trust the surgeon to tell the truth about their 'problem.'

The conversation with John below seems to echo the *worrying* experienced by many in the study about not being told the truth by the surgeon:

**John:** "It was a very hard time for me and this oaf [a surgeon] just sat there I remember. He told me nothing. I had something done to my leg and a professor walked into the room. I learnt by accident that I had a kind of cancer and this oaf of a consultant told me nothing. He said it was an ulcer or something on my leg. It was an extremely bombshell example of shocking information. Can you believe that I had asked for information and was not told the truth by this surgeon, at another hospital, by the way not at this one? How can I trust these guys again? I worry so much now; I have become an awkward patient now before I used to trust doctors. It worries me when you cannot trust the 'experts.' "

**FcD:** *Awkward?*

**John:** "Yes, I do not trust these guys [doctors] anymore, this worries me greatly."

The wealth of health information that is made available to patients via media such as the Internet, the mass media and more specialised published literature appears to contribute heavily to experienced feelings of *worry*. There was a sense that the patients' level of knowledge and comprehension of freely available information relevant or related to their particular situations resulted in an often-misguided reaction or emotion. For example many patients appeared to worry about hospital-acquired infections should they require any surgical interventions - this type of worrying can be attributed to recent and ongoing publicity around the prevalence of infection in hospitals, for example Methicillin Resistant Staphylococcus Aureus (MRSA). Rose and Jean sum up this feeling of *worry* regarding possible post-operative infection below - all those participating in this study expressed this feeling:

**Rose:** "Oh, I don't want any surgery, I've heard so much about infections in hospitals you know, and how patients get really ill. I am really worried in

case I have to have surgery."

**Jean:** "I hope I don't have any surgery, I worry about the infection business in hospitals, and the wards are closed because it is so bad."

Sam seems to expand a little more as to where this *worrying* is coming from and seems to identify specifically the media and her 'lay referral structure' (her neighbour) as the main sources:

**Sam:** "I mean these days when you come into these hospitals you worry, you hear of so many things that go wrong in hospitals, the media and the Internet keep you informed don't they?"

**FcD:** *Like what Sam?*

**Sam:** "Germs and all that, patients get infections from hospitals and they are so ill. They pick up germs and are kept in hospital for so long. It is terribly worrying. My neighbour, she had surgery, which went very well. But she got this hospital bug and was so ill, with 'mra' or something, you read about it in the papers so often nowadays. I watch the six o'clock news, and you know they actually shut down some wards because patients keep getting infected in hospitals, this is a real worry for me."

There was a sense in the interviews that there was a new level of 'worried well.' The enhanced access to media sources particularly the Internet resulted in *worrying*, leading them to seek clarification or assurance from healthcare professionals. The Internet has created a virtual library of medical information that can be surfed and sorted via search engines. These offer information about the disease, treatment, and clinical trials among other topics. (Hardey, 1990)

Patients seemed to be worried about the *uncertainty* of their illness and were *seeking truth* (discussed in Chapter 5 - *Seeking Engagement*) yet they were also worried about hearing the truth.

Sam seemed for example to worry about the negative aspect of her 'bleeding piles' and therefore chose not to see her GP about it. However, she appears to have sought expertise because of her experience of *guilt* and the potential of losing control over her healthcare decisions:

**Sam:** "You know I worry about what he [the doctor] will tell me, yet I must know more so that I can get the treatment and be in control again, don't you think? I left it for so long hoping that the problem would cure itself or go away. Now I am worried about it. It is my fault really but you worry what the doctor will tell you. So I am here seeking his help."

**FcD:** *You say it is your fault and you are now worried, what do you mean?*

**Sam:** "It is worrying to hear the truth but I must face it, if I want to remain in control and get cured. I know I am guilty here, I should have taken care and got it seen to."

The media's influence on the patients' attitude to healthcare management appears to have triggered self-conscious emotions such as *guilt* and *shame*. This seems consistent with Hardey's (1990) claim that one should worry about the consumerisation of healthcare via the Internet - particularly because it is embroiled with personal responsibility ideology. Sam's emotion of guilt is analogous with Lewis and Haviland-Jones' (2000) view of guilt as a corrective action, which an individual can make or take to repair the 'failure.' The tendency of some patients in this study to approach or avoid emotion-inducing situations it appears has been associated with one's desire/need for affect. For example, Epstein's (1972: 212) cognitive-experiential theory suggests that individuals possess two distinct information-processing systems namely that which is based on affective experience, and the other which is "analytical and based on rules of reasoning."

This diversity of thought is consistent with Maio and Esses' (2001:585) view who explain patients' diverse reaction to emotion-inducing situations by defining effect as the "general motivation of people to approach or avoid situations and activities that are emotion inducing in themselves or others, and includes the belief that emotions are useful for shaping judgements and behaviours." In addition, this preference for effect is related to a number of individual differences in cognitive processes such as the need for cognition or emotional processes such as "repression-sensitisation or behavioural inhibition and activation, such as sensation seeking." (Maio and Esses, 2001:251)

The open nature of the interview technique used in grounded theory appears to have facilitated a sense of there being a coping mechanism which is in use as a response to the emotion of *worry* for many in this study. It seemed to have acted as a tool for recalling the 'triggers' of the emotions experienced and for the format of their

consultation with the surgeon. Sarah and Kady sum up these sentiments in the statements below:

**Sarah:** "I am glad I had this conversation with you. It was good to talk about my worries about this visit and my problem. I suppose I am able to see a few things more clearly now, you know, sort of make sense of all that was going on in my head about my illness and all that, and what I would like to say to him [the surgeon]."

**Kady:** "I feel a lot better after talking to you; I was so confused because I was worried about my health it went bad for so long. Now I know what to say to the doctor, tell him everything and not forget some problems, I know my worry will make me forget some things."

This behaviour of rehearsing for anticipated events is recognised by Bruhn (1990) as a productive adaptive action of *worrying*. Bruhn claims that this takes place when patients are allowed to voice their concern in a safe environment, gaining information and learning ways of dealing with potentially detrimental circumstances. The *worrying* behaviour is comparable too with Turner *et al* (1992) who also see the patients' manner of coping or dealing with a problem by *seeking expertise* (**discussed in Chapter 5 - Seeking Engagement**) as being prompted by the feeling of *worry*. Whilst *worrying* seems to be seen as a patients' effort in problem solving, there is a sense too that some patients feared the known, tangible and conscious danger of their 'illness' and the feeling of *fear* appeared to be imbued with *uncertainty*.

## **Fearing**

An analytical discussion on the data of the emotion of *fear* appeared a little repetitive with that of the essence of *worry*. In a sense the patients in the study appeared to express these two emotions of *worry* and *fear* interchangeably or cross-indexed. Patients for example used phrases such as "*I was frightened about it*" or "*it is worrying*" which appeared to suggest that a patient's feelings of *worry* and *fear* conveyed different messages. Further doubts as to the distinction between these two emotions are cast by the presence of the signs of anxiety in both as described earlier in the section on the emotion of *worry*. This appears consistent with Consedine *et al* (2004:502) who suggest that anxiety, fear and worry are "variously described as

facilitators and barriers to help seeking, making it difficult to coherently interpret them and thus develop practical solutions and interventions.”

However, Bruhn (1990: 557) suggests that fear (as noted in this study) is a “reaction to a known tangible, objective and conscious source of danger”, whereas worry is an effort in problem-solving. He goes on to claim that anxiety the emotion common to both fear and worry is the “alerting mechanism” to worry and a “reaction to the known, tangible, subjective and conscious source of danger” to fear. *Worrying* seemed to be triggered by some *uncertainty* whereas *fearing* seemed to denote the presence of some ‘real’ danger in this study and both emotions seemed to be governed by anxiety and patients’ loss of control over their ‘illness.’

There was a sense that patients had a real fear of inevitable outcomes of a threatening issue or problem. Jane for example, seemed to fear that the lesion on her back would be cancerous and took action by seeking help from her GP.( It was not unusual for patients with ‘general’ surgical problems to be referred to this surgeon/clinic in order to contain the waiting lists). Her fear seemed to be compounded by a sense of guilt because she had not adhered to health warnings on over-exposure to the sun. Jane’s fear seems realistic because she was aware of the hazards of over-exposure to the sun and that the likelihood of the lesion being sinister or malignant was considerable. Ingrained in this fear is her *accepting blame*, which will be discussed later in this chapter.

**Jane:** "I went to see the doctor [GP] with this mole on my back that I was frightened about and he said that he would refer me here [the hospital] to be looked at. I have just returned from a holiday in Australia and I know they say that too much exposure to sunlight is dangerous...it, causes cancer."

**FcD:** *'They' Jane?*

**Jane:** "Yes, its all over the papers and magazines: they keep warning us of the danger of too much sun tan and so do holiday programmes on TV don't they?" "I guess I should have been more careful, it is my fault, now I fear the worst about this mole."

Patients’ accounts seemed to resonate with a sense of their awareness of a moral obligation to adhere to the socio-functional norms of society and as a result they appeared to fear society’s ‘chastisement’ for violating these norms. Government health warnings too seemed to play a role in augmenting their feelings of fear.

Sarah for example, was referred to the surgeon by her GP for the management of her 'gastric' problem because she feared the 'uncontrollable passing of wind' in public, which she seemed to think was not an accepted social norm. She seemed to fear the presence or threat of the consequence of violating the norm. This feeling of *fear* appears to have triggered the self-conscious emotions of *accepting blame* and *feeling shame* (to be discussed later in this chapter):

**Sarah:** "Well, I am in the same position, same pains in my stomach...yes, the wind passing it is terribly loud and I have no control. I fear about it at work and everywhere I go. I know that I am guilty it all boils down to my eating habits, over-weight, eating the wrong things I suppose. The government keeps giving messages of correct eating habits and keeping fit, but I fear I fail them on all counts and I am ashamed."

In a similar vein, John's feelings of *fear* seem to dwell on the outcome of his presenting problem and of society's expectations of his masculinity:

**John:** "Oh, it was good to talk to you, really I mean it, and I hope Mr. X [the surgeon] will help with my problem, as I am getting married soon and I want everything to be OK. I am so afraid of my problem and losing my lovely girl [bride to be]."

**FcD:** *You are afraid John?*

**John:** "Yes, I fear because she is a lovely girl I must put it right. I am afraid a little because I might be compromised sexually, we want a family and I want nothing to go wrong in our lives together."

John's fear of the consequence of his 'illness' seems also consistent with Leventhal and Nerenz's (1985) features of an illness representation in which consequence is seen as an individual, subjective perception and is dependent on what is at stake.

The fear of a loss of control when *seeking expertise* appeared to resonate in all accounts in this study. Patients feared the thought of not understanding the medical jargon during the consultation. James, an ex-nurse, seemed to recognise the value of some medical knowledge as it gave him certain amount of control of the consultation, despite this knowledge however he still feared that it was not sufficient for him to be able to remain in control of the consultation:

**FcD:** *James, some patients expressed concern that they may not understand what the doctor tells them, what do you think?*

**James:** "Oh, yes sure, I mean I've got a good bit of knowledge so I could sort of work things out. I am an ex-nurse and from my past experience I feel that some patients would have great problems. I remember from my experience, some patients did not have a clue as to what the doctor told them or proposed as a way of treatment. The whole thing gets stranger and stranger and you begin to get frighten, because you are lost in this 'jargon.' They talk to you as a case not a person, I feel that way right now."

**FcD:** *You say stranger and stranger and [James interrupts]*

**James:** "I mean there is a sudden loss of control which you had been in until you come to the hospital, it is a frightening feeling."

**FcD:** *So you regret seeking this expertise?*

**James:** "It is difficult to say yes, or no, it is just frightening yet unavoidable. You want to remain in control and that is really possible if you understand the medical jargon and all that the doctor tells you. You feel they use this language to control you."

This *fearing* appears consistent with Coston (2006) who claims that patients' self-perception of vulnerability represents the cognitive component of the emotion of fear.

Patients seemed to add another dimension to their fear by asserting their lack of understanding of medical jargon, which they believed would mean that the surgeon would not have enough time to offer an explanation or individualised consultation. Gary summarises the feelings of many in the study below when he describes his fear about the time allocated for each consultation and the fact that this would not be conducive to facilitating individualised interaction:

**Gary:** "I will get specialist information, after all I know nothing about my problem. But I do have some questions about it and I will make sure he [the surgeon] gives me answers. I must say that I fear that the surgeon will not have the time to see to all my doubts and concerns. They [the surgeons] are so busy they hardly wait for you to complete a sentence and off they go with a prescription pad. I fear that time will not be taken to make sure that I understand what I am told."

The feelings of *fearing* seemed to emerge too from the patients' anticipation that they might need surgical intervention and general anaesthesia. Patients appeared to verbalise their fear of having surgery, of dying or waking up during surgery as is shown below:

**FcD:** *Correct me if I am wrong Jane, do I detect some fear of having surgery?*

**Jane:** "Yes, I said I was afraid of having surgery, I know that I might need

surgery of some sort but I am truly frightened out of my wits of not waking up from the anaesthesia."

The media appears to have compounded this fear by publishing incidents of surgical errors in hospitals as is described below by Dave:

**Dave:** "You know you may *get* all the information you want about the operation but what I fear is having the wrong operation being carried out on me. It is frightening to think that people have the wrong leg amputated, yeah did you read the one in a hospital not far from this one?"

This survival consideration by patients in the study either contemporary or in an evolutionary perspective is consistent with Arrindell *et al*'s (1991) study which identified *fear*, (amongst other emotions), as being related to death, surgical procedures, and also incorporated the fear of losing control, contracting infection and threats to health.

### **Accepting blame**

Resonating amidst the emotions of *fear* and *worry* seemed a guilt-ridden emotion of patients *accepting blame* for their illness. Much of this 'acceptance' appeared to be triggered by health promotion messages and the media. In the example below Tim seems to be coping with the emotion of *accepting blame* by what appears to be a form of self-defence. He seems to present the researcher with details of his effort to prevent the onset of his 'illness' which included adhering to healthy options such as healthy diets and exercise whilst also admitting that his problem or illness is self-inflicted and that he is not in control of his health. There was a sense too that patients were *regaining control* over the situation as is shown in Tim's account below which resonates with his awareness of the changes that need to be made in order to optimise his health status:

**Tim:** "You know I'm always careful as to what I eat; I mean I eat healthy food. I drink a lot of water and that kind of thing. Ok I walk a lot. Now I don't know because I do most things that doctors and the Government tell us to do in order to keep healthy. You read about it all the time in the newspapers and see it on the TV. It's messages, messages do this or do that. You know it must be me, I am to blame because I lack a bit of control over my eating sometimes. I love eating a lot, a few pints of the old lager too. I suppose I have to accept blame for this over weight thing and this

problem that I have."

**FcD:** *Accept blame?*

**Tim:** "Yes, it is embarrassing to accept it but I am to blame I suppose, they [the healthcare professionals] do not hesitate to tell you so anyway. I must take control now."

Like Tim, Sarah and Rose seem to be admitting that they are fully aware of the health behaviours expected of them in order to remain healthy but are unable to adhere to the concept. They, like many in this study, seem to be accepting of the fact that they have let themselves down and as such seem to be *accepting blame* and appear to be *seeking expertise* (discussed in the next chapter, *Seeking Engagement*) to control this 'behaviour':

**Sarah:** "It is my fault, I know I am overweight...well I mean I don't always stick to a healthy diet or medical advice. I know I should, I know it."

**FcD:** *Stick to medical advice Sarah? What do you mean?*

**Sarah:** "I mean it is obvious and I understand that certain things are no good for you and that I must avoid them. The TV is always saying something about us overweight folks. I don't always succeed in carrying out my honest intentions you know."

**FcD:** *Why are you not always successful then?*

**Sarah:** "It is hard and I feel it is easier not to follow all that is written in the papers and the TV that promotes healthy life."

Some patients like Rose appear to blame it all on their 'nature' or genes:

**Rose:** "In truth I am weak; it is in my nature to love all the wrong things. I accept this, it is my fault I always did since I was very young, some things just will not change, but I try."

What seems to be evident is that those interviewed want to correct their unhealthy 'habits' but then only seem to get as far as intending to do so and no further. This behaviour appears comparable with Prochaska *et al's* (1992) notion that patients' non-committal attitude to health problems is recognised in the behaviour of a 'contemplator.' This person they believe is one who is aware that a problem exists, thinks seriously about tackling it and then does not make any commitment to take action.

The behaviour displayed by patients experiencing the emotion of *accepting blame* seems consistent with Janoff-Bulman's (1979) two categories of behavioural and characterological self-blame. Sarah's response to her health problem for example is

noted in 'behavioural self-blame' which is seen as an adaptive, control orientated response and involves a modifiable source such as one's behaviour and the general intention of avoiding any future negative outcomes.

Rose on the other hand appears to fit into the 'characterological – self-blame' because she feels it is difficult to change since it is in her character, and therefore her behaviour cannot be modified. Her acceptance of blame seems to dwell on the 'deservingness for past negative outcomes', which is akin to Janoff-Bulman's (1979: 1798) claim that it is a "self-deprecating response."

Some patients in the study did however accept blame reluctantly with statements supporting the fact that they were only human and therefore both fallible and vulnerable. Sheila, who was overweight, admitted to being responsible for her eating behaviour, however, she seemed to feel that she needed occasional support to stop her from relapsing and experiencing a loss of control over her health management:

**Sheila:** "It is my fault, may be I am over weight because I don't always stick to the medical advice regarding my weight and blood pressure. I need help sometimes with all this. I am only human you know."

**FcD:** *Human?*

**Sheila:** "Yes, it's not as easy you know to be in control. As they advise in various magazines. I accept blame for my poor health but I need help not to keep going back to the bad habits."

Sheila as in many accounts in this study seemed to convey the message that she cannot always sustain her healthy behaviours. This behaviour seems to be recognised within Prochaska *et al*'s (1992) evidence that in the maintenance stage of behaviour change (as in Sheila's case for example), the path does not run smoothly, particularly in addictive behaviours, as relapse is likely. This stage of behaviour is described as a "dynamic stage" a continuation of and not an absence of change, "a dynamic spiral" (Prochaska *et al* 1992:1104).

Earlier in this chapter when the emotion of *fearing* was discussed it appeared that some patients delayed seeing the doctor with their problems because they feared the outcome. When the problem got worse the patients appeared to experience guilt and as a result were seen to be *accepting blame* for the outcome and sought help to be in control of

their health again and some peace of mind. An example of this behaviour can be seen below:

**Sam:** "I was afraid to hear the truth from the surgeon, I was afraid it might be cancer. So I simply pretended that everything was normal, and so I let it go on. It is worse now than before. It is my fault, I accept it, and I need help from the expert because I want to be in charge, be normal again."

**FcD:** *Be normal again?*

**Sam:** "Yes, I want to be in control of this thing, my problem, sort it out, get some peace of mind, so that I know what to do."

The emotion of guilt experienced by the patients in this study appeared to be the stimulus to their *accepting blame* and *seeking expertise*. This 'acceptance' is congruent with Pask's (1994) claim that guilt is an emotion of self-assessment because it is derived from the belief that a certain rule or norm, which carries authority, has been transgressed. There is a sense that Sam's guilt like those of others in this study appears to be 'functional' which seems akin to Bradford's (1984) view that guilt occurs when individuals violate their own internal standards of how they feel they should behave.

The patients' action in this study appears to be consistent with the views of Lewis and Haviland-Jones (2000) and Pask (1994) who claim that the motivations and behaviours which arise from functional guilt tend to promote a corrective action, which an individual can or may take to repair the failure and to remain in control of their life.

### **Feeling shame**

Closely associated with the emotion of *accepting blame* is the emotion of *feeling shame*, which appears to be triggered by the passive role, played by the patients in their healthcare management. There is a sense that patients were embarrassed by the prospect of not opposing the prescriptive nature of a consultation with a doctor. Like the emotion of *accepting blame*, where societal norms often appeared to trigger guilt, the present climate, which expects patients to participate in self-care and decision-making, appears to nurture this emotion of *feeling shame*.

However, the conversation shown below sees Dave defending his experience of shame by what appears to be his comparison of the cultural message of medical practice to that

of a religious message. He and others in the study feel they must conform to this view and appear to have difficulty in opposing it:

**FcD:** *Dave you say you feel ashamed because you do not question the doctor, why is this so?*

**Dave:** "Well, I guess I come across as a weak individual but you know you are expected to just take their word as gospel [the doctors'], and do as they say. You were brought up to believe in everything that the doctors tell you. You just accept everything, no questioning. It is embarrassing because that is where I come from. I do not question the doctor."

Others in the study seem to struggle with *feeling shame* because of today's expectation of a patient's role in healthcare and their culturally inherited submissive role being in opposition to each other. In the conversation below James seems to show that he is ashamed by his 'passivity', which he seems to find very stressful, and blames it on his culture:

**James:** "You know it is not part of my cultural baggage, you just accepted what was out there and got on with it. I find it stressful to be part of the new patient image, the patients' rights and all that."

**FcD:** *You resent it then?*

**James:** "Oh, no, I am a lecturer and I see how the 'new' student of today is always challenging what is taught and I applaud it. But I find my new role as a patient very difficult to embrace, really I feel awkward because I find it difficult to change."

**FcD:** *Why do you feel awkward then?*

**James:** "It is because I am not seen to be that new patient and I go about being told what to do I guess. It is a cultural thing and I guess there are quite a few of us with this hang-over of our past."

Ruth and Tim, like many others in the study, appear to challenge their experience of *shame* brought on by their 'passivity' by changing their attitude to the unquestioned acceptance of the medical opinion:

**Tim:** "The old days when doctors sat on pedestals and dished out information and we just sat there and accepted it all, is gone. We [the patients] want to be a part of this meeting with the doctor: and want to play a bigger role, have a say in decision-making. We are not prepared to simply listen anymore."

But then it appears that government initiatives and healthcare dictums also have a positive effect on others in this study.

Ruth, for example, seems to feel that her experience of 'passivity' induced *shame*, is a thing of the past because the present health climate has helped to change this:

**Ruth:** "In my mother's time total acceptance was the thing, they were ashamed to ask for information or explanation. It was so awkward to question these guys (the doctors). They simply accepted what was thrown at them. Today, we are asked to be assertive and this, I am afraid has made suffering shame a thing of the past. There is nothing about feeling awkward nowadays for me when I see a doctor."

The patients' experience of *shame* in this context seems consistent with Izard and Ackerman (2000:260) who claim that the capacity for experiencing this emotion reflects the "vulnerability of the individual to the sanctions and criticisms" (as in the case of Government dictums and expectations). In addition, the behaviour of James and Tim in relation to their experience of *feeling shame* appears akin to Izard and Ackerman's (2000) suggestion that embarrassment is more likely to occur when the exposed self appears inadequate or some aspect of the self seems 'inept.'

Again the behaviour of many in the study, like that of Ruth and Tim (as shown above), who have acknowledged that unquestioned acceptance of medical decisions is a thing of the past and have changed their attitude, is analogous with Lewis's (2000) notion that *shame* plays a role in the development of self-adequacy. Patients appear to be seen to oppose the social 'conformity' that is brought about by the force of the emotion of *feeling shame*. (Lewis, 1971).

Tim and Ruth's experience of *shame* also appears comparable with Tangney (1989) and Lewis (1971) who recognise the force for social conformity and social cohesion within the emotion of shame. This they believe made individuals subjects of ridicule and contempt [for example by the Government] because they have failed to fulfil their responsibility for health. Lewis (1971) who saw the role of 'shame' within the emotion of *fear*, as one which aids in the development of self-adequacy, is supported by Izard and Ackerman (2000) who claim that emotions per se, have a unique function in motivating, organising and regulating behaviour.

Many accounts in this study appeared to share those sentiments of experiencing *shame*, which seems to be akin to Darwin's (1998:325) claim that shame is triggered by the cognitive process of "thinking about others, thinking of us." It appears that patients come to consultations with the 'expert' with a story to tell - one which is about themselves and their *experiencing crisis*. They are driven to this narration by feelings of *uncertainty* aroused initially by their GP's referral to the surgeon at the hospital. However, this emotion appears to be influenced by both intrinsic and extrinsic factors, which do not seem mutually exclusive.

There is a sense that patients are trying to make sense of their symptoms and signs and failure of 'event congruence' seems to trigger primary or basic emotions of *anxiety, worry and fear*. These emotions appear to have as their precondition, cognitive processes which seemed 'real' or anticipatory. Others appeared to be incited by extrinsic factors such as Government initiatives or healthcare dictums. However there also seemed to be 'cultural issues' which further contributed to this *experiencing of crisis*. The cognitive processes appeared to also be the elicitors of *self-conscious* emotions which seemed to depend on 'sensitivity' to the opinion of others whether good or bad, such as *accepting blame* and *feeling shame*. *Shame*, for example, seemed to draw attention to some patients' failures and weaknesses in the functioning self.

All of the emotions experienced by the patients in this study, which have been described in this chapter, culminate in the patients *experiencing crisis* in relation to their current state of health and their pre-consultation position. The build-up to the surgical consultation caused patients to reflect on the journey they've taken to get to this point in time, their previous experiences of hospitals and surgeons and their wider knowledge regarding hospitals and healthcare. Patients appeared to be *seeking engagement* with the surgeon and taking action with a view to *regaining control* of their situation. This behaviour appears consistent with Izard and Ackerman's (2000) claim that the role of emotions as unique adaptive functions in motivating, organising, and regulating behaviour. (Izard and Ackerman, 2000)

This need to engage with the surgeon, to understand their condition further and to have some form of resolution for their current situation is discussed more fully in the next

chapter, *Seeking Engagement*. **Figure 4** overleaf shows the linkages between Experiencing *Crisis* and the other parts of the theoretical framework.



# CHAPTER 5

## SEEKING ENGAGEMENT

### Introduction

The previous chapter, *Experiencing Crisis* highlighted and explored the 'emotions' experienced by patients prior to a consultation with the surgeon. These emotions were born from the patients' innate survival instinct triggered by feelings of anxiety and fear of the unknown. In turn it was evident that these strong emotions initiated, directed and sustained behaviours, which were identified as being the patients' coping mechanisms or adaptive/restorative processes found in their *seeking engagement* and *regaining control* via the consultation with the surgeon.

This chapter will explore how patients use the adaptive process of *seeking engagement* with the surgeon as a response to their *experiencing of crisis*. The category of *seeking engagement* is closely linked with that of *regaining control*, in that are seen as adaptive or restorative actions or processes used by patients in an attempt to regain control and 'peace of mind' with regard to their health status.

However, there are distinct differences between these two categories whereby the process of '*seeking engagement*' seems to give rise to a sense of enquiry, of asking for 'mutuality' or 'parleying' in an effort to gain control, whereas the process of *regaining control*, conveys a simple message of the unequivocal desire for control. The 'difference' between these two categories can be summarised as being one that reflects the depth of control or involvement an individual would like to exercise in the 'consultation' and it is this that will be explored in more detail in the next two chapters.

Data presented in this chapter of the category *seeking engagement* seems to reveal that patients not only want information in order to understand their problems, 'seek causality' and choose the best treatment, but they also want information in order to be able to share or regain the 'power' over their bodies and healthcare in general in conjunction with the surgeon. It is contended that the patients' action of *seeking engagement* is representative of a 'new' patient culture which sees patients taking more

of an active role in healthcare consultation, diagnosis and treatment decision-making. Furthermore, this culture is seen as being a result of modern medicine and government initiatives.

The concepts or elements of *acknowledging expertise*, *trusting expertise*, *seeking expertise*, *expecting an exchange*, *appreciating individualised information*, *hoping for answers*, and *seeking truth* were identified as the building blocks of the category of *seeking engagement* and are discussed in detail here.

### **Acknowledging expertise**

The concept of *acknowledging expertise* appears to be responsible for the first move made by patients in securing and *seeking engagement* with the surgeon. In addition this 'acknowledgement' seems to convey a message of *trusting expertise* and *seeking expertise* (both concepts to be discussed later in this chapter), all of which appears to have culminated in the GPs' action of referring patients to the 'expert' at the hospital.

This process of *acknowledging expertise* seems to help alleviate some of the 'uncertainty' experienced by patients during their illness (**discussed in Chapter 4 - Experiencing Crisis**), and prompts adaptive actions such as *seeking involvement*, (also evident in *regaining control*), *seeking expertise* and *hoping for answers* (discussed later in this chapter) in order to maintain a 'status quo' and return an individual to some form of normality.

The excerpt below is a good example of a patient acknowledging expertise. James' apparent optimism, like many others belies a sense of thankfulness for the expertise of the surgeon and has more than an air of 'religiosity' about it:

**James:** "He [the surgeon] is in a better position than me to know what is best for me."

**Fcd:** *That is interesting please explain it a little more to me.*

**James:** "I mean he is the expert and will know what and when to act for my good. He has the answers, thank God, I have faith in Him up there, because he knows all there is to know about my problem, that is why I am here today to see him [the surgeon]."

This 'religiosity' is consistent with Dunkel-Schetter *et al* (1992:79) who refer to 'intrinsic religiosity' as a personal relationship with a Supreme Being that occurs through prayers as a means for supportive transaction "cognitively reframing the stressful situation and finding meaning in the experience."

Despite the need for patients to acknowledge the expertise of the surgeon, they still also appear to want to maintain or have control. The following example sees Joseph relating how he respects the 'expertise' of the doctor; yet at the same time it also clearly shows him articulate that the decision-making would ultimately remain his in the end:

**Joseph:** "He is the doctor, the expert he knows about my problems very well. He will give me all the information I seek and what is good for me, that's great, what will make me well again and all that. Really he is the expert there is no doubt but I may refuse though...I may say I don't want to go with what is suggested or told."

**FcD:** *What you are told?*

**Joseph:** "Remember, I fully acknowledge his [the surgeon's] expertise and thank Goodness he is the expert; but it will only work with us talking about the problem together, my problem I want us to talk together about it."

Whilst patients accept the expertise of the surgeon there does also appear to be a definite sense of scepticism, which is evident in many of the accounts taken during the course of this study. Patients seem to feel that although 'expertise' brings with it an assurance of 'answers' to problems, it may also encourage or contribute to doctor-led decision-making or treatment compliance.

This sense of scepticism is illustrated well by Jane who seems determined to ensure that the decision making process is a shared process. Jane appears to reflect the view of many in this study when she acknowledges the expertise of the consultant, but in spite of this acknowledgement she is not prepared to allow it to foster a practice of unilateral decision-making by the surgeon or perpetuate paternalism. Jane, like others seems to hope for and aspire to have an 'engagement' with the surgeon:

**Jane:** "So I will listen to the expert's opinion, he is well informed on my problems, and I need his help as the expert, to participate in decision-making. It won't be all one sided, I must also have my say, my own idea, it is my body you know, I will have a say and I will make the decision with help and guidance from the surgeon."

*Acknowledging expertise* seems to advance patients' coping with the 'uncertainty' of illness because the 'recognition' of surgeon expertise appears to have an inherent sense of 'cure' attached. At the same time it appears that any concerns experienced about the depth of the 'engagement' by patients with the surgeon are dismissed on the grounds of their *trusting expertise* (discussed later in this chapter). This is shown clearly in the following excerpt from Gary:

**Gary:** "Well if there is some treatment involved and it is going to make me better then fine, I guess the expert knows best. We will decide what is best together, and I will go ahead with his [the surgeon's] expert opinion. I know he will cure this problem, I trust his expertise to sort my problem, to get well."

The process of *acknowledging expertise* undertaken by patients in this study does also seem to nurture a sense of *hoping for answers* to their problem. This in turn is seen as being an example of patients taking action by *seeking expertise* at the consultation.

### **Seeking expertise**

The concept of *seeking expertise* appears to be a natural sequence to *acknowledging expertise*, as both processes seem to present the 'expertise' of the surgeon as central to the purpose of the patients consultation at the hospital. In the former case it appears that patients seem to be *seeking expertise* to test their own hypothesis of the presenting illness. There is a sense that *seeking expertise* is a means of gaining knowledge which patients then seem to use to "level the hierarchal relationships that exist between the surgeon and patient in order to help demystify medical information." (Savage and Armstrong, 1990: 969)

For example, in the following excerpt Mary seems to have followed the history of her presenting symptoms and appears to test her self-assessment of her 'problem' with that of the expert:

**Mary:** "The symptoms are very like the ones I had before, which went away eventually; I feel they are not too bad and will go away but I feel I must check this out with the expert, see if his diagnosis will match mine...mind you he is the expert on my type of problems."

Similarly James appears to be *seeking expertise* as a coping mechanism in order to regain a sense of control over his particular healthcare issues by probing for information relating to procedural interventions:

**James:** "Oh, yes, I am here to find out if I need an operation or an injection from the expert; he knows [the surgeon] all this and I gather he will treat this problem as he has a particular interest in this condition I hear. I mean I am hoping to get the gist of what I have in store, so I know what to expect."

Joseph appears to echo similar sentiments to those voiced by James in the excerpt above, but he also seems to emphasize the reality of '*uncertainty*' in illness and the value of assurance, which he seems to think is inherent in the act of *seeking expertise*:

**Joseph:** "I am so unsure about myself, my illness, I am here to seek expert advice, because I do not know what to expect. I must know from him if I need another colonoscopy, how often I am going to have one of these. I also need to know if these tumours are likely to return and if they can get malignant."

The patients appear to also associate the surgeon's expertise with his use of the power of technology and its value in solving problems or supporting diagnosis. They seem to have an expectation that this 'technology' will be evoked to confirm their diagnosis. Rose, as in many accounts in this study, appeared to have some idea of her illness, but seems to have an expectation that various tests and procedures will be carried out before the final decision regarding appropriate treatment is made:

**Rose:** "I guess it is too early at this stage to get answers or to test the wisdom of the surgeon's expertise. No doubt it will need more tests and investigations to give me the answers. I mean for him [the surgeon] to analyse these and give me his expert view and diagnosis or treatment for my problem."

The expectation from the patients that the surgeon will carry out various procedures and tests in order to cure them is reminiscent of shamanism, where different enactments and rituals carried out by the shaman were part of the healing process. Grim (1983:724) offers a psychological insight into the 'role' of the shaman who uses hypnotic drumming and chanting to establish a therapeutic field that "functions to ease the patient and promote a curative atmosphere."

Others in this study appear to be *seeking expertise*, but seem happy to leave the decision-making to the 'expert' on their behalf. They want to be in receipt of adequate information as to why the surgeon recommends one intervention over another and wish

to remain central to the consultation, but are content to allow decisions regarding treatment to be made on their behalf.

Gary for example, appears to suggest that the 'expert' is better informed to make decisions on his behalf, however he seems to insist that he must also have a presence in the consultation:

**FcD:** *And you feel that the surgeon has all the answers and will make the final decision on your behalf?*

**Gary:** "No, listen, what I am saying really is that I must be part of this consultation, I want to hear what the doctor has to say, after all he is the expert, he has all the answers that I have been looking for. I must kind of have a presence, it is me Gary that it is all about, share some thoughts in the decision-making but in the end I will go with his expertise. He will make the decision with me. I must be sort of engaging in this thing, do you understand?"

**FcD:** *You insist on the "we" bit Gary, can you explain a little more to me?*

**Gary:** "I mean, I am here to get the surgeon's expert opinion because I do not understand what is happening to me. He [the surgeon] does. But I must be part of this process of making decision, I want it to be a shared effort, you know."

The process of *seeking expertise* appears to move the patients' closer to the goal of resolving their 'uncertainty.' This resolution appears to exist in the process of *hoping for answers* during the consultation with the 'expert', which will be discussed next.

### **Hoping for answers**

This concept of *hoping for answers* was an *in vivo* code, which resonated in each patient's account and was embedded in the processes of *acknowledging expertise* and *seeking expertise* (as discussed earlier). There was a sense that the process of *hoping for answers* was seen as another coping response to the emotion of 'uncertainty' (discussed in *Chapter 4 - Experiencing Crisis*).

This 'hoping' appears to have a positive connotation in that patients appear to seek expert help from the surgeon at the hospital. For example, Sarah's visit to the hospital clinic to see the 'expert' seems to be underpinned by her hope that she will get the answers to her problems and be 'cured':

**Sarah:** "I am hoping that he [the surgeon] will have the answers, and if he can put it right, then

put it right, I know he will because he is the 'expert' with my type of problems, I do not know what to do so I am hoping he has the answers."

**FcD:** *What do you mean by answers, Sarah?*

**Sarah:** "Yes, I mean a cure, a solution to my problem; he is the expert and I want him to give me answers which I am not able to find on my own, and share the treatment plan with me."

**FcD:** *Share, Sarah?*

**Sarah:** "Yeah, deal with it together. I want us to talk about it together, make decisions so I am part of it. I am really hoping for answers to my problem"

There was a sense that like Sarah, Gary too seems to pin his hope of a cure on someone else, as he appeared to have been unsuccessful in helping himself to date. Gary appears to be unsettled by the unpredictability of his 'condition' because it seems that it did not follow a logical sequence which might have offered him a sense of control over his illness. Patients' process of 'hope' in this study seems comparable with Farran *et al* (1995:21) who suggest that hope functions as a "challenge rather than a life sentence" and that the human spirit can make a difference affectively, cognitively, and behaviourally to give an individual a sense of control.

Gary's search for control of his illness, which seems to be caused by 'uncertainty', (discussed in Chapter 3) is consistent with Staub *et al* (1971:157) who postulate that "predictability is usually a precondition for control and that unpredictability may have similar psychological effects to lack of control."

The dimension of 'hope' displayed by Gary in the example below corresponds with Porn's (1993) belief that hope is implicitly found in a patients' desire to be cured and is expressed as confidence in the surgeon or 'expert' and with Farran *et al* (1995: 21) who suggest that hope involves the individual reaching within himself or herself for "the best apothecary and accepting the challenge to confront a new situation."

**Gary:** "Well, you see I could not handle this problem myself and you have the expertise and resources, so I am hoping for answers to my problem. You see I have carried out everything that my GP instructed me to do and nothing has improved. I am fed up and you know now there's got to be an answer for me, something here at the hospital with the surgeon, I am hoping this will happen"

This process of *hoping for answers* by patients in this study is analogous with Wong and Weiner (1982) who claim that people spontaneously engage in causal searches

when faced with negative, unusual or unexpected outcomes. It also corresponds with Murray (1990) who further claims that attributing causality is a patient's way of achieving a sense of predictability and control over the environment. Furthermore it highlights the patients' intent to label or name the illness experienced so that they could have a sense of control over it. This relates to views expressed by Linn *et al* (1982) who suggest that this behaviour is a crucial step towards an individual's control over what is happening and also in "regaining a degree of mastery over what may have been a frightening symptom" (Brown and Gary, 1987:169).

It has been observed that well-resourced hospitals and the surgeons who work in them are also prompting this process of *hoping for answers*. The example below seems to be influenced by the 'hype' created by the media and the Internet with regard to the advances being made in medicine:

**James:** "Well, I guess I want some reassurance that there is nothing serious or wrong going on. I am hoping for some answers today because there is so much advanced technology around in hospitals and the Internet tells you many things and keeps you informed, including things like operations, cures, drugs and all that. I think that this hospital has a scanner, is that right? I am hoping I get answers so that I can get back my life."

**FcD:** *A patient I interviewed earlier said something about hope and technology in hospitals, do you too pin so much hope on it James?*

**James:** "Yes, we have advanced so much in medicine, it has given us so much hope for cure of ailments. The answers he gives you initially are speculative, the surgeons have to do some tests and others and after all my hope is that he [the surgeon] will solve my problem."

It appears that the patients' behaviour of hoping is in itself a driving force for taking action to resolve 'uncertainty.' This behaviour seems to correspond with Farran *et al* (1995) who see hope as 'going beyond emotion' and working as an energising force, and assumes with some certainty that a perhaps dreaded possibility or outcome will not happen.

