

Chapter 6

Informants' Construction of the Medical Discourse of Cancer

Introduction

As individuals proceed through the diagnosis and treatment processes they are exposed to more elements of the professional medical discourse and make new interpretations or change previous interpretations of these. Individuals perceive that some of these elements of the professional medical discourse either conflict with elements of the common sense discourse of cancer or other elements of the medical discourse. Interaction with health care professionals during treatment continues to raise for individuals the dilemmas identified in Chapter Five. At the same time it provides a new dilemma: resolving the incongruence between some beliefs within the common sense discourse and individuals' perception of how the medical discourse describes, categorises and makes meaning of the disease and between this perceived medical discourse and their subjective encountering of the cancer experience.

The purpose of this chapter is twofold. Firstly, to identify the objectified elements of the medical discourse that, for informants in the current study, create dilemmas for them during their subjective encountering of the disease of cancer. Secondly, to identify how these perceived elements influence interaction with the disease and illness experience.

Engaging the medical discourse

During the diagnostic and treatment processes individuals interact with a range of health care professionals, such as general practitioners, specialist medical practitioners (e.g., physicians, surgeons, oncologists) and other health care professionals (e.g., nurses, radiologists, social workers, psychologists). All of these professionals may present elements of the medical discourse in slightly different ways. Patients engage elements of the medical discourse either actively or passively. Individuals may actively seek information and knowledge concerning their own illness. Alternatively, patients passively engage elements of the medical discourse by being enlisted by medical staff to act as 'treatment ambassadors' for other patients.

Active engagement

People react to encounters with the medical discourse in different ways. Some individuals actively seek more information about the disease, its treatment and course. For example, some informants asked specific questions:

- 6.1** After I got over the initial shock I asked a lot of questions — and I asked why I didn't have the radiotherapy and the chemotherapy. (Josie, 1207-1209)

The active seeking of information is implied by another informant who states:

- 6.2** They answer all your questions. Well, they answered all mine. I wanted them answered right from the beginning. I didn't want anything held back ... so they answered me honestly. (Doris, 1389-395)

Other informants are more proactive and, as well as asking specific questions, actually request additional background information concerning the disease:

- 6.3** The first thing I said to Dr ... [oncology registrar] ... "I want you to know right now — that I want to be fully informed — kept fully informed about everything." I said, "I do not want things kept from me." I said, "I want you to give me as much information as you possibly can." And, boy, did I get it, you know, Photostat pages out of the cancer journals and all this stuff, uhm — treatment sheets about the various uhm — chemotherapy treatments that I'd be undergoing. (Jan, 1756-764)

Informants whose questions were answered speak positively about their interactions with medical professionals and the medical discourse. Alternatively, when patients perceive that the medical staff do not adequately address their concerns they discuss their experiences in negative terms. Not all informants are able to obtain satisfactory answers to their questions and, therefore, construct a different interpretation of the medical discourse or aspects of it. For example, one informant expresses her anger visibly and audibly as she recounts her experience seeking answers to her specific questions:

- 6.4** I've been