### **Imperfect example**

Contrary to previous assertions the assumption that cure is related to the diagnostic procedures and the expertise of the surgeon was not a generally held view in this study. Sam in the example below appears to offer an example of this assertion by claiming that doctors do not always have the answers to patients' problems:

**FcD:** *Oh good, then are you saying that doctors have all the information and the answers?*

**Sam:** "Oh, No! Not always, I was disappointed because I was so sure he [the doctor] would have the answers to my problem, he didn't you know. I was so disappointed, really down about it, all those tests and all. They do not have all the answers even though they tell you all about all these scanning machines and that."

It appears that the much-publicised value of diagnostic procedures and advanced technology has sensitised the expectation of cure among patients and as such there seems to be a sense of disappointment when their expectations are not met.

Jane for example feels betrayed by the 'hype', which surrounds technical advances in healthcare:

**Jane:** "I don't know, I am thinking, why am I still in the same state as I was in nearly two years ago? Still not any better. You know doctors don't always have answers even when they send you off to have so many tests and X-rays. You know I even had a scan, and I know that it costs a lot of money. A scan is a great thing for finding out what is really wrong with you and it still did not help. You get disappointed, you feel kind of let down because you want answers after all this time because you want to get some control of your life again."

**FcD:** *That is really interesting Jane, what do you mean by some control?*

**Jane:** "You see when you are ill you want to get better by taking over your problem and curing yourself, and being in control. You feel good you know. But when you can not do this you rely on the doctor after all he is the expert but then again, you do not get answers even from the expert."

The concept of *hoping for answers* appears to be consistent with Lazarus and Folkman (1984) who postulate that hope can function as an emotion, as an antecedent to patients' desire to be cured of their ailments. However, this hope seems also to be embodied in additional external factors such as patients' expectations of referrals to hospitals, which they appear to think are manned by experts and serviced by specialised equipment and resources. Patients' experiences of the emotion of 'hope' in this study and its trigger to regain control in illness is recognised by Farran *et al* (1995), as making positive comparisons and determining positive value from negative events.

## Expecting an 'exchange'

There is a sense in this study that patients feel that the 'expertise' which they appear to be seeking in the consultation will be realised in an 'exchange' with the surgeon. In the conversation below Tim appears to expect a 'chat' with the surgeon so that there is a dialogue between them:

**FcD:** *Yes, then tell me how involved would you like to be in this consultation?*

**Tim:** "Well, I don't mind who starts off but I don't want this let's look and see business. I want us to talk about it; me tell my bit and he his. You know kind of chat about it like adults. I am involved. It is not a business where he tells me what he wants me to know and that's it."

**FcD:** *That is very interesting Tim, the last patient I spoke with said something like "I want an open talk" and "to feel part of the consultation" what do you think?*

**Tim:** "Yes, that is exactly it, I have come here to enjoy the benefit of his [the surgeon's] expertise, but I want us to discuss things informally, not the textbook way which only he understands."

**FcD:** *Textbook?*

**Tim:** "Yes, the hard grafted medical talk, I am saying let us have a chat about my problem, I have a contribution to make."

Patients do not however appear to associate this 'exchange' with communication and John seemed quite adamant that the word communication is often 'abused' as is shown in the exchange below:

**FcD:** *That is interesting, do I gather from you then that you seek communication with the surgeon and that it is a key issue for you?*

**John:** "I don't accept calling it a key issue, it is a fudge. I think it is about people wanting to say something, not being able to, wanting to. It is an unwillingness to communicate."

**FcD:** *Unwillingness, John?*

**John:** "Yes, by the doctors. It is about not allowing the other to have a say as a rule...I mean simply chat, say what one feels."

**FcD:** *Yes. But why unwillingness?*

**John:** "Yes, people should be allowed to present their side of it, I mean their illness as they feel it, and then both start chatting about it, an open exchange. But then if you are not allowed to have your say you simply are not willing to communicate."

John's view on this issue appears to be reflected in many of the accounts obtained during the course of this study. However, another patient in the study, Sam thinks that the doctor's one-way communication is a thing of the past:

**Sam:** "I mean I do remember you know the old days when doctors sat on pedestals and dished out information ad nauseam. You just didn't say a word, anything even if you wished to. But it has changed now. You know my dentist draws my teeth and makes jokes about them. But we chat about it, I am part of what he has in mind, his process."

There is a notion then it seems, that communication or the exchange is only possible if patients are comfortable with the surgeon. Mary for example, appears to suggest that she will disclose information only if she feels that the surgeon's attitude is right and appears to 'hint' at being averse to paternalistic behaviours in doctor/patient encounters:

**Mary:** "I will explore my problem with the surgeon only if I am comfortable to chat with him."

**FcD:** *You say explore and then if comfortable, tell me a little more about this please.*

**Mary:** "I mean to say that if you are sort of listened to when you talk to someone then you are prepared to share things with them. You must be comfortable with them too. You would not talk to someone if they were arrogant or sat there as if they had all the answers and that you did not matter would you?"

**FcD:** *This arrogance that you refer to what exactly do you mean?*

**Mary:** "The doctor who believes that he has all the answers does not even bother to let you finish what you want to say. All what he says matters; you are just a vehicle for him to practice on. A doctor is always right doctrine."

It appears that the main element underpinning this concept of *expecting an exchange* is a 'dialogue', a two-way system of communication, 'mutuality' in exchange.' Patients seemed to want the consultation to be less formal and be more of a chat – a light familiar discourse, one which will also foster an environment for *appreciating individualised information* in order to ultimately realise the 'engagement with the surgeon.'

### **Appreciating individualised information**

The patients' desire for an 'exchange' between the surgeon and themselves seems to echo their sense of appreciation for individualised information, the quality of which appears to be dependent on the various modes of delivery. There seemed to be a consensus amongst all those participating in the study that doctors were generally good at explaining things, although they thought that some were better than others in the manner which they disclosed the information.

Sam for example, appears to sum up the sentiments expressed by many in this study who thought that 'drawings' were good examples of communication and of communicating concepts or information because they encourage questions:

**Sam:** "Doctors are pretty good who I have met, they explain most things quite good"

**FcD:** *That is good news and what makes this pretty good for you Sam?*

**Sam:** "They [the doctors] explain everything thoroughly, my doctor did drawings and showed me where the 'mass' was in my body."

**FcD:** *What did this exactly do for you?*

**Sam:** "It gave me time to take in what was being told, then you know you get interested in the drawing because it means something to you. You feel like asking questions because the drawings kind of invite you to say something or to point to bits you have not understood"

Furthermore it was shown that the patients' perception was that the drawings 'capture' or represent information to the patients in a way that makes them think that it has been specially tailored for them:

**FcD:** *David, a patient I spoke with earlier told me that drawings and charts helped her to understand what was going on within her better, what do you think?*

**David:** "Well, you know for me these drawings are invaluable because they keep me focused, I am so anxious to retain all that is told that I miss out a lot of stuff. When the doctors draw the things it kind of stays there to be absorbed at my pace. Sometimes the doctors rush a bit but I can still look at the drawing to think about what was said. I am lucky, my GP takes time explaining and then she goes through it again after drawing things. It's good, I appreciate it; it personalises information. I wish I could take the drawings away with me."

**FcD:** *Are you serious David? Why?*

**David:** "I can look at them at home and may be even think back on what was said."

An extension to this is shown in the example below where Gary appears to add a further dimension to the value of 'illustration' by suggesting that the presence of medical students in the room enriches the quality of the information given by the doctor:

**Gary:** "I quite like the drawing bit, especially when they [the doctors] are teaching the students. The students are quite amazed at what the doctor tells them. Some know so little so the doctor has to explain it all and I too learn then. There is no pressure on me so I can listen at my pace and the drawings help a lot. They are most helpful."

However, despite all of this there was a perception that not all of the patients wanted to receive the same depth of information. There was a sense that some simply wanted procedural information but then most appeared interested in receiving information relating to how long they would need to be away from work or family. The patient example shown below suggests that the depth of information given to patients would be dependent on the individual patient - their need for information and capacity to absorb and analyse that information when presented to them:

**John:** "Of-course you know this need for information would be different from patient to patient. It would depend you know on the person really, some would just want enough to get by others would want far more."

**FcD:** *What about you John?*

**John:** "Oh, yes, I mean I've got a bit of background knowledge myself as an ex-nurse, but I too would appreciate information that is directly related to me as a person, I don't understand everything."

Patients' appreciation for individualised information appears to stem from their concern that the 'press' is overloading them with information. The view shown below is one shared by many in the study and shows some concern about the media hype and states that she finds it difficult to make sense of the information given on health issues by various sources:

**Jean:** "Yes, the press, the press you get all these bits of information about diseases and if you have this symptom or that you should go and see the doctor. They have a whole documentary on health problems and you do not know what to think. Does it apply to you or not? That is why I would really appreciate information that applies to me alone. There is so much information out there now; you know my neighbour worries me a lot. She brings me information from the Internet and it is so frightening and confusing"

The process of *appreciating individualised information* appears to assume that this information will be based on 'truth' and as such it is something that all participants in this study actively seek.

### **Seeking truth**

It appears that whilst patients acknowledge the expertise of the surgeon and actively seek it in order to address the 'uncertainty' of illness, they also seem to expect an exchange between the surgeon and themselves to be based on truthfulness.

The example below shows clearly that Jane is in no doubt that she wants to hear the truth about the problem she has presented the surgeon with:

- FcD:** *So what exactly are you seeking here when you say you want to hear everything?*
- Jane:** "I would like to know everything, one way or another, exactly what is happening to me. I want the truth, you know."
- FcD:** *The truth? Would you want it even if it were bad news?*
- Jane:** "Yes, no fudging just tell me as it is, then at least I know how to deal with the consequences. I have to act to deal with it one way or the other. I need the truth."
- FcD:** *Is that important to you?*
- Jane:** "Yes, yes, that is very important to me I must trust him to tell me the truth if I am to tell him all about myself. We (patients) are tougher than you think you know, need to know about our problem"

However, this seems not to be the norm, as some patients appear to claim that doctors have not always told the truth in the past. John for example, appears unrepentant when he accuses doctors of being economical with the truth:

- John:** "I am worried about the content of the information given by the doctor not the quality."
- FcD:** *John you seem a little angry am I right?*
- John:** "Oh, yes, I have every reason to be. You see I had cancer and I was not told about it, I asked about the results. I was not told the truth. I just discovered it by mistake when someone blurted it out in front of me. This oaf of a surgeon, how can you ever trust these guys. I used to be so trusting before, now I am an awkward patient."
- FcD:** *Oh, I am so sorry, and you say you are now awkward? But do you think they were keeping the bad news from you, kind of protecting you?*
- John:** "No, no, whatever news good or bad it must be disclosed because it helps to make plans. You know we (the patients) are here for just that and not to be lied to. Yes, I mean I do not trust them, I feel so betrayed by a profession that I always looked up to for its integrity. I am awkward because I don't tell them everything."
- FcD:** *Why not John?*
- John:** "I don't trust them to tell me the truth."

However it appears that this search for truth is not common practice for all patients. It seems that cultural issues, whereby some patients accepted information at face value and never questioned it, influence it:

- James:** "I am of that generation, it is not part of my cultural baggage to question any discrepancy and you just accepted what the doctors told you."

In the example below this cultural issue is relayed by the suggestion that fear of challenging the doctors led to total compliance regardless of the truth:

**Sarah:** "In my mother's time there was no question of even querying the truth, you were afraid of upsetting the doctor. You simply accepted it. My generation expects the truth and will challenge any deceitfulness from the doctor."

There is a sense imparted here that the doctors' minimalist culture of divulging information to patients is seen as their way of concealing the truth.

Mary for example appears to compare the 'openness' of information sharing between the doctor and the patient in her own country as a way of sharing control, to that of the rather secretive and controlling attitude apparent in this country:

**Mary:** "You see doctors are mean with the information that they give you in this country."

**FcD:** *Yes, what do you mean?*

**Mary:** "They tell you everything in my country, they show you the x-rays, and results of tests and explain exactly what is wrong with you, but not in this country. Doctors simply rush over things that they do not want to tell you, and are constantly fudging their way round in a bid to hide the truth"

**FcD:** *You say hide?*

**Mary:** "Yes, they do not tell you the truth, they [the doctors] struggle to tell you the truth. How can you trust them as a result? It is as if they do not want to tell you everything so that they can feel in control over you, the secret."

**FcD:** *So I gather you like the system you had at home, is that correct?*

**Mary:** "Yes, then you know what is happening to you, you have control of the situation because you have actually had the chance to discuss the results and things like that, you have been told the truth even if it is not so good a news."

The question of 'truthful disclosure' seems to prevail in this category. The symptoms presented by patients in this study were potentially 'sinister' and patients who seemed 'otherwise informed by media resources and the Internet', feared the outcome of the consultation more than those who were not so informed. However, most patients in this study when asked about this 'disclosure' appeared to want to hear the truth and this finding is consistent with studies by Tuckett (2005), Leydon et al (2000), Gillan et al (2000) and Dunsmore and Quine (1995) which revealed that in general most patients but not necessarily all, patients want truthfulness about their health. Reeder (1988)

appears however, to evoke the 'uncertainty principle' for not revealing the truth on the basis of there being no certainty in healthcare and therefore no absolute truth to reveal.

In summary this category of seeking engagement appears to highlight patients' motivation to seek the surgeon's expertise at the hospital's out patients clinic. This seems to be based on their need to learn more about the presenting illness, in order to gain a sense of 'predictability', coherence and control. The elements in this category appeared to focus on this 'informational need', and were based on acknowledging expertise, trusting expertise, seeking expertise, expecting an exchange, hoping for answers and seeking truth as well as taking the form of directed action to seeking engagement with the surgeon. The essence of this category therefore seems to centre on a need for a psychological reassurance through the presentment and exchange of 'information' and the need for 'mutuality', an 'exchange' which will help foster control over their healthcare in the consultation.

The element of acknowledging expertise seems to advance coping with *uncertainty* (discussed in **Chapter 4 - Experiencing Crisis**) and appears to be the first step towards patients seeking engagement with the surgeon in the consultation.

Initially, patients seemed to seek expertise in order to test their own hypothesis of the presenting illness the 'cognitive schema' (Mishel, 1998) and to level the hierarchal relationship that exists between patients and the surgeon, in order to 'demystify' medical information and to allay their *worrying* and *fearing*. Patients also appeared to be *seeking expertise* by probing information on procedural interventions as a means to *regaining control* (discussed in the next chapter). However, there is a sense of scepticism that with the 'answers' from the expert the consultation will come a doctor-led decision-making or patient treatment compliance. Conversely, some patients appeared to leave the decision-making to the 'expert' so long as they had a presence in the consultation or a 'shared-decision making.'

Inherent in the patients' search for expertise it appears is their expectation of an 'exchange' in which they seem to desire an 'open dialogue', or a 'chat' promoting a feeling of informality and not as Sam expressed in the data: for example, a "textbook way which only the surgeon will understand and participate in." Patients opposed doctors' unilateral communication and claimed that the behaviour was a thing of the

past. But then the patients' 'disclosure' in the exchange seems subject to a 'safe environment', that is if the surgeon had the right attitude, if he listens and is not 'paternalistic.'

This 'safe environment' it seems included patients' desire for informality in the consultation, which they appear to think will facilitate their *appreciating individualised information*. Patients seemed to particularly single out the informational value of diagrammatic, illustrations of 'the offending anatomy or physiology', its explanation and thoroughness of its delivery. It seemed that such mode of information exchange allowed patients time to think about the disclosure and ask questions, in other words this 'practice' suggests their use as 'pacers' of information delivery.

This 'engagement' with the surgeon also seemed to be about *hoping for answers*, a driving force in helping to resolve the 'uncertainty' patients experienced (see **Chapter 4 - Experiencing Crisis**). It is also about receiving cure or cure information and to address their 'event incongruence' (Mishel, 1990). In addition it seems that this *hoping for answers* was embodied in external factors such as patients' expectations of referrals to hospitals, which they think are 'manned' by experts and serviced by specialist equipment and resources.

In summary the patients' adaptive response of *seeking engagement* with the surgeon appears to be based on a sense of 'mutuality.' Patients seem to address their *uncertainty*, which triggered complex emotions and the *experiencing of crisis* by *acknowledging expertise, seeking expertise, and hoping for answers*. This it seems will be realised in the process of *expecting an exchange* during the consultation with the surgeon and is based on *appreciating individualised information* and *seeking truth*. However, there was also a sense of assertion imparted in the engagement, which seemed to evoke one's rights and one's terms of 'engagement.' This concept will be discussed in the next chapter *regaining control* a 'restorative' response to that of *experiencing crisis*.

The patients' *experiencing of crisis* appears to trigger two adaptive processes, those of *regaining control* and *seeking engagement*. These adaptations appear to be consistent with the types of doctor-patient interactions identified during a consultation by Bensing (1991: 217) as systems, which reflect patients' need for 'cure' and 'care' when visiting the doctor. *Regaining control* appears to seek the need to 'know and understand' (cure)

and *seeking engagement* seems to seek the need to 'feel known and understood' (care). The process of *Regaining Control* will be discussed in the next chapter and does not reflect any order of significance or priority.

**Figure 5** overleaf shows the linkages between *Seeking Engagement* and the other parts of the theoretical framework.



# CHAPTER 6

## REGAINING CONTROL

### Introduction

The last chapter explored the category *seeking engagement* one of the two identified adaptive/restorative responses to *experiencing crisis* in 'illness.' This chapter explores *regaining control* the second adaptive/restorative response revealed in the data of the initial patient and researcher interview prior to the 'consultation' with the surgeon. However, these two responses do not appear mutually exclusive, and *seeking involvement* was an element found to be common to both.

The 'mutuality' in these two categories is seen in the patients' adaptive processes in attempting to achieve respite from the emotional crisis triggered by the illness. (See **Chapter 4 - *Experiencing crisis***). The 'exclusivity' seems apparent in the patients' ethos of control over decisions relating to their health of either *regaining control* by means of assertive behaviour or *seeking engagement* by employing a more partnership-based approach, 'a parleying' approach to decision-making, with the surgeon (as discussed in **Chapter 5 - *Seeking Engagement***).

The theme of *regaining control* appears to be divided into those concepts which provide a more defined effort towards 'assertion' such as *weighing-up options*, *exercising rights*, and *asserting one's terms* and those which seek control such as *seeking involvement*, (which was also an element of *seeking engagement*) and *wanting to be heard*. In essence this category resonates with a sense of 'proactiveness' as well as an invocation of patient 'rights' in *regaining control* of issues related to their own healthcare.

This chapter will be introduced with an argument that in the light of a sudden and dramatic proliferation of 'medical policing' (Foucault, 1973), patients have been forced into accepting responsibility for their health maintenance, and as such *regaining control* of healthcare issues becomes an expectation of their role in decisions related to their

health. This assertion is however something which patients may or may not wish to exercise.

### **Weighing-up options**

The concept of *weighing-up options* appears to give the sense that patients have an expectation that the consultation with the surgeon will offer information, which they in turn will deliberate and respond to.

Jane's deliberation below appears to be based on her critical assessment of the information given to her by the surgeon about the mole on her back. There is a sense that she is willing to listen to the 'expert' but that despite this she will make up her own mind about the matter:

**Jane:** "I just want him [the surgeon] to talk me through what it means, the mole on my back, and what the treatment will be. Then I shall weigh it all up and decide for myself what I want to do."

There also appeared to be an expectation amongst those interviewed that they will be offered adequate information, which will allow them to make independent decisions. This expectation reflects their desire to regain control as demonstrated by Rose and then later by Sam in the excerpts shown below:

**Rose:** "If there are options then I would expect the doctor to make them known to me. I need to hear them, and think them over...I mean think about what I want to do, what decision to make and more importantly, do it my way; how it suits me you know."

Sam adds a further dimension to this assertion by suggesting that she will not be coerced into making any decisions by the 'power' held by the doctors:

**Sam:** "At the end of the day, I've heard it all, I understand what I am told and at the end you know, I will listen and make up my own mind, you understand what I mean? I will think about what I am told by the surgeon, treatment and all other things, pros and cons, and make up my own mind."

**FcD:** *Make up your own mind? That is so interesting what do you mean Sam? Another patient said something similar to me earlier today.*

**Sam:** "I mean you know when you come to see these experts at the hospitals, they offer you all kinds of information, possible diagnosis and treatment. Their opinion is so powerful that you are almost forced into accepting anything they offer without question. I mean me, today

well; I will make up my own mind. I am not going to be coerced into accepting just like that. I want to sort of...umm...how to put it? Think over the facts before jumping into a 'yes'"

There is a sense in this concept of *weighing-up options*, that patients were embracing the elements of informed consent. Sam in the example above appears to be requesting information including the options, understanding or digesting what was proposed to her and then accepting it voluntarily.

This behaviour appears consistent with the concept of informed consent, which is seen by ethicists as the protection of the autonomy of individuals and implies the right of individuals to have a say in the decision-making process (Beauchamp and Childress, 2001). Again, the behaviour of many patients in this study is allied to Faulder's (1985:37) definition of informed consent, which is described as follows:

**"An adequate disclosure from the informant met by adequate understanding from the person receiving the information thus enabling the latter to give or refuse his/her consent."**

It seems therefore that the moral underpinnings of such assertions promote not just the autonomous decisions of individuals but also the rights of individuals to exercise such autonomy or control.

### **Exercising rights**

The concept of *exercising rights* appears to support the essence of deliberation and autonomous decision-making as noted earlier in *weighing-up options* lending further weight to the category of *regaining control*.

Sarah for example in the three excerpts below appears to be using her 'right' to enforce the role she wishes to play in the consultation with the surgeon, that is she wishes to remain in control of the decision-making process:

**Sarah:** "I would like to have the choice, umm...decide what I want to do treatment-wise."

**Sarah:** "Well, yes...I've got a right: I am a person in my own right. I've got a right you know."

**Sarah:** It's my body and I want to know what is going on or what is wrong; I am in control of

my body, of my body, you know it is my right to decide."

Patients' accounts also appeared to resonate with an air of defiance within this concept of *exercising rights* to healthcare decisions, which they seem to claim, is unequivocal. Both Tim and Jane appear to articulate this sentiment, although Tim's defiance seems to be exaggerated by his past experience of professional bullying:

**Tim:** "It's my body, it belongs to me and I go by what I feel...umm... When I am not well, I exercise the right to seek help from the doctor but I am the one who makes the final decision, well, whether to accept or reject the treatment offered. I will not be bullied."

**FcD:** *Oh, Tim, you sound a bit. [Interrupted]*

**Tim:** "Yes, I will not be bullied because I have a right to think about what is going on, what is on offer to make decisions when it involves me, my body and not by some great oaf as mentioned earlier about my experience with the consultant at another hospital. I want to be in control again."

Jane's account seems to reflect some of Tim's sentiments, but like many accounts in this study, the tone appears less aggressive and more assertive:

**Jane:** "Make no mistake, I know my rights. I know I am seeking expert advice at this consultation, but I have no intention to let him [the surgeon] take over. It will be my right that I exercise here and I have my own decision...aah...opinion. At least at the end I know that the decision was mine and I take ownership you know."

**FcD:**  
*Ownership?*

**Jane:** "Yes, responsibility for my decision be in control over my life."

Patients seemed to use strong, affirmative language in order to enforce their desire to regain control in decision-making on issues relating to healthcare in the consultation environment. This behaviour is consistent with Gillon (1995) who appears to recognise this position and suggests that people have certain basic moral rights, which can be 'pit' against any tendency of others who are stronger, either individually or collectively.

Patients' expectations of the 'experts' at the hospital, together with their assertion of rights appears to also be recognised in Diamond's (1999) claim that the language of rights has emerged from patients' raised expectations of medicine, hospital care and healthcare professionals. Such behaviour it seems is the fodder for prompting the concept of *asserting terms* in healthcare.

## Asserting terms

The concept of *asserting terms* seems to be very closely linked with *exercising rights* (as described above), in that the inherent element of control offers patients ammunition to safeguard 'self-led' action in decision-making. Most patients in this study appeared armed with the 'terms' on which they wish to see the consultation conducted. In other words they seemed to be setting the agenda for their encounter with the surgeon in advance.

Rose seems to articulate the sentiment of many in this study and appears adamant that any information received from the surgeon during the consultation will be comprehensive and delivered at her level of understanding. In addition she appears to 'fear' the controlling nature of the power of the language of medicine, rejects the concept of paternalistic control (**discussed in Chapter 4 - Experiencing Crisis**), and seems to respond by setting-out her terms of engagement before the 'encounter':

**Rose:** "I don't want I suppose to have words or language used that I cannot understand the meaning of or have control over. I want things told to me on my own terms...my terms. Oh, yes to be explained simply so that I understand it and so respond on my terms you know. It is what I say on my terms."

**FcD:** *Yes, can you explain this a little more I am not too sure if I have understood it. Please?*

**Rose:** "What I am trying to say you know is that when we [the consultant and the patient] talk, the doctor must realise that I am a big part of this meeting and that he must explain things to me on my terms, answer things that I want to know about my problem and generally I suppose what I am saying is that I want to have a say and on my terms."

**FcD:** *Why do you feel this way Rose?*

**Rose:** "You know I have come to this place [the hospital clinic] with the belief that I will be in control of decisions regarding my problem, that I will assert my terms here in this meeting with him [the surgeon]. Just getting back some control over my life. There will be no power game here for him (the surgeon) No I am in charge thing."

**FcD:** *Power game, Rose? That is interesting, what does that mean?*

**Rose:** "I mean this business that doctors are always right, and you just sit there and listen. Not now, patients want their say like I do you know."

It appears that when patients are *asserting terms* there is also a sense of *wanting to be heard* (also to be discussed in this chapter) and of *appreciating individualised information* (**discussed in Chapter 5 - Seeking Engagement**).

However, there seems to be a slight 'lightening-up' of the pressure on the assertion of terms, in that patients appear to think that their expectations were desirable but not necessarily realistic. Patients appear to be conscious of the pressure of time and the need for having their expectations met during these consultations.

John seems to summarise this view below, which appears to centre on the issue of needs versus resources:

**John:** "You know I sometimes worry about the time the doctor takes explaining and recapping things that he has told me. It takes a long time man, and it doesn't go down well with the nurses and receptionists who want to go to lunch or home. Yet funny enough you want him to spend time with you, do what you want."

**FcD:** *That is really interesting, I never thought of that, tell me some more.*

**John:** "You know you want to sit with him [the surgeon] and make absolutely sure that he understands you and acts on your terms. Yet you know this all takes time and there are so many patients waiting outside to be seen by him [the surgeon], you feel so bad even for the nurses I mean."

Gary on the other hand, seems to assert his terms for a longer consultation but offers a suggestion to cope with the need for individualised information. He appears to suggest that all first referrals to the surgeon are allocated a longer consultation time:

**Gary:** "I think when a patient sees a surgeon for the first time a longer consultation time must be allocated. Then we know that he [the surgeon] is looking after you as an individual, a person with a need. By this I mean as someone who is there to discuss the problem and act on her or his terms and get better. You know I feel this will actually give him [the surgeon] time to actually sit down with you and meet you on your terms or at least on equal terms. Not be rushed or kind of dismissed the "off you go and who is next?" thing on the grounds of time limits or consultation slots."

This assertive behaviour is analogous with Alberti and Emmons (1979:2) who believe that assertive behaviour is one "which enables a person to act in his best interest, to stand up for himself without undue anxiety." Telford *et al* (2006: 458) recognise the

patients' concern about the time limits on consultations and also warn that when the patients feel dismissed during contact with a healthcare professional they may feel "diminished and unsupported" and it is this behaviour that aggravates one's fear of paternalism in health practice. However, acting in one's 'best interest' as afforded by assertive behaviour, seems to motivate the patients' action of *seeking involvement* in the consultation with the surgeon.

### **Seeking involvement**

The assertive behaviour noted in the above concept of *asserting terms* seems to forge the patient's action of *seeking involvement*, so that they have a 'voice' in regaining control over the management of their healthcare. This 'involvement' appears to have a sense of 'mutuality' between the surgeon and the patient and also seems to lend credence to the category of *seeking engagement*.

Generally patients seemed to express a desire for *seeking involvement* in the consultation; however, the depth of the involvement itself appeared to vary in many accounts. Tim for example appeared determined as noted below to be totally involved in the decision-making process:

**Tim:** "There is no doubt about it, this consultation must see me as the stakeholder, I must be involved all the way."

**FcD:** *That is interesting; tell me a little more please.*

**Tim:** "What I am saying really is that I want to be involved in the whole process, in any decisions that need to be made relating to my health. I want to remain in control of my life events, you now regardless of what happens, the implications, good or bad. I must know everything for my peace of mind "

John seems to offer a similar sentiment to that of Tim; however like many others in this study he wishes to determine the level of his own involvement in the consultation. He appears to resist any paternal gestures, which dictate the patients' role in decision-making:

**John:** "It is important that I feel consulted at every step of the way and I want to be involved. Yes I mean that there will be no pre-determined medical protocols telling me what to accept, I simply want an open and free involvement."

**FcD:** *An open involvement?*

**John:** "An open involvement meaning that I have freedom of choice and control in deciding what I want at the end of the day. I want to be involved even if the surgeon is the

expert. This is important to me, the choice of how far I wish to be involved in consultation."

The concept of 'involvement' appeared to have another slant to it. There was a sense that some patients acknowledged the surgeon's legitimacy, and personal qualities and sought expert guidance but yet they also insisted that they maintain a sense of responsibility on their part ensuring that there should be a mutual involvement, a sense of joint decision-making on issues relating to their healthcare.

Dave and Rose offer an example of this disparity of involvement and in contrast with the concept of *asserting terms* they seek some 'mutuality' in decision-making:

**Dave:** "I want to hear all about myself, however I would need guidance. We [the GP and Dave] just discussed if she should refer me to the surgeon at the hospital or not. So I am here to be guided into making some decisions on my own about my treatment but even then I must see that I am involved, this is very important to me."

**FcD:** *Guided? What do you mean here? You say you must be involved am I right?*

**Dave:** "Yes, yes, what I am saying is I know the surgeon will have all the answers that I seek, he will tell me things but I will also tell him things, and together then I feel involved a sense of I am getting back some control, some peace and agree to what suits me."

The actual process of *seeking involvement* (in the context of *Regaining control*) as part of a patient's response to *experiencing crisis* (**discussed in Chapter 4- Experiencing crisis**), seems to resonate with the message of *wanting to be heard* and relays the message for participation in the 'consultation', which must include the patients' involvement, their voice – a patient's perspective in the consultation.

The sense of *regaining control* by seeking involvement seems consistent with Gattellari *et al* (2001) who found that patients who were given the opportunity to participate [get involved] in decision-making, consistent with their participation preferences, experienced significantly greater decrease in anxiety and resultant 'control' post consultation compared to those whose participation was greater or less than preferred.

## Wanting to be heard

The concept of *wanting to be heard* in order to establish a presence in *regaining control* appeared to resonate in many accounts and seemed to convey a message that patients no longer wished to play a passive role in decisions, which involved their health.

This 'need' appeared to be intense in many accounts and carried with it what seemed to be a disdain at being 'objectified' and not being treated as an individual with personal needs. The example below sums up this sentiment:

**Tim:** "Oh, I can not bear the doctor who barely listens to what you have to say. He is so busy looking through his book or the notes all the time and if your 'story' of the illness does not match with that of the book's criteria or his, then he thinks there is nothing going on, I am not ill. He totally ignores what you have to say on the matter, your side of the story I mean. You know he [the doctor] is so busy looking-up the prescription pad or the 'recipe' or something."

**FcD:** *Oh, dear that is amusing Tim, what do you mean by recipe book?*

**Tim:** [patient laughs] "I mean they [the doctors] have a set of ideas about what is wrong with you, they do not ask you how you feel. You know they are technocrats, is that the word? What I am trying to say is they are like human robots who refer to the book of medical wisdom or something [patient laughs] and forget about what you are saying as a person with a personal story or problem."

There was also a view that doctors played a role as 'technocrats' and that such behaviour stems from their ritualistic medical practices. In the example below Mary shows that she seems to think that these ritualistic practices have taken precedence over patients' needs. Furthermore, this role seems to have conveyed a sense of mystic authority over her, something the doctor practiced on her:

**Mary:** "My doctor washed his hands before and after seeing me, it was amazing you know."

**FcD:** *That is a good thing you know Mary. It is good news that he was washing his hands; you do not appear to appreciate this, am I right?*

**Mary:** "I would appreciate it if he examined me or something. No, he did not even do that or listen to what I had to say about my problem. You know as I spoke about my problem he was busy writing it all down, and just once looked up at me to see if I had stopped talking or...umm...was I distracted by something? He then wrote down something and asked me to take it to the pharmacy and stood up and believe me made his way to the hand basin. They [the doctors] are so busy with their technical knowledge and medical things, rituals I call them that they do not listen to what you have to say. I feel that I have no say, no control over what I want him [the doctor] to hear about my problem."

**FcD:** *Go on please Mary, I am listening.*

**Mary:** "What I really mean is I come here because I have a problem, I am here to be cured, I ask to be listened to, I have feelings you know. I get all these drugs it is as if I have no say. I don't want to be a vehicle for doctors to practice their rituals on, I want to be heard and not hidden away among medical rituals."

The reference made to the 'technocratic' approach of doctors, by many patients in this study seems to suggest that this approach is responsible for the distancing of the 'person' from the illness that is the distancing of the psyche from the soma.

James seems to think that this 'distancing' begins with the power of the medical language, which he feels creates a 'social isolation' in the consultation with the doctor. He appears to feel that patients are somehow the silent partners, because they are ignored in the consultation discourse:

**James:** "He [the doctor] has the technical knowledge but at the feelings level. I am not too sure. Doctors speak so much medical stuff it is difficult to understand or even get a word in to say, " I didn't get that." You are never a part of this conversation you know just a silent partner in the whole consultation, no one listens. The doctors use these big words and forget that you do not understand, and if you say something they hardly listen for more than a second. I want to be heard, I want to have some say, but will they listen? They are powerful or intimidating with all they throw at you in their medical speak."

This sentiment appears to be consistent with Chessell's (1985:108) view that the patient's story of illness has two protagonists, namely the body and the person. He argues that the "facts about the body's function must be separated from the meanings that the patient has attached to them", if healthcare professionals truly want to know who the person really is.

The view of James and that of many in this study, that doctors are not interested in what patients have to say, is congruent with the sentiment expressed by Laski (1931) and cited by Freidson (1960:19), who believed that professional 'experts' were "over narrow and 'insular' in their vision of what is good for the public." Furthermore the mood of the patients in this study in relation to the 'power' of language is reflected in Rueschemeyer's (1964) view that expert knowledge is used as a resource of power and as a basis of privilege and social control. Similarly Duranti and Goodwin (1992)

suggest that professionals hold the right to talk and in claiming expertise have the power to control those ignorant of such discourses.

Deeply embedded in this category of *Regaining control*, is the behavioural variance in the type of control patients wished to assert in a surgical consultation (as noted in the depth of the emotions expressed in chapter 3 *Experiencing Crisis*). This 'variance' seems to be consistent with the framework 'health locus of control', which is favoured by Rotter (1966) and Wallston and Wallston (1978). It represents people's perception of the controllability of health outcomes and whether responsibility for illnesses resides in their own behaviour or outside influences.

It suggests too that there are three distinct dimensions to this belief structure the first of which is that control of health is internally based and is therefore making the individual responsible. The second being that health and health decisions are controlled by powerful others such as physicians and other healthcare professionals, and finally the belief that health outcomes are due to chance and therefore entirely out of an individual's control. It seems that the thinking within this framework, particularly the latter two dimensions, may have influenced patients' adaptive behaviour of *seeking engagement* and or *regaining control*, where 'the internal and external' balances of control are realised.

In summary the restorative or adaptive process of *regaining control* appears to manifest itself in the two key behaviours, that of an assertive and control seeking behaviour both of which resonate a sense of 'pro-activeness' as well as an invocation of patients' rights. Generally, it seemed that *regaining control* was about patients protecting or retrieving their autonomy in decisions related to their healthcare. In essence patients in this category were upholding the doctrine of informed consent. In asserting that they will be *weighing up options*, there seems to be an assumption that patients are *seeking involvement* in the encounter and *appreciating individualised information*.

Again *weighing up options* appeared to imply that the information given must be 'simple' to understand in order to avoid the 'social isolation' created by the power of medical knowledge, which only serves to make patients silent partners in the consultation and healthcare process because they are ignored in the initial discourse.

The mood of patients in this study in relation to the 'power' of language appears to centre on their rejection of the paternal behaviour of doctors and is reflected clearly in Rueschemeyer's (1964) view that expert knowledge is used as a resource of power and as a basis of privilege and social control. Patients therefore are seen to be *exercising rights* to ensure that they have a 'say' in decisions relating to their healthcare management and *Seeking involvement*.

However, the depth of involvement sought by patients seemed to vary in many accounts. Some wanted to maintain a sense of responsibility and desired a 'mutual involvement' based on guidance from the 'expert.' They seemed to want to feel 'involved' in order to have some control and some peace of mind.

Other patients wanted to be heard in order to convey the message of total involvement in decision-making. This depth of 'variance' corresponds with the framework 'health locus of control' which is favoured, by Rotter (1966) and Wallston and Wallston (1978). It represents people's perception of the controllability of health outcomes and whether responsibility for illnesses resides in their own behaviour or outside influences. It seems that the thinking within this framework, may have influenced patients' adaptive behaviour of *Seeking engagement* and or *Regaining control*, where 'the internal and external' balances of control are realised with a search for some kind of peace of mind.

Therefore it might be suggested that *Experiencing crisis* in illness triggers two sets of adaptive/restorative responses *Seeking engagement* and *Regaining control*. The 'responses' seem to focus on gaining individualised information in 'an exchange' with the expert in order to facilitate 'event congruence', predictability and therefore control of their healthcare. Patients seem 'fired up' in their rejection of the paternal behaviour of doctors, which they recognised as being controlling and perpetuating 'passivity' and affecting their peace of mind. In essence patients in *exercising their rights* are upholding the doctrine of informed consent, which seeks information, alternatives and risks, an understanding of the information presented and a voluntary acceptance of the recommended treatment or intervention by a competent individual.

The next chapter asks "*What went on?*" in the surgeon and patient interview and it measures the 'intent/effect' of the patients' adaptive /restorative responses on/in the '*Consultation*.'

**Figure 6** overleaf shows the linkages between *Regaining Control* and other parts of the theoretical framework.

**Figure 6 - Diagram of conceptual links between *Regaining Control* and other categories**

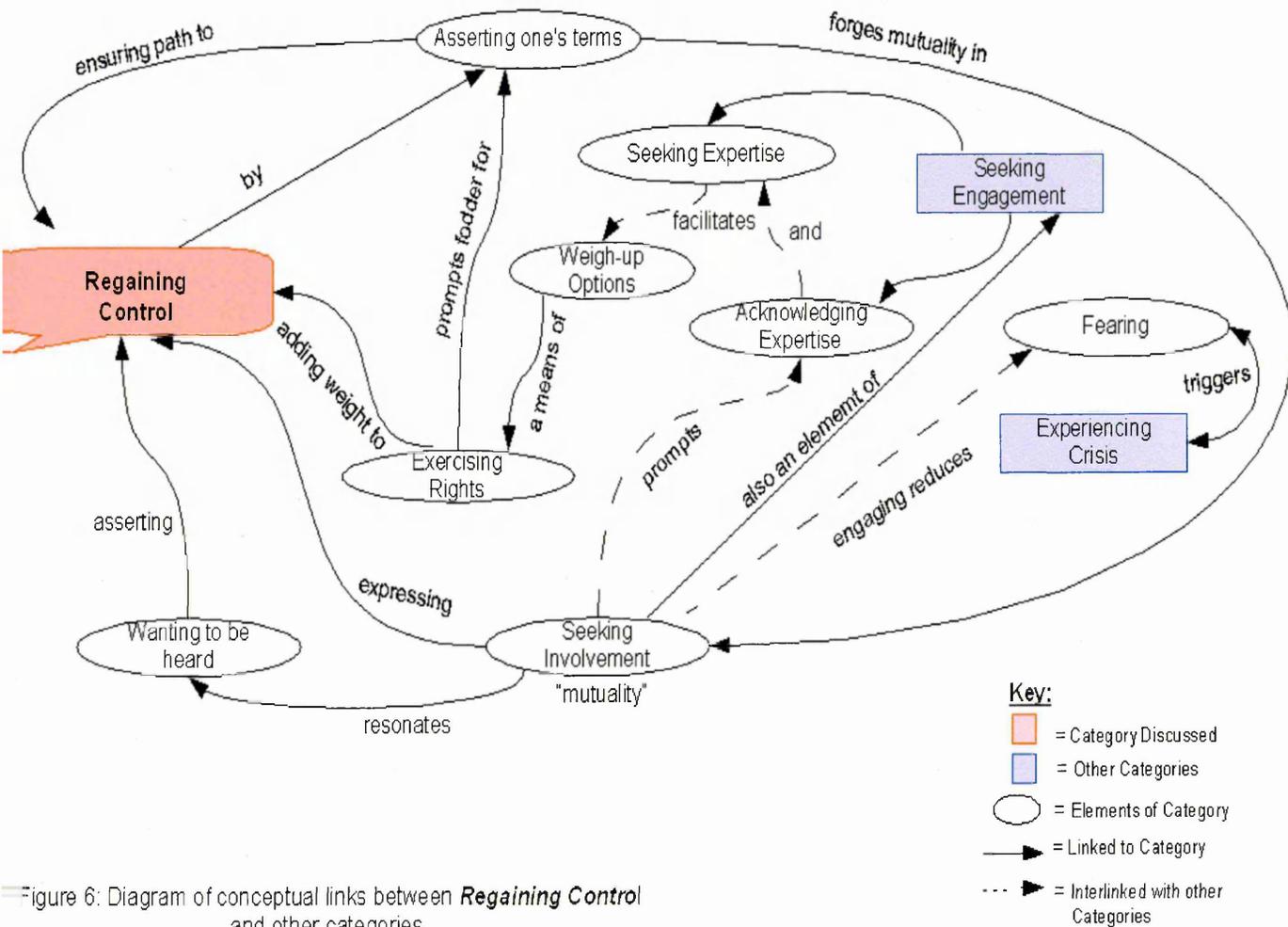


Figure 6: Diagram of conceptual links between *Regaining Control* and other categories.

# CHAPTER 7

## CONSTRUCTING A PARTNERSHIP

### Introduction

This chapter describes the processes that took place during the surgeon and patient (surgeon/patient) consultation describing *what went on?* It follows on from **Chapters 4, 5 and 6**, which revealed the findings of the initial researcher/patient interviews prior to the patients' consultation with the surgeon at the hospital. The pre-consultation findings revealed that patients were *experiencing crisis* and as a result of this were *seeking engagement* with the surgeon with a view to *regaining control* over issues relating to their healthcare.

The concept of *constructing a partnership* between the patient and the surgeon was evident at the onset of the 'encounter.' The surgeon's warm and polite manner put the patient at ease and together they rapidly moved into engaging with each other. There was a sense that patients were seeking engagement and regaining control in the 'meeting' and the surgeon was facilitating these actions. The consultation seemed to proceed in a 'mutual' tone, and respect for each other's role in the healthcare agenda. There was no sense of urgency in the surgeon's behaviour to resolve the 'illness' pattern without including the patients' interpretation or 'story' of that 'illness.'

The researcher was not present during the surgeon/patient consultation so as to avoid any 'prompts' or contribute to a *Hawthorne effect*. In order to maintain patient confidentiality the surgeon/patient interviews were audiotape recorded after the surgeon\*<sup>2</sup> had noted the patients' personal details, and carried out the necessary physical examination. The same consultant surgeon saw all of the patients who volunteered to participate in this study. The clinic nurse working with the surgeon was charged with commencing the recording of the surgeon/patient discourse at the appropriate time.

The researcher was aware that the 'observational' data obtained during these consultations would not reveal the total "emotional reaction triad" consisting of three

components (Johnstone and Scherer, 2000:220), namely feelings (the subjective experience), physiology, and expression (of face, voice and gestures). However, the subsequent analysis of the data was done in such a way as to pay particular attention to the 'paralanguage' in the recording, which includes the rise and fall in the tone of voice, stress and loudness of speech, tempo, silences and the length of each encounter.

The data obtained from the recorded consultations were transcribed verbatim to elicit 'what went on in the consultation.' The data that were captured resonated a sense of *constructing a partnership* between the patients and the surgeon, and the processes or concepts of *rapid engaging, transcending formality, sharing information, fulfilling expectations, inspiring confidence* and *empowering* appeared to be the main building blocks to this category. Both the surgeon and the patient appeared to initiate and contribute to these processes, and in a sense it seemed that the surgeon was 'rejecting' paternalism and laying down the foundation for a 'reciprocal engagement' which seemed to sustain patient empowerment.

Prior to the consultation each of the patients waited outside the consulting room and were subsequently invited in by the surgeon who addressed them by their title and surname. The consulting environment consisted of a room that was divided into an 'undressing room', an examination area, and a further room where the surgeon, the patient, the medical students and the attending clinic nurse sat down for the 'consultative dialogue.'

### **Rapid engaging**

Following a brief exchange of formalities between the surgeon and the patient, it appeared that the surgeon moved very rapidly into the 'seeking engagement phase' with the patients. There was a sense that he was bringing the 'encounter' to a personal and informal level by using phrases such as 'let's have a chat' thus making it explicit that the two-way dialogue was being sought, or by remarking on personal events in order to set an informal tone to the consultation.

For example, the surgeon asks Sam to tell him about her problem using a seemingly caring tone of voice:

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<sup>2</sup> Same surgeon consulted for complete study

**Surgeon:** "Tell me about it, have a seat."

"I see that it was your birthday yesterday, happy belated birthday."

In another example, the surgeon appears to ensure that the 'equality' of the encounter is not compromised and that Kady's physical privacy is respected following her physical examination when he asks:

**Surgeon:** "OK, please get dressed and come round, and let us have a chat."

There is a sense of therapeutic alliance emerging from the consultations here and patients who are *expecting an exchange* (discussed in *seeking engagement*) appear to be participating with ease in the 'encounter':

**Jane:** "Right then, where would you like me to sit? It looks good outside today, have you been outside at all doctor?"

**Surgeon:** [laughs] "No, not yet, the sister won't let me out." [laughter in the room]

This *rapid engaging* of the surgeon seems to be as Neighbour (1987) describes a 'connecting' one of the five 'checkpoints' of a consultation or getting onto the same wavelength as the patient.

Respect and warmth towards his patients is also something that is shown by the surgeon. This in itself also appears to create a patient-centred ethos, and the patients seem to reciprocate with 'gratuitous' responses. For example, Mary is asked how she is coping with her repeat prescription:

**Surgeon:** "Who is looking after your arthritis? You need regular prescriptions don't you and so who gets them from the Chemist for you?"

**Mary:** "Oh, thank you but I manage. I go to the chemist on the good days. It is an excuse to get out too. But thank you, you have been so thoughtful thinking about me, bless you."

The surgeon's behaviour is reflective of Lazarus' (1979) view that respect, empathy, genuineness and warmth are crucial to the efficacy of the 'therapy' being offered to the patient.

## Transcending formality

There is a sense that the surgeon's attempt at 'engaging' with his patients had diffused their anxiety and transcended the formality of the 'exchange' by creating an ambience, with a style of communication that is warm, friendly, and person-centred. It seemed that the 'encounter' was vested of power relationships and devoid of formal language codes that one associates with 'medical consultations.' This mood seems to echo in the patients' tones of affirmative exchanges such as; "I see", "Oh, yes," "Yeah", and "That is great."

It is also seen in exchanges, which appear to reflect the patients *appreciating individualised information (noted in Chapter 5 - Seeking Engagement)* from the surgeon:

**Helen:** "I see, I did not realise that it was caused by my last pregnancy. That's much clearer now thanks, I see now. Gosh, you imagine all sorts of things you know doctor, at least now you have explained it to me personally."

**Joseph:** "Thank you doctor, I feel better you know, you tell me all this information, and it is good because I feel I know about it, it is for me about me before I knew nothing."

There is a sense that the non-reticence created by this 'informality' of communication, is encouraging patients to seek expertise with a touch of 'bartering' about what they would like done and *asserting terms (noted in Chapter 6 Regaining control)*. The tone of this interaction appears to be sustained by some exchanges of light humour, from both the patients and surgeon. Mary's behaviour and that of others in this study for example, appears to demonstrate this observation quite clearly:

**Mary:** "So while you [the surgeon] are down there with my problem how about repairing the old scar so that I am bikini-worthy this summer?"

**Surgeon:** [laughs] "So plastic surgery is included in this package of colorectal consultation is it? I see, OK."

**Mary:** "It's a deal then?"

Henry and Moody (1985) discuss this use of humour in a consultation and suggest that it offers a way to cope with anxiety and stress and to view life's trials in a new light and with an emotional distance. Davidhizar and Newman-Giger (1995:64) state similarly that when something undesirable occurs, humour offers a way to "reconceptualise the

situation and to make the unchangeable more tolerable." Furthermore they claim that humour creates an informal situation, which promotes and encourages communication. However, Davidhizer and Newman-Giger also offer a word of caution that humour should be reserved for situations in which lesser degrees of anxiety are present. Bagdanovich (1993) warns that humour could be used to block discussions of real feelings both by the healthcare professional and the patients in some instances where perhaps anxiety is more pronounced.

This 'informal' tone seems to be reflected in the ease with which patients seek expertise and in the surgeon's empathy and thoughtful responses given to the patient. Jane's voice for example sounds a little tense when she asks for procedural information about the proposed colonoscopy. The surgeon however seems to respond in a 'humane' manner, taking on board what appears to be his perception of her anxiety about the procedure:

**Jane:** "This colonoscopy, what is....what is it about? I mean I have not had one done before. Will I be awake?"

**Surgeon:** "We will give you an injection to make you sleepy and very relaxed. It is like a 'gin and tonic'. What is your favourite drink?"

**Jane:** [laughs] "That will be fine, but do not forget the ice." [both laugh]

The surgeon's adaptive behaviour and level of communication appears consistent with several writers such as Comstock *et al* (1982) who claim that patient satisfaction has a direct correlation with how well the 'physician' is able to adapt the level of language used in the consultation to the patient's own level of comprehension and whether patients are allowed to tell their own story in their own words (Stiles *et al*, 1979) and express their feelings (Stewart, 1995). The surgeon's behaviour in this study is very much in keeping with Neighbour's (1987) term or description of 'gift wrapping' which he explains as being the surgeon's ability to tailor an explanation or instruction to the patient's own concepts and modes of expression in a consultation, so that the patient is more likely to feel understood which in turn will help to build rapport in order to aid compliance.

The excerpt below reflects the mood of the '*informal*' overture of communication when Dave is heard relating his medical history. He appears to claim amusingly that his accent was responsible for his last general anaesthetic:

**Dave:** "I had tonsils and adenoids removed under general anaesthetic. I don't think I needed to have my adenoids removed, I just had a Midlands accent and I talked through my nose you see."

**Surgeon:** "Oh dear was it that bad? But at least this time we will not judge your accent or speech."  
[Surgeon and patient laugh]

The surgeon seemed to invite the patients to convey the mundane aspects of their experience of illness and coping, assessing the impact of 'illness' on his patients as well as helping with the repair and restoration of its meaning thus encouraging 'event congruence' (Mishel,1998) and control. He appeared to be establishing or dealing with patients' prior learning history in order to assess patients' perceived control beliefs described by Wallston *et al* (1987) as 'distal causes of perceived control beliefs, an antecedent of perceived control. He seems to allow them time to speak, and more importantly listens to what they have to say before offering them what appears to be a structure to work through the 'unconscious elements of a half-written personal story.' (Greenhalgh and Hurwitz, 1998:76) The patients appear to oblige by relating the 'story as it is' and then *hoping for answers* (**discussed in Chapter 5 Seeking Engagement**). This is consistent with Buckman and Kason (1994: 13) who claim that it is not always easy to estimate the impact of an illness on a patient from a healthcare professional's knowledge of that particular illness "as what may appear as a trivial illness might be devastating to the patient." The illness could be a "treat to his/her hopes, ambitions, expectations or social standing." In other words they claim that the impact of illness on an individual can only be assessed in the context of the patient's life.

The surgeon seems to be asking specific questions about the pattern of symptoms, the familiarity of the symptoms and actively seeks clarification, using devices such as paraphrasing patient responses to show that he is listening and recapping so as to ensure that they have both understood each other:

**Surgeon:** "Yes, tell me about it, you say sometimes you have a bleed?"

**John:** "Quite a number of years now, I don't remember exactly. The problem is sometimes when I get constipated it is bleeding, sometimes not. Sometimes it is worse or sometimes better. I don't think I have had any diarrhoea."

**Surgeon:** "That is OK, don't worry...[a pause] Now can you remember when this bleeding is worse you think? Is it worse when you strain in the toilet?"

**John:** "Yes, yes, I think it is worse when I am in the toilet in the mornings, it is really hard and

I have pain as well as bleeding. My toilet tissue it has so much bleeding. You will tell me then what is wrong?"

**Surgeon:** "So you say there is a bleed and you have a pain. Am I right?....[pause]... OK, that's all right, we will sort it out, I will explain why it is happening to you."

The surgeon's management of the patients' history of 'illness' and his attempt at providing some structure is consistent with Mishel's (1998:225) claim that providing patients with a structure to deal with the 'uncertainty' of illness, helps them to make sense of it. Mishel suggests that 'structure' could reduce the uncertainty of illness directly when the patient expects the healthcare providers to "interpret the events" or indirectly when the providers "aid patients in determining the pattern of symptoms, the familiarity of events and the congruence of experiences." The surgeon's behaviour also appears comparable with Balint's (1957) view that the role of the 'doctor' is to organise unorganised illness that is to reorganise the patients' symptoms, problems and worries so as to help make sense of them.

The 'spontaneous flow' of communication however seems a little 'restrained' when the surgeon appears to encroach on sensitive issues as identified in Tim's case below, it is also something experienced and evidenced by others in this study:

**Surgeon:** "I see that you are prone to warts, internal and external, Mr .... A virus causes these. I did not examine your penis, have you any warts there?"

**Tim:** "No, no, none down there?"

**Surgeon:** "I just ask because if you do have them down there you have to be very careful because you may transmit them to your partner. You must come to the special skin clinic to be treated."

**Tim:** "No, no, I know. It must be those beta-blockers that are giving me these warts."

This patient 'restraint' is comparable with Neighbour's (1987) description of 'speech censoring' which he associates with certain physical signs of verbal and non-verbal cues such as 'non-sequiturs' where as in the case of Tim's history the symptom 'spread' does not 'add up' or is denied.

The permissive atmosphere created by the surgeon seems to facilitate a release of tension among the patients, and supports Gorden's (1987) view that catharsis is to be encouraged in a therapeutic interview. The surgeon seems to behave in a manner that facilitates the patients' uninhibited expression of themselves, providing them with an environment and opportunity to speak openly and ask questions.

In creating an environment where patients are able to express themselves without feeling inhibited, the surgeon also appears to be sensitive to the effects of catharsis on the patients and seems to respect their 'psychological privacy' by not pursuing the matter directly. He appears to sense that he is encroaching on patients' inner conflicts and tensions and therefore waits for what seems to be the right moment to retrieve or collect the vital information necessary for an effective diagnosis and treatment.

If we go back to the recent example of the conversation between the surgeon and Tim regarding his skin condition, the surgeon acts by negotiating the date for surgery with Tim, he also explains the tests involved and only then does he appear to revisit tactfully the issue of the visit to the 'skin clinic':

**Surgeon:** "It is hard I know to talk about some things, it is not as straightforward in life. I understand, but give it a thought. Obviously as I said, I will ask one of my colleagues at the skin clinic and the special clinic to see you before that [the day of surgery] to start you on the special ointment."

There is a sense that in Tim *wanting to be heard*, (noted in Chapter 5 *Regaining Control*) he also appears to be aware of the surgeon's perception of his needs and as such he seems to be *trusting expertise* (noted in Chapter 5 *Seeking Engagement*) that is being provided by the surgeon. Tim therefore appears to respond agreeably to the surgeon's offer of an appointment at the skin clinic and the special clinic:

**Tim:** "Right, I think you are right and I appreciate your thoughtfulness, I trust your judgement on this one, you know, you know... how I feel, so you will organise that for me won't you please? Thank you, I've had a think, that is fine by me."

Tim's attempt to secure 'privacy' for example, (and that of others in this study), is comparable with Parrott *et al* (1989:1381) who claim that this 'privacy' entails the "individual's right to determine with whom and under what circumstances he/she [the patient] would share thoughts and feelings or reveal intimate information."

This seemingly sensitive and perceptive behaviour exhibited by the surgeon is reflective of Gorden's (1987) view that sympathetic understanding and the creation of a non-judgemental atmosphere encourages patients' trust and the disclosure of 'sensitive' information.

The surgeon's behaviour of *transcending formality* also appears to nurture a sense of unrestrained seeking of information, explanation, expertise, and *seeking involvement* in healthcare issues by patients. For example, Philip enquires about the possibility of his 'problem' recurring in this exchange with the surgeon:

**Philip:** "What is the likelihood if I decide to have surgery of one of these abscesses recurring? What do I do about it, Doc?"

**Surgeon:** [The surgeon seems to proceed to explain in detail why they happen and concludes with] "Do you understand what I mean? Is it clear? I can draw it for you. Pull your chair up here a bit, between the two medical students." [The surgeon appears to be fulfilling his dual role as 'consultant' and educator]

Similarly, Ray seems comfortable about asking for an individualised explanation of one of the tests prescribed:

**Ray:** "Bowel preparation, I am sorry I do not understand. Is it an operation?"

The informality in the 'exchange' seems to also prompt individualised information as appears evident in the surgeon's explanation of 'problems' to patients with the aid of a diagram. He allows Ray time to take it all in and then asks:

**Surgeon:** "Is that clearer now...have I helped to answer your question?"

The patients' action of asking questions openly and frequently within the 'environ' of 'informality' supports Sutherland *et al's* (1989) claim that the frequency with which patients ask questions seems to be strongly related to the prevalence of doctors' information-giving behaviours. However, this 'informality' does not seem to cloud the patients' desire for control, of *seeking involvement* or *regaining control*.

In the example below, the patient, Sarah, appears to be at ease with the surgeon but there is a sense of 'assertion' that while she acknowledges the surgeon's expertise she seems to be *seeking involvement* and *asserting terms* in the decision-making process:

**Sarah:** "My GP sent me to you because you are the expert. You know about my type of problems, the bowel things. So I am here to see you about it, use your expertise. Hoping please that you will tell me everything about my problem, everything I ought to know."

**Surgeon:** "Yes, yes, that is what you are here for, to know about your problem, to understand it."

**Sarah:** "I want to be involved you know, I want to know enough....about this problem of mine, so that I am involved in decisions."

**Surgeon:** "Yes, of course we will sort it out. How about you telling me about your problem and how you feel about it first, then we can sort out the problem by using what you call 'my expertise'." [both laugh together]

The 'informality' in the 'encounter' seems to facilitate the process of *wanting to be heard* as is apparent in the manner in which patients assert for example their choice of medication. Sam who had previously had a bowel 'prep' asks the surgeon if she might have a more palatable 'drink' for her bowel preparation:

**Sam:** "What I was going to say was, is that [the medication] the only type of bowel preparation there is?"

**Surgeon:** "Why? No there are different flavours and types to be taken, small sachets dissolved in a glass of water. There are chocolate flavoured ones too you know."

**Sam:** "Right, let's have that one, please, because two litres of the other stuff was so awful, so salty and horrible, was just more than I could stomach."

It appears that this informality of communication in the surgeon/patient 'exchange' has encouraged *sharing information* and this seems to have moved the 'culture' of the 'encounter' to one of 'mutuality.'

### **Sharing information**

There is a sense that the patients are relaxed with the surgeon and the environment, and as such seem prepared to share their 'information' with him; the surgeon in turn appears to reciprocate by sharing his expertise on an individualised basis. There seemed to be open exchanges of information and the roles of 'patient' and 'surgeon' seemed complimentary rather than competitive, meeting patients' needs of *seeking involvement*. Although patients appeared to participate in the consultation in all accounts in this study, the surgeon seemed to take the lead in the consultation. This is comparable with Roter *et al's* (1987) report that physicians contributed to 60% of the communication, and the patients only 40% in a consultation. However, it seems there is a 'notional balance' in this interaction because the surgeon seems to be representing expert knowledge, which the patients are seeking, whilst at the same time he seems to be respecting the patient's expertise.

The audiotape recordings seemed to resonate the 'enthusiastic' tones of the surgeon's knowledge, explanation and health promotion. The health promotion perspective appeared to particularly enrich the communication between patient and surgeon because it emphasised issues of empowerment, competence and control.

The ratio of 'interaction' time appears to be evident in Thomas' case and is typical of all other cases in this study, where both parties listen and respect what each other has to say. Patients appear to be *acknowledging expertise (noted in Chapter 5 Seeking engagement)* and participating whilst the surgeon fulfils their expectations:

**Thomas:** "Well, what is your verdict then Mr [the surgeon]? What is happening down there?"

**Surgeon:** "There are two polyps, the first one looks benign and the second one seems a little inflamed. But there is no evidence of malignancy; we will send it off to histology, to be looked at for anything sinister. If you look at what I have drawn here, where is the other student? [Surgeon addresses the medical students] The polyps are situated very close to this.... sphincter. There is a fissure down there, which makes Mr.. [the patient] bleed each time he defecates." [The surgeon then brings Thomas into the conversation]

"Can you see what I have drawn Mr.. [the patient], this is where your entire problem stems from. You have a small anal fissure like a cut in the skin in the corner of the back passage, similar to when you have a cut in the corner of your mouth and it's a bit uncomfortable and it bleeds when you try to open your mouth. Don't worry we will sort it out."

**Thomas:** "Right I see, what do I do about it? How can I stop this from getting worse now?"

**Surgeon:** "Ok, let's try this [surgeon proceeds to teach him how to cope including paying attention to the dietary habits].... [Thomas interrupts]

**Thomas:** You mean I will have to do all that? All right, let's have a go, you are the expert after all, I'll try it, you right, I'll do it."

The surgeon then seems to move into education mode and questions and advises Thomas on his dietary habits. He appears to be moving away from his 'sharing style' to a 'directing' style, and using the 'weight' of his expertise he engages Thomas and encourages him to reflect on his dietary habits.

**Surgeon:** "What is your daily intake of fluids a day? You should drink at least two litres of water a day and eat plenty of fruits and vegetables. And when you go to the toilet do not sit for longer than five minutes."

**Thomas:** "How many glasses?"

**Surgeon:** "At least ..... try it I know you can if you tell yourself that it will work, it will be good for you."

**Thomas:** Oh, it does help? Oh, I see after I have my dinner and again later. Ok, I will eat lots of vegetables as you say, you are the boss."  
[Both laugh and Thomas says].  
"I'll definitely try it, I must improve my eating habits I guess, no problems with the alcohol and diet I hope?" [Patient giggles]

**Surgeon:** [Laughs] "Everything in moderation you know."

The interventions in this 'sharing' of information as illustrated in Thomas' case, are comparable with Lauver *et al's* (2002:252) tailored and individualised interventions. The former is considered as delivering contents and goals that have been pre-determined and the "degree of individualisation is finite", whereas individualised interventions are only partially pre-determined, "the degree of individualisation is infinite, and the intervention is determined as a result of researcher- [patient] interactions."

It seemed however that some patients needed reiteration of the information because the surgeon's enthusiasm for his surgical 'speciality' appeared to race ahead of the patients' capacity to understand and retain the information being imparted. Many examples of this need for confirmation or reiteration of information by the patients were apparent in the data collected; the following is but one example:

**Surgeon:** "Any questions?"

**Sarah:** "Well, I did not understand the thing about my mole, I am sorry you were too fast for me and I did not catch what you said about the scar. Please repeat it."

There was a sense that *sharing of information* was also accommodated by patients' trust in the surgeon. Patients appeared willing to share their stories of 'illness' with the surgeon because they trusted not only his expertise but also his integrity, to tell the truth as shown below:

**Surgeon:** "I will have to remove much of the dead tissue around the lump and then pass a scope through your back passage?"

**Pete:** "So you are going to do it then? Have you done a lot of these before?"

**Surgeon:** "Yes, I do this operation a lot and I have not had any problems thank god. They are pretty straightforward, but that does not mean that I cannot make a mistake. I have had no problems up to now."

**Pete:** "Doc, that was very honest of you man, I trust your skill anyway and you are a genuine person, it is not hard to believe in you."

The importance of being told the truth and the concept of trust in '*sharing information*' is emphasised in Tim's account of his experience with a surgeon at another hospital:

**Tim:** "I am afraid I am not a very good historian now because I was not told the truth by the surgeon at the last hospital, he was such a..... I cannot tell you."

**Surgeon:** "Oh dear, was it a bad experience? Were you alright?"

**Tim:** "No, I was not, I did not appreciate being told a lie. I was very open with everything and I co-operated with whatever was prescribed, because I trusted the doctor. It is hard to share things with people like that."

**Surgeon:** "I am sorry to learn of your unfortunate experience, we must be honest with each other, that is the only way forward to sort things out, talk things through."

It appeared that much of the instruction and education from the surgeon was repetitive and professed in most consultations. The surgeon appeared in control of his subject matter and patients were not always passive and seemed to offer their opinion or initiate a discussion. There was however a flaw observed regarding the enthusiastic overture of this 'expert chat.' Harry, for example, had bouts of diarrhoea and the surgeon appeared to instruct him (as he did the others in this study), to 'keep his bowels moving.'

**Harry:** "But I am not constipated. I have had diarrhoea for the last few days, and I have this discomfort down there."

**Surgeon:** "Oh dear, I am sorry, I must be in autopilot I instruct all my patients about their dietary habits. I am so sorry..... about this diarrhoea, how long has this been going on?"

The surgeon appeared to be so intent on conveying the message of maintaining a 'healthy bowel habit' that he did not seem to 'listen' to what the patient was telling him. It appeared to be a case of 'speciality ritualistic habit', one that seemed to present specialisation as blinkered expertise.

Once again, it appeared that when patients requested information on other specialities of surgery, the surgeon seemed less forthcoming with information. For example, when Tim asked about the potential risk of impotence following a prosectomy, the surgeon appeared to respond with less 'gusto':

**Tim:** "Right, OK, one thing about prostate is always a frightening word."

**Surgeon:** "No, the prostate is like a big gland [the surgeon then explains the physiology]."

**Tim:** "There is a kind of sexual connotation, which is always frightening."

**Surgeon:** "Well, yes it is one of the possible complications after surgery. There are tablets on the market, which may help, I'll leave it up to the urologists or the water works specialists to decide. The auditors will tell you what the figures are but impotence is rare."

There is a sense that the surgeon did not want to enter into discussions with the patient about specialities that he felt he was less informed about, nor did he seem to want to encroach on other specialities. This aspect of the consultation appeared a little 'reserved or guarded' in the otherwise established engaging surgeon/patient atmosphere.

It appears too that patients were not so forthcoming with their family medical history; this too seemed to contribute to these 'guarded' moments in the 'exchange.' A typical example of this lack of forthcoming by patients can be seen in the following example, where James is a little incoherent in providing family history due to its involvement with the 'cancer' issue and the death of his father. James appeared to deny the cause of his father's death but revealed after some sensitive probing from the surgeon that he had indeed died of cancer of "the back passage":

**Surgeon:** "Do you have a history of cancer in your family?"

**James:** "No, no I don't think so. It is just my problem."

**Surgeon:** [later in the consultation] "Do you know what your father died of? Heart disease? He was seventy-three years old then and the likelihood of you being at high risk is negligible, his type of cancer comes with age."

**James:** "Yes, he had a colonic cancer and he died in hospital."

However, the strength of the *engaging* and *informal* atmosphere and the consequential 'mutuality' of the exchange seem to have contributed to *fulfilling expectations* of the patients.

### **Fulfilling expectations**

A sense of satisfaction resonated in all accounts in the surgeon/patient 'encounter.' The patients appeared to have expectations of the surgeon and the surgeon in turn seemed to fulfil these expectations.

Examples of patients' reactions such as "Yes, that's exactly what I feel" (Helen) and "Oh, God, well thank you for explaining, for being so thorough" (Sam) seem to sum up the mood of fulfilment in the surgeon/patient encounter.

Sarah for example, like a few others in this study, appeared, in *wanting to be heard* to present her total life history and the inherent 'problems' to the surgeon. He in turn seemed to listen to what she had to say and responded by giving *individualised information*:

- Surgeon:** "OK, all this matters a lot to you, you want to get on with your daily things. We will do all the tests we need, do a full MOT more or less, and then go from there, is that OK?"
- Sarah:** "Yes, that is fine."
- Surgeon:** "Any questions?"
- Sarah:** "No that's great, this is the best consultation I have had for a long time. I feel much better now. You have gone over everything with me."
- Surgeon:** "Obviously the colonoscopy is the most accurate method of screening for bowel cancer that we have got. It is not 100% effective; it is about 95% effective. There are no 100% effective screening methods for any conditions."
- Sarah:** "I trust your judgement Mr [the surgeon], you have been very kind and honest with me, thank you so much, this is my best consultation."

Again, there is a sense that patients' expectations have been met by the accommodating nature of the surgeon. He appeared to offer options of dates for surgery or diagnostic procedures on 'individual' needs and there was no sense of coercion:

- Rose:** "How soon will I have this operation done?"
- Surgeon:** "Well within the next month or so and if you would like us to postpone it even further we will, that is fine, think about it and you give us a ring when you are ready."

In a further example of the surgeon accommodating patient requirements, Mary appears to be 'relieved' because she was allowed to negotiate the dates offered for the 'interventions':

**Surgeon:** "So, shall we arrange a time which will suit you?"

**Mary:** "Yes, please, you see my sister is coming over from Australia in June, it would be nice to have some family company."

**Surgeon:** "That is no problem, when would you like to have the colonoscopy? And don't forget I need to excise that tag too."

**Mary:** "That is so kind of you doctor, you are so thoughtful you know, it all makes you forget you are sick."

**Surgeon;** "What do you mean are you cured already?" [both laugh]

A final example of this accommodation of the patients' needs is shown by James, who seems satisfied with the surgeon's information and reassurance that he can call anytime, should the problem recur:

**Surgeon;** "If we discharge you, you have an open appointment to come and see us with any problems related to the lesion. Just ring the clinic and say that I asked you to come in."

**James:** "That is really reassuring, I appreciate that doctor. I think it was really nice of you clarifying for me that there is a chance of the fistula recurring if we did not go ahead with the operation. It is so much nicer to be given information and to be told the truth. Really, thank you doctor."

Conversely, there was also a sense that some patients felt 'pressurised' by information overload when the surgeon it appeared was directing/instructing patients to make various appointment bookings for tests and x-rays. The surgeon seemed to continue in the informal mode of the 'encounter', which included what appeared to be an assumption that the patients were familiar with the hospital areas and terminology.

John's voice for example seemed to reveal a sense of hesitation, of being pressured when the surgeon was instructing him to go to various departments in order to make appointments for tests and x-rays:

**Surgeon:** "Go down to the X-ray department and book the barium enema, then come back here and book an appointment at the clinic desk to see me two weeks after you have had the barium enema. These are the blood test forms and....."

**John:** "Right, my goodness, as long as I do not have to remember all this. I mean somebody will have to tell me in a minute what I have to do."

John's reaction is evidenced by Quill and Townsend (1991), who claim that the extreme emotional reaction that some patients experience after a consultation may lead to cognitive distortion and affect the way patients understand information. Harry too appeared to be 'stressed' by the responsibility of making appointments because he was not familiar with the tests or the departments where these would need to be carried out:

**Harry:** "Can you [the surgeon] say that again, I am sorry I did not catch all of it? You say oh, I forget, that I must go to the blood test place, sorry where? I hope I remember it all because it is so much to remember as I have not heard of these things before."

It seemed that up to this stage of 'mutual exchange' patients appeared happy with their role in the consultation and how their management of health was to proceed. However, there appeared to be a sense of 'anxiety' when the patients perceived that they were now being given the control of organising the tests/procedures, which would be the 'linchpins' of their diagnosis and treatment. This reaction is consistent with Ohman's (2000) claim that this 'free-floating anxiety' is intense and far above the given objective danger or threat, "which makes patients helpless and unable to cope and impedes psychosocial or physiological functioning." (Marks and Lader, 1973:76)

The consultations between the surgeon and the patients seemed to resonate with a sense of fulfilment in that patients appeared to be meeting their agenda based on their desire for involvement, sharing of information and engagement with the surgeon.

This outcome appears to be consistent with what Bensing (1991) describes as the two types of interactions in a consultation. One which seeks the 'need to know and understand (cure) and the other, which seeks the 'need to feel known and understood' (care). This sense of patients' 'fulfilment/satisfaction with the consultation also seems to be *inspiring confidence* in the surgeon.

### **Inspiring confidence**

It appears that in all accounts in this study, the surgeon's clinical skills and more importantly his honesty about his knowledge and skills has inspired confidence in his patients' belief in his skills and expertise. This is comparable with Buckman and Kason (1994) who suggest that in real life the honesty shown by a healthcare professional always strengthens the relationship, increases trust and encourages honesty in return. Similarly Mishel's (1999) theory of "uncertainty in illness" suggests that patients who perceive their physician as a credible source of information are able to use that information to construct meaning to their illness experiences, thereby reducing uncertainty and improving health outcomes. Patients seemed happy for the surgeon to take the lead in the diagnostic and treatment realm because they felt involved, were understood, were allowed to ask him questions and trusted his responses.

In the following example, Dave appears confident in the surgeon's ability to make the right decision for him because he seems to respect the genuineness of the surgeon:

**Dave:** "You tell me what is wrong with me and what I should do. I know you are fully aware of my type of problems, and you were actually listening while I was expressing my problem. I know that you will do what you feel needs to be done; I have trust in your expertise. Mr [the surgeon] you have been so honest with me up to now and I respect you for that, so genuine, I guess I feel confident you will do the best for me."

Kady, who tried to assert her 'lay' knowledge and experience on her GP, found that such an attempt was strongly resisted. Her experience with this surgeon seems to add another dimension to Dave's sentiment, and sums up what many echoed in their accounts in this study. Kady appears to trust the surgeon's expertise, she feels listened to, and is confident that her questions will be answered and was not forced into accepting what the doctor says:

**Kady:** "You see, you know your work doctor and you're not pushy and do not want me to do this and that. When you are speaking, I see you are interested by what I am saying. I see your eyes doctor you are listening and your head it moves. You are a very kind doctor, you tell me everything about my problem, and I am happy today to see you, thank you doctor."

Patients' confidence appeared to be generated by both the surgeon's clinical competence and his humanness in dealing with them. This is comparable with Roter *et al's* (1987) view that patients judge competence mainly by their doctor's technical behaviour and Blanchard *et al's* (1983) view that patients base their evaluation of the doctor's performance on the quality of the interpersonal skills they possess. Kady's expectations and that of others in this study seem consistent too with the ethics of informed consent which embraces the elements of information, understanding, capacity and voluntariness. This concept it seems is the very essence of being empowered.

### **Empowering**

The surgeon's initial move to engage with the patients, transcending formality, the sharing of information and 'collaboration' during the consultation seems to have set a precedent of empowering the patients to self-determination.

Both Dave and Phillip like many in this study, appear to seek self-determination by *seeking expertise* about their 'problems', they ask for clarification, and then seem to suggest that they will make up their own mind:

**Dave:** "Is this condition.... I wonder if you could tell me if this is hereditary. You see my mother too had these problems, and I am a bit apprehensive now. I need to know and make decisions about anything you suggest, which I trust implicitly. I want be able to make up my own mind about my health and future problems."

**Surgeon:** "Yes, of -course, you must make these decisions. I will offer you my diagnosis and possible treatment, but for now let us talk a little more about your problem. Don't worry. You know I need to make a diagnosis first, you must lead me, as it is your problem, you are the best to know how you are feeling. So you must take some responsibility too, as all patients must. You are concerned about this being hereditary; tell me about your mother's symptoms, what did she complain of?"

**Dave:** "That is great, I feel good about this set up you know doc, I think most of us like this set up."

**Surgeon:** "Set up?"

**Dave:** "Yes, about being made to feel that we are taking the lead in our care with your

assistance. We know about how we feel and what we are going through. We must make the decisions with your help."

Phillip seems to be seeking empowerment too but he appears to be unsure of his capacity to do so and therefore seeks help with this:

**Philip:** "I appreciate you are sort of getting me involved and listening to my problems. I see you are trying to get me to decide what it is I want from here [the consultation] but I am not too sure how much, need your help with it."

**Surgeon:** "Yes, of course we will work together on this, I will not ignore your feelings about it just because you are here to seek my expertise. Am I right? And you matter, I want you to feel that it was your decision at the end."

There was a sense that *empowering* was a dynamic process, where power was both taken and given as evidenced by Hegar and Hunzeker's (1988) claim that power is shared in empowerment. Some patients however, appeared to seek it more than others in this study as for example in the case of Dave and Phillip. This is comparable with Guadagnoli and Ward's (1998) claim that not all patients will want to take control of their medical care. However they felt, as did the surgeon that it was still important to ensure that the patients' concerns, desires and values were incorporated into decisions relating to their care.

Again the surgeon seems to foster a sense of control and self-efficacy by helping the patients to empower themselves. He places much importance on 'their' story of the illness and 'their' experience of it and accepts that they will make decisions that are different from what is decided for them.

In the following example, Sarah, like many others, seems to be given information; alternatives and risks about her illness and is then allowed to own her decisions as her right:

**Surgeon:** "There are two ways of dealing with this problem and I am happy with which ever route you choose. I am happy with your decisions, but you must be clear about them both. Do you understand me?" [The surgeon re-visits the information in a simple and clear manner]

**Sarah:** "Yes, OK, I see what you are saying, I need to be sure of both options. You are kind and I appreciate that bit about choice and support. I feel OK now about making a decision. It feels like you trust me too, because I trust you, you know."

There seems to be a sense of partnership built on the mutual respect between the surgeon and the patients, also on the trust and the 'support' offered by the surgeon. This seems consistent with Simmons and Parsons (1983) who claim that for empowerment to happen there must be a mutual respect between the healthcare provider and the patient and that the interactions are mutually beneficial [to construct a partnership]. A view consistent too with Ashworth *et al* (1992) who indicate that participation is threatened unless the [patient] is assured that there is a possibility of self-representation.

The surgeon/patient consultation appeared to be based on two strands of action, one from the surgeon and the other from the patients, which intertwined to construct a mutual partnership in healthcare. The encounter appeared to be a meeting of two 'experts' where patients were allowed to 'own' their story, and the underpinning ethos of the 'exchange' was 'you tell me your story and I'll tell you mine' – a meeting of two minds. Both strands seemed to complement each other and there was a very real sense of fulfilment in the exchange and subsequent patient compliance. The surgeon appeared to be sensitive to the prevailing anxiety of the patients and therefore rapidly engaged with them to bring the status of the consultation to an informal and mutual encounter.

Patients appeared to meet their expectations in receiving expertise, by being told the truth, in being listened to as individuals and most importantly in being empowered by having a 'say' in the decision making process. There appeared to be times however, when patients were reluctant to disclose information, which encroached, on 'sensitive' issues but this seemed to be addressed by the sensitive and humane disposition of the surgeon.

The non-threatening, informal environment created by the surgeon appeared to facilitate a mutual partnership in which patients seemed 'fulfilled' and confident in the expertise of the surgeon. There was a sense of patient satisfaction in all accounts in this study and it appeared to be engineered by the engaging and empowering behaviour of the surgeon.

The surgeon and patient 'encounter' appears to suggest that patients' experience of 'crisis' triggered by the uncertainty of illness, the accompanying emotions and their adaptive/restorative responses of *seeking engagement* and *regaining control* were in essence embraced by the surgeon's caring disposition and his perception of a patient's bio-psychosocial need in healthcare. This hypothesis will be tested in the next chapter, which asks *How do patients describe what went on in the interview?*

**Figure 7 on the following page shows the links between *Constructing a Partnership* and the other parts of the theoretical framework.**



# CHAPTER 8

## SENSING RELIEF

### Introduction

This chapter, which follows the 'patient/surgeon consultation', seeks to elicit how patients describe *what went on during the 'encounter'?* It seeks to establish if the patients' needs were met in the consultation, which was based on a 'partnership' and empowerment.

The last chapter described '*what went on*' during the surgeon/patient consultation and appeared to reveal a sense that patients were given the opportunity to 'play out' their role as experts of their illness. It seemed that while there was some active recognition of and value placed on medical diagnosis and treatment with the use of sophisticated technologies, patients still sought interpersonal skills. In addition, patients appeared keen to let the surgeon lead in the arena of medical expertise so long as they were actively involved and able to voice their concerns and needs. This behaviour was consistent with the elements of 'informed consent', which was comprised of receiving information from the surgeon, understanding it, ensuring they have the capacity to comprehend and most importantly being allowed to make the decision without any coercion.

The researcher's post-consultation enquiry about the outcome of the 'encounter' appeared to be greeted by an almost spontaneous and pleasant sense of relief from the patients. There was a sense that patients were experiencing the 'feel good' factor, *Sensing relief*, because they had done something about addressing their 'problem' by seeking out the medical expertise and knowledge and in doing so had found that the surgeon had fulfilled their needs and expectations and offered some sense of peaceful outcome. One patient, Tim embodies this "feel good" factor or feeling when he says:

**Tim:** "I am so glad it is over, you know, I am getting married to this beautiful person soon, I am over the moon now that I have my problem seen to and I know all is well with me. He has such a persona, always listening, always kind of polite and gentle, yet he is so informed. I am so relieved, such a weight off my mind."

The post-consultation interview between the researcher and the patient appears to reveal a change in the mood of the patients. Prior to the consultation there was a sense of 'crisis' and a search to regain control and/or to seek engagement with the surgeon over healthcare issues. Post-consultation however this seemed to be replaced with a contradictory stance whereby patients examined the characteristics of the surgeon and expressed their appreciation of his authority in terms of his medical expertise and 'humaneness.' Patients experiencing and achieving some sense of relief from their 'crisis' also accompanied this contradictory stance.

Embodied within this achievement of *sensing relief* were a number of basic building blocks which patients appeared to identify as the surgeon's *engaging persona, genuineness, approachability, tailored explanation, empathy, unrushed manner, and empowering.*

### **Engaging persona**

The post 'encounter' euphoria appeared to be influenced by much of "what went on" during the surgeon/patient consultation. There was a sense that the patients felt the surgeon had engaged with them and treated them as equals throughout the consultation.

Many of the patients in the study seemed to refer to previously long-held attitudes and views that a doctor's behaviour in a consultation was generally one of being distant and 'unconnected' with the individual. The short conversation below shows quite typically, the patient view that their recent consultation experience had been one that was very different to the previously perceived norm:

**FcD:**

*"How did you get on then?"*

**Sam:**

"Oh, very well, yes, very well, nice lovely doctor."

**FcD:**

*"Lovely doctor?"*

**Sam:**

"Yes, because you could just sit down and chat, he is that kind of person, so warm in his approach; whereas some doctors can be a bit frightening, stiff upper lip type in their approach. I could talk to this surgeon and open up to him."

**FcD:**

*"What was the frightening bit?"*

**Sam:**

"Well you know, when there is bad news there is no reaction on their faces, they can be very, very straight laced. Whereas Mr [the surgeon] was like a friend. I have come away thinking I have known him for years, this is such a relief."

This feeling of familiarity, the 'inclusiveness' experienced by patients seems to stem from the surgeon's *engaging persona*, which is felt to contribute to the patients' relaxed manner and their more active involvement in the 'encounter.' An example of this can be seen in the excerpt shown below:

**Gary:** "He calms you down, it's his whole approach, the eye contact, the handshake. It seems so less formal, very friendly. I really felt that I had been included in everything that he [the surgeon] suggested. What a nice person."

What patients appear to be appreciating in this 'engaging persona' is the surgeon's social relationship. This is something also expressed in the views of Buller and Buller (1987), Hall *et al* (1987) and Garrity (1981) who believe that 'good manners', friendliness, laughing or making jokes and a general social orientation are 'necessary ingredients' of a social relationship.

### **Genuineness**

Genuineness, (an *in vivo* code), was considered to be an attribute of the surgeon and one which resonated in all the patients accounts in the study. Patients seemed to feel that this attribute was responsible for the 'openness' or frankness of the dialogue experienced between them and the surgeon.

Jane, for example, appears to sum-up the sentiments of all those interviewed in the study by asserting the belief that the success of the consultation was as a direct result of the surgeon's genuineness, his honesty and his listening skills. These attributes were instrumental in her being able to talk about anything that worried her 'inside':

**Jane:** "He was great, he was really helpful and friendly to begin with, which was the real reason why it all went so well, it's nice."

**FcD:** "*Real reason, what do you mean? Please explain.*"

**Jane:** "You know it is hard to pinpoint but there was a feeling of sincerity, a genuineness about him, I could talk and knew that he was listening and respected what I had to say. He was genuinely interested in what I was saying about my problem."

In addition to the perception that the surgeon was genuine and honest, there also appears to be a feeling that the surgeon was sincere and that there was a large degree of "frankness" in the consultation dialogue as shown below:

**Mary:** "You know whatever question I asked of him he seemed so genuine in his response. He answered me frankly and you felt comfortable with it."

**FcD:** *"That is interesting Mary, the last patient I spoke with said something similar, can you tell me a little more what do you actually mean by frankness?"*

**Mary:** "I mean, you know when you talk to him he seems really interested in what you are saying and he talks with you and not at you, I mean no lectures and that "do this" or "do that." He was so honest, kind of sincere about the whole thing, my illness, his medical 'stuff' and suggestions."

**FcD:** *"Sincere? Do you mean he told you the truth about your illness? Is that what you wanted whether it was good or bad news?"*

**Mary:** "Yes, he is a genuine, honest person, that's it, a whole lot of weight off my shoulders. I didn't mind if the news was bad or good because I needed to know, it is about getting down to the bottom of things. It is great to have someone like this when you have problems you know. I felt that we had a kind of mutual trusting between us, so respectful."

Others like Sarah seemed to feel that the surgeon's genuine disposition helped to calm their anxiety and made them more able to relate their "problem" to the consultant in a rational manner. However, despite this the patients did still feel that they had to make their symptoms visible, both real and physical in the 'encounter' in order to be perceived as credible patients:

**Sarah:** "He [the surgeon] was so kind, really genuine because he just made you feel that you were important to him and what I said was of significance. I felt so miserable before I came to this hospital because I did not know what was wrong or how to put forward my problem so that it would appear significant. That I would be listened to. You know but he made me see what it was all about and understand it. Do you know what I am saying?"

**FcD:** *"I do Sarah, you say genuine, what do you mean? That is interesting please explain."*

**Sarah:** "Yup, the surgeon was not sort of patronising me, he respected what I had to say. No big talk, just honest, down to earth, my earth and what I felt. You could kind of go through your aches and pains in a sort of order and not be harassed to finish."

**FcD:** *"Honest Sarah?"*

**Sarah:** "Yes, I mean so open about giving me facts, why this and why that and down to earth, my level of thinking."

**FcD:**

*"You also said something about not being harassed about finishing Sarah?"*

**Sarah:**

"Yes, he allowed me time to tell him what I wanted to say, he never rushed me at any time. He was such a warm and kind person. I honestly felt that sense of something ease inside me. I felt relaxed because I was so tense before I came."

This genuineness of the surgeon seems to be consistent with Carl Roger's (1975) client-centred theory, which suggests that the core conditions crucial to the efficacy of any interaction between the doctor and patient are respect, warmth, empathy and genuineness (Garfield,1980).

## **Approachability**

There was a sense that patients felt that the surgeon's 'genuineness' also made him more approachable because they seemed to feel comfortable enough to ask him questions, seek explanations and talk about things that did not always seem directly related to the presenting 'problem.' Many patients seemed to smile when referring to his 'approachability' and referred to his humour and ability to put his patients at ease as shown below:

**FcD:**

*"Oh John, do I detect a little smile?"*

**John:**

"Oh yes, he has a sense of humour, it really diffuses your anxious thoughts and feelings, and you then feel you can tell him anything even if it does not make sense to you. He just answers any questions with enthusiasm and care you know, it's so good."

Patients appeared to appreciate the light-hearted humour of the surgeon, which they felt had helped to put them at ease and allay their anxiety. This observation is consistent with Iggulden (2006) who claims that humour could be a powerful tool in human interactions where patients feel fear and anxiety. Similarly Rosenberg (1989) and Simon (1988) also describe the physiological benefit of humour and laughter in reducing tension. They claim that the biological function of laughter relieves the tension that accompanies fear, anger and grief. Conversely McCreddie (2006) and Bagdanovich (1993) postulate that when patients use humour in their history giving they may be doing so in an attempt to hide their true feelings, to mask them and divert attention away from the underlying issues.

One patient, Jane, feels that the surgeon's approachable manner was very helpful and compares the outcome of the consultation with her previous experiences with other medical 'consultations' at the hospital:

**FcD:** *"It is interesting that you say he [the surgeon] was very helpful Jane, what do you mean?"*

**Jane:** "I mean he was very approachable and offered all of the answers, all of the information without being pushed for it. I've been to some doctors who are very reluctant to part with information. It made you defensive. He was so good, I felt I could ask him anything without fear of being put down or be made to feel stupid you know what I mean? It was very good; you could talk to him. It is such a relief when you meet such nice doctors when you are ill."

**FcD:** *"Defensive Jane, what, what do you mean?"*

**Jane:** "Kind of angry may be a little suspicious that they are not telling you the whole truth. You feel that they want to be in charge of the whole consultation, 'doctor knows best' kind of thing, and you can't ask them anything."

This example of patient behaviour seems consistent with Pendleton *et al's* (2003) claim that patients often referred to their long-held attitudes and opinions of doctor's behaviour in consultations. Conversely, one patient, Maureen, seemed uninhibited in presenting her 'history' to the surgeon:

**Maureen:** "You know he was an awfully nice man, so approachable, you wouldn't think he was high-up, a doctor. He listened to my back problem, and then my knees, they are real bad, he has booked an X-ray for me. I told him about my arthritis and he asked about my diet and weight. I know I have to lose weight, he was so patient, and he gave me a full check-up. It has been a long time since any doctor spent more than two minutes with me. It has been prescription pad exercise, as an easy solution to end the consultation as quickly as possible and off you go business, you know."

**FcD:** *"And did you feel pressured into finishing your chat?"*

**Maureen:** "No, not by him by any means but I felt I was using more time than allocated because there were so many people waiting to be seen outside. I am not surprised he is so lovely. I wouldn't mind how long I waited to see him." [Researcher and patient laugh]

Whilst patients appeared on the one hand to enjoy this unrestricted time 'encounter' with the surgeon, they also seemed somewhat perturbed because they were conscious of other patients waiting outside to be seen by the surgeon. These feelings of pressure in relation to the consultation time are voiced in the example below by Dave, who as a result of having felt pressured in terms of time spent in consultation with the surgeon, suggests that any "new" referrals are allocated a longer initial consultation time as a default value.

**Dave:** "I feel bad about the length of time I was able to chat with him [the surgeon]. It was good for me the best ever consultation but you know the NHS and its problems and you feel guilty for taking up his time. You know honestly I think the first time a patient sees the surgeon more time must be allocated. Then you don't feel so bad for him... you know the sister (the nurse in charge) was sometimes looking up at the clock...aaaaa... I don't mean she was rushing anybody, but you know it is getting on and others are waiting."

John too appeared to think that 'time' was a premium in clinics, and this was something that often prohibited fuller discussions. This concern is comparable with Paterson's (2001) where patients felt that scheduling of clinic appointments reduced the time they felt they had to build a relationship with, and to ask detailed questions of, the clinicians. Also comparable is Henderson's (1997) assertion that factors embedded in the context of care, such as time and task-orientated practice, often inhibit participation.

**FcD:** *"How did you get on with the consultation, John?"*

**John:** "Very well, fine. I felt he explained everything very nicely, I mean he answered my queries, he listened and noted my responses."

**FcD:** *Right. And?"*

**John:** "One thing I did notice towards the end there was a difficulty, I hadn't quite understood something and I wanted to say. Oh, I didn't understand that could you tell me again. I felt that I couldn't do that because I would take up more time and it's a concern. I know Mr .....[The surgeon] would willingly explain it all but you feel time is important the clinics."

There was a sense that the 'mutuality' created by the 'engaging persona' of the surgeon was being rewarded by patients who appeared to be protecting him from the pressures of 'getting the job done' within the limits of the clinic hours. In a sense they were

displaying a feeling of empathy, which they seemed to have recognised in the surgeon's behaviour during the 'encounter.'

## **Empathy**

There was a sense of passion in the patients' tones as they described their appreciation of the surgeon's empathy. They appeared to feel he was aware of their 'needs' and understood where they were coming from.

For example Mary's enquiry as to the date of her surgery was met with a surprise when the surgeon offered her a choice of dates to accommodate her needs. The surgeon seemed aware that she had children and have the forthcoming school holidays.

**Mary:** "He asked me about my domestic arrangements, he remembered that I had a daughter who will be on holidays soon. So I said I had to prepare the practicalities at home, go to the supermarket beforehand so that my daughter has food in the house. He was so understanding, really nice."

**FcD:**  
*"Did this matter to you Mary?"*

**Mary:** "Yes, very much, you know when you are ill it affects your family too and the domestic arrangements. I know I am not the only patient he has but at least he asks you and that makes you want to accommodate him too. He is so understanding, I feel he kind of thinks about you as a whole person."

**FcD:** *"'Whole person', that is interesting, tell me more please?"*

**Mary:** "I mean to say he [the surgeon] thinks about more than my sickness, he was thinking about how I would manage things at home plus the operation. He seems to think about my whole being emotions and all. It is so helpful when this happens because you too want to help him then, like coming into hospital when it suits him [the surgeon] he is a busy man you know."

Again this empathy seemed to be realised by the action of the surgeon sharing with the patients his understanding of the difference in cost of purchasing drugs prescribed by the hospital doctors versus those prescribed by the GP.

Sarah for example seemed amazed that the surgeon was thinking about her domestic and physical state when prescribing her medication.

**Sarah:** "The surgeon, you won't believe it, he asked me about my tablets and how many I take a

day. He said that the GP was in a better position than he was to write up my tablets for more than two weeks at a time. You know he said that I would not need to run up to the chemist so many times if the GP wrote out the prescription for a month, and that it was cheaper too. I think, I think he is so thoughtful, so understanding, really, he seems to think about what you want what is best for you, everything."

**FcD:**

*"You are saying something so.... [Sarah interrupts]"*

**Sarah:** "He sort of feels for you, like he knows what you are going through, you know what I mean? He helps to unwind all that tension that sense."

The surgeon's empathetic behaviour seems congruent with Rogers (1975:4) definition of empathy as being non-judgmental, of understanding and communicating one's understanding to another, as well as "checking with him/her as to the accuracy of your feelings, and being guided by the responses you receive." The surgeon's 'affective response,' as seems apparent in the case of Mary and Sarah, is consistent with Eisenberg and Strayer's (1987) claim that empathy is an affective response which stems from the apprehension or comprehension of another's emotional state or condition, and that it is identical or very similar to what the other person is feeling or would be expected to feel.

### **Tailored explanation**

The surgeon's empathetic behaviour also appeared to be reflected in the manner in which he explained things to patients. Patients seemed to appreciate, for example, the surgeon's explanation in simple terms of the procedures, the aetiology of the 'illness' and the reason for proceeding with specified 'interventions.' Furthermore he appeared to repeat things to help them recall some of the information to ensure they had fully understood it.

Patients seemed generally content with the 'pitch' of the language used, the depth of explanation given and the mutual discussion that evolved during the consultation. The sentiment expressed by many in the study regarding the surgeon's manner and approach to the consultation is well represented by the comments provided by Joseph below:

**FcD:**

*"Well, Joseph how do you feel at the end of the day?"*

**Joseph:** "Yes, I was pleased, I was told everything, clear to date, we [the patient/surgeon] went through everything, the tests I had, the examination, and he spoke very simple,

and I could understand him. Any questions I asked he answered very simply, yes. I am so happy it is all over, he was very nice to me."

Gary appeared particularly excited about the surgeon drawing a diagram of the 'offending' anatomy and felt it was so personal:

**Gary:** "Wow, it was nice to be informed, you know the surgeon explained everything very calmly and drew a diagram to show me what was wrong and how he would remove it. It just helps knowing what is happening and what will be done. It is better than going home and reaching for the medical books or the Internet. You know what? He let me take the drawing away, of-course I asked him first, it was great."

The ethos of giving 'individualised' information and supporting changes in behaviour in this study seems consistent with what Ong *et al* (1995) refer to as an instrumental and affective behaviour approach, furthermore it seems congruent with the views of several other writers. For example studies seemed to reveal some instrumental exchanges such as giving information, asking information, and giving directions (Roter and Hall, 1992), explaining reasons for treatment (Meeuwesen *et al*, 1991) and also affective utterances, such as being friendly, open and honest (Buller and Buller, 1987), in addition to showing concern and engaging in small talk. (Siminoff *et al*, 1989)

The 'tailored' approach taken by the surgeon when requesting the patients' 'family history' in an attempt to find a link to the current presenting problem did cause some patients to become anxious.

James, for example, displayed feelings of frustration and anxiety when questioned about his family history which seemed to stem from his having trouble recalling some 'events' as is shown below:

**James:** "I was impressed by the detail of information given. It was inspirational. He showed interest when drawing out all the information he needed from me but it was frustrating."

**FcD:** "*Why frustrating?*"

**James:** "Because I should know the dates my parents died and of what, but I couldn't."

**FcD:** "*Why couldn't you James?*"

**James:** "I suppose he was thinking that it could happen to me and I felt nervous, yet to be fair he asked what I should know."

**FcD:** "*So am I right in thinking that you were a little upset about recalling the information*

*regarding your parents' death?"*

**James:** "Yes, yes, but I still feel foolish for not remembering, he is a kind fellow, he means well, it is for my good."

It seems that the surgeon's accommodating role in the 'encounter' had created a scenario of patient compliance and one, which the patients seemed to accept.

In contrast another patient, Hannah, seemed to offer a negative aspect of this *tailored explanation* because she could not concentrate on the surgeon's 'chat' during her physical examination. She felt that she was unable to get involved in a discussion with the surgeon while she was lying in a 'compromising' position. It seemed to have aroused anxiety and a sense of vulnerability because she could not control the 'interaction' and seemed to have problems of information 'recall' and retention:

**FcD:** *"You appear a little hesitant about it [the interaction] Hannah, what is it?"*

**Hannah:** "You see it is very difficult to concentrate while the surgeon is carrying out an examination. I mean it was on my back passage and it was painful as well as embarrassing. It makes you so vulnerable. I know he was talking to me and it was about me but I wish we could talk after it was over. Honestly, there was nothing wrong with him [the surgeon] just that I could not concentrate and felt so awful, so powerless in that position I was in, and worse still I could not remember a thing."

**FcD:** *"Was he giving you information when you were down there or was he sort of asking you to indicate where the problem actually was as he was examining you?"*

**Hannah:** "Yes, I know he had to press down here and there to check with me but he also asked questions like when did I notice it and how long have I had it. I found it hard to concentrate and felt really sort of exposed and unable to speak out."

Despite this however it seemed that on issues related to 'information giving' by the surgeon, patients appeared to appreciate 'tailored information' and seemed to think that 'group teaching' for example, when the surgeon was teaching the medical students present, was a particularly useful mode of gaining information.

Joseph seems to illustrate this position well:

**Joseph:** "Yes, the surgeon he gave me all information, but I liked when he was teaching the students. I could listen and also understand. It seemed like we all wanted to know."

**FcD:** *"What do you mean by that Joseph?"*

**Joseph:** "I mean you took your time to listen no pressure on you directly, like 'do you understand it Joseph?' No, it was for all of us but I know it was for me

mostly. And of course they asked questions and he [the surgeon] answered so nicely, quite easy to understand."

There is a sense that patients had an expressed preference for the pacing of information being given during consultation and also for its mode of delivery. This pacing seems to make retention of information easier and reduces the pressure on the patients' 'attention span' when it is shared with others in the room, during for example group teaching. This seems comparable with Ley's (1977) assertion that clarity and organisation of the 'intended' message in a consultation has a powerful effect on reception, comprehension, and retention. Thus he claims that a message must not only be specified, "it must be organized and delivered in a manner that will allow the patient to attend to and to process it completely." [unrushed] (Ley, 1977:173)

### **Unrushed manner**

Patients appeared to appreciate the surgeon's unrushed manner, which they seemed to feel helped to sustain stability in their communication with the surgeon. Despite this however, there was a sense that this 'manner' was beyond their expectation because of the plural nature of much of the medical responsibility, their clinical autonomy and the primacy of their interest as illustrated by James in the following exchange:

**FcD:** *"So James, you say that he had time for you, umm... was this important to you?"*

**James:** "Yes, very much so. It felt like my problems were important to him [the surgeon] and that he wanted to listen and help. It was inspirational, he was so unrushed, and he had time for me."

**FcD:** *"Wow, you say inspirational?"*

**James:** "Yes, doctors are simply interested in diagnosing, that is their priority, so when they hear enough, out comes the pen, it is note writing time and off you go and the next patient is sent for. This was definitely not the case, he was so unrushed, and he made you feel important."

**FcD:** *"Off you go, that is funny..." [patient interrupts]*

**James:** "Yes, but this one [the surgeon] he was inspirational."

Carol puts forward another perspective as to the value of the 'unrushed manner' of the consultation by claiming that the 'chat with the doctor' was not about sitting down and having a cup of tea with the surgeon, but about the content of the consultation; an exchange of important information between two 'experts':

- Carol:** "He [the surgeon] seemed to have time, didn't seem particularly rushed."
- FcD:** "*Was that important to you?*"
- Carol:** "Yes, it was, yes obviously he is a busy man and you can tell that he wasn't going to sit there and offer me a cup of tea. That's not what I expect. He seemed to have all the time to listen to my problems, answer all my questions. He answered all of them and then offered his expertise. You have no idea how good that feels."
- FcD:** "*Feel good?*"
- Carol:** "Yes, the feeling that my problems were important to him, he was taking his time to let me unfold my concerns and put my mind at ease."
- FcD:** "*Put your mind at ease Carol?*"
- Carol:** "Yes, taking away the anxiety of not being listened to, getting answers and made feel part of this referral. It is such a relief to have such a lovely surgeon. It gives you that peace of mind too."

Rose appears to associate the unrushed manner of the surgeon with that of his interest in her 'person':

- Rose:** "He took time to ask me about myself. He asked if the journey this morning was pleasant and if I managed to have some breakfast before I left home. I was so touched, really, how kind is this really?"

This *unrushed manner* of the surgeon is seen as being a direct result of his respect for the individual, their right to represent themselves and to be guided in the consultation. Furthermore this behaviour seemed to nurture a sense of patient *empowerment*.

## **Empowering**

There was a sense that the *engaging persona* of the surgeon was fundamental to the category of *sensing relief* and for the successful outcome of the consultation. It seemed that his *genuineness, approachability, tailored explanation, empathy* and *unrushed manner* were all traits that worked towards *empowering patients*, and bringing about a sense of relief. The surgeon's attempt at encouraging information exchange in the encounter appeared to be key to the process of fostering decision-making competencies, a view consistent with that of Makoul *et al* (1995) who refer to the 'competence gap' as the extent to which physicians can help patients increase appropriate control over their health and hence their decision-making abilities.

The surgeon's creation of the consultation as one of 'mutual participation' seemed to facilitate decision-making allowing time for patients to deliberate over issues raised.

This seems consistent with the Mutual Participation model by Szasz and Hollander (1956) in which a patient assumes a more active role in decision-making, which is facilitated by the provision of relevant information. This view is also consistent with DiMatteo's (1994) assertions that patients must be actively encouraged to participate in issues related to their health and be made to feel that the decisions were made by them following a process of careful deliberation as is shown in the example below:

**FcD:** "And how do you feel now?"

**James:** "Oh, God, great and what is really nice, there is an open door."

**FcD:** "*An open door?*"

**James:** "Yes, I can still come back and decide. I can ask for more details and decide what I want to do, he gave me the clinic number, and I think it is here he wrote it down for me. So I shall make up my mind."

**FcD:** "*So that is what you will do?*"

**James:** "Well, yes, I think I will go with him, I respect his decision. He was very fair and honest with me. When I asked about his expertise in my type of problem he was so honest and humble. He simply said he knew what he had to do but he was human too, I liked that."

Some patients felt that being offered options of dates for surgery accommodated their needs and as such empowered them in some way:

**FcD:** "*So you feel in control now Susan?*"

**Susan:** Yes, in full control. He [the surgeon] said that if I wanted to have the surgery sooner than later I was to go to the second floor and see the secretary before I go home. I was thinking about this option, I need to have a holiday before August but I also need this surgery. The surgeon and I discussed the urgency of the operation and I have some thoughts about it. I have made up my mind, I am willing to go up to the second floor, and I have made the decision to have it."

**FcD:** "*So you feel part of the decision taken?*"

**Susan:** "Yes, very much so, we [the surgeon and patient] discussed the matter and I took the ownership of this decision, it feels great. It kind of gives you the feeling of being in charge you know what I mean? A kind of relief, some peace because I have got what I came here for."

**FcD:** "*You say 'a kind of relief,' I don't understand that Susan.*"

**Susan:** "I came with the fear that all this would be out of my control and that the surgeon would dictate what should happen. Instead I have never experienced such a talk with the 'Gods' of medicine you know what I mean? This surgeon was there for me he allowed me to tell him my part of the story and he listened. You know I even felt that I ran the 'consultation' at times [patient laughs] because he [the surgeon] allowed me

to voice all my concerns and opinions. It's so good to feel part of making decisions even though he [the surgeon] led most of it. I simply felt included and learnt what has been really my problem all along. It is that relief from anxiety from what might happen."

It seems that this notion of sensing relief weaved throughout patients' accounts of being empowered and emerged from both relief from their 'uncertainty' of illness and from their being allowed to regain control. Dave, reflects the views of all patients in the study when he articulates the supportive sentiment below:

**Dave:** "You know I feel so much part of what has gone on here [the consultation]. I felt I was given the chance to express myself, to get information in order to find out all I needed to know about this problem, and to decide what to do, I mean what was best for me. Boy am I relieved, it is such a weight off my mind, you have no idea. I worried all the time before I came here [to the clinic]."

**FcD:** "*That is interesting Dave, would you feel the same if it was less than good news?*"

**Dave:** "Well, yes because when you do not know what is happening down there you worry. Then you have doubts. He [the surgeon] was so kind he just made you feel at ease and you told him everything. You feel so light again a kind of relief, a peace of mind. No more if's and but's, you just face whatever has to happen next. Do you see what I mean? I gather it is a question of relief from my tension at seeing the surgeon too."

The patients' experience of *sensing relief* seems to be the pinnacle of the whole experience of making the decision to see the surgeon, about addressing the uncertainty of their illness and regaining some control over their healthcare issues.

Patients appear to have managed to achieve this *sensing relief* born from the inner conflict of '*emotional crisis*' triggered by their ill health. They appeared to be 'fired-up' by their fear or worry about the unequal 'power' relationship between them and the surgeon and the paternal behaviour of 'doctors.' This anxiety is aggravated by what appears to be the disparity of interests evident in the consultation.

However, it appears that the surgeon's 'engaging persona', his genuineness and approachability had set the scene for this 'encounter' and it seems to have perpetuated a sense of relief amongst patients. They seemed relieved that they were being empowered and that they were regaining control which was made possible through tailored information, the surgeon's empathy and his unrushed manner. However,

deeply seated in this sensing of relief is that resolve, that seeking of peace of mind often articulated by patients in the study.

There is a feeling too however that this sensing of relief alludes to a therapeutic overture of the outcome to the encounter. This is consistent with Charon et al (1994:955) who claim that the therapeutic potential of medicine "requires the ability of the doctor and patient to meet in conversation, both its verbal and non-verbal elements, and to work together in the cognitive and affective realms entered through talk."

There seems to be a balance of power in the surgeon /patient consultation which is achieved through the empowerment process and is nurtured by the surgeon's action of offering *tailored explanation*, his *engaging persona*, *genuineness*, *approachability* and *empathy*. This 'balance' seems to be actualised by both 'experts' (the surgeon and the patient), who seem to be learning about each other, and are making mutual adjustments through an 'open dialogue' facilitated by the surgeon's approachability. In addition, the information 'exchange' within the consultation seems to have achieved a certain harmony, and 'agreement' as to how the 'presenting problems' are to be managed.

Furthermore, the surgeon's *engaging persona*, *genuineness* and *approachability* seem to have encouraged patients to express their feelings and to complete their cycle of experience of being 'ill' thereby seemingly contributing to the fulfilment of their 'expectations' and eventual *peace of mind*. This process seems consistent with Chard's (2006) claim that 'closure' involves putting to rest interpersonal or emotional issues and conflicts and is a primary path toward sensing relief and eventual *peace of mind*.

The findings in this chapter appear to validate the 'know how' of a consultation offering a solution to '*experiencing crisis*' in illness and highlighting the surgeon's role of engaging with his patients and fulfilling expectations by producing the 'feel good' factor thus resulting in patients sensing relief. This is what Buckman and Kason (1994) describe as being 'transference' of the emotional effects of the doctor on the patients.

In summary it seems that patients were *experiencing crisis* because of the 'uncertainty' of their illness and the fear of the paternal disposition of the surgeon in the consultation. They worried about not understanding the medical 'jargon', about not being 'understood' beyond the physical need in the consultation (the illness not the person

being examined) or not having a say in decisions relating to their health. They experienced shame and accepted blame inflicted by the much publicized health promotion edicts. All the emotions experienced and observed by patients in this study seemed to trigger adaptive and or restorative actions inherent in *seeking engagement* with the surgeon and *regaining control* of those issues related to their own healthcare.

Patients' responses to their 'crisis' were facilitated and addressed by the 'partnership' constructed by the rapid engaging of the surgeon, his empowering disposition, and fulfilment of patient expectations. Patients' satisfaction and compliance was noted in their *sensing relief*, that their needs were met by the surgeon's engaging persona, his genuineness, empathy, tailored information, approachability, unrushed manner and empathy, and were traits, which paved the pathway to the essence of the surgeon/patient encounter *seeking peace of mind*.

Rummel (1981) who likens 'peace of mind' to a social contract which is active not passive and is created through negotiation, adjustment, resolution and decision-making is conveyed in this adaptive process by the patients. In addition, he claims that the social contract constructed is comprised of predictions (expectations) about the future and that peace is achieved through co-operation and interaction and depends on congruence with the balance of power. Again, it seems that the patients' capacity to control and to make assertions regarding their health decisions are congruent with Rummel's association of the meaning of peace through a number of social principles.

For example, the 'conflict principle' where Rummel sees conflict as a "balance of powers among interests, capabilities and wills" shows a mutual adjusting of what people want, can get, and are willing to pursue. The outcome of the consultation, which reflected harmony and agreement between the 'two experts', also seems comparable with Rummel's 'cooperation principle' where he argues that 'peace of mind' depends on a harmony of expectations congruent with the balance of powers that are achieved by conflict.

It appears that the patients' *peace of mind* was realised during the surgeon/patient encounter where the surgeon's *engaging persona, approachability, empowering, genuineness* and *empathy* 'defused' the patients emotional 'hang-ups' about consultations at hospitals and their 'inner conflicts.' In a sense it seems to have revealed the '*know how*' of an exchange in a surgeon/patient encounter.

**Figure 8 Overleaf shows the links between *Sensing Relief* and the other parts of the theoretical framework**



## CHAPTER 9

### PLAYING THE RULES OF ENGAGEMENT

#### Introduction

The researcher felt the need to carry out further theoretical sampling in order to test the emerging theory. This chapter therefore seeks to explore further the ethos and origins of the surgeon's consultation with patients who are referred to him at the hospital by the general practitioner (GP). The surgeon seemed to be *playing the rules of engagement* using a template of 'early learning', which appeared to culminate in offering 'patient satisfaction and compliance.'

The decision to interview the surgeon (following the analysis of all three sets of data, pre- and post-consultation interviews with the researcher, and consultant/patient interview) was taken in order to ascertain the source of the 'interactive and perceptive' behaviour, which created an environment which was seen to encourage and promote an enquiring, interactive patient as opposed to one, which disallowed that communication. In addition, this chapter seeks to qualify patients' satisfaction and confidence in the surgeon. The interview was audiotape recorded with the consent of the consultant, who was 'briefed' regarding the context of the interview.

Following approval from the Ethics Committee for a surgeon and researcher interview, the surgeon was approached and a date for the interview was set. The surgeon was given a brief resume of the study to date and the need for further information on issues related to his 'training' was requested. A request was also made for an audio tape recording of the interview, which he kindly agreed to. The interview was carried out in one of the University's 'meeting rooms' where the scene was set for an informal interview and a cup of coffee. This interview was more focused because in essence it followed the theoretical sampling mode of the study and tested the researcher's hunches/ hypotheses about the surgeon's persona and work ethic; that he gained his communication and interpersonal skills on the 'job'; that reflection was an invaluable learning tool; and role models may play a role in sculpturing prospective doctors and healthcare professionals. He seemed to recall many of the issues raised by me.

The questions asked of the surgeon were focused on exploring the ethos of his consultation, the source of his communication skills, his strategy in the delivery of information, his perception of patients' information needs and his views on patients' decision-making skills. This process in essence was a retrospective exploration of patient satisfaction with the surgical consultation and is consistent with the views of Buller & Buller (1987), Roter *et al* (1987) and Stewart (1995) amongst others who all suggest that certain aspects of the doctor-patient communication influence patient behaviour in a positive manner - for example a display of satisfaction with their care and adherence to treatment, plus improved recall and understanding of medical information. The elements identified as the 'building blocks' to *Playing the rules of engagement* were *role models, communication, tailored/individualised information, patient-centred ethos, and surgeon-led input.*

The researcher's initial question - "*What is the ethos of your consultation?*" - prompted a response from the consultant that seemed to dwell largely on reflection and the value that he placed on the 'role models' provided by healthcare professionals whom he had encountered during his 'formative' years as a Junior House Officer. The consultant's own learning from reflection appeared to set the precedence for his 'meeting' with patients as is shown in this excerpt from the interview:

**Surgeon:** "My aim is to establish a good rapport/relationship with my patients, by respecting them as individuals, not just a hernia but a hernia which belongs to a person. I want my patients to be part of the consultation, to understand what is happening to them. That is important to me to give them that sense of peace, ease of anxiety. It is my personal agenda learnt from past agendas."

The surgeon seemed to associate the development of his values, attitudes and behaviour in patient management with the 'role models' he encountered in his early learning as a House Officer or Junior Doctor, and narrates learning through reflection on the action of his consultants.

### **Reflection on Action**

The surgeon claimed that reflection on the action of his 'bosses' (Consultants) as a junior 'house doctor' taught him how to treat or rather how not to treat patients. He

seemed to recall through reflection both the positive and the negative role models encountered.

He observed for example, that many patients were simply treated as 'cases' to be operated on and not as individuals with needs or lay theories to relate to the consulting surgeon. The result of this treatment subsequently led to him having to spend many hours answering patients' questions, talking with them, listening to what they had to say, addressing their anxiety and explaining procedures to them prior to surgery. Here we see him summing-up this concern as follows:

**Surgeon:** "As a junior house doctor I learnt that patients' expectations were quite different from those of some of my 'bosses' [consultants] really, they [the patients] hardly featured in the consultation. They desperately sought some relief from their fear and anxiety. But no, at most times it was all about what procedure they [consultants] saw fit to carry out, would do the job, and they hardly spoke to the patients."

The surgeon also reflected on the positive role models, the attitudes of other consultants who were more patient-focussed and as a result had satisfied, and compliant patients:

**Surgeon:** "You know Mr X was my role model, I learnt so much from him. He is a wonderful man and caring, always prepared to listen to his patients. They [the patients] used to tell him everything and you know he addressed everything as if they were very important even if they were not relevant. He had so much time for his patients, and I tell you the patients loved him, they were so relaxed and reconciled to whatever Mr X told them. Mr X taught me so much about patient care and what patients really wanted from us (doctors) some feeling of relief, some calming of their nerves."

This reflection is comparable with Schon (1983) who defines 'reflection on action' as retrospective thinking, looking back and learning from what did or did not work. Schon also asserts that invaluable insight can be gained through reflecting on dilemmas that are encountered within practise. Within this 'thinking' it seems was the surgeon's 'new' learning from consultants who were his role models.

### **Role Models**

The surgeon appeared to associate his early learning as a house officer with the consultants whose skills and manner he admired and respected and who therein acted as

his role models and trainers in the clinical field. Paice *et al* (2002) support this view and they suggest that the use of 'teaching staff' as role models for professional values, attitudes and behaviours has long been an informal part of medical training and therefore an important part in the making of a good doctor.

In addition, the surgeon's reflection appears to focus on his admiration of the consultants' ability, attitude and quality of care and he was attracted to the values which his consultants imparted to him and which seemed akin to his own. This is consistent with The New Dictionary of Cultural Literacy (2002) which claims that the act of picking a role model consists of first evaluating what are ones own values answering the question "What kind of things are important to me?", and then finding a person that exhibits the majority of those values and then emulating that 'person.'

The surgeon also appears to refer to two aspects of the role model portrayed by his consultants. He considers the performance of the consultants and traits associated with their personality and clinical skills. This is congruent with Paice *et al* (2002) and Elzubeir and Rizk (2001) whose studies revealed that students and residents considered the most important qualities in role models to be those where physicians displayed enthusiasm for their speciality, clinical reasoning skills, doctor-patient relationships and viewing patients as a whole. They also appreciated those physicians who showed compassion and enthusiasm as well as clinical competence.

Reflection also appears to have taught the surgeon that when his consultants negotiated or shared decision making with their patients there was a sense of patient satisfaction, and compliance with treatment, which generally promoted a quicker recovery spell. This outcome, the surgeon argues, was based on good communication skills, and is comparable with Garfield's message which suggests that the 'core conditions, which are crucial to the 'efficacy' of psychotherapy are communication based on respect, empathy, genuineness, and warmth' (Garfield, 1980).

### **Communication**

The surgeon recalls that he was never taught communication skills in medical school and that 'history taking' from patients was the official line of 'communication' with

patients. He admits that much of his communication skills were learnt from observing his colleagues and the nurses who looked after patients on the Oncology wards:

**Surgeon:** "They [doctors and nurses] showed such respect for their patients and worked in partnership. It was good, the feeling of engaging with them [the patients]. Patients taught you so much too, you simply felt committed to easing their minds of the burden of perhaps dying or death so that they had some peace in their lives. They shared their feelings and optimism in illness and in so many ways offered help with the diagnosis and plan of their care."

The consultant offered a negative example of communication, which involved one of his consultants who completed a ward round consisting of twenty-seven surgical patients in ten minutes and then had a half hour coffee break in the ward office.

**Surgeon:** "I learnt a lot from the consultants I worked for. As well as their attitude towards their patients, their communication with patients varied so much. I remember this guy [the surgeon] who would simply stand at the foot of a bed and say to the patient, "OK, we will see you tomorrow in theatres, we will fix it", and walk away. He hardly spoke with the patients, and then I found myself providing the information deficit created by the surgeon and allaying their anxiety, really bringing back some peace to the situation."

He gives a further example of 'poor' communication referring to an incident where the patient was disappointed that the 'hernia' remained un-repaired and that instead he had had a gall bladder removed:

**Surgeon:** "You know this consultant hardly took time to ask the patient what the problem was. One patient came in for a hernia repair, and the consultant asked the 'juniors' to carry out various tests. Then he [the consultant] discovered that the gall bladder looked a little unhealthy and off it came. The patient on discharge sat in his bed claiming that the hernia remained un-repaired. No one had said a word to him."

The surgeon observed that the patient did not appear to feature in the clinical decision-making and information giving seemed to be the privilege of the consultant:

**Surgeon:** "... the surgeon only told the patient what he felt he ought to know. He did not involve him at all. It seemed that it was his [the consultants] right to make decisions for the patient."

## **Tailored/Individualised Information Giving**

The surgeon claimed to have a set criterion for giving information. He offers a systematic progress through the information zone with several stops and starts for reinforcement, and then checks to ensure the patient is on board with the process. At first he gives a layman's interpretation of the 'illness' by using the patients language, then introduces it in the technical language, then he writes down the word/words as a visual aid and then returns to the layman's language of the same.

This behaviour seems consistent with Lauver *et al* (2002) who claim that tailored intervention customises information to the characteristics that the patients express and individualised intervention tends to be highly customised to a particular individual, to his or her specific situation. This underlying ethos seems comparable with Tuckett *et al* (1985) who claim that sharing information with patients in the context of 'mutual exchange' of views is a *sine qua non* if the aim of giving information is to facilitate choice in decision- making.

**Surgeon:** "I tell the patient what is wrong with her/him in a layman's language always using some of their own phrases and then give the theory and technical explanation. I write down the 'medical terminology' and then I return to the layman's language. I ask them if they have any questions. I wait for a while like I have plenty of time for them then I repeat my information several times if I feel that the patient has not taken it all in."

Furthermore, the surgeon's action is consistent with Tuckett *et al* (1985) who suggest that experts must communicate their specialist assessment and advice to patients and translate it in such a way that at least the patient who is not privy to the expert knowledge can comprehend the essence of their ideas correctly, in the context of there being less of a 'power-struggle' between him and his patients.

## **Patient-centred Ethos**

Good communication in medicine seemed to be the exception and not the rule. The surgeon felt that step-by-step history taking from patients contributed to 85% of the diagnosis of patients' problems, yet 'physical examination' is given a higher importance in terms of time allocation during consultation. He learnt that, as a junior doctor, history taking and the act of allowing patients to tell their story, was a valuable tool of

diagnosis and of building a relationship of trust and satisfied patients. A view also consistent with Stiles *et al* (1979), Stewart (1983), and Lee & Garvin (2003) who suggest that allowing patients to tell their story in their own words will prompt more satisfied and trusting patients. Ong *et al* (1995) too felt that patients accepted both diagnosis and treatment far more readily when they left the consultation with a feeling that they had told their story and had been acknowledged.

The surgeon seems to embrace this rule and remains 'patient-centred.' He seems to believe that patients have a story to tell and that it is his job to listen, that it is imperative he listen to their words. He encourages his patients to have some influence on the consultation so that they are able to express all their reasons for coming to see him including symptoms, thoughts, feelings and expectations.

**Surgeon:** "It is very important to let the patients tell their story because very often GP referrals are not accurate. Sometimes the problem was something completely different, they [the patients] sometimes disclosed so much behind the human screens if only you listen."

The Surgeon supports this view by referring to the Researcher's question as to how he filters all of the information disclosed by his patients:

**Surgeon:** "You [the researcher] ask me how I filter all the information patients give and the questions they ask. I aim to answer the questions no matter how trivial they may appear, you know because it means a lot to them. They raise all sorts of issues, remember you [the researcher] were saying about the patient with a knee problem, then her weight then all sorts of things, far removed from her initial problem of flatulence? It does matter to me because it matters so much to her."

### **Surgeon-led Input**

The surgeon does not claim to be a neutral player in the consultation and acknowledges that his role is to provide his 'medical' knowledge and expertise which favours the pre-determined best interest of the patients and that he will remain honest with his responses as shown below:

**Surgeon:** "Patients ask me quite frankly how good I am at my job. They ask me how many

cases I have done of the recommended procedure. I answer quite honestly that I have done many and could do so with my eyes shut, but I also tell them that I am human and could make mistakes. I do not mind telling them this, I prefer being honest that is the way I operate. Believe me not a single patient has turned me down, 'touch wood'. [the surgeon laughs jokingly]. This is the assurance they seek in order to have some control over their lives, peace of mind in the end"

Despite this or as a result of this the surgeon also appears to want to ensure that any decisions needing to be made are patient-led ones resulting from there having been an exchange of information from patient to doctor and vice versa -an open and honest dialogue:

**Surgeon:** "I offer my expertise and match it with the patients' agenda and expertise. It is really a two-way process, I just set out to meet their needs and they cooperate by sharing their history of illness: the symptoms, concerns and what they would really prefer and such with me. I really give details of my diagnosis and make several suggestions as to the treatment, respecting their right to question me or to make their own decision."

This behaviour seems comparable with what Levenstein *et al* (1989) call 'reconciling the two agendas' or Roter and Hall (1992) call 'mutuality.' A 'mutuality', which the surgeon appears to base on respect for his patients.

This interview appears to have offered the foundation to the outcome of the surgeon/patient consultation, which revealed 'sensing relief' among patients and respect for the caring surgeon's persona.

It also highlighted the significance of 'role models' as a learning tool for clinical staff. Patients' sense of relief appears to stem from a two-way communication where the patient is allowed to lead the way and the surgeon picks up the cues from the patients as a means of addressing their 'uncertainty.' There is a sense of 'mutuality' in the consultation, which seeks to offer patients *peace of mind*.

**Figure 9 overleaf shows the linkages between *Playing the rules of engagement* to the other parts of the theoretical framework**



# CHAPTER 10

## SEEKING PEACE OF MIND

### Introduction

*Seeking peace of mind* emerged as the core category of this study, which set out to elicit patients' experiences during a first referral consultation with a surgeon in a hospital outpatient's clinic. There was a sense that patients were seeking some reassurance, some relief from their personal 'turmoil,' some peace of mind, and (an *in vivo* code). Patients expressed sentiments, which resonated the feeling that seeking expertise was a means of acquiring that 'peace,' as noted below:

"All I want is some relief, peace of mind you know" or "I feel so much better in my mind, some peace in me at last, he (the surgeon) was so good, he put me at ease"

There was a presence of this 'resolution' in the categories *experiencing crisis, regaining control, seeking engagement, constructing a partnership, sensing relief and playing the rule of engagement*, which emerged from the data.

*Seeking for peace of mind* seemed to be patients' reaction to the experience of crisis, which they hoped would be achieved by being relieved from the burden of uncertainty and insecurity, which was created by it in the first place.

The search for peace of mind was also inherent in patients' adaptive processes of *seeking engagement* and *regaining control* of issues related to their health, because they wished to return to their 'normal' life, (that is to each individual's status quo), which was sustained until illness disrupted it.

This search for peace of mind however, seems to be actualised in the categories of *constructing a partnership, sensing relief and playing the rules of engagement* which made this 'search' a reality for the patients who are being offered peace of mind or were experiencing it following their consultation. Peace therefore appears to be a dynamic process, a continuum between psychological rest and unrest.

The patients' search for peace of mind seems to stem fundamentally from the *uncertainty* of their illness and from *fearing* that the surgeon may make them victims of technology or objectify them at the consultation.

There were many features of illness that patients were uncertain about and feared, (particularly the paternalistic overtures of consultations with doctors and other healthcare professionals), and each patient seemed to have a unique and individual combination of fearing and concerns but what underpinned this behaviour seems to be their search *for peace of mind* and this too was unique to an individual. Examples, of the notion of *seeking peace of mind* in the categories will be identified to support this emerging theory or core category.

When patients presented with problems even when they had the potential of being 'sinister', *seeking peace of mind* was the focus of their intent. They seemed to want to hear the truth in order to secure that goal. For example Christopher in the excerpt below, made it quite clear to the surgeon that hearing the truth mattered to him, because he was *seeking peace of mind*:

**Christopher:** "I don't mind you see, I like to be told the truth about my condition. That way I know what is wrong, my head feels better than worrying all the time. It is hard I know but the truth is good you think not? Because it is about my peace of mind, this feeling of openness that I want anyway. I need to know, if it is not right down below".(rectal lesion)

Germaine expressed a similar sentiment and also highlighted the value of peace of mind as a psychological and physical preparation in the following excerpt:

"It is the peace in one's mind that is important, it heals most things. I could prepare myself for what is to come, and of course, I am afraid but at least I know, I am certain about something at least; sort of control of my destiny, you understand what I am about here don't you?" (Germaine addressing the researcher)

This process of *seeking peace of mind* seems to have evolved from the emotions, which triggered patients' *experiencing crisis*.

## Experiencing crisis

In the initial researcher/patient interview, the category of *experiencing crisis* seemed to be the trigger, which made patients seek an alternative to the mental unrest. It seemed like patients were deeply engrossed in the uncertainty of their illness and were trying to cope with the emotions, which emerged. There was a general sense that they were seeking a 'way out', a calm from the upheaval of being 'ill' and the emotions of *uncertainty, fearing, worrying, feeling shame and accepting blame*. Patients appeared to be seeking that 'equilibrium' the normality, which nurtures peace of mind. Their crisis seemed to stem from the loss of control over their body, and as such they were *hoping for answers* in the consultation with the 'expert' in a bid to secure their search for peace of mind as is illustrated in the following excerpt:

**Sam:** "Oh, I do worry about not knowing, I feel I am losing control over my life just now. I simply want to know from the expert [the surgeon], whatever it is, what is going on for my peace of mind."

Similarly, this search for peace of mind underpinned Jean's worrying that her 'goals' to return to 'normal' were unmet, and she therefore was *seeking expertise* and *hoping for answers* (elements of *seeking engagement*):

**Jean:** "I am so worried because it has gone on for so long...I need to see the expert [the surgeon] and get some answers, I need some relief from this worry, it is the peace you know, that relief from all this not knowing, that is why I am here."

But then it seems that in the dilemma of wanting to hear the results of diagnostic procedures and the fear of what they might reveal, patients opt for the former in order to secure their peace of mind, and as a means of addressing their challenged state of psychological unrest. Sarah illustrates this below:

**Sarah:** "You want to hear the results but then you worry about what they might be. Good or bad and in the end you know you simply want them whatever, for just some peace up there [patient rests her right hand on her head] in your head; push away that negative thing that keeps nagging you all the time and brings on more worry, you feel so unsettled, you want some peace of mind."

This behaviour seems comparable with Sorabji's (2000) summation of the views of ancient philosophers that emotions were seen to involve a lack of control, in the sense

of conflict with one's better judgement. However, he also claimed that Plato had argued that such a conflict shows the 'self' to be divided into different kinds or parts of the soul, mind and body

It seems that when the question of receiving bad news, (which is stereotypically associated with a terminal diagnosis), is also present in illnesses that are more commonplace in the medical field, there is a resonance of a search for peace of mind. The fact of the 'illness' presenting at an inopportune time and the worry associated with the potential effect of that for example, has shown patients' desire for peace of mind as a solution to patients' hyped emotional state as illustrated in the reactions from two patients below:

**Tim:** "Oh, I am so relieved, I am getting married to this beautiful person and I just did not want to hear anything that would spoil it for me, it is such a relief, such a peace of mind for me. I could have hugged him (the surgeon) and now you, (the researcher), It has lifted so much off my shoulders, I feel at peace now."

**Jane:** "I feel so good, because I was afraid and unsettled about what he might find, cancer and such. I cannot afford to go off sick; we are so busy at work. Also my children will be on holidays soon, this is definitely a huge relief, peace that's what I wanted, what I had hoped for."

This reaction is consistent with Buckman's (1984:1597) definition of bad news as "any news that drastically and negatively alters the patient's view of her or his future" and Knutson and Post (2006) and Vandekieft (2001) who suggest that a patient's reaction to bad news is often influenced by his/her psychosocial context causing psychological unrest and their search for peace of mind. For example diagnosis of diabetes which is generally regarded as a common condition in today's health arena, may be devastating to a patient who associates it with a relative with amputations.

Peace seems to be sought as an antidote to the emotions of *guilt* and *accepting blame*, which are triggered by patients' violations of the axioms of health promotion messages. This is noted in the example below:

**Jane:** ".... it is my fault and now I fear the worst about this mole. I just want it taken off to ease my mind, my guilt to give me some peace of mind, malignant or not, so that I can get back to normal. This guilt is an awful feeling and unsettling."

This behaviour reflects observations made by Lewis (2000) and Pask (1994) who claim that functional guilt tends to promote a corrective action, an adaptive process to remain in control of one's life and focuses the patients' efforts to regain that peace of mind. This behaviour is also congruent with that observed by Sorabji (2000) who believes that the concept of 'will' has a role to play in the search for peace of mind. He argues that the will to take action has two important clusters, freedom and responsibility on the one hand and willpower on the other. The latter it appears is governed by one's locus of control.

### **Regaining control**

Patients' desire for *seeking peace of mind* seems to be deliberated in *regaining control* and appears to be manifested in their *seeking involvement*, and *wanting to be heard* in the 'consultation' (both elements of the category *regaining control*, and an adaptive process of *experiencing crisis*). The process of *seeking peace of mind* therefore seems to present itself in patients' action of seeking a 'presence' in the 'consultation' with the surgeon (which is evident in the majority of the patient accounts) and which is clearly illustrated in the following excerpt:

**Tim:** "What I am really saying is that I do want to be involved with any decisions about my health. I need to seek some relief, ease my mind from this worrying I am experiencing. .... I can then control some part at least of what is happening, the situation. Do you know what I am saying? I need to give my views and he [the surgeon] must listen and then at least I feel that I had some say in my health. I can get some good feeling, some peace you know; otherwise it hangs over you all the time when you are sick that you are not being listened to, you are just sitting there and they take over your life, you are an object to them [the doctors]."

This search for some peace of mind appears to be present in John's sentiment too. His search for peace of mind is helped by *asserting one's terms*, that will allow 'flexibility,' and by *weighing-up options* which will dictate his depth of involvement as a means of *regaining control* in health issues and achieving a peaceful outcome.

**John:** "I want an open discussion which will allow me to get involved as much as I want. You know I want to have a say in my health, ..... You know I have been thinking about this before I came here [the hospital]. I want to be cured, feel somehow in control of my life. Breathe again."

**FcD:** "*Breathe again, how interesting, tell me what you are thinking John, because I think I heard a similar comment made by another patient.*"

**John:** "Yes, I want peace again, my normality, live again and also not have to worry if I will be listened to by these doctors or not because I want to make my claim in the consultation. It is important to me, listen I need the answers a mental cure, this peace "

However other patients in the study appear to seek peace of mind by simply engaging with the surgeon with whom, they are expecting an exchange as a means of easing their 'internal unrest.'

### Seeking engagement

*Seeking engagement* (also an adaptive process of *experiencing crisis*) appears to signal patients' desire for respite from the 'uncertainty', which seems to have disrupted their peace of mind.

Many in this study (like Joseph and Gary below), seem to use 'searching' and 'trusting' the surgeon's expertise, as a guarantee for 'cure' and a vehicle for *seeking peace of mind*.

**Joseph:** "I know he [the surgeon] is the expert with my kind of problem. My GP told me about him. He knows and I am sure he will put my problem right. .... My worry is whatever next? But here I am I know his [the surgeon's] expertise will solve my tension give me back some peace in my life, I need it."

**Gary:** "Well I know he [the surgeon] has the answers, he is the expert ..... I guess he knows best. I know he has experience with my type of problem, honestly, I feel he will ease my frustration because I have gone through so much. Give me that break, that feeling that things will be back to normal, will ease my mind, which is all over right

now. Oh! you have no idea, it is that relief, that peace of mind, that I have come here (the hospital) for.”

*Seeking truth* seems to be a vital ingredient in *seeking peace of mind*. Debbie like many in this study seems to have no doubt that that her search for peace of mind will be conditional on being told the truth by the surgeon, and illustrates this in no uncertain terms in the following excerpt:

**FcD:** *"So what exactly are you seeking when you say you want to hear everything?"*

**Debbie:** *"Yes, everything, one way or another, exactly what is happening to me. It may come as a shock because things could go either way, but I want the truth."*

**FcD:** *"Truth?"*

**Debbie:** *"Yes no fudging, just tell me everything as it is. Then at least I know how to deal with the consequences, some honesty, will mean some peace for me regardless if the news is good or bad, I just want to put my mind at rest today."*

**FcD:** *"But Debbie would you feel the same if it was not such good news? I mean would you still want to know?"*

**Debbie:** *"I certainly would, as I am sure a lot of people do too, because it is a question of getting control of what is going to happen next to you, do you understand what I am saying. Of course I fear bad news and right now I am so nervous I am almost wetting myself, it is a growth on my back, but in the end I need to hear the truth for my own peace of mind."*

The patients' desire to hear the truth appears to hold firm despite any initial shock that they might feel on having their suspicions confirmed just to secure some peace of mind. A view consistent with Jones (1981) and Cassileth et al, (1980); but seems to undermine that of Hinton (1980) who suggests that truth is withheld from patients because it is thought that truth may be damaging, and that disclosure of true medical facts may destroy patients' hope or motivation or even their sustained peace of mind. Buckman and Kason (1992) however, support Jones and Cassileth et al by claiming that patients are overwhelmingly and consistently in favour of hearing the truth regardless of its contents good or bad as a means of achieving some respite, some peace.

Tuckett (2004) refers to the 'uncertainty' principle to argue for not revealing the truth suggesting that there is no certainty in healthcare therefore no 'absolute truth' to reveal. Drickamer and Lachs (1992: 948) too had conceded earlier that the absolute truth is "rarely achieved in medicine" and suggest that an open, honest presentation of

information as it is, “actually understood and known should be given to patients,” respecting therein their desire for control and peace of mind.

Interestingly however, it seems that a patient’s search for peace of mind is associated with ‘cure’ which is inherently linked to advances made in medical technology available in hospitals, and is influenced by media hype - a ‘pill for every ill.’ For many like Dave below for example, a ‘resolve’ is associated with confidence in ‘technology’, which seems to offer an assurance of ‘peace of mind’:

**Dave:** "Of-course, he [the surgeon] as an expert in my type of problem has to carry out various tests, x-rays and such things before he comes to a conclusion, I hope. You can't expect answers straight off. These things sort out our problems and at least then we can be assured of some calm, a peaceful psychological settlement in our lives that has been knocked out by this illness."

This behaviour is reflected in McWhite’s (2004: 2) narrative, which highlights an individual’s coping mechanism where she is seen to resort to ‘technology’ regardless of its cost, in order to restore a sense of well-being. “My peace of mind cost my insurers \$2,700, was it worth it? You bet it was...it gave me a priceless sense of comfort.”

### **Constructing a partnership**

This category *constructing a partnership* (the surgeon/patient consultation) offers an unprompted response to patients’ search for peace of mind. *Empowering*, (the key element of this category), is about the ‘construction’ of a partnership by engaging with patients, and giving them control of their lives to ‘seek’ and to be ‘seen’ in the consultation. In essence the surgeon appears to address the psychological factors at work in a consultation. This view is comparable with Balint (1957) who points out cognitive factors such as a patients’ ideas and beliefs, emotional factors such as feelings and concerns, and behavioural factors such as coping mechanisms, which he maintains are at work in all experiences of illness and in all consultations.

The surgeon’s *rapid engaging*, seems to have set the tone for an informal consultation, which encouraged patients to seek engagement as a means of securing their search for peace of mind.

In addition, patients' search for peace of mind seems to come to some fruition as a result of the surgeon's method of *transcending formality*, creating a relaxed environment, which nurtures *sharing information*, and the sense of *fulfilling expectations*.

Like many in this study Thomas' drive for peace of mind is sustained by the value he has placed on a relaxed environment for the consultation (created here by the surgeon *transcending formality*) as is shown in the excerpt below: (note the relaxed interaction between the 'two'):

- Thomas:** "Well, what is your verdict then Mr.[the surgeon]? What is happening down below?"
- Surgeon:** "*There are two ...*(The surgeon reciprocates by offering information and reassurance....) *can you [the patient] see what I have drawn here? .....*(surgeon continues to explain the diagnosis to the patient and says...) *...don't worry we will sort it out.*"
- Thomas:** "Right, I see now, so what do we do about it? How can I stop it from getting worse?"
- Surgeon:** "*Ok, let's try this. ....*"(The surgeon proceeds to teach Thomas how to deal with his constipation and bleeding piles and educating him to eat healthy.)
- Thomas:** "...All right, let's have a go, you are the expert after all and I want some relief from all this disruption, want it all gone no more problems, some peace you know."

Although it seems that the surgeon did a lot of talking in this interview, there was a 'notional' balance in the interaction between him and the patient which seemed to convey a sense of sharing, a peaceful disposition. This espoused a sense of *fulfilling expectations* of patients and their search for peace of mind because they had a 'presence' in the decision-making process. This observation is echoed by Roter *et al* (1987), who claimed that in a successful consultation, physicians contributed to 60% of the communication and patients to 40% of the communication.

The excerpt below epitomises this 'connection':

- Surgeon:** "OK, all this I know means a lot to you, you have shared your concerns, I see that it affects your life, you want to get on with your daily things. Let's do all the tests that we need to address this problem, do a full MOT more or less and then go from there. Is that OK? Is there anything else you wish to discuss?"
- Sarah:** "No that is fine."
- Surgeon:** "Any questions?"
- Sarah:** "No, that is great, this is the best consultation I have had for a long time. I feel so

much better now, so relieved, I have peace of mind, now that you have gone over everything with me. It is clearer now and I feel more happy now more rested in my mind."

**Sarah:** "I trust your judgement Mr [the surgeon] you have been very kind and honest with me, thank you so much for this reassurance, this peace of mind, this is my best consultation."

There was a sense that patients' 'peace of mind' was analogous with patient fulfilment with the consultation and this was a significant milestone in the surgeon's intent of *empowering* his patients as is noted below:

**Surgeon:** "Yes, of-course let us work on this together..... You see I can give you my expert opinion but you too can get involved and decide what suits you best I suppose. The main thing is that you understand the problem you have..... Make another appointment don't worry. It is your right you know To be satisfied with all you set out to get from this chat of ours, put your mind at rest." (both laugh)

**Peter:** "Yes, I know what you are saying doctor. I also have a chance to decide, I like that because I know nothing about my problem but you can do something. Yes, I will say 'yes' or 'no.' I like your idea better so I make up my mind. It is my decision to say 'yes' to you doctor because I feel good, happy. I know you have listened to my side, so I have peace and satisfaction in this way."

### **Sensing relief**

There was a sense of achievement and relief in the post-consultation category of *sensing relief* where patients verbalised their gain of peace of mind. Sentiments such as "Oh, such a relief, I feel at peace now" or "Thank God, now my mind is at rest" conveyed the message of fulfilment in their search for peace of mind.

There was a sense that when patients were experiencing the 'feel good' factor they had in essence gained some peace of mind because the surgeon had met/fulfilled their expectations and in a way also accommodated their search for peace of mind. They seemed satisfied with the information and advice given, which enabled them to make sense of their symptoms and achieve a sense of control over their illness. Tim embodies this 'feel good' factor or feeling in the following excerpt:

**Tim:** I feel good about myself, that I actually made the decision to see this guy (the surgeon).....I am so relieved, such a weight off my mind, such a peace of mind for

me, it is something great you know. And you know I haven't felt like this for a while since I was ill. "

Carol on the other hand seems to find that peace of mind in the surgeon's '*unrushed manner*' which seems to give her a feeling of her own importance in the consultation as shown below:

**Carol:** "He seemed to have all the time to listen to my problems, so unrushed, answered all my questions...you have no idea how good that feels. It put my mind at ease, it felt so calm and easy amid all my anxiety of coming here (the hospital) today; it is a wonderful feeling and he [the surgeon] made me feel important, not a case to be seen and treated at the hospital."

The surgeon's ethos of *empowering* patients seemed to be most important contributor to patients' peace of mind, which complimented *regaining control* over issues relating to their healthcare. There was a sense that patients were leading the dialogue in the consultation and as such appreciated the 'ownership' in decision making and promoting their peace of mind. Dave appears to reflect the views of all the patients in this study when he articulates the supportive sentiment below:

**Dave:** "You know I feel so much part of what has gone on here [the consultation]. I felt I was given the chance to express myself, to get information in order to find out all I need to know about this problem of mine, and to decide what to do. Mind you, if I didn't want to know, that seemed fine too by the surgeon. I liked that. It is such a weight off my mind. No more 'ifs and buts', you just face whatever has to happen, good or bad news. I gather it is a question of getting honest answers, enlightenment for want of a better word I suppose, that's peace of mind for me."

The patients' experience of *seeking peace of mind* seems to be the ultimate goal of the whole experience of taking the decision to see the surgeon, about redressing the uncertainty of their illness and the attempt to regain control over their healthcare issues; care that is patient-centred and tailored to their needs.

### **Playing the rules of engagement**

In this category, *playing the rules of engagement*, which was in essence a theoretical sampling to test the emerging theory from the data, the surgeon's mind-set appears to facilitate a patients' search for peace. This was developed in his 'formative' years as a house officer and informed by concepts of *role models, communication, information giving, patient-centred ethos* and *surgeon-led input*.

### **Role models**

The surgeon's early learning appeared to be associated with his recognition of the effective role models from those less effective in producing 'patient satisfaction' and the ultimate patient's peace of mind.

The surgeon's admiration of qualities in his consultants such as their ability, attitude and quality of care were also akin to his own values, which addressed the needs of his patients, which were embodied in *seeking peace of mind*. This is supported in the excerpt below:

**Surgeon:** "I have learnt so much from Mr [the surgeon] who had a wonderful bedside manner and he was so patient-centred..... and made them feel important. .... I really enjoyed working for him, I learnt how he cared and respected his patients. You know what? As a junior doctor I was hardly ever called to the wards to explain what the 'Boss' [his consultant] had discussed with them. Never. They had that satisfaction, reassurance, that peace of mind that the 'Boss' had answered all their queries truthfully. There were a few good consultants like him thank God [he laughs] each had something positive to offer, that is satisfaction and peace of mind for their patients"

This excerpt provides an excellent example of the effect of having a 'good' role model. It has inspired him by example and has stimulated admiration and emulation (Wright and Carrese, 2002), as is evident in his behaviour in the category *constructing partnership* and the patients' feedback in the category *sensing relief*.

## Communication

The sensitivity with which the surgeon communicated and the manner of information giving to his patients, was as a direct result of his having learnt from the behaviour exhibited by his role models during his placement in the 'sensitive' environment of the oncology wards. He learnt about the 'rules of engagement', which were enhanced and supported by good communication skills and which fostered patients' search for peace of mind, an example of which can be seen below:

**Surgeon:** "They [doctors and nurses] showed so much respect for their patients and worked in partnership. It created a peaceful environment for the patients and the staff. It was a good feeling of engaging with patients, they taught you so much, so much to learn from them..... they appeared relaxed, as if at peace with the decisions made with their involvement. You know I too experienced that 'satisfaction and fulfilment at the end of the day when patients looked fulfilled"

## Patient-centred ethos

The surgeon's own learning from reflection of putting patients mind at rest appeared to have set the precedence for his meeting with patients and has played a major role in his ethos of the care provided, as can be seen in the following excerpt:

**Surgeon:** "My aim is to establish a good rapport/relationship with my patients, by respecting them as individuals,..... I want my patients to be very much the part of the consultation, to understand what is happening to them. If one takes this stance, there is patient satisfaction,..... It is about giving them control and satisfaction. Anyway it puts their mind at rest, gives them peace of mind, I have learnt. It is my personal agenda learnt from past agendas [referring to the consultants he had worked for]."

Patient satisfaction seems to be equated with achieving peace of mind and is consistent with Buller and Buller (1987), Roter *et al* (1987) and Stewart (1983) who suggest that certain aspects of the doctor-patient communication can influence patient behaviour in a positive manner, for example helping patients meet their goal in *seeking peace of mind*.

Patients in this study appear to be *seeking peace of mind* as a solution to their experience of 'crisis' due to illness. This is 'fired-up' by their fear or worry about the

unequal 'power' relationship between them and the surgeon, and further compounded by what appears to be the disparity of interests evident in consultations.

There seems to be a balance of power in the surgeon/patient consultation in this study, which is achieved through the empowerment process and is nurtured by the surgeon's action of offering *tailored explanation*, his *engaging persona*, *genuineness*, *approachability* and *empathy*. This 'balance' seems to be actualised by both 'experts' (the surgeon and the patient), who seem to be learning about each other, and making mutual adjustments through an 'open dialogue.' In addition, the information 'exchange' within the consultation seems to have achieved a certain harmony, and 'agreement' as to how the 'presenting problems' are to be managed.

This process is consistent with Rummel (1981) who likens 'peace of mind' to a social contract, which is active not passive and is created through negotiation, adjustment, resolution and decision-making. In addition, he claims that the social contract comprises of predictions (expectations) about the future and that peace is achieved through co-operation and interaction and depends on congruence with the balance of power. Again, it seems that the patients' capacity to control and to make assertions regarding their health decisions are akin with Rummel's association of the meaning of peace through a number of social principles. For example, the 'conflict principle' where Rummel sees conflict as a "balance of powers among interests, capabilities and wills." It also shows a mutual adjusting of what people want, can get, and are willing to pursue.

The outcome of the consultation, which reflected harmony and agreement between the two 'experts', seems also to be comparable with Rummel's 'cooperation principle' where he argues that 'peace of mind' depends on harmony of expectations being congruent with the balance of powers that are achieved by conflict.

It appears that a patients' search for peace of mind was realised during the surgeon/patient encounter where the surgeon's *engaging persona*, *approachability*, *empowering ethos*, *genuineness* and *empathy* 'defused' the patients' emotional 'hang-ups' about consultations at hospitals and their 'inner conflicts.' In a sense it seems to have revealed the '*know how*' of an exchange in a surgeon/patient encounter that supports a patients' efforts for *seeking peace of mind* when *experiencing crisis*.

From a practical perspective it appears that the initial patient/researcher interview acted as an exercise of 'reflection in action' for the patients. It seemed that patients, in relating their expectations of the surgeon to the researcher, were also reflecting on their story of their 'illness' and on what brought them to a consultation with an 'expert' at the hospital as is shown in the dialogue below:

**Helen:** "I am so glad I had the chat with you before I went in to see the surgeon. It really helped me to have control over what I wanted to tell him [the surgeon]. You were great to listen to me, you put me at ease."

**FcD:** "At ease?"

**Helen:** "I felt that it was a rehearsal for me so that I would not forget to tell him [the surgeon] everything, and most importantly, when it happened and how, you know my bleeding and all that. I would feel more worried if I forgot some things."

James below reflects a similar sentiment:

**James:** "It was very useful our chat before going in to see the surgeon. It made me think straight and have a plan in my mind. It made me think about how it all happened and what to ask him so that I don't come away thinking that I have forgotten something.... May be important? You understand what I am saying don't you?"

Patients appeared to use a reflective cycle similar to that described by Atkins and Murphy (1985) for a systematic 'recall' of events, for expressions of emotions and as attempts at seeking a rationale for their symptoms and future action. They appeared to recall the process of the illness by describing its symptoms, and attempting to analyse them but then seemed to fall short of any synthesis in most cases, as they could not make sense of them or the illness.

It is the completion of this cycle, that patients seemed to be seeking from the 'expert', and which appears comparable with what Chard (2006) refers to as the 'closure', the putting to rest of emotions and conflicts in order to move towards the pathway of peace of mind. For some patients this closure seemed to come at the end of the consultation, with the advice and reassurance given by the surgeon and the transfer of further care to their GP. For others, it was a closure of one loop which appeared to embrace the loop of the next stage of care and needs, putting the process of cure and care on an even keel in the established 'partnership.'

In summary it seems that patients' search for peace of mind focused on tailored information, being treated as individuals with individual needs, patient-centred interventions and being allowed the autonomy in decision-making on issues related to their healthcare management. The 'individuality' seeks an understanding of patients as individuals with individual needs. This then constitutes the recipe for their search for peace of mind.

**Figure 10 overleaf shows the linkages between *Seeking Peace of Mind* and the other parts of the total theoretical framework**

Figure 10 - Diagram of conceptual links between *Seeking Peace of Mind* and other categories

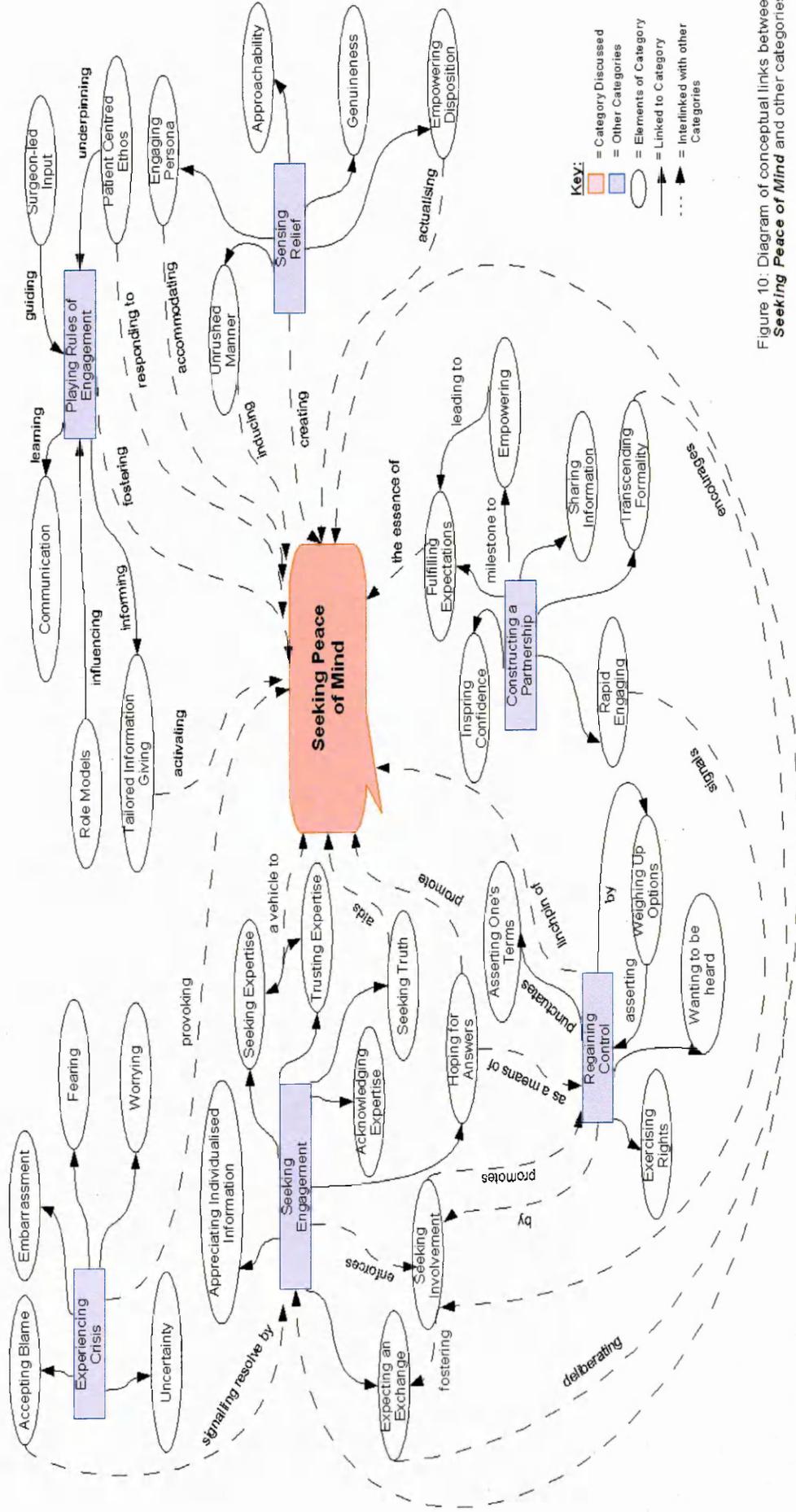


Figure 10: Diagram of conceptual links between *Seeking Peace of Mind* and other categories.

# CHAPTER 11

## ENABLING PEACE OF MIND: THE ESSENCE OF HEALTHCARE PROFESSIONALS' INTERVENTIONS

### A DISCUSSION

#### Introduction

The discussion chapter, the penultimate stage of this study focuses on the core category *Seeking peace of mind*, which manifested when patients experiencing crisis in 'illness', were seeking help in a first consultation with a surgeon in a hospital's outpatient clinic.

The chapter begins by offering the reader a context to the rationale and origins of this study highlighting the bi-partite responsibility of both the patient and the surgeon within the Government's initiatives in healthcare and then proceeds to make known how the core category *seeking peace of mind* evolved from the three sets of data collected in the study.

A strategy called by the researcher the 'assessment triad' is presented as the 'actuator' of patients' search for peace of mind. The bio-psychosocial ethos of the assessment triad is offered as a guideline for present and future professional development, keeping as its focus patient-centeredness and patients' search for peace of mind in illness.

#### Context

The backdrop to this chapter is the 'metamorphosis' of the patient's traditional role from passive to active, the increasing expectation that patients engage with and take the 'driving seat' in Government initiatives and the sparse exploration of the patients' perspective in the substantive area of patient and surgeon consultation. The latter was the main concern and rationale for suggested use of the assessment triad in this study.

The Government initiatives imply that healthcare professionals move beyond their usual 'chores' of diagnosis and prescription and shoulder some of the responsibility for educating their patients whilst enabling and respecting their right to make their own informed healthcare decisions. In addition, consumers of the health service are not only being given greater control but also greater responsibility for their own health. (DoH

2001) This ‘responsibility’ is in essence bipartite – involving both the patient and the healthcare professional, and has embedded within it patient empowerment and an understanding of what it takes to generate patient co-operation/partnership promoting healthcare and patient-centeredness.

### **Responsibility**

Brown (1993:2566/7) defines ‘responsibility’ as a “charge, trust or duty”; and being ‘responsible’ as being “answerable or having authority or control; being accountable for one’s action; something you must do because it is morally or socially right.” Reflecting on these assertions it could be argued that healthcare professionals are ‘charged’ with ensuring that patients are helped to be responsible for maintaining good health, mastering authority and control over it, (health promotion) and through mutual trust, transform their vulnerability into strength.

In seeking expertise for example, patients take their first step in exercising some responsibility for their own care, but in seeking involvement, (as in the case of the patient/surgeon consultation), they also ask for help with appreciating the measure of responsibility involved in healthcare maintenance.

The ‘bipartite’ responsibility therefore begins with the healthcare professional who must seek ways of accommodating patients’ levels of desire for taking responsibility for decision-making and self-care and assist them in their search for peace of mind, (a process identified as the core category or overarching theory in this study), by ensuring that patients’ views are listened to and acted upon, thereby giving voice at every level of the NHS. (DoH, 2004; 2001; 2000) This ‘voice’ is echoed in this study’s data, “a generated abstraction from their doings and their meanings” (Glaser, 2002) and from which emerged the substantive theory offered, which incorporates patients ‘*seeking peace of mind*’ in a health ‘crisis’ and accommodated in the utility of an assessment triad, which could assist in ensuring the meeting of patient-centred needs.

### **The theoretical emergence of the core category *Seeking peace of mind***

A brief resume of the findings, from the three sets of data; the patient/researcher pre-consultation interviews, the patient/surgeon ‘encounter’ and the ‘recall of the patient/surgeon ‘encounter’ with the researcher that follows, is used to show how the

substantive theory described in this work emerged as patients' reaction to their experience of 'crisis' in illness and their adaptive responses to it, when seeking help in a consultation with a surgeon.

### **The patient/researcher pre-consultation interview**

The pre-consultation patient/researcher interviews revealed a diversity of human needs and make-up. Patients were experiencing 'uncertainty' of the 'illness' and of their role in decision-making within the 'consultation' environment. They sought involvement in the consultation as a means of *seeking engagement* with the surgeon *and/or regaining control* over their healthcare and the presenting 'illness.'

Patients worried about their inability to establish a 'cognitive schema' of the illness, suggestive of Mishel (1998) defining of patients' subjective interpretation of illness events and their treatment. The presence of an 'event incongruence', which is the inconsistency between the expected and the experienced in illness-related events (Mishel, 1998) also aggravated patients' feelings of *uncertainty* and triggered emotions of *worrying* and *fearing*. It seemed that the 'uncertainty' had upset their equilibrium and patients were therefore seeking that 'balance'; that peace of mind.

There was however a variance in the way that the patients reacted to the *uncertainty* of their 'illness.' Some were *worrying* because they were not 'cured' by their General Practitioner (GP) in spite of their co-operation with the treatment regimen prescribed by the GP. Others feared the consequence of the presenting symptoms, specifically of being diagnosed with 'cancer' or contracting the much-publicised hospital acquired infections should they require any surgical intervention.

The most striking cause of 'fear' however was that of the 'paternalistic' nature of a 'medical' consultation. They feared that the surgeon would not listen to them, that he would have his own agenda in the consultation and that they would be passive participants in their health management decisions. Some of the patients that were observed were seen to be affected by the 'health dictums' of the Government in that they accepted the blame (and experienced the shame) (Lewis 2000) for not keeping themselves healthy.

Patients were therefore seen to be employing adaptive and restorative processes such as *seeking engagement* with the surgeon and/or *regaining control* of issues relating to their health in order to gain some peace of mind. The data revealed that a patient's search for 'engagement' was built on a psychological search for assurance behaviour such as *acknowledging, trusting* and *seeking expertise* from the surgeon, and expectations of behavioural stances which offered '*individualised*' information, and answers to their problems based on *truthfulness*.

More assertive behaviour was noted in patients' attempts at *regaining control* of health issues. Patients were seen to assert their terms of involvement, by *weighing-up options* offered by the surgeon, by *exercising their rights*, by '*wanting to be heard*' and by *expecting an 'exchange'* in the consultation.

The patients' journey to *seeking peace of mind* however, also consisted of several stops at the 'lay structure' of family and friends, with emotions hyped to a varying degree by the media and the Internet, which were seen to be an increasingly prominent aspect of the patients' 'lay structure.'

In summary, the patients' reaction to their 'illness' was manifested in an 'experience of crisis' and emotions, which energized, directed and sustained a coping/adaptation or 'restorative behaviour' of *seeking engagement* with the surgeon and/or *regaining control* over their health-related issues as a means of *seeking peace of mind*. In other words, there was a sense of prevailing responsibility in patients' seeking peace of mind in a consultation with the surgeon in a hospital's outpatient clinic. (*see Chapter 9*) and a reciprocal responsibility of the surgeon to offer a patient-centred response.

### **The patient/surgeon 'encounter'**

Analysis of the surgeon/patient consultation data revealed that the 'encounter' was based on the surgeon's ethos of *empowering* and '*constructing a partnership*' with his patients, which contravened the basis of paternalism and offered the patients a sense of peace of mind. The concept of '*empowering*' within the category of *constructing a partnership*, for example, was seen as a dynamic process, where power was both taken and shared as evidenced in Hegar and Hunzeker's (1988) claim that power is shared in empowerment.

The surgeon developed his model of '*constructing a partnership*' principally from his 'role models', (i.e. the consultants who were charged with imparting the 'art' and 'craft' of doctoring) and from being taught the '*rules of engagement*'. More detailed analysis of this aspect of *Playing the rules of engagement*, is found in **Chapter 9** where observation and discussion of the researcher and surgeon interview revealed concepts such as the value of *role models, communication, tailored/individualised information, patient-centred ethos* and *surgeon-led input*. These 'learned' attributes of the surgeon formed the basis and practice of patient-centeredness and fostered patients' peace of mind.

### **'Recall' of the patient/surgeon 'encounter' with the researcher**

The patients' post-consultation interview with the researcher revealed that the surgeon's 'learning' was applied consistently and systematically to the benefit of the patients. Patients leaving the consultation were seen to be *sensing relief* and satisfaction, they were experiencing the 'feel good factor' resulting from the fact that they had sought 'help', that their needs were met, that they had some 'fulfilment' and had achieved some form of 'peace of mind'. There was also a 'compliance' with the surgeon's suggestions and management of their care although this was not a passive act but one based on information and dialogue. Patients attributed their compliant behaviour and peace of mind to the surgeon's *engaging persona, genuineness, approachability, unrushed manner, empathy, empowering disposition* and presentation of *tailored information*.  
*See Chapter 8*

Central and interesting to the researcher in the findings of this study were the surgeon's patient-centred ethos and the empowering of his patients, which were congruent with the expectations of the patients in their search for patient-centeredness, satisfaction and ultimately peace of mind. The consultation was based on the dual agendas of the surgeon and the patient; the patient searched for peace of mind in 'illness' and the surgeon accommodated this search with patient-centred interventions. *See figure 10* for a composite 'story' of the emergence of *Seeking peace of mind*.

In summary therefore, when patients are in a health induced 'crisis' they seek help from the surgeon (the expert) in a consultation in order to restore their 'status quo'/ seek peace of mind. They respond to this 'crisis' by *seeking engagement* with the surgeon and or by *regaining control* over their lives and in decision making.

Each of the patient's adaptive responses manifests in various forms and depth and are therefore noted as an 'individualistic response' to illness. *See figure 4* for the conceptual links between *experiencing crisis* and the adaptive responses *seeking engagement* and *regaining control*.

The surgeon's ethos of *empowering* and *constructing a partnership* with his patients appeared as an antidote to patients' *experiencing of crisis* whereas *sensing relief*, and a sense of fulfilment in patients, was a 'confirmation' that patients' search for peace of mind was actualised by the surgeon's 'tailored' interventions in the consultation in a hospital's outpatients clinic.

Furthermore, it conveyed the message that the patient is not only seen as a set of signs and symptoms of some disease or illness, but as a person whose 'view' lies behind the words uttered, "the subjectivity behind the words." (Armstrong, 1984:742)

Therefore considering the 'individualistic response' of patients to 'crisis' in illness and their sense of relief, satisfaction and peace of mind that was triggered by empowerment and partnership created by the surgeon with his patients in the consultation, healthcare professionals are offered a validated and 'grounded' evidence (patient-induced) for future assessment of patients' needs in a consultation.

This is accommodated for example, by the three components of the 'assessment triad', which reflects the bio-psychosocial needs of patients as revealed in the patient/researcher pre-consultation interview.

The following section offers a solution, based on the findings of this study that can be employed by medical or other healthcare practitioners to the task of promoting a patient's regaining peace of mind – the assessment triad.

### **The assessment 'Triad'**

This section looks back at the three sets of data collected for this study, which were based on three questions: *What do patients want from the consultation? What goes on in the patient/surgeon consultation?* and *How do patients describe what went on in the consultation?*

What the data revealed (as described in the section above) was a testimony that what patients 'wanted' and 'received' from the surgeon in the consultation had advanced their search and gain of peace of mind.

Therefore focusing on the 'cyclic' emotions and responses revealed in the three categories of *experiencing crisis*, *seeking engagement* and *regaining control*, (the latter two were not mutually exclusive), will offer an insight into patients' reaction and behaviour in illness. More importantly, it offers a patient induced format for exploring the emotions patients express or exhibit, and their response to crisis, be it engaging in the 'problem solving or decision-making' and/or regaining control of their lives in illness.

These three categories are therefore seen as the three components of the assessment triad. This is an assessment tool, to be used in a consultation, which has the potential to elicit patients' needs and to prompt patient-centred interventions in clinical practice.

**See Figure 11 overleaf**

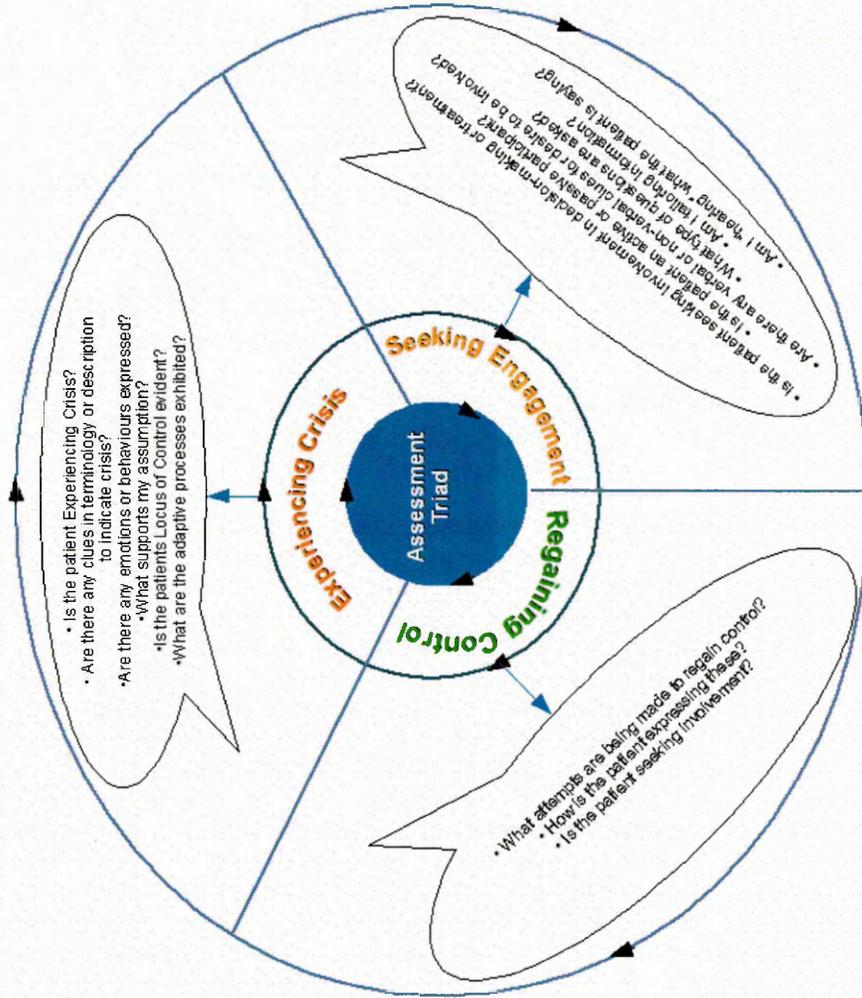


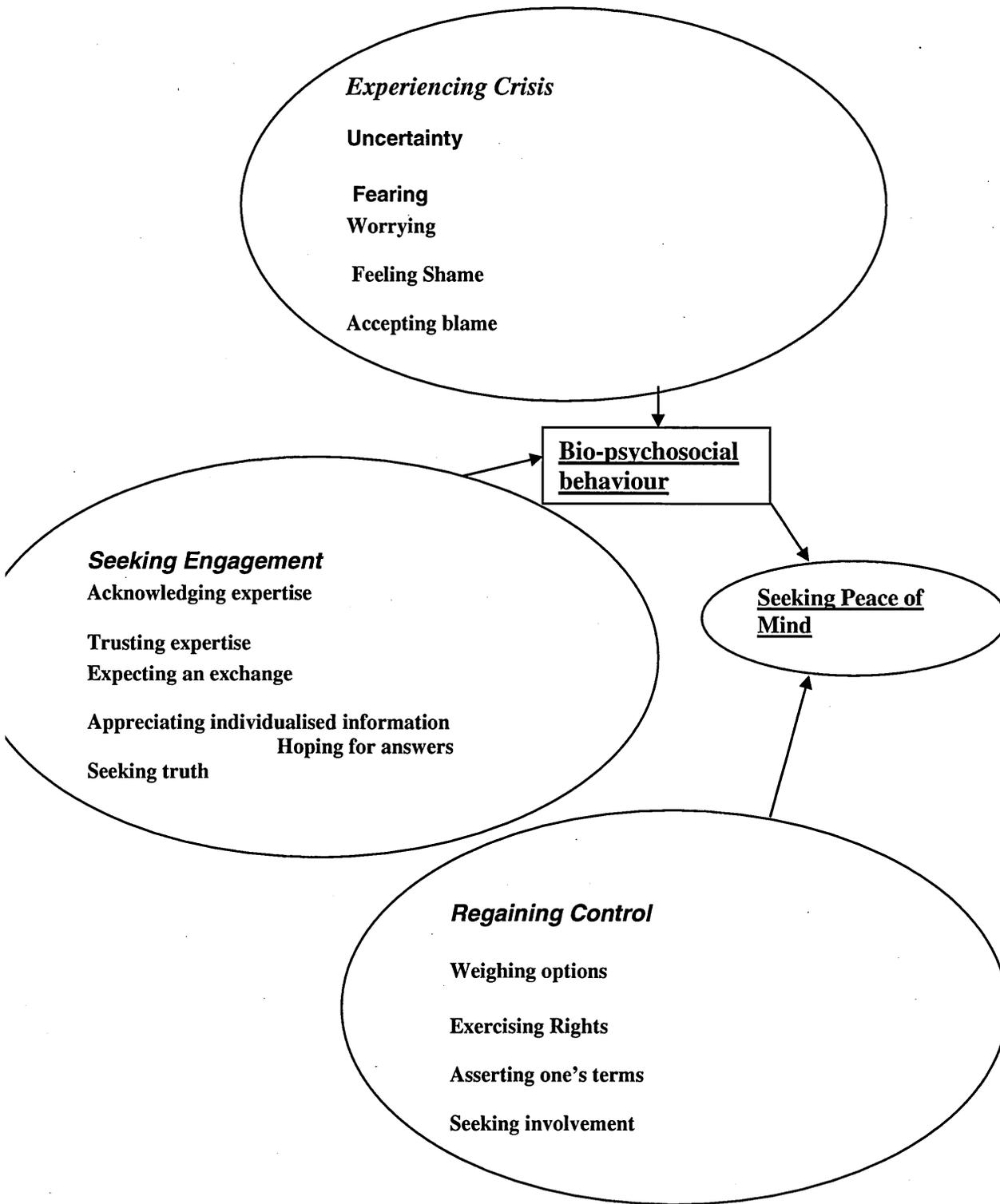
Figure 11: Diagram of the Assessment Triad

The theory generated offers the potential to respond to patients' needs through the development of an assessment tool that enables the 'consultant' to promote 'peace of mind'. The 'triad' guides the consultant through significant concepts in the theory and enables the partnership to achieve patient determined goals.

For example, the patients' behaviour in *experiencing crisis* (a component of the 'triad'), is triggered by both intrinsic and extrinsic emotions. Exploring these and being mindful of the 'variance' in their depth and 'timing' in a consultation *per se* will foster an understanding of the origins of the emotions and the art of 'tailoring interventions.' In addition, the search for clues and signs as to how patients respond to 'crisis' could be facilitated by an awareness and knowledge of the other two components of the 'triad', *seeking engagement* with the surgeon and/or *regaining control* over decisions related to their healthcare.

However, as alluded to earlier in this chapter, these emotions and responses vary in depth and are dynamic in nature, therefore the concepts or building 'blocks' of each of the three components of the 'triad' (see *Figure 11a overleaf*), can act as an 're-enactment' of patients' bio-psychosocial behaviour and needs in an consultation with the surgeon (as the patient 'tells it') and have the instant 'grab', which can sensitize people to seeing a pattern in an event. "In a word, the person feels like he or she can explain what they see." (Glaser, 2002) It will also offer the 'know how' for the 'exploration' of the three components of the assessment triad whilst encouraging patient-centred interventions by healthcare professionals and promoting/facilitating patients' sense of peace of mind.

**Figure 11a: Concepts of the 3 categories –Pre-consultation Patient/researcher interview**



The assessment triad *See Figure 11* represents patients' varied experience of crisis in illness and consequently, their choice of either *seeking engagement* with the surgeon

(the expert) and/or *regaining control* in order to sustain patient-centeredness and to restore that ‘equilibrium,’ their peace of mind in a consultation with the surgeon.

It also meets Neighbour’s (1987) call for a patient/doctor consultation, which explores and reconciles the ‘diversity’ in patients’ experience, behaviour and reaction [with a surgeon in the hospital’s outpatient clinic].

For example, the concept ‘hoping for answers’ of the category *seeking engagement* with the surgeon, was analogous with Wong and Weiner (1982) who claim that people spontaneously engage in causal searches when faced with negative, unusual or unexpected outcomes. Using the assessment triad (AT) to encourage the patient to ‘explore’ or label the illness experienced, may instil a sense of engagement and control over it. On the other hand, the concept ‘weighing up options’ of the category *regaining control* is consistent with the elements of informed consent, which encourages patients’ ‘deliberation’ of the information given along with the risks and alternatives to a proposed intervention (Beauchamp and Childress, 2001) and perpetuates patient-centeredness.

Therefore the bio-psychosocial ethos underpinning the ‘triad’ encourages doctors and professionals allied to medicine to foster a patient-centred culture in a consultation with patients, an environment, which facilitates the ‘cognitive schema’ of events that lead to the ‘illness’ and offers an ‘event congruence’ (Mishel, 1998), thereby allaying the ‘emotional crisis’, addressing the biological needs and fostering patients’ search for peace of mind.

An important element of the assessment triad is about listening to what patients' narratives of their 'illness' might reveal, for example, their intrinsic fear of paternalism, of not being 'heard' or 'listened to' in a consultation and/or the 'real' fear that the 'illness' may prove to be sinister. This skill of 'listening' to patients upholds the concept of patient-centeredness and therefore strengthens patients' search for peace of mind.

In addition, this skill of 'listening' needs to be extended to incorporate analytical skills in order to take the content provided by the act of 'listening' and determine what aspects or parts of the information provided are important or most important to the patient. This analysis can be effective if it is based on an iterative action interspersed with additional questions posed to provide support to the analysis and to prove/disprove assumptions in order to achieve a good end result for the consultation and in particular for the patient and their 'peace of mind.'

Furthermore, the depth of exploration of each component, which varies from patient to patient requires a close scrutiny of the verbal and non-verbal messages relayed in the 'encounter', and is vital to the successful implementation of the assessment triad, the remit of which is to open up the negotiation channel, foster 'congruency' with the health beliefs of patients and ensure partnership and adherence to treatment.

This element of the assessment triad concurs with what Rummel (1981) likens 'peace of mind' to - the social contract, which is active, not passive and is created through negotiation, adjustment, resolution and decision-making, and with Zaner (1990) who suggests that the rubric of a healing relationship is best conceived as a form of dialogue.

The assessment triad also prompts a solution to Pellegrino's (1983: 163) diagnosis of 'sickness' as when a "person experiences some disturbance in his accustomed state of balance between body, psyche and self" (likened here to disturbance of 'peace of mind')

The individuality of patients is inherent in the bio-psychosocial ethos (holism) of the assessment triad is reflected in the cues (*aide memoirs*) associated with each component of the 'triad', (*See Figure 11*), where generic questions are posed and are NOT presented as a didactic *tick system* of questions to be addressed. The prompts are key to exploring the holistic status of an individual and are intended to remain as such, ensuring that the findings in the data of this study are not subjected to the criticism levelled at the questionnaires and prompts noted in several other quantitative research studies, which include those of Savage and Armstrong (1990) and Stewart (1984).

The assessment triad is also offered as a cyclical format, (*see Figure 11*), implying that in the 'story telling', patients are likely to disclose further information, recall an event or offer a different perspective to a previous 'thought' when they feel 'safe' to disclose it. It also takes accommodates the patient's hierarchal order of needs. In other words the 'format' encourages a 'cognitive schema' and the patients' ownership of the story of their illness, propagating a sense of patient-centeredness in an 'encounter' with a surgeon or a healthcare professional and a 'therapeutic alliance', which encourages responsibility, openness and ownership owned by all and [does] not solely reside with the professionals. (Campling and Haigh, 1999)

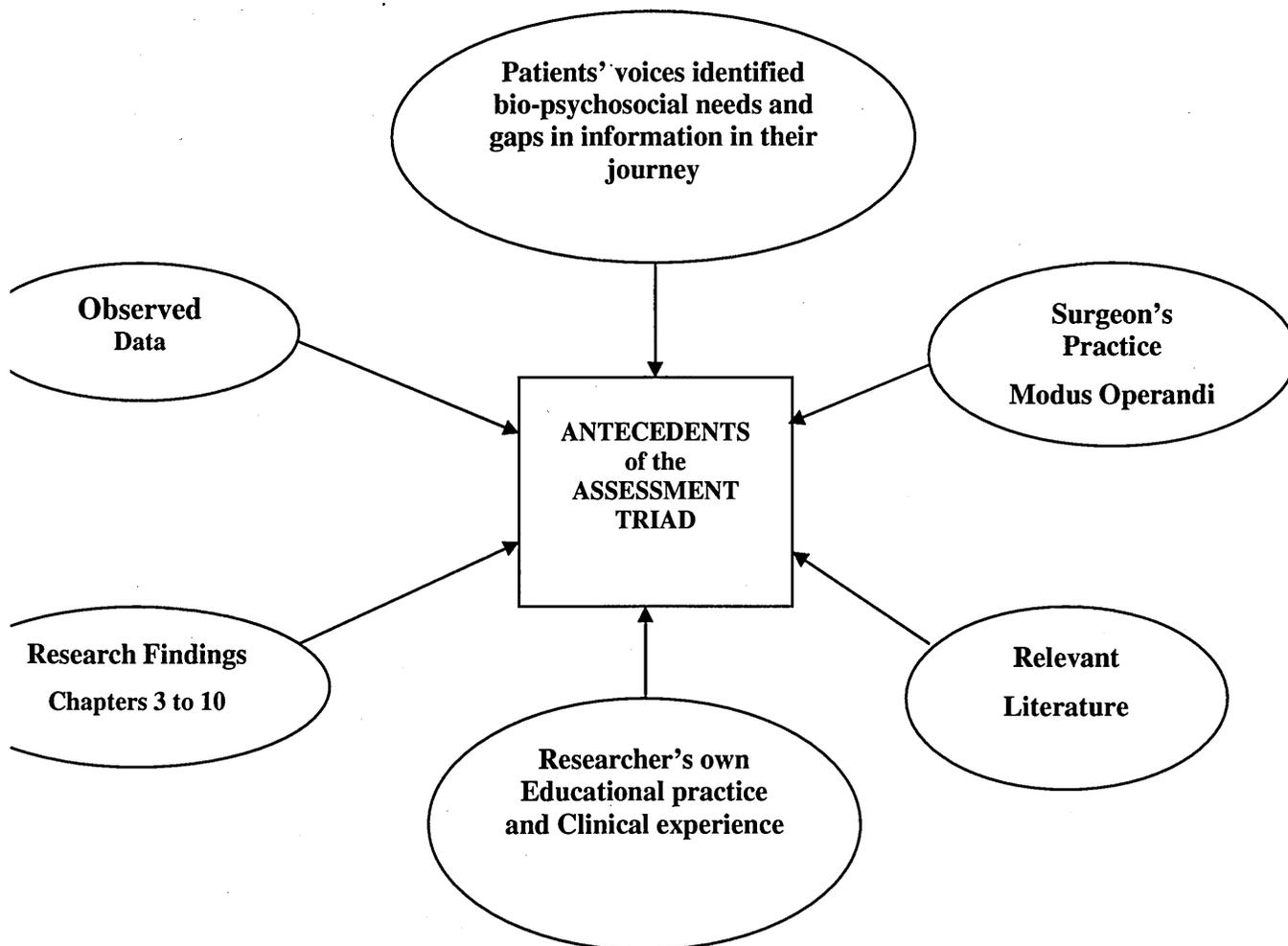
**See Figure 12 overleaf for a diagrammatic summary of the antecedents of the Assessment Triad**

The 'triad', which is grounded in patients' voices and a 'matrix' of theoretical underpinnings, embraces the ethos of the bio-psychosocial model, so that the patients' experiences, coping processes and [search for peace of mind] are rigorously understood and incorporated systematically into clinical methods [assessments]. (Zaner, 1988) It articulates the patient's wish to be involved in decisions, which relate to the delivery of healthcare and also to their search for peace of mind that is instigated by a lack of control triggered by emotions and a sense of conflict with one's better judgement. (Sorabji, 2000)

The responsibility for the ‘effective’ implementation of the assessment triad rests with its users. Therefore, at the patient/surgeon negotiation table must sit the bio-psychosocial agenda and the surgeon’s or the healthcare professional’s ability to select appropriate theories to foster an understanding of the patient’s situation. The assessment triad goes beyond the words, sees past the obvious, accesses the underlying and hidden, and “enlanguage the often present yet invisible process/culture/experiences.” (Cutcliffe and McKenna, 2004)

Generic theories on patient behaviour, which could possibly enhance the use of the ‘triad’ abound in the healthcare arena but their application to practice remains relatively academic. Therefore education of the healthcare professional in transferring the messages of theories beyond the ‘substantive’ use to a formal theory will increase their wider use and prompt effective healthcare interventions outcomes.

**Figure 12: Antecedents of the Assessment Triad**



The next section will discuss the value of the assessment triad in the wake of calls for change in some aspects of the culture of the 'medical model', as noted earlier in the 'context' of this study and the historical perspective of consultations *per se*. It also refers to the various studies used as data in this study and suggests that in reality these have remained partially 'isolated' (situation specific). Theories in health and social sciences are therefore viewed in this section with the intent to move them beyond their substantive informing culture to a generic application, so as to change healthcare professionals' thinking 'beyond the obvious' and to bring the ethos of the assessment triad to fruition.

### **The value of the assessment triad to the medical model**

The ethos of the most pervasive model in healthcare, the medical model, was based on the theory that normal health exists in terms of bodily structure and function, and that successful therapy restores "disease processes to, or in the direction of normal, thus curing or improving the patient's illness." (Neighbour, 1997:33) However, there was a distinct absence of the patient's psychological and social being in this model. In the context of this observation, the holistic culture of the assessment triad responds to McWhinney's (1981) argument for inclusion of a holistic approach to the medical model as he considered that man cannot be understood in isolation from his environment.

McWhinney, who initially was reluctant to reject the reductive (disease) nature of the medical model, suggests that introducing the holistic approach, which recognises that illness is closely related to the personality and experience of the patient, enlarges the scope of the medical model. This inclusion of the holistic view endorses the introduction of the bio-psychosocial model into medical training.

Again, this assessment triad is offered as a solution to Neighbour's (1997) identification of the problem that doctors and patients have 'two heads' each in a consultation and that it is the 'inner' head consultation, with thoughts that go back and forth between the individual and the 'second head' that needs to be explored or become more prominent during the 'consultation.' The three 'components of the triad, offer an exploratory 'tool' of this latent' or inner consultation, which can be explored by the surgeon '*in situ*'

(contextualise), in order to ensure that both the outer and inner heads of each 'person' in the consultation are represented in the decisions made in healthcare.

Neighbour's focus on rapport building, recognising minimal cues, the physical signs of mental states and listening within a medical consultation will be accommodated by the communication skills, (both verbal and non-verbal), that are used to explore the three components of the triad. That is seeking the origins of the emotions expressed by patients and the manifestation of adaptive or coping responses to illness (i.e. the behaviour patients display when *seeking engagement* and/or *regaining control* in the consultation).

The 'aesthetic and empirical' value of informing theories and their 'transferability' into practice will be highlighted next, whilst challenging other theories for their lack of integration with practice. An educational perspective will also be offered.

### **Use of relevant studies**

Findings in this study concurred with many studies in the field of health, psychology and sociology and it was particularly so from the behavioural sciences perspective. For example, the work of many authors who offer evidence which supports patient-centeredness (Lauver *et al* 2002, Mead and Bower 2000; Smith *et al* 2000; Huff and Kline 1999; DeVries and Brug 1999; Prochaska *et al* 1992), patient compliance (Leventhal and Cameron 1987; Leventhal, Zimmerman and Gutmann 1984; Becker and Maiman 1975), patient satisfaction (Turris, 2005; Oermann *et al* 2002; Ashe and Manzo 2002; Dougall *et al* 2000; Kaplan and Ware 1995; Strasser and Aharony 1993), as well as theories such as health locus of control (Laffrey and Isenberg 2003; Wallston and Wallston 1980; Rotter *et al* 1972; Rotter 1954), and informed consent (Beauchamp and Childress 2001; Johnstone 1999; Ubel and Loewenstein 1997; Gillon, 1995). However, what seemed evident was that these 'theories', which are inferred or associated with various patient behaviours or clinical situations, are not always presented as 'formal' theories and their usage remained as aesthetic value in certain substantive areas.

The informing theory of patient-centeredness (Lauver *et al* 2002, Mead and Bower 2000; Smith *et al* 2000; Huff and Kline 1999; DeVries and Brug 1999; Prochaska *et al* 1992) for example, could be associated with the patient *seeking engagement* with the surgeon

in the consultation or the theory of informed consent (Beauchamp and Childress 2001; Johnstone 1999; Ubel and Loewenstein 1997; Gillon, 1995), with patients *regaining control* in the consultation.

There appears to be a lack of a 'transferable' or analytical forethought evident in the studies, as these informing theories appear to focus on their immediate 'use' or solution, and therefore compromise the full potential of their findings.

### **Informing theory**

The value of the use of these 'informing theories' to enhance the full potential of the assessment triad in a patient/surgeon consultation and its 'wide' bio-psychosocial perspective and patient-centred ethos is demonstrated next from an educational perspective

### **Hierarchy of needs**

Maslow's (1970) postulation for example, that there is a hierarchy of innate needs "a ladder of motivations, which activate and direct our behaviour" (Gupta and Gupta 2000:116), and that an individual's behaviour to satisfy these needs are not innate but learned and therefore will differ from person to person, are embedded in the underpinnings of the three 'components' of the assessment triad, namely *experiencing of crisis, seeking engagement* and/or *regaining control*.

For example, patients' physical needs are incapacitated by their 'illness' and as such they are seen to be seeking help from the expert in the consultation in order to secure their safety and security needs, which are achieved by a "personal survival drive" (Maslow, 1970:89), that is by *seeking engagement* and or *regaining control*. Embedded in this search is also the patients' "emotional drive"(Maslow, 1970:82) for acceptance of their 'story' of illness, reassurance by healthcare professionals and resistance to social isolation, created by the paternalistic stance of the surgeon in a consultation, (*experiencing crisis* and seeking resolve, via the assessment triad).

Patients are driven by their "values and interest" (Maslow, 1970:88) for self-respect and recognition and seek to be treated as individuals with a degree of respect in order to

achieve self-actualisation (Gupta and Gupta 2000; Maslow, 1970) by *regaining control*, that is by being empowered to make decisions related to their healthcare. Self-actualisers, it is suggested, experience transient moments of peak experiences, and Maslow explains that patient satisfaction, and ‘fulfilment’ (as indicated in *Chapter 8 - Sensing Relief*) characterises this peak experience.

### **Patient satisfaction**

This concept of patient satisfaction though under theorised, has both practical and political relevance in the current healthcare system as it is often used to guide research into patients’ experiences of healthcare (Williams, 1994). However, patient satisfaction is understood as being more of a ‘product’ than a process and it ignores an underlying problem with the system. Patient satisfaction surveys it is argued, are currently used by a large number of health maintenance organizations (Weisman *et al*, 2000), as they imply, perhaps erroneously that if patients are satisfied then they have received good care. (Turris, 2005)

Another point worthy of note is that healthcare professionals use these ‘surveys’ to measure the levels of patient satisfaction in the quality of healthcare encounters as they consider low levels indicate that patients delay seeking future treatment, which is often associated with negative health outcomes. (Edwards and Staniszewska, 2000; Becker and Newsom, 2003) Researchers have linked high levels of satisfaction with patients’ adherence [compliance] (Strasser *et al* 1993) and positive outcomes. (Kaplan and Ware, 1995)

The findings of this study reflect this assertion by offering empirical evidence to suggest that patients have identified ‘peace of mind’, a dynamic concept, with patient satisfaction. However, patients’ delay in seeking future treatment being associated with non-compliance seems debatable and it might suggest that the behaviour exists where healthcare professionals initiate changes that are not congruent with the health beliefs of patients, thus ignoring the underlying problems of patients. (To be discussed later in this chapter).

The bio-psychosocial or holistic elements which underpin the assessment triad and which portray patient satisfaction as being embedded in mutuality, respect and honesty (*See Chapter 8 Sensing Relief*), will prevent the culture of patient satisfaction from

being measured as a product and will instead enhance patient-centeredness, patient compliance, and help engender patients' responsibility and their sense of peace of mind. Strasser and Aharony's (1993:221) emphasis on patient satisfaction as a "perceptual, multidimensional, relativistic, dynamic, patient-centred, attitudinal and individual process," may appear a little cautionary yet it relates to this study's findings, which are contextual and acknowledge its inherent dynamism.

The assessment triad based on findings developed from a theoretical underpinning of symbolic interactionism, continues to interpret the symbolic meaning of the individual's environment and acts on the basis of this imputed meaning (Blumer, 1969). This, when used during a patient/surgeon consultation, will translate patients' meanings into the 'encounter', and be guided by the relevant informing theory and respond with a 'tailored' intervention. For example, listening out for the 'untold' messages related by the emotions, the patients' response to illness or the role they wish to play in its management, will ensure compliance because it is 'congruent' with the particular needs of the patients and is patient-centred. Thus promoting patient satisfaction as an 'indicator' for patients' search for peace of mind.

### **Patient-centred interventions**

Patient-centeredness, a concept which underpins Government initiatives that are focused on reshaping the NHS around the needs and aspirations of its patients (DoH, 2004), is the crux of the assessment triad, a composite of patients' experience and needs in a consultation with a surgeon in a hospital's outpatients clinic. For example, it initiates a 'congruence' of the patients' needs and the healthcare professional's interventions and addresses Lauver *et al*'s (2002) concern that there has been little research on whether the dimensions of interventions that researchers choose as patient-centred are the same dimensions that patients would choose as patient-centred.

The study revealed that the patient-led interventions encouraged by the 'empowering ethos' of the surgeon guaranteed that the dimensions of the interventions selected by patients were congruent with their needs; resulting in the fulfilment of the patients' expectations, their sense of relief, and most importantly achieving their goal for peace of mind. Patients' dimensions of patient-centred interventions included the surgeon's *engaging persona*, his *genuineness*, *approachability*, *unrushed manner*, *empathy*, *tailored information*, and *his empowering disposition*, and are recognised as

'behaviours', which responded to their 'crisis' and the adaptive/restorative processes and as such are being offered here as 'tools' for the implementation of the assessment triad.

The consultation process revealed that patients were exercising their 'responsibility' by seeking help from the surgeon in the consultation. The surgeon's 'responsibility' was manifested in empowering his patients, constructing a partnership with them, and accommodating the 'interventions' patients sought in the consultation. This positive response from the surgeon contributed to the patients' feelings of 'satisfaction' and 'self-actualisation' and also to their peace of mind; thereby constructing a harmony between the surgeon's dimension of patient-centred and patient-led interventions which are customised instead of the more common 'one-size-fits-all' practices. (Kreuter *et al* 1991)

It is suggested that if patient-centeredness is the quality benchmark of a clinical encounter then Lauver *et al*'s (2002) 'concern' for congruity between patient and consultant should focus primarily on the assessment triad, which has the capacity to increase the healthcare professionals' awareness of the value of a therapeutic relationship with patients, transforming their 'vulnerability' into strength, instead of increasing a feeling of disempowerment for the patient. (Werner and Malterud, 2005) In addition, it has a natural affinity to yield patient-led interventions, and to prompt change (compliance) in health behaviour through an understanding of how the human mind works in the healthcare arena.

The 'dynamism' in patient behaviour therefore, warrants interventions that increase patients' 'self-awareness' by "customising interventions to the individual's stage of adoption" and to "move the individual from one stage to the next." (Lauver *et al*, 2002:248) An effective tool of intervention (by healthcare professionals) for example, is facilitated in the 'trans-theoretical' model (TTM) consisting of several stages that an individual could be at in the process of adopting particular health behaviour namely, pre-contemplation, contemplation, preparation, action, and maintenance. (Lauver *et al*, 2002)

This 'customisation' (patient-centring) of interventions to the individual's stage of adoption is couched in the assessment triad, in order to promote patient satisfaction, fulfilment, and their peace of mind in consultation with a surgeon in a hospital outpatient clinic, all of which may indicate increased patient compliance.

### **Non-compliant or 'difficult patient'**

In healthcare the degree to which patients follow a healthcare professional's advice is referred to as 'patient compliance', and an earlier reference made in this chapter to patient satisfaction and 'compliance' revealed that patient satisfaction surveys indicated that high levels of satisfaction were associated with patient compliance. (Strasser et al, 1993) However, in today's Western industrialised nations where acute diseases with obvious symptoms are being overshadowed by chronic, asymptomatic diseases, "management" is replacing 'cure' as a medical goal" (Robbins, 1980:705) and patients are expected to be actively involved with the healthcare professional in both restoring and maintaining health. (Guze, 1981) All of these things are now contributing to changing the 'urgency' of the concept of compliance in the healthcare arena.

Guze (1981) and Ozuna (1981) acknowledge that the intractability of the problem is largely due to the variety of forms that non-compliance can take. They cite for example, patients not taking the medication when they begin to feel better regardless of instructions to finish all of the medication or those instances where the "prescribed" treatment regime requires alterations in lifestyle or behaviour such as smoking cessation, reduction/abstinence from alcohol, or changing established eating habits or patterns.

Malman and Becker (1980) suggest that the most important aspect of patient compliance is the relationship between the healthcare practitioner and the patient, a view supported by Falvo *et al* (1980) who claim that compliance is greatest in those patients whose physicians take time to explain themselves and exhibit sincere regard for the patient's concerns. This includes listening to the patient's spoken and unspoken fears and responding in a supportive and constructive fashion. This stance is offered in the assessment triad, which is portrayed in a format that encourages healthcare professionals to scan for clues and cues in the 'encounter' from the patient's perspective.

This study identified that 'compliance' was a dynamic concept, which emerged when patients understood the rationale for action or appreciated the 'value' for change in behaviour. Compliance was also noted to be progressive and operating within a hierarchical order of needs, where a good inter-personal relationship was crafted by the surgeon's 'social relationship' in order to create a safe environment in which patients could 'share information' about the 'illness', establish the 'cognitive representation' of their illness, create a coping or action plan, or appraisal of the 'coping action' or its modification (Leventhal, Nerenz and Steele, 1984), and negotiate interventions.

Furthermore, the surgeon displayed his 'responsibility' for the patient involvement through the methodical application of various modes of communication whereby he tailored information, used diagrammatic illustrations, and recapped information as necessary. In addition he interjected occasional humour to help diffuse anxiety/tension, helped to achieve clarity and had a powerful effect on patients' 'reception, comprehension, and retention.' (Ley, 1977: 32)

This 'practice' conveyed and convinced the patients that the proposed 'intervention' was worthwhile, and ensured 'compliance' (the embodiment of responsibility), as there was no discrepancy between the surgeon's and the patients' views of the illness problem. The surgeon addressed the '*real*' needs of 'patients' both physical and psychological, which were related to the *situation* that they presented with in the consultation, (Italics are the researcher's emphasis) and concurs with Pendleton *et al's* (2003) study, which claims that compliance improved when the treatment regimen was clearly stated by the doctor.

The assumptions made about the concept of patient 'non-compliance' have implications for healthcare practice. The decisions taken by patients to see a surgeon or a healthcare practitioner (HCP), offers evidence of help seeking from 'experts.' Therefore HCPs who traditionally label non-conformists as 'difficult or non-compliant patients' (a patient's response it is suggested to paternalism) must be considered as being misguided and ill informed. Non-compliance is not a symptom of patient-hood but a cause of 'incongruence' when HCPs initiate changes that are not congruent with the health beliefs of patients.

Theories on compliance tend to present it as a multi-factored problem that is influenced by the characteristics of the disease, the treatment regimen and setting, as well as a “variety of both relatively stable dispositions and highly variable states of the [patient].” (Leventhal and Cameron, 1987:118) Leventhal and Cameron’s review of the literature showed that a great variety of techniques have been used to overcome the compliance barrier with varying degree of success. They therefore propose an eclectic theory such as the Self-regulative Systems theory, which incorporates a variety of techniques that would address compliance.

The theory conceptualises the patient as an active problem solver whose behaviour reflects an attempt to close the “perceived gap between his or her current status and a goal, or ideal state.” (Carver and Scheier, 1982: 114) However, it seems that the “multivariate and transactional character” of the Self-regulative model makes it difficult to use and Leventhal and Cameron concede that the absence of a standardized measurement tool is a ‘plus’ as it requires “the ‘investigator’ to think of ways of asking questions or generating manipulations appropriate to the specific health problem and situation.” (Leventhal and Cameron, 1987: 130)

This assertion is accommodated in the ethos of the assessment triad, which offers a generic framework or an *aide memoir* to generating ways of asking questions when exploring patients’ experiences of their first consultation with a surgeon in a hospital outpatient clinic and thereby ensuring a compliant response to healthcare interventions.

In addition, contemporary theories of health communication no longer view today’s patient as the generic, rational receiver of care and information, but rather as a complex individual who constructs very personal and unique meaning about health and disease (Stone *et al*, 1998). Healthcare professionals can therefore, (under the aegis of the assessment triad), trust what patients are telling them, since they generally are the best source of information about attitudes, beliefs, and lifestyle issues that affect their acceptance of medical treatment.

The assessment triad executed by the healthcare professional’s *engaging persona*, *genuineness*, *approachability* and *empathy* (social relationship), offers a pragmatic yet empirical solution to patient non-compliance. It encourages patient ‘owned’

interventions, addresses the underlying issues related to individual experiences of 'illness,' and fosters the empowering skills of the healthcare practitioner.

Furthermore, the assessment triad, which is driven by patients' search for peace of mind in illness, will make non-compliance resulting from needless misunderstandings between patients and healthcare professionals, a thing of the past. It will obliterate 'uncertainty' through information, and particularly liberate individuals from the fear of paternalistic attitudes of healthcare professionals. In essence the fundamental basis of the assessment triad regards patients as autonomous, knowledgeable individuals whilst upholding the axiom to compliance in healthcare practice as the patients' peace of mind.

### **Rescinding paternalism**

A significant finding of this study was that the 'empowering' ethos of the surgeon based on a 'partnership', built on 'trust' and honesty, contributed to patient satisfaction and 'peace of mind.' This outcome could consider 'empowering' of patients as a powerful tool for Government initiatives that foster a culture of a 'fully engaged' public (DoH, 2004) and a health service, which is patient-led where "people have a far greater range of choices and of information and help to make choices." (DoH, 2005: 7)

The surgeon's tailored and individualised information for patients during the consultation for example, ensured that patients received comprehensive information including the inherent risks and alternatives, and fostered 'rational deliberation.' Furthermore, his encouragement of patients to self-determine and self-govern inferred a freedom of choice and abstained from any attempt at coercion. The surgeon in principle was seen to uphold the moral doctrine of informed consent and was contravening the 'culture' of paternalism in medicine where doctors without an understanding of patient values would tell patients what they should do. 'Empowering' in essence is embodied in the doctrine of 'informed consent', which opposes paternalism.

Generally, in healthcare practice, the doctrine of 'informed consent' has been evoked as a preventative measure to ensure that patients' rights have been protected, for example, before any medical or surgical intervention. However, inherent in this practice of obtaining an informed consent is the scrutiny of every act and intervention for its

‘legality’ which has blurred the patient-centeredness, the moral obligation in its function in healthcare in favour of a ‘calculative’ paternalistic thinking, as a preventative measure from ‘litigations.’

Costa-D’Sa’s (1996) study, which explored nurses’ understanding of the informed consent process from an ethical perspective for example, revealed that although nurses acknowledged informed consent as the competing principle that reminds HCPs of the “primacy of human autonomy” (Maslin, 1994: 154), they were unable to relate to the ‘elements’, (other than the informational needs), which constituted the concept such as information giving, understanding, competence and voluntariness (Beauchamp and Childress 2001). They generally addressed the ‘psychological discomfort’, which resulted from ethical dilemmas by resorting to its ‘legal connotations’, such as the fear that the hospital or an individual may be sued in cases of clinical errors and did not see it from the patient perspective.

Most writers on this subject for example, Agard, (2005); Schildmann, *et al*, (2005); Doyal, (2002); Berg *et al*, (2002); Faden and Beauchamp, (1986); Lidz *et al*, (1984); Culver and Gert (1982), agree in principle that healthcare professionals should always strive for informed consent from patients; however less is known or written about how they should do this. Schildmann *et al*, (2005) for example, express concern about pre-registration house officers’ lack of knowledge with regard to the procedure of obtaining an informed consent from the patients despite a comprehensive undergraduate programme in ethics, law and communication. They therefore suggest that there is a need for applied education regarding the clinical procedures for which pre-registration officers are obtaining consent.

In a similar vein, Berg *et al*, (2002) suggest that the concept of informed consent be viewed as a process which is consistent with both patient autonomy and good clinical practice; and reflects current thinking in an era in which patients are asked to navigate an increasingly complex healthcare system. In other words, moving healthcare professionals’ focus on ensuring that the consent form is signed to the more appropriate focus on ongoing discussions with patients over the course of treatment or research and addressing therein their need for seeking *engagement* with the surgeon in the consultation.

The underpinnings of the assessment triad, which uphold the principle of patient autonomy, offer a wider utility of this doctrine in practice. It behoves the healthcare professional to take responsibility for moving the theoretical underpinnings of informed consent beyond the 'confine' of consent *per se* to a generic application, for example, to all healthcare encounters with patients in order to rescind patients' fear of the paternalistic overtures in healthcare consultations.

Patients in this study worked in partnership with the surgeon whose honest 'delivery' of tailored and individualised information, and the allowing of time to deliberate or self-determine – provided patients with the opportunity to act freely and so fostered patients' *regaining of control*. Beauchamp and Childress (2001) suggest that a person can only be acting freely and autonomously when acting independently from controlling influences, in other words acting independently from the controlling influences of paternalism in healthcare.

In summary, the elements, which constitute the doctrine of informed consent can be used as an overarching template in the assessment triad to not only guide 'the patient and surgeon consultation' but also to ensure that paternalistic 'traits' in medicine are minimised and patient-centred interventions come to the fore. Dwelling on the autonomy and right of the individual to make decisions in healthcare will eradicate patients' feelings of helplessness or loss of control and fear, which paternalism represents for patients in a consultation with a 'doctor' or other healthcare professionals allied to medicine, and will promote patient centred interventions. Ultimately, focusing on the three components of the patient induced 'assessment triad', will rescind 'paternalism' in practice and nurture the patients' search for peace of mind in illness.

### **Challenging 'short-sighted' theories**

The next section prompted by the findings in this study, challenges the accepted 'absolutism' of theories that evolved to explain patient behaviour or clinical practice and proposes that 'said' theories must be examined beyond their utility to experience their full potential. In other words clinical based research must be examined for its application to patient-centred interventions and 'transferability' to practice.

### **Relocating 'locus of control theory'**

The depth of 'involvement' or control sought by patients in decision-making in this study varied greatly, yet despite this all the patients in this study revealed a sense of relief that the surgeon had fulfilled their expectations and offered some peace of mind in the consultation. This variance in behaviour is understood in principle, within the theory of health locus of control, which describes the depth of an individual's control over issues relating to the 'self' and the extent to which individuals attribute outcomes to their own behaviour (Rotter, 1954) and that, which can influence their own health behaviour. (Seeman and Seeman, 1983)

People with an internal locus of control believe that what happens to them is a direct result of their own behaviour or attributes, whilst those with an external locus of control believe that what happens to them is unpredictable or a matter of luck, fate, chance, or the actions of others more powerful. (Arakelian, 1980)

The findings of this study however challenge the 'absolutism' of this theory or question its application in some aspects to practice. Many patients for example, acknowledged and accepted their fate or the action of 'powerful others' in their health management, however, the therapeutic communication in the 'encounter', supported by information gleaned from the media and in particular Internet resources, were seen to shift the nature of this 'unpredictable, fate-related insecurity' to one of a 'psychological diffusion of the action of powerful others.' Patients were observed as being tentatively open (playing the field) in their 'exchange' with the powerful others.

This reticence was recognised and accommodated by the surgeon's *empowering* disposition, *genuineness* and "active patient orientation, which include[d] communicating positive attitudes and expectations towards a patient's ability to perform treatment recommendations." (Wallston *et al*, 1987:14) These were traits or behaviours, which boosted patients' 'self-efficacy', their belief that they have the ability to behave in such a way as to produce desirable outcomes. (Bandura, 1977) In addition, the surgeon's offer of choice, time of treatment and involvement in decision making,

increased what Langer (1983:56) describes as the “illusion of control” which he defines as the perception of control over outcomes in chance situations.

The findings in this study are analogous with Wallston *et al's* (1987) view on the stability of perceived control that beliefs and systems of belief are amenable to change given differing experiences in a particular situation. The management of ‘particular situations’ was guided by the surgeon’s perception of the patients’ perceived locus of control and his assessment of their self-efficacy in relation to the presenting ‘illness.’ In other words whilst the theory of health locus of control or perceived control explains patients behaviour in illness it also offers guidelines or a framework for patient-centred healthcare interventions and fosters patients’ adaptive response of *regaining control* in illness.

If one reflects on the three components of the assessment triad and the flexibility it offers in the interpretation of individual’s emotional status or a patient-centred need, in the search for peace of mind, then ‘control’ perceived by or within the locus of control paradigm must be seen as multi-faceted (the person’s health values and other behavioural and outcome expectancies) and dynamic. Wallston *et al's*, (1987:21) claim that an assessment of the individual’s “psychological situation [which] plays a major role in determining, which expectancies and values [are] operative at any one moment [in a consultation with a HCP]”, and the need for change in behaviour, are met within the rudiments of the assessment triad.

### **Management of change**

The patient’s metamorphosis into this ‘new patient’ from being a passive patient to an informed, autonomous patient, presents healthcare practitioners with a new challenge. It is one that prompts patient participation and patient-centred actions, and conforms to the generally held and widely promoted belief that patient participation makes for better consultations. (DoH, 2004)

The expectations of Government initiatives, that health professionals across the healthcare domain support patients or healthcare users in making adaptive changes in the ‘fear zone’ of a medical encounter, which has the potential of ‘disempowering’

patients, are supported in the findings of this study. This suggests that change strategies are therefore patient focused and not 'institutionally' derived.

The theory and management of change has generally remained the 'utility' of education and action research and yet it appeared to function within the 'surgeon/patient consultation' in bringing about effective change in health behaviour (compliance) and empowering of patients. Chin and Benne's (1976) patient-centred strategies of change, which include the *empirical-rational*, the *power-coercive* and the *normative-re-educative*, underpinned the surgeon's action, and involved the selection of an appropriate change strategy for each patient's situation or adaptive mode, in order to bring about effective change.

Patient-centred interventions are seen for example in the surgeon's use of the *empirical rational strategy* when he offers patients information regarding health behaviour and promotion in order to prompt 'change.' This strategy assumes that people are rational and will adopt change if it is rationally justified and if they can see some possible gain by making the change. He then 'jerks' a little more attention by informing them of the side effects of neglect using the *power-coercive strategy*, in order to move the cognitive process into action.

People with less power, as assumed in the patient's role in a doctor-patient encounter, tend to comply, however this behaviour is short lived and exists only to comply with the wishes of someone else. It is not exactly valued or integrated into an individual's value system. (Chin and Benne 1976) In some cases the surgeon is seen to use the 'power-coercive' strategy in order to 'shift' the mind set of fear of 'change', by referring to the family history and its hereditary implications to the problem presented by patients (*see Chapter 6*).

In some cases the surgeon's intervention based on the patients' receptiveness and co-operation with the health messages communicated, is directed at the bottom-up approach initiating the *normative-re-educative strategy*. He seems aware that his patients are guided by their "actions, roles, and relationships, by social norms, personal meanings, habits and values" (Chin and Benne 1976:34), and as such he addresses each individually. For example the surgeon shows awareness of a patient's need to have

surgery at a time when she has help with caring for her children at home (*see Chapter 6*).

The surgeon's patient-focused management of 'change' *per se* is also noted in the high proportion of time allocated by the surgeon to information giving, ensuring understanding and allowing for deliberation in an environment of trust, empathy and empowerment in the interview. Empathy and empowerment were significant levers of change management, and were reflected in the surgeon's offer of a choice of times and dates of future appointments, his concern about the expenses incurred by 'repeat' prescriptions and an awareness of patients' other 'life' away from this 'illness.' What is evident in the surgeon's behaviour and reflected in the positive outcome of the 'consultations' (as noted in *Chapter 8 Sensing Relief*), and what is requested emphatically in the various Government dictums, is the surgeon's patient-centred ethos and interventions in a healthcare 'encounter.'

The adaptive or coping responses of *seeking engagement* with the surgeon and/or *regaining control* in illness induced 'crisis', (two components of the assessment triad), are about change of attitudes or cultural thinking, which patients intimate in the consultation, in order to seek peace of mind. Therefore within the assessment triad patients' adaptive or coping strategies, articulated or implied in the consultation, need to be supported or 'secured' within the assertion of the appropriate strategy of change. Movement and selection between these three strategies in order to 'tailor' and secure change and to empower patients, emphasises the much sought after culture of patient-centeredness in the healthcare arena and strengthens patients' search for peace of mind.

Therefore health statements, which use phrases such as 'difficult to engage' to describe 'health encounters' with patients (Kings Fund Briefing Paper, 2005:48) may reflect the healthcare professionals' lack of perception and skill to 'tailor' these management strategies to individual needs to bring about change in behaviour (educate), and to value patient-centred interventions in the management of change.

In summary, bringing the inherent value of theories to practice and broadening their usage to support 'patient-centred' interventions endorses the 'responsibility', with which every healthcare professional is charged. This charge also implicates

educationalists that are responsible to make this 'transference' to practice and patient-centred interventions a reality. The next section will indicate how this educational responsibility can be actualised in practice.

### **An Educational perspective**

The Government dictum that healthcare professionals should shoulder some responsibility for educating patients highlights another perspective to this responsibility that of educating future doctors, nurses and professionals allied to medicine. The findings of this study suggest that for a clinical-based practice such as medicine and those allied to medicine, role models are forerunners to learning in action [practice] and support this 'educational' imperative.

The format of the assessment triad and its theoretical underpinnings offer grounded evidence of what patients seek in a consultation and what contributes to patient 'fulfilment' and their peace of mind. Furthermore, in the context of the researcher's personal practice it has implications for the role of a specialist/expert nurse lecturer in perioperative nursing, which includes teaching nurses, medical students and operating department personnel (ODPs) in the perioperative area.

There is the potential for example, of sharing the findings with the surgeons initially so that future teaching of medical students will include grounded evidence of patients' needs and concerns in a surgical consultation, in order to move beyond the 'obvious' and to embrace the holistic approach to a human being, by taking account of the patient's perspective in the 'encounter.' (Armstrong, 1984) More importantly, the three 'components' of the assessment triad will help the surgeon to organise unorganised 'illness' by constructing a "dense web of interconnections between feelings [emotions] symptoms, and social context." (Balint, 1956:58)

This seems like an exciting conclusion to my initial meeting five years ago with the surgeons at their surgical 'grand round', when I presented them with my research proposal and requested access to their patients in the clinics. They all responded generously and seemed keen to support the value of such 'projects.'

It is anticipated that many of the surgeons present at the surgical 'grand round' will have heard it all before but few will be prepared to admit to putting the findings into practice or even attempting change in practice. My role will therefore include presenting the surgeons with the empirical 'emergence' of the assessment triad, and its use by patients as a tool to seeking peace of mind, the very 'intent' of their search for surgical expertise in a consultation.

The 'message' embedded in the assessment triad will confirm too, that medicine's decision to 'obliterate' the hang-ups of the process of "interrogation and... examination" (Hutchinson, 1935:23) in a surgical encounter was appropriate, and that listening instead to patients' stories of their illness (of which they are the best authors), will ultimately influence their teaching strategies in medical education as a way forward to upholding the ethos of patient-centred care.

The holistic or bio-psychosocial underpinning of the assessment triad will also address Neighbour's criticism of medical students' affinity with the medical model, which they found most attractive because it stretched their intellects, and spared them much involvement of their feelings, and will coach them into the humanistic and holistic mode of thinking and acting.

Furthermore, from the educationalist perspective, the holistic or patient-centred value reflected in the 'assessment triad', will also sustain the [surgeon's] shift from the almost exclusive causal-etiological analysis training (Cassell, 1985), to one that recognises the patient as an unique sick individual, whose body and personal life must be interpreted precisely, and only as these are actually and fully presented; only then will the central and governing purpose of [surgery] that is therapy, be properly conducted (Zaner,1990). Medical students will be introduced to the 'assessment triad' during their surgical placements, which includes care of the patient during the perioperative journey to a surgical intervention.

Since the care delivered by surgeons, anaesthetists and nurses in the perioperative arena embrace the principles embedded in the assessment triad, (that is the recognition of patients emotional 'crisis' and its origins and the manifestation of their adaptive or coping strategies), its utility will be extended to other branches of medicine or practices allied to medicine, for example surgical and perioperative nursing. An example of this for instance is presented next.

### **Perioperative nursing perspective**

The assessment 'triad', which is grounded in the patients' 'voices' has significance in the area of perioperative nursing and offers a 'face' which hides behind the constant advances in technology and yet proclaims a role in perioperative nursing (Bolger, 1998). The implementation of the assessment triad in essence begins with a preoperative visit carried out by perioperative nurses to patients in the wards prior to surgery.

The rationale for such practice (often carried out within time constraints), though well intended and noted as offering 'holistic care' to patients, generally focuses on pre-operative preparation of the theatre for surgery, physical assessment of the patient and addressing (within the remit of the nursing profession), their psychological needs by patient 'orientation' to the routine of the impending surgery. Information giving to allay anxiety (Martin, 1996; Hayward, 1977) in an effort to increase patient 'control' of the situation and to hasten recovery (Boore, 1978), are presented as empirical rationale for the practice of pre-operative visits.

More recently too, the practice of pre-operative visits to patients is underpinned by a raised awareness of the need to seek patients' permission to carry out nursing interventions in order to prevent accusations of 'assault' during the perioperative journey of the patient. Furthermore, pre-operative visits are carried out as a means of justifying the presence of 'nurses' in theatres, who are considered as an 'expensive commodity' (Brown, 1994) thereby fulfilling a financial and political expediency.

In recent times however, this 'expediency' has increased the profile of pre-operative visits and the well-meaning 'practices' or intuitive behaviours are required and expected to be incorporated into strategies, to ensure that perioperative nursing interventions are

patient-centred and that patient safety and satisfaction remain paramount in an area of healthcare where patients are seen to be most vulnerable. McGarvey *et al* (2000) however, argue that perioperative nursing should be carried out in any area that relates to a surgical journey, be it outpatients departments, [clinics], an intensive care unit or a surgical ward.

In summary the concept of pre-operative visits and its practice is vague and lacks any formal structure or established rationale other than those linked with information giving intended to allay anxiety (Martin, 1996; Hayward, 1977), increase control and hasten recovery. (Boore, 1978) There is also limited empirical evidence to show how this 'practice' should be structured and delivered in the arena of surgical care of patients.

The antidote to the *laissez-faire* attitude, which surrounds care given by perioperative practitioners to patients during their perioperative journey, is the patient grounded assessment triad. It offers a template, which embraces the physical, psychological, social and spiritual aspects of an individual's needs. More importantly it assists perioperative practitioners and healthcare professionals across the surgical domain, to focus on patient-centred or rather 'made-to-measure' interventions, and to actualise patients' search for peace of mind.

For example, pre-operative visits carried out by perioperative practitioners will be based on their understanding of what brings patients to a consultation and what they seek from it (guided by the three components of the triad), and then delivering interventions that are both patient-led and patient-centred as a result of that achieved understanding.

Therefore, in practice the perioperative practitioner sits with the patient, assesses the physical state, and uses an unstructured 'interview' grafted in a 'social relationship' and hinged on 'mutuality and empowerment', to establish the emotional status, its origins and explores and accommodates any evident adaptive or coping mechanism displayed by the patient. The focus throughout the 'encounter' remains patient-centred and the preoperative 'brief' is concluded mutually, providing a 'clinical audit' for patient satisfaction and fulfilment of the political and financial expediency.

My own experience in perioperative nursing and later as a lecturer in this area, gives rise to the suggestion that the assessment triad or '*Pre-operative bio-psychosocial assessment*' (*PBPSA*), which infers a holistic 'appraisal' of an individual scheduled for a surgical intervention, and offers a more meaningful template for an interaction in clinical practice, replaces the term 'visit.' I argue that this 'new' terminology will capture the patient-centeredness embedded in the triad and prove to be a valuable replacement for the term 'pre-operative visit' (as used presently), as it has a casual 'overture' of interaction with patients.

Furthermore, it will change the perioperative practitioners' non-directive attitude to pre-operative visits, the numerous interpretations of the role of the 'visits' and the low priority given to them in an environment of hectic theatre usage and increased pressures for 'productivity.'

I am reluctant to offer a definitive template or protocol for the assessment triad (*see Figure 11*), as this will constrict lateral thinking, preventing a more comprehensive understanding of this area of healthcare management and practice. It will also perpetuate the 'check list' approach for patient engagement. Instead I would favour an *aide memoir*, that has the capacity to be flexible, yet allows the practitioner to explore and to focus on individualised or patient-centred interventions, so that the experience of one patient does not become confused or muddled by the experience of others. (Turris, 2005)

### **Role models**

Another aspect of the 'health educationalist's' responsibility rests within the concept of role models in clinical practice. Role models were identified as a powerful force in the 'learning' process of the surgeon in this study, who practices reflection on action (Schon, 1983) to identify positive role models and emulated them during his 'formative' years as a house officer. This was identified in the category *Playing the Rules of Engagement*, (*see Chapter 9*), which was in essence a result of a working hypothesis constructed during the process of theory building, which claimed that 'clinical skills' were learnt on the 'job.'

The surgeon identified the personal characteristics of the positive role models (specifically surgeons he had worked under), as being: honesty, respect for the patients and their families, good listeners, competence, enthusiasm, knowledge and being a good teacher. These qualities or traits were internalised and emulated by the surgeon by his 'consciously' bringing them into his day-to-day practice in order to help create an environment, which 'actualises' the basic tenets of a patient-centred consultation. This is in keeping with social learning theory, that learning is enhanced when 'learners' can observe and emulate the thinking and actions of the expert role models. (Bowen and Carline 1997)

The above tried and tested traits are considered significant and have therefore been incorporated into the culture of the assessment triad.

The impact of role models on the surgeon's behaviour and the positive outcome of patients' encounter with him could therefore be used as an exemplar of a clinical learning tool under the aegis of the assessment triad. This means that the 'learner' scrutinises the practice of an expert and engages in 'reflection-on-practice' through a critical dialogue with the 'expert' where the learner is testing and confirming and the expert is evaluating both his/her own and the learner's practice. In other words, the result of this is 'clinical practice policing' for the benefit of promoting patient-centeredness in their practice.

Furthermore, the significance of perpetuating the inherent 'value' of role models is seen in the recruitment and retention aspect of 'staff' (particularly in areas where recruitment is difficult), because good role models are often responsible for "shaping and reshaping the views of their future careers [of HCPs /learners]." (Wright *et al*, 1997:54) This view is also reflected by Mutha *et al* (1997:637) who suggest that 'learners' "gravitate towards specialities where they see inspirational role models." This proved so in the case of the surgeon in this study who acknowledged that he himself had gravitated to the speciality of colo-rectal surgery because it was the field where certain 'role models' had inspired him.

Studies, which highlight the attributes of good role models, (Wright *et al*, 1998; Elzubeir and Rizk, 2001; Paice *et al*, 2002; Skeff & Mutha, 1998) also offer selection

criterion for both students and HCPs within the healthcare profession. Fundamentally, it includes an individual's therapeutic qualities, 'social orientation', non-judgemental attitude, honesty, friendliness, empathy and genuineness. They suggest that these are essential and need to be present in an individual if they are to identify what is important to them as they pursue a career in the healthcare profession and learn 'on the job' via role models. Over time these 'students' will qualify in their chosen professions and become the very 'role models' who will instigate good practice both by example and through reflection.

The surgeon's 'new' learning in his formative years, as a house officer was identified as the result of reflection on action (Schon, 1983), a process that offers support to the present trend in education; for example students are encouraged to keep a 'reflective journal' on practice, to enable them to identify good and bad practice, as well as the actual situations and scenarios which made it so.

Such action will also help to develop the 'practice' regardless of the status of the 'practitioner.' Designated sessions in the curriculum must continue to be devoted entirely to 'open' discussions on good and bad practice encountered by 'learners' to provide a mechanism for both self-discovery and to identify learning/developmental needs to contribute to an improvement in an individual's ethos of care. In addition such dialogues should give them confidence to challenge poor practice when/if they come across it.

### **Evidence-based messages**

Evidence-based healthcare/practice has become one of the major driving forces in the NHS, with an impact on education, policy making and research, and therefore has direct interest and relevance to all health teaching and research in universities. (Bonner, 2003) This study offers the assessment triad as a means of understanding patients, tailoring interventions, and making healthcare patient-centred. The 'triad' has evolved from the patients' story of their illness, a generated abstraction from their doings and their meanings. (Glaser, 2002)

Healthcare professionals are obliged to respect their patients by taking on board this grounded 'triad' of assessment and educationalists must begin to introduce and challenge/test new knowledge as a means of advancing critical thinking in practice. In other words, practice must reflect evidence of a "conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients." (Sackett, *et al*, 1996:71)

A more recent definition of evidenced-based practice (EBP) suggests that EBP requires that decisions made about healthcare are based on current relevant evidence and most importantly that decisions "should be made by those receiving care, and informed by tacit and explicit knowledge of those providing care, within the context of available resources."(Goldenberg, 2006:2622)

The assessment triad offers 'external' clinical research evidence, which in essence is inspired by patients and questions previously accepted practice in a [patient/surgeon] consultation and replaces it with a more efficacious, accurate and safe mode of practice. (Sackett, *et al*, 1996)

Patients' needs and expectations, as revealed in the pre consultation interview with the researcher, were observed as being met in the consultation with the surgeon and confirmed by the patients in the post consultation interview with the researcher. The emphasis in evidence based practice on the dissemination of information, as well as its collection, so that the evidence can reach clinical practice, has commonality with the idea of research-based practice, a concept being proposed here to support evidence-based practice.

Each component of the triad for example, offers a new perspective to 'old' thinking. Emotions for example have multiple interpretations and connotations and what it means in the context of a 'consultation or healthcare encounter' with the patient deserves a fuller exploration if empowering patients is the responsibility of every healthcare professional.

Theories on patient-satisfaction or an individual's locus of control for example, offer grounds for negotiation in an encounter, a compromise or a 'mutual resolve' on the

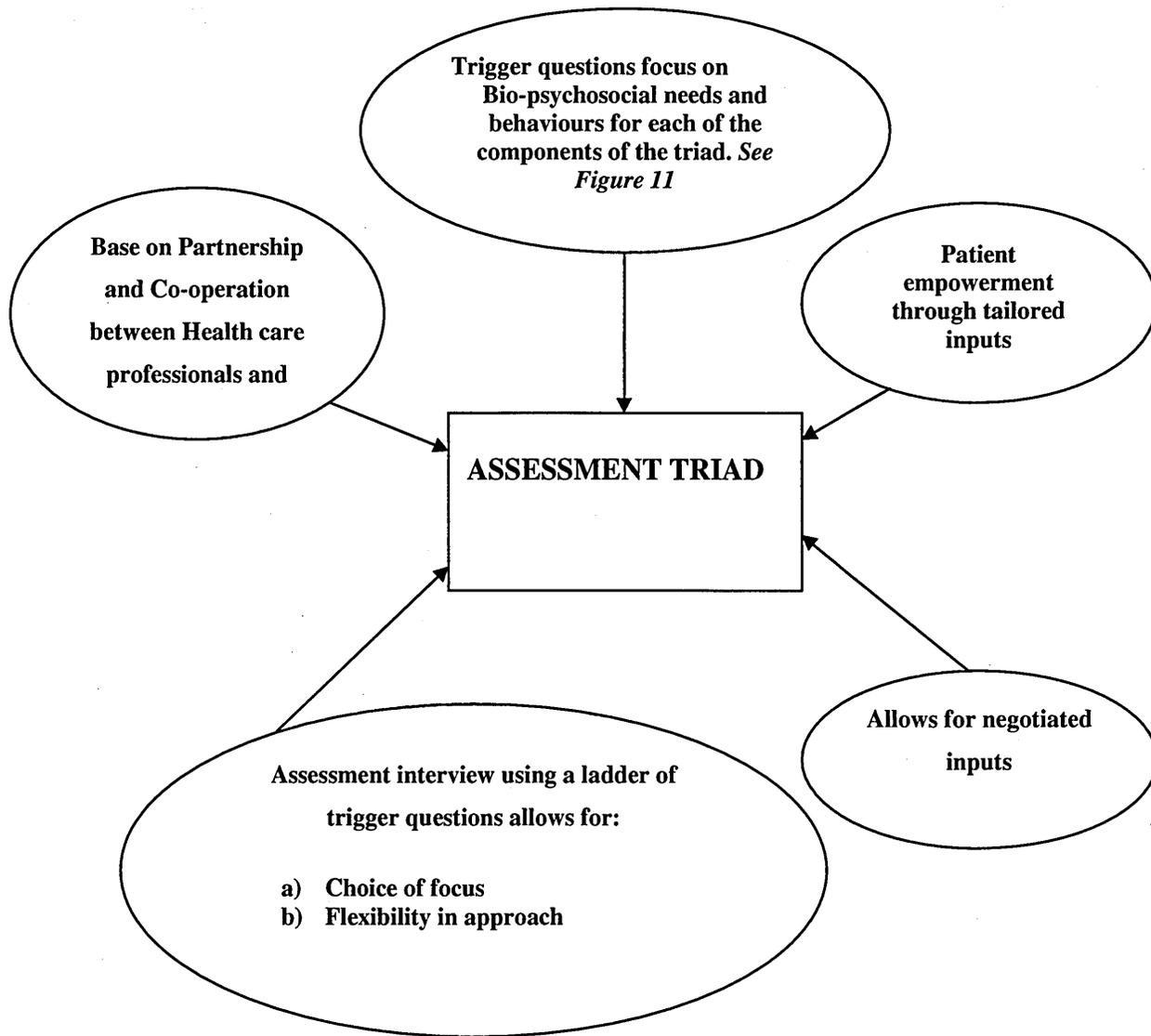
strength of that evidence to patients and to the educationalists the opportunity to encourage 'students' to look beyond the immediate uses of theories *per se*, to integrate active thinking into practice and foster their empowering skills in practice.

In summary, this study offers empirical evidence from a patient-centred research, that patients seek the 'expertise' of a surgeon [HCPs] in order to resolve their uncertainty of illness and loss of control and therefore seek ways of *seeking engagement* in the 'consultation' with the surgeon and/or *regaining control* of the 'situation', in order to restore the 'status quo', their equilibrium as a means of seeking peace of mind in the consultation.

The message to healthcare professionals is that in each encounter with the patient s/he will relate a story, which has a discrete 'beginning and an ending.' Although the process of their story telling may not fit with the professional's 'technical thinking', it is possible to deliver patient centred interventions as long as the healthcare professional listens to the patient and attends to patient identified needs. To achieve this, the healthcare professional would be using additional skills such as observation, reflection on and in practice, embedded in the assessment triad thus demonstrating 'shared responsibility.'

**See Figure 13 below for the potential attributes of the Assessment Triad.** (Its value is considered as 'potential' at this stage because it has not been tested as yet)

**Figure 13: Potential attributes of the Assessment Triad**



## Conclusion

The discussion has drawn attention to the 'status' of the three stakeholders, the patient, the professional [in this research, the surgeon] and the policy makers, as the overarching instigators for change in patient care in the Health Service. It has been the aim of this study to elicit how patients describe their experiences of a first consultation with a surgeon in a hospital's outpatients clinic. Historically, each has evolved to meet the 'dictate' of advancing health demands, but the 'responsibility' of each to activate a 'chain', which links care to patient-centeredness, remains relatively elusive.

The patient's metamorphosis into the 'new patient' is aided by Government initiatives, which are seen to harness their energy on maintaining the primacy of patients in the healthcare arena. Furthermore, the media resources and particularly the Internet (the virtual library), have armed patients with 'new' knowledge (good or bad) and in a sense created the patients' desire for self-care or autonomy in decision-making in healthcare.

The practice of medicine as reflected in 'consultations with patients' in particular has made a slow but positive progress from being doctor-centred to being patient-centred. However, this progress could be described as still rooted in covert paternalism and is determined by the 'knowledgeable healthcare professional', knowledge, which promotes individuals to a position of power. (Klein, 1989)

Historically, medicine has remained reluctant to relinquish its power within the holistic theory of disease recognising it as the 'scientific basis of medicine.' However, knowledgeable patients of today have made inroads into this 'sanctum' and medicine has succumbed, by enlarging its scope to overcome its limitations. It has re-modelled the previously preferred pervasive 'medical model' to a bio-psychosocial model, which acknowledges that the holistic approach recognises that "illness is closely related to the personality and experience of the patient, and that man cannot be understood in isolation from his [her] environment." (McWhinney, 1981:78)

The Government's for instance, influenced by the public's opposition to medicine's excessive paternalism, lack of respect for patients and their right to make decisions about their care. (Ham, 1999) Today, patients' rights, user involvement, and attempts at

creating a powerful alliance between knowledgeable patients and knowledgeable doctors and healthcare professionals allied to medicine, are 'tools' used by the Health Service to resolve the doctor/patient divide and to create 'patient-centeredness' in their 'encounter.'

The findings of this study revealed that in illness patients experience 'an emotional crisis,' the sense of helplessness and unpredictability, the response to which is that they seek peace of mind by *seeking expertise* from the surgeon. Armstrong (1990: 969) suggests that gaining 'knowledge' is a means of levelling out the "hierarchal relationships that exist between the surgeon and patient in order to help demystify medical information."

The three components of the assessment triad, a composite of patients' experiences and adaptive responses from the pre-consultation interview with the researcher activate this 'search' for peace of mind. When experiencing *crisis*, patients are seen to be *seeking engagement* with the surgeon and/or *regaining control* to achieve their goal of *seeking peace of mind*, or maintaining their equilibrium.

These adaptations were consistent with the types of doctor/patient interactions, in a consultation identified by Bensing (1991) as systems, which reflect patients' needs for 'cure' and 'care.' *Seeking engagement* was about the need 'to feel known and understood' (care) and *regaining control* was about the 'need to know and understand' (cure).

The adaptive processes also showed variations in depth and behaviour for example, the element of 'hoping' observed in the category *seeking engagement*, concurred with Porn's (1999) belief that hope is implicitly found in the patients' desire to be cured and is expressed as confidence in the surgeon's expertise, or with Farren *et al* (1995: 21) who offer a psychological stance that hope involves the individual reaching within himself or herself for the "best apothecary and accepting the challenge to confront a new situation."

Seeking involvement, an element of the category *regaining control* on the other hand, was consistent with Gattellari *et al* (2001) who found that patients who were given the

opportunity to participate [get involved] in decision-making, consistent with their participation preferences, experienced significantly greater decrease in anxiety and resultant 'control' in the post consultation environment, compared with those whose participation was greater or less than preferred.

It is therefore this 'dynamism' and variance in patient behaviour and reaction in 'crisis', that requires a format, which will facilitate 'eliciting' of patients' experiences and needs. One that is flexible, is able to 'tap' into intrinsic and extrinsic factors that influence patient emotions and behaviour and enter that 'inner consultation', which holds the key to patient-centeredness and the deployment of 'tailored' interventions. The assessment triad meets with this requirement.

Exploration of the 'informing' theories and the few presented as 'absolutes' has also enhanced the potential and applicability of the 'assessment triad' in a consultation, and offered 'transferability' to practice where the bio-psychosocial interpretation of a patient's 'being' is paramount to patient-centred interventions, fulfilment and the ultimate patient goal of seeking peace of mind in 'illness.

This study offers a new insight into patient -centeredness and patient satisfaction in the substantive area of patient/surgeon experience in a first consultation in a hospital outpatient clinic. It does not assume what patients seek in the 'encounter' and offers a 'grounded' assessment triad, (patient induced), which reflects a holistic approach to 'consultation.'

Furthermore, the presentation of the assessment triad in a cyclical format, anticipates that respect, empathy, genuineness and warmth, which are crucial to the efficacy of the 'therapy' being offered [by the surgeon as in this study] to the patient (Lazarus, 1979), will elicit the 'inner needs', when the environment is conducive to an 'open two way dialogue.' The outcome of the surgeon/patient consultation '*constructing a partnership*' (see *Chapter 7*), and the patient/researcher post consultation outcome interview '*sensing relief*' (see *Chapter 8*), are testimonials to this end and to the fulfilment of the patients' needs and their peace of mind.

Patients' search for peace of mind, the core category or overarching theory in this study stands to bring together the three stakeholders of this process. The Government's intent that the needs of the patient and not the needs of the institutions are at the heart of the new NHS (DoH, 1997), are actualised in the assessment triad, which determines what processes govern the 'transition' of patients into the participatory realm.

Medicine has embraced some 'change' and has shown intent towards the 'therapeutic alliance' and an awareness that the challenge of achieving patient involvement also resides in the accommodation of the 'modernised', informed and assertive patient of today.

Neighbour (1977) proposes the patient-centred model, which sees the need to find out and to understand why an individual patient has sought help and advice and together to be able to agree the most appropriate way forward. These are encouraging signs within medicine, and the format of the assessment triad could be an *aide memoir* to making patient-centeredness a reality in a consultation with patients.

The patient on the other hand is 'consulted' within the remit of a patient inspired/induced assessment triad, which makes the 'one size fits all' approach and the fear of paternalism a thing of the past.

### **Limitations of the study**

I am aware of the criticism levelled at qualitative work however, my participative role was part of the strategy and I contained 'bias' by being aware of my own perspective and acknowledged my influence on the data by just being there.

Abdellah and Levine (1994) who acknowledge the participation of the researcher in qualitative research, place the researcher squarely into data collection and analysis phases of the study. My involvement as the researcher as prescribed by a qualitative approach in order to uncover a better understanding of human behaviour and relationships through an in-depth exploration of real life experiences (Abdellah and Levine, 1994) for example, fits with this study's commitment to elicit patients' experiences in a first consultation with a surgeon in a hospital's out-patients clinic.

This use of 'self' in a qualitative interview is in contrast with the structured, systematic and objective interviewing techniques that are noted generally in quantitative studies where the researcher consciously stands apart from the production of the data. (May, 1991) It stipulates that there is a testing of a pre-determined theoretical framework through the collection of responses that can be statistically analysed and be as free as possible from the influence of the collector of the data.

As the interviewer in qualitative work I did not distance myself from the process of data collection and I participated in data production and concur with May (1991) assertion that the success of qualitative interviewing is dependent on the researcher's skills in interpersonal communication and that these skills are not readily learnt. May further argues that the use of the self in qualitative interviewing can be extremely challenging and asserts that the common use of the interview provokes assumptions that everyone knows how to do it and that its complexity and challenge are often overlooked.

There is also an inherent problem of my nursing role and that of the interviewer role becoming blurred. (May, 1991)

The pre-consultation researcher and patient interview provided the most relevant context in which to assess preferences as the patients were about to become 'recipients' of the consultation approach. Little *et al* (2001: 468) indicate that an impending consultation with a particular problem may "plausibly change priorities and preferences and therefore provides a 'real' rather than abstract or theoretical basis for patients considering questions and answers." There is a risk however, that specific discursive practices and forms of knowledge are influenced by institutional settings. (Johanson *et al*, 1996)

Furthermore, patients in the study expressed gratitude for the 'pre-consultation chat' with the researcher because their participation in this process enabled them to prioritise and formulate their needs and rehearse their level of 'participation' prior to the consultation with the surgeon. In essence they were offered a 'safe' environment in which to express their 'feelings and their innermost fears' that accompanied them in their decision to consult with the 'expert.' Everyone knew that the consultation was

under scrutiny but the effect of this is unknown. Furthermore, although I did not lead the patients to a particular way of thinking, potentially the interview may have changed their thinking, clarified their thoughts and focused the questions to ask of the surgeon.

In contrast however, the researcher saw the value of a pre-consultation interview (by default), as a casual cognitive 'rehearsal' for patients' narration of their stories of 'illnesses' and therefore would still recommend this practice in areas where healthcare professionals carry out pre-assessment clinics across the healthcare domain.

The surgeon's comment (in the researcher/surgeon interview) that GPs' referrals did not always reflect patients' 'problems' would have been more illuminated had the researcher widened her 'engagement' to include patients' experiences with their GP before the referral itself. It would have offered additional grounded information for assessing where patients' needs actually originated and if they in essence were related specifically to the meeting with the expert or not. Although most patients made reference to the GP's 'need' for referral to the 'expert' at the hospital, perhaps questions such as "Tell me about the information you received about this 'ailment' from your GP" or "Why did your GP see the need to refer you to this clinic?" may have been a good starting point to focus on this aspect in the study.

As a sole researcher of this study, it is difficult to determine if a balance was struck between introducing bias and responsibility in the use of self as an instrument in theoretical sensitivity. Measures were taken however to acknowledge and address this potential tension in the research design.

I suggest too that even though patients' 'stories' included their experiences of consultations with other 'doctors', a further limitation is associated with the study's focus on only one surgeon's outpatient clinic.

Finally, the written word also has limitations as a vehicle for conveying aesthetic aspects of patients' experiences/emotions in the consultation with the surgeon as shared at the time of the interview. It can only be hoped that my respect for the data, which

emerged from the interviews is reflected in the presentation of the findings, the theory generated and ultimately the recommendations.

Although Grounded Theory offers precise procedural 'steps' to theory development these were by no means linear and were informed by a matrix of analytical thinking and synthesis. My constant questioning of what was going on in the data albeit on bus or train journeys or even during mere domestic chores, were informed by my personal experience, intuition or a certain 'grab.' This 'emergence' or new insights were unexplainable because they just happened and are difficult to capture on paper, proving to a certain extent the limitation of presenting transparency of thought in this study. See exemplars **Figures 14a and 14b overleaf.**

**Figure 14a:** An exemplar of theory building analytic operations of **Empowering**

Narrative Exemplars	Conceptual label	Sub-Category	Category	Theory
<p><b>Dave:</b> "...I want to be able to make up my own mind..."</p> <p><b>Surgeon:</b> Yes, of course you must make these decisions. I will offer you my diagnosis and possible treatment, first you must lead me as it is your problem, so you must take some responsibility too...</p> <p><b>Dave:</b> "That's great, I feel good about this set up...about taking the lead,...we must the decisions with your help"</p> <p><b>Philip:</b> "I appreciate that you are getting me involved...."</p> <p><b>Surgeon:</b> Yes, of-course, we will work together, I will not ignore your feelings...you matter; I want you to feel that you owned the decision made.</p>	<p>Seeking ownership</p> <p>Offering autonomy</p> <p>Offering ownership</p> <p>Asking for help with ownership</p> <p>Appreciating involvement</p> <p>Offering 'partnership'</p> <p>Encouraging ownership</p> <p>There is a sense of wanting to 'regain control'? and the surgeon giving back control?</p>	<p>There is a sense that these elements are building blocks of the subcategory <b>Empowering</b>. It seems like a 'dynamic' process. Power was both taken and given. Evidenced in Hegar and Hunzekar's (1988) claim that power is shared in empowerment. There appears to be a variation in the depth of power patients seek in the two exemplars and concurs with Guadagnoli and Ward's (1998) claim that not all patients will want to take total control of their medical care'</p>	<p>Sub categories of <i>rapid engaging, transcending formality, sharing information, fulfilling expectations, inspiring confidence</i> and <i>empowering</i> are the elements of a higher category <b>constructing a partnership</b></p> <p>Each element seems to resonate a sense of patient-centeredness, of sharing "a degree of individualism is finite" (Lauver <i>et al</i>, 2002).</p>	<p>This feeling of being empowered, <i>regaining control</i> and working in 'partnership' (<i>engaging</i>) with the surgeon has alleviated their fear of the paternalistic overtures of a 'consultation' and addressed patients' goal of <i>seeking peace of mind</i>, when seeking help with their 'illness' It is about the conflict principle, 'a balance of powers among interests, capabilities and wills' (Rummel, 1981) offered in the patient-centred ethos of the surgeon</p>

**Figure 14b:** An exemplar of theory building analytic operations of *Transcending formality*

Narrative Exemplars	Conceptual label	Sub-Category	Category	Theory
<p>Mary: “So while you are down there (working with the rectal region) with my problem how about repairing the old scar so that I am bikini-worthy this summer?”</p> <p>Surgeon: [laughs] “so plastic surgery is included in this package of colorectal consultation is it? I see”</p> <p>Mary: “it’s a deal then?”</p> <p>Jane: “This colonoscopy...will I be awake?”</p> <p>Surgeon: “We will give you an injection to make you sleepy and very relaxed, it is like gin and tonic. What is your favourite drink?”</p> <p>Jane: “That will be fine but do not forget the ice”</p> <p>[both laugh]</p>	<p>Informality in tone of dialogue</p> <p>Feeling safe to barter</p> <p>Voicing inner desire</p> <p>Using humour to create informality</p> <p>Appreciating a deal? sort of partnership?</p> <p>Expressing concern</p> <p>Alleviating anxiety</p> <p>Using humour</p> <p>breaking formality in a social question</p> <p>responding to informality</p>	<p>There seems to be sense of <i>transcending formality</i> in the surgeon’s interaction with his patients to create a ‘bond’ in their ‘encounter.’”</p> <p>Patients seem relaxed and therefore able to disclose their desire and inner feelings. Humour was infectious and produced the effect of informality. This ‘transcending’ formality concurs with Henry and Moody (1985) who suggest that the use of humour in a consultation offers a way to cope with anxiety and stress and to view life’s trials in new light and with an emotional distance. Davidhizar and Newman-Giger’s (1995:64) s claim that humour offers a way to “reconceptualise the situation and to make the unchangeable more tolerable” seems to echo in the surgeon/patient interaction in this consultation</p>	<p>Breaking down the barrier of ‘power’, which exists in the surgeon’s relationship with patients, and creating an ‘informal tone’ through humour is akin with Neighbour’s term or description ‘gift wrapping’ that is tailoring an explanation, and creating a sense of patient satisfaction and rapport ; ultimately laying down a foundation to <i>constructing a partnership</i>.</p>	<p><i>Constructing a partnership</i> with its building blocks or concepts, <i>rapid engaging, transcending formality, sharing information, fulfilling expectations, inspiring confidence and empowering</i> embraced a ‘social’ contract, which is active and created through negotiation, adjustment, resolution and decision (Rummel, 1891);upholding the ethos of patient-centeredness, rescinds paternalism, encourages patient participation and achieves their goal of <i>seeking peace of mind</i> in a consultation with a surgeon/’expert’</p>

## **Recommendations**

Based on the findings of this study and recognising the limitations discussed above, there are a number of tentative recommendations that can be made. These focus on the core category *seeking peace of mind* in illness and the inherent value of the ‘assessment triad’ in meeting this need and are structured around the themes of patient-centred care; professional education [theory and practice] and training; and future practice-based research.

### **Patient-Centred Care**

This would involve restructuring practice whereby the purpose of pre-operative assessments is changed from the non-directional attitude to a purposeful dialogue to meet patients’ self identified needs/gaps using the assessment triad. For this to happen, the pre-surgical ‘engagement’ with patients needs to be based on a framework, which enables the identification of patients’ needs and resonates with their expectations. By replacing these loosely structured *laissez faire* ‘pre-operative visits’ with a structured evidence-based ‘pre-operative assessment visits’ would allow the perioperative practitioner to capture the patients’ bio-psychological and spiritual needs in a holistic manner and ensure a purposeful professional engagement.

The assessment triad offers a generic framework for this assessment for use by healthcare professional including surgeons and other professions allied to medicine. The use of this assessment triad by ward staff for example, will offer a baseline assessment for the admission process and preparation of patients for surgical interventions, and put in place a line of direct communication with the perioperative practitioners. This in turn will encourage continuity of care for patients during their ‘perioperative journey.’ Thus the use of a meaningful, patient-centred assessment should promote patient-centeredness in healthcare interventions, patient satisfaction and contribute to the patients’ search for peace of mind.

It is recommended that a patient-centred model of care as also proposed by Neighbour (1987) replace the medical model so that the assessment triad improves the quality of the interviews by for example:

- Tailoring interventions to individual needs [as opposed to applying generic models].
- Fostering patient education strategies:
  - a) Which are tailored to their level
  - b) Using language or range of communication aids to reflect the patient's ability and capacity.

### **Education and Training**

The healthcare professionals' responsibility to be clinical role models, clinical supervisors, clinical and patient educators is proposed as the strategy for formalising the adoption of the assessment triad in practice.

At a clinical level, practitioners would have to be prepared and mentored in the use of the assessment triad so that they in turn can supervise, mentor, educate and role model the desirable behaviour of conducting patient centred perioperative assessment and care. In-service training for clinical role models in the use of the assessment triad and encouraging the use of a reflective journal will create 'role models' of good practice for present and future learning.

As an educationalist I shall be encouraging an integrative approach of the 'humanities' and social sciences, in curricula across the health spectrum so that healthcare professionals develop the skill of transferring the inherent value of informing theories to practice, and questioning those that remain 'elusive' to application. Furthermore, I intend to use my influencing skills in pre-registration medical education when I teach the art and science of perioperative practice to fourth year medical students. I recognise that it presents a golden opportunity to sensitise medical students to the perioperative needs of patients and instil in them that they [medics] have a responsibility to contribute to the patients' search for peace of mind. Similarly, I intend to modify the study programme for pre-registration nurses undertaking the surgical placement in perioperative practice to reflect this quest for patient centeredness.

While I can see the potential and need to include the assessment triad in post qualifying medical education, I am cognisant of the fact that the framework would need to be tried and tested in practice before approaching the regional deanery to negotiate input into post-qualifying medical education.

If people are to be given back responsibility for their health [as per Government initiatives] then one must consider the 'who, what, and when' for this proposal to be effective. I would suggest that the time to encourage people and prepare them to take charge of their own health, (and which precedes the need for an assessment triad), is not when individuals need healthcare inputs, but is instead at a time when these messages, skills and behaviours can be internalised to a tacit level. The most opportune time would be during the formation years by including 'health and health responsibility' into the 'compulsory education curriculum', e.g. as a component of the 'Citizenship' unit of study in senior schools. This should then ensure that the building blocks of preparing the adults of tomorrow with the notion of 'responsibility for self care' are in place.

### **Research**

The holistic underpinnings of the research based assessment triad will avoid 'silo research' by ensuring synergy between human and social sciences, and would uphold the principle of patient-centeredness in care and inform curricula.

I recognise that there are clear opportunities to implement or use the assessment triad and to expand on this research in the future. For example, future research could be extended to General Practitioners [GPs] and other surgical specialities. The rationale for including GPs is two-fold: (a) as the first place of call for the patient, GPs make clinical decisions about the management of the patient; (b) as gatekeepers to specialist referral centres, GPs make clinical decisions about when to refer and where to refer the patient for an opinion. Extending the research to include GPs would enable a more in-depth study of the period of patients' initial search for help and their peace of mind, as it forms the basis of the eventual surgical consultation.

As this research has focussed on a single surgeon and speciality, as well as a single research site, there is ample potential for it to be extended to other surgical specialities

and sites. Such research would allow clinicians to explore the needs of patients from different perspectives and in time identify commonalities between them, thus contributing to theory development and testing.

The introduction of the assessment triad to other specialities will also foster a 'standard' tool for measuring patient outcomes in surgery. In time such research should be extended to medical specialities because it perpetuates patient-centeredness, continuity of the ethos care and the primacy of the patient role in healthcare. Since substantive theory is grounded in research on one particular substantive area as the patient's experience of a first consultation with the surgeon in a hospital's outpatient clinic, it might be taken to apply only to this specific area. However, a theory at this conceptual level has important general implications and relevance, and therefore can become a "springboard or stepping stone to the development of grounded formal theory." (Glaser and Strauss, 1967:79) This can be done with further theoretical sampling and constant comparisons. (Glaser, 2002) For example, in eliciting an individual's behaviour and response when confronted by 'crisis' or a difficult 'situation. In other words moving the utility of this substantive 'theory' *seeking peace of mind* to a formal status, which informs and supports individuals' behaviour in other forms of 'crisis'

### **Reflexivity**

Reflexivity describes the struggle that exists between the researcher being a 'researcher' concomitantly with being part of the culture being studied. It is inevitable that at some stage the researcher becomes part of the phenomenon being explored' (Streubert and Carpenter 2003), and may 'alter' it. This is a major issue with the researcher being the 'instrument' of qualitative research. Maslow (1966: 45) asserts that 'there is no substitute for experience, none at all', and points researchers towards the value of 'self-dialogue and discovery.' Walsh (1995: 335) supports this view and further claims that researchers who begin their research with the data of their experience seek to 'embrace their own humanness as the basis for psychological understanding'.

However, the reflexive validity, that is the researcher's attempt to constantly examine the biases, suppositions and pre-suppositions of the study (Finlay and Gough 2003, Reason 1994) offers a true insight into how significant the researcher's influence was on the study, and how credible the story she relates as being the 'insider' truly is. Hence I

offer transparency through my reflective account of my journey into exploring patients' experiences of their first consultation with a surgeon in a hospital outpatient's clinic.

## **Reflection**

The rationale for embarking on this study stems from the combination of three decades of professional experience as a theatre sister and lately as a 'nurse lecturer' in the field of Operating Theatre Nursing within the researched setting. My move into nurse education was triggered by my awareness and frustrations associated with the theory practice gap I was witness to when supervising new staff in the theatres. I knew that I could use clinical experience to reduce the theory-practice gap by taking a practice based approach to my teaching thus giving back to this specialist practice the value of my *aesthetic* experience. During this journey, I undertook undergraduate and postgraduate studies which confirmed for me that as a practitioner-teacher, I needed to become involved in the empirics of practice. Thus, it was inevitable that I would wish to research topics that were intrinsically linked to my specialist area of practice, i.e. the care of 'vulnerable' patients during their perioperative journey of anaesthesia, surgery and recovery. My intention was that my participation in research would benefit the patient experience; something which I could utilise in my day-to-day work in the practice and education settings.

I had become acutely aware that much of the nursing input in theatres focused on technical excellence; often at the price of 'nursing excellence'. With hindsight I admit that my own clinical practice [as theatre sister] had been firmly rooted in the technical excellence of the theatre happenings, therefore not only did I perpetuate it but condoned it. The shift back to focussing on nursing excellence is due to higher-level cognitive studies that led me to reflect on and challenge my own behaviours and assumptions. Recognition of patient vulnerability led to me questioning how 'informed' they were about their impending surgery, as many interventions proceeded beyond that which they had originally consented to. I identified that I did not really have a first-hand knowledge of "*What are the information needs of patients undergoing surgery?*"

To an extent, the impetus for this research came from my previous research [as part fulfilment of the MSc in Nursing], which elicited nurses [recruited from five hospitals in

London] understanding of the concept of informed consent in practice. The [MSc] study confirmed that when confronted by ethical dilemmas nurses initially used moral and ethical reasoning within their comfort zone but quickly resorted to the legal bandwagon. In this current study, I moved beyond what healthcare professionals consider as ethical maxims of informed consent to a more fundamental issue of eliciting patients' information needs in a consultation with a surgeon in a hospital outpatient's clinic. However, the structure, guiding my early interviews into the exploration of patients' information needs was based on the doctrine of informed consent, namely respecting the autonomy of individuals and embracing the four elements of information including risks and alternatives, understanding, competence and voluntariness. (Beauchamp and Childress 2001)

My 'entry' into the outpatient clinic was unproblematic probably because I had invested much time negotiating with the nursing and medical staff. This strategy ensured that they were fully informed about the research; had clarity about their roles; and they were in the know about the operational side of the research process [e.g. when I would be in Outpatient Clinic; the room I would use for interviewing patients]. I was encouraged by the support and encouragement from Outpatient Clinic staff and the surgeon. I was very aware that my presences in the Outpatient Clinic altered it in: (a) the fact that I occupied a room in the clinic for interviewing the patient, may/not have increased pressure on room occupancy; (b) the staff nurse's working practice was modified due to her involvement with the research project, i.e. she was responsible for switching the tape recorder on and off at the appropriate times, and she escorted the patients back to me for their final interview; and (c) the surgeon knew that his clinical consultation was under scrutiny – albeit in an indirect manner. I conducted the interviews in the most unobtrusive way that I could, (e.g. choosing to go and look for the patients for the final interview should the staff nurse have forgotten to escort them back to me, and not popping in to see the surgeon between interviews), so that I did not alter the ambience or structure of the Outpatient Clinic more than necessary.

While my interpersonal skills facilitated successful recruitment of patients to the study, I was alert to the concepts of '*academic armor*' and '*physical armor*' that researchers may be impeded by. Lerum (2001: 468) refers to the '*academic armor*', as that which prevents the intimate emotional engagement often required in qualitative research and

the '*physical armor*', as the professional clothing and demeanour. Lerum indicates that dropping this 'academic armor' allows richer and more intimate acceptance into the lives of participants, which Denzin (1997:83) considers is a visceral way of 'moving beyond seeing to understanding'.

Each interview was a therapeutic experience for me; reviving the sense of 'mutuality' in patient contact often lost behind the screens of technology in perioperative nursing; it took me back to my 'professional roots'. When patients began to divulge some very intimate and private information, I had to confront the role dilemma of someone who is there as a researcher and not a nurse. In these instances, I had to remind myself and the patient that I was a researcher first and then a nurse. I found this a little daunting as 'the researcher me' was required to continue conducting the interview as researcher and not as a clinician. It would have been very easy for the 'nurse-me' to have followed-up the prompts from such conversations in a different way, whereas the 'researcher-me' was required to hold in check this unguarded enthusiasm so that I did not lead the patient into a particular way of thinking.

I remain appreciative of the patients who willingly consented to participate in the study and gave their time generously for all three points of data collection. The only way [other than thanking them for their contribution] I could show them my appreciation and gratitude for their input into the study, was by escorting each patient to the relevant departments for 'bookings' of appointments for diagnostic procedures or by escorting them out of the hospital building; both actions served as a formal means of closing the researcher/patient 'encounter'.

On listening to and reflecting on the early interviews, I discovered that my 'chit chat' often led me to missing 'cues' which could have been picked up and followed up to probe the issue/s in more depth. It may be that initially I was too casual in my approach or that I was not fully attuned to utilising the data being divulged to its full potential. A similar exercise with later interviews indicated that the process was more dynamic as I was better at following up lines of questioning. I felt that my approach to data collection was more mature and honed – resulting in richer data sets.

Something that I had not envisaged occurring was a chance meeting with the 'participant patients' in the clinical setting. Therefore, it surprised me when in the course of my clinical visits to the surgical wards [as a link lecturer and personal tutor], I found myself being greeted by them. These encounters are indicative of the mutuality established at the interview stage, as well as extending engagement with each other beyond the research setting. Another surprise was that these participant patients were actually interested in the progress of the research as I found myself being quizzed me about. Yet another element of these post surgery conversations was the revelation that whilst they continued to appreciate the surgeon's personal qualities and excellent 'surgical-craftsmanship', they were critical about some aspects of care received/given on the wards. It would seem that the direct line of communication and interpersonal link created between surgeon/patient in the outpatient clinic was severed in the wards through the shift pattern system, which requires inputs from numerous junior grades of medical staff, as well as nursing staff. The patients found that the quality of information from both staff groups was weak, often contradictory in nature or inadequate. On reflection what the patients were describing is a sense of 'loss of individuality' and a return to the 'conveyor belts' of clinical input and output.

For me this was a cause for further concern with regard to nursing practice, as I sadly realised that once more good healthcare practice was not a universal phenomena but continues to 'excel' in pockets, which do not add up to the sum of the whole. This conclusion has made me keener than ever before to explore the patients 'needs' and to offer clinicians a 'grounded' guide (not purely theoretical or academic ones) to encourage and promote patient-cantered interventions. I strongly believe that there is a need to raise the profile of the 'knowing' in aesthetic practice in medicine, nursing and professions allied to medicine if patient involvement and patient-centred care is to be central to healthcare delivery.

As stated earlier, this study emanated from my combined clinical and teaching experiences; I believe that these roles have complemented this research by offering both 'personal and aesthetic' knowing enhanced by empirical knowing. (Carper, 1978) My key lesson from undertaking this research and one that I would wish to share with other healthcare professionals is that: 'if we deliver on involving patients in decision making, then we are assisting and enabling them with their search for peace of mind'. This

concept is reflected in Rommetveit's (1989:52) statement that we should not forget that man is embedded in 'an immanently meaningful world, and hence in certain respects [is] incomprehensible unless you engage in interpretation of that subjectively meaningful world from within and take for granted that it is –at least partially-shared [en route to their being empowered by you]’.

At a professional level, this is an exciting finding; the study offers a substantive underpinning to introduce a new way of thinking to the clinical areas and enabling clinicians to test the assessment triad in relation to this finding. I am confident that I can proceed with changing practice. I have given the issue much thought: I think the best way forward would include sharing the findings of this study collectively and meaningfully in the surgical arena of the research setting before moving on to other areas within the healthcare domain.

## **APPENDIX 1**

## 1 : Literature Search for "CONSULTATIONS"

Scope Note for: *Physician-Patient Relations*

**MeSH HEADING: PHYSICIAN-PATIENT RELATIONS**

**SCOPE: The interactions between physician and patient**

### REFERENCES:

See Related:

**TRUTH DISCLOSURE**

Used For:

**Doctor-patient relations**

**Doctor patient relations**

**Physician patient relations**

**Physician patient relationship**

**OVID MEDLINE (R) 1950 to June week 3 2007**

#	Search History	Results
1	exp* Physician-Patient Relations/	20019
2	exp * "Referral and Consultation"/ed, st, es, hi, td [Education, Standards, Ethics, History, Trends]	1467
3	1 and 2	55
4	limit to (humans and English language)	38
5	from 4 keep 1-38	38
6	from 4 keep 1-38	38

**1a: Literature Search for "CONSULTATIONS"**

**Scope Note for: "Referral and Consultation"**

**MeSH HEADING: REFERRAL AND CONSULTATION**

**SCOPE: The practice of sending a patient to another program or practitioner for services or advice which the referring source is not prepared to provide.**

**YEAR of ENTRY: 1968**

**PREVIOUS INDEXING: Interprofessional Relations (1966-1967)**

**REFERENCES:**

**Used For:**

consultation  
gatekeepers, health service  
hospital referral  
second opinion  
consultation and referral  
health service gatekeepers  
hospital referrals  
referral  
referral, hospital  
referrals, hospital

**OVID MEDLINE (R) 1950 to June week 3 2007**

#	Search History	Results
1	exp* Physician-Patient Relations/	20019
2	exp * "Referral and Consultation"/	15758
3	1 and 2	415
4	limit 3 to (humans and English language)	313
5	from 4 keep 1-200	200

## **APPENDIX 2**

Dear Patient,

I am a nurse teacher who is currently conducting a study to establish what information patients seek about their health condition, for which they have been referred to the consultant at the hospital.

I am inviting you to very kindly volunteer to participate in this study, which will involve two interviews with me and an audio-taped observation of your interaction with the doctor.

The interviews with me will take place in a private room at this clinic and will with your permission, also be audiotaped. This will facilitate an accurate record of my questions and your answers and will of-course not distract you with my action of note taking. The interviews will last approximately 30minutes and will NOT affect your appointment schedule with the consultant.

Interview one will be conducted between you and I before you see the consultant. The clinic nurse who is aware of this interview schedule will call for you when the doctor is ready for you. If the interview is completed before then, I shall take you back to the waiting area of the clinic and inform them of your return.

I want to stress that the recording of the interaction between you and the consultant will NOT include your personal or medical history. It will only be a recording of your interaction following examination and diagnosis and offer of any medical 'intervention or investigation'. I will not be in the room with you and therefore the audiotape recorder will be switched on be the nurse looking after you.

The second interview with me will take place immediately after your 'consultation'. I will meet you outside the room and escort you to the interview room. Again this interview will take approximately 20 to 30 minutes.

I will if you so wish, escort you to the first department where you will be asked to call at for further tests or to book appointments for the same.

I appreciate that this second interview means asking you for more of your time and for this I am truly grateful.

I want to assure you that I will treat all the information received in the strictest confidence and that the information will not be used for any other purpose than that intended. The recordings will not include your name, as I will allocate a number to the tape, which will in turn only have your hospital number for my reference only. May I also ask if you would very kindly allow me to use some bits of conversation as direct quotes as it will help to enforce my thoughts or analysis?

All audiotapes will be locked up in a secure cabinet to which only I have access and on completion of the study these tapes will be stored for ten years and then destroyed.

It is VERY IMPORTANT however; that you are aware that you do not have to participate in this study and that if you wish not to do so, it will not affect the treatment you receive at the hospital. Again, remember that if you do decide to participate and then later change your mind it is your prerogative, and you are completely free to do so.

Whatever, your decision, my best wishes to you, and should you wish any further enquiries, I can be contacted at the hospital on: (omitted for confidentiality)

Thank you

Fanny Costa-D'sa

## **APPENDIX 3**

## Consent Form

Please sign the consent form after you have answered the following questions:

1. Have you read the information sheet, which gives details of this study?
2. Have you had the opportunity to ask questions and discuss this study?
3. Have you received satisfactory answers to your questions?
4. Have you received enough information about this study?
5. Do you understand that you are free to withdraw from this study:

At any time?

Without any reason for withdrawing?

Without affecting your future healthcare?

6. Do you agree to take part in this study?
7. Do you agree to my using bits of our conversation as direct quotes in the study?

Having addressed the above questions and after careful consideration, I am willing/am not willing, to participate in this study.

Signature of Patient:

Signature of Researcher:

## **APPENDIX 4**

1<sup>st</sup> February 1999

Fanny Costa-D'Sa  
Senior Lecturer  
Middlesex University  
10 Highgate Hill  
London N19 5ND

Dear Fanny

I enclose a letter to the Ethics Committee concerning your interviews.

Yours sincerely

Encl

An  
**NHS**  
Trust



  
**UCI**  
MEDICAL  
SCHOOL

1<sup>st</sup> February 1999

Re: Research Study on Patients Information Preferences

Fanny Costa-D'Sa, Senior Lecturer, Middlesex University

This is to confirm that patients may be interviewed in my clinic if they consent to the research study.

Yours sincerely

An  
**NHS**  
Trust



  
**UCL**  
MEDICAL  
SCHOOL

## **APPENDIX 5**

Senior Lecturer

Date as per postage

Dear Dr

Re:

I am carrying out a research into 'Patient information preferences from initial consultations with hospital consultants'. This involves asking patients questions about their expectations in terms of the information they would like to receive about their treatment. Specifically, the research intends to explore the elements of informed consent namely, information, understanding, voluntariness and capacity from the patient's perspective.

The interview was tape recorded and assurance was given that the contents of the recording will be used for the purpose intended and for that alone.

Mr. has given me permission to approach his patients on the premise that they consent to it. I have made it very clear to the patients that participation in this study is purely voluntary and that there is no inherent penalty for any refusal. In addition, I have informed them that I have no access to their medical notes or health information.

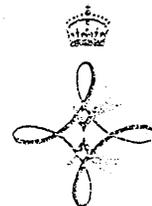
Please do not hesitate to contact me if you require any further information on the study in hand. I can be contacted at the bleep 2630.

Thanking you.

Yours sincerely,

Fanny Costa-D'sa

Sen.Lecturer



9<sup>th</sup> July 1999

Mrs. F F Costa-D'Sa  
Department of Cardiology  
Middlesex University  
59 Wilton Road  
Muswell Hill  
LONDON  
N10 1LX

Dear Mrs Costa-D'Sa

**99-18 Patients' Information Preferences – An ethical perspective**

I refer to your recent application to the Local Research Ethics Committee regarding the above project and I am pleased to inform you that you have been given **Chairman's Approval** to proceed with your study.

The Ethics Committee will meet again on the 6<sup>th</sup> September 1999, and will review your submission again at that time.

The Ethics Committee must be informed of, and approve, any proposed amendment to your initial application that has a bearing on the treatment or investigation of patients or volunteers.

A copy of the patient consent form and information sheet must be lodged in the clinical notes.

I am sure that every effort is already made to preserve the confidentiality of any patient information used in this study. Please ensure that the team of investigators is aware that everyone who has access to patient information appreciates the importance of maintaining confidentiality particularly in respect of the use of computers, and the statutory regulations laid down in the Data Protection Act 1984.

Yours sincerely

**Chairman - Local Research and Ethics Committee**

## **APPENDIX 6**

# CONFIDENTIAL

## TRUST ETHICAL PRACTICES SUB-COMMITTEE OF THE DISTRICT LOCAL RESEARCH ETHICS COMMITTEE

This form should be completed in typescript and returned together with 21 copies and the original to CREED, Level 2, Jenner Building,

Ref: .....

Name (in block letters) FANNY COSTA-D'SA.....

Date: 1st September 1998...

Appointment held...Senior Lecturer Dept: Health, Environment and Biological Studies.....

Address for correspondence: 59 Wilton Road, Muswell Hill London N10 1LX.....

Name of Head of Department or

Sponsoring NHS Consultant: ...Prof...  
Studies

Director of Research and Post Graduate

1 (a) State the title of the proposed subject:

**Informed Consent at Grass Roots : The need for a protocol in clinical practice**

(b) Give an outline of the proposed project: (attach further details where necessary).  
Sufficient detail of the protocol must be given to allow the Committee to make an informed decision.

Currently, the issue of informed consent has a higher profile in the health care arena, than at any other time in the history of the NHS.

Recent events at a hospital in the West of England have spelt out a warning that patients and their relatives no longer wish to play a passive role in health care decisions. Patients are asking to be informed of that 2% failure rate and not the 98% success rate. It is therefore implausible for nurses and doctors to make beneficence the only fundamental aim of health care practice.

Politically, informed consent in health care is policy driven. The White Paper (1997) in an effort to bring quality and efficiency together, aims to create a powerful alliance between knowledgeable patients and knowledgeable professionals. It is suggested that nurses and other health care professionals who best understand the patients' needs will shape the service given to patients. Informed consent is therefore integral to the quality agenda within clinical effectiveness, and partnership within health care teams, the NHS, patients and the public.

Access to information by patients in clinical decision making, within this present climate, has therefore come to be viewed as a 'right' of an individual whilst the responsibility of nurses and doctors to provide information has come to be seen as a moral obligation (Beauchamp and Childress 1994). This raises questions of the paternalistic actions of health care professionals that have gone unchallenged for years ( Pietroni 1991).

A Triangulative technique research method will be used to seek answers to :  
What are the information preferences of adult patients for whom English is a first language, in relation to the four elements of informed consent and clinical decision making?

It is suggested that a further study should follow to elicit the cultural differences in information preferences.

A proposal of a protocol in a format which reflects these findings, is to be used in conjunction with the practice of medical and nursing history taking by doctors and nurses.

2. Please provide evidence of scientific background and rationale of the proposed study.

Triangulation of qualitative and quantitative research methods which helps to overcome the shortcomings inherent in any single method, will be used to elucidate the presence of the four elements of informed consent, namely, information, understanding, voluntariness and capacity, within the patient information preferences of adults. A qualitative analysis of themes generated by the open interviews (audio-taped) together with a quantitative analysis of the responses on the 'scale' set in the questionnaire, will ensure confidence in the validity and reliability of the findings.

3. State the intended value of the project (if this project or a similar one has been done before what is the value of repeating it?):

Although studies have been carried out in the UK to address the issue of information preferences of patients they do not overtly look at the presence of the four elements of informed consent namely, information, understanding, voluntariness and capacity within the ethical scenario of patients' decision making. Respect for an individual's right to an autonomous decision making must surely be borne out of ethical reasoning.

4. Specify the number, type and method of recruiting subjects for the study. Attach a copy of any advertisement to be used. (Names of UCL student volunteers in commercially sponsored research must be notified to the Registrar, UCL):

A purposive sample of male and female patients (even distribution) for whom English is a first language, and are first referrals to the consultant, will be used as a sample for the study. The number of the sample will be dependant on 'saturation' of the data. "Naturalists sample in ways that maximise the scope and range of information" (Lincoln and Guba 1985) p224

The Out-Patients Manager at the \_\_\_\_\_ Trust hospital has been approached about the prospective study and decisions have been made as to the access of the sample and the allocation of a designated area for the interviews to be carried out. The researcher will have no access to the patients' health records to maintain confidentiality.

The patients will be approached on the morning of their appointments. The purpose of the study will be made clear to them and they will be assured that participation is strictly voluntary and that at no time will their refusal to participate influence or effect their care in hospital.

A semi-structured interview will require the researcher to ask a number of specific questions in relation to the four elements of informed consent, following the 'open' question. The 'open' response afforded by a semi-structured interview will allow informants to define their own terms of reference, which will be clarified by the researcher by 'funneling' (Lincoln and Guba 1985)

5. State the likely duration of the project and where it will be undertaken:

**It is proposed that the study will be of a 2 year duration and will be carried out in the out-patients clinic at the Trust hospital. SUBJECT TO ETHICAL APPROVAL.**

6. Specify whether the following procedures are involved:

any invasive procedure	No
physical contact	No
any procedure that may cause mental distress	No

Outline the procedures involved in your study.

**NOT APPLICABLE- no physical or psychological intervention**

7. State the potential hazards, if any, and the precautions being taken to meet them (include information on hazardous substances that will be used or produced, and the steps being taken to reduce risk):

**NOT APPLICABLE**

It is a requirement of the Health and Safety Executive that a formal risk assessment must be made. **Please attach a copy.**

8. State the procedures which may cause discomfort or distress and the degree of discomfort or distress likely to be entailed by the subjects.

**NOT APPLICABLE**

9. State the personal experience of the applicant and of any assistants involved in the study in the field concerned. In the case of student or non-experienced applicants, please state the name and experience of the supervisor, and the degree of supervision:

**Bsc (Hons) in Nursing with Education - Action Research in theatres.  
Msc in Nursing - A qualitative study to elucidate Nurses' perception of informed in clinical practice**

10. State the manner in which consent will be obtained (i.e. verbal, written, witnessed) and supply a copy of the information sheet. Health volunteers and patients will require different information sheets, and consent forms - separate from the information sheets - are required.

**A written and verbal consent will be obtained, the former in letter form and the latter on audio tape at the time of the interview.**

Please state (if applicable) what steps have been taken to inform

- (1) the patients GP's NOT APPLICABLE
- (2) the Pharmacy (essential in any drugs trial): NOT APPLICABLE

11. Is the study initiated/sponsored by a pharmaceutical or other industrial company?

No

12.(a) Does the project involve pre-marketing use of a drug/appliance or a new use for a marketed product?

**No: if NO go to question 13**

(b) If **Yes** does the Company agree to abide by the guidelines on compensation of the Association of British Pharmaceutical Industry (ABPI) Clinical Trials - compensation for medicine induced injury in respect of **patients**?

If **Yes** a written statement from the Company to this effect should be **attached**.

(c) In a study on **healthy volunteers** does the Company agree to abide by the current guidelines of the ABPI for healthy volunteers?

If **Yes** a copy of the proposed volunteer contract should be **attached**.

(d) What is the regulatory status of the drug under the Medicines Act 1968: Product Licence/Clinical Trial Certificate (CTC)/Clinical Trial Exemption (CTX)/Doctor or Dentist Exemption Certificate (DDX)? **If CTC, DDX a copy of the certificate should be attached.**

13. If the project is not covered by an ABPI no-fault indemnity agreement, nor is it part of usual patient treatment, state what insurance cover is in place. Please note that investigators may be required to contribute to the cost of such indemnity.

**NOT APPLICABLE**

14. Please specify any financial or other direct interest to you or your department arising from this study.

**A full declaration** should be included in this stage, or on an attached sheet.

**NOT APPLICABLE**

15. Will payments be made to subjects?

**No**

If **Yes** give details:

**NOT APPLICABLE**

16. Please ensure that this study is peer reviewed by a Consultant / Head of Department who has experience with the proposed study.

Name of Consultant / Head of Dept undertaking peer review

.....

Signature of Consultant/Head of Dept undertaking peer review

Date

9.9.98

Comments of Consultant/ Head of Dept following peer review

This research proposal addresses a very important area of informed consent and its methodology. Proposed in Journal.

17. Include any other relevant matter, e.g. letters to subjects : questionnaires to be used etc.

**PLEASE ANSWER THIS QUESTION FOR ALL THE INVESTIGATORS INVOLVED**

State your professional qualifications in the field of the study.

**Registered Nurse, Registered Midwife, Diploma in Nursing , Bsc in Nursing with Education, Msc in Nursing**

Who is your employer?

**Middlesex University**

**HEBES**

**10 Highgate Hill**

**Highgate Hill**

**London**

N.B. IT IS THE RESPONSIBILITY OF INVESTIGATORS TO ENSURE THAT ALL ASSOCIATED STAFF, INCLUDING NURSING STAFF, ARE INFORMED OF RESEARCH PROJECTS AND ARE TOLD THAT THEY HAVE THE APPROVAL OF THE ETHICS COMMITTEE.

IF DATA ARE TO BE STORED ON A COMPUTER IN SUCH A WAY AS TO MAKE IT POSSIBLE TO IDENTIFY INDIVIDUALS. THEN THE PROJECT MUST BE REGISTERED UNDER THE DATA PROTECTION ACT 1984. PLEASE CONSULT YOUR DEPARTMENT DATA PROTECTION OFFICER FOR ADVICE.

THE COMMITTEE MUST RECEIVE IMMEDIATE NOTIFICATION OF ANY TRIAL ADVERSE OR UNFORESEEN CIRCUMSTANCES ARISING OUT OF THIS TRIAL

Signature of applicant Fanny Costa-N'Sa Date 14.9.98

I have discussed this project with the applicant and I approve the same:

Signature of Head of Department/NHS Consultant.....

Name in Block Letters ..... Date 9.9.98

## Resource Implications / Research Grants

**N.B. Please ensure that this page is completed to enable the resource implications of this project to be identified.**

### Resource Implications:

Please state here the resource implications arising from this project. These will be taken into account before formal Trust approval is given for the project to proceed.

Financial implications of transcribing of interviews will be met by the researcher

### Health Service Guidelines:

Health Service Guidelines state that the Local Research Ethics Committee must be consulted about any research proposal involving:

NHS patients (i.e. subjects recruited by virtue of their past or present treatment by the NHS, including those treated under contracts with private sector providers):

Access to the records of past or present NHS patients:

Foetal material and IVF involving NHS patients:

The recently dead in NHS premises:

Use of or potential access to NHS premises or facilities.

The guidelines further state that all research proposals which involve human subjects, including for example questionnaires, should receive Ethical approval.

Responsibility for clearing projects with the Ethics Committee rests with the researcher, and where such approval will be required, projects **MUST** be cleared before submission.

**Please return the completed application form to:**

**Administrator, CREED, Level 2,**

**- for onward submission to the Region's**

**District Hospital and Primary Care Committee.**

## REFERENCES

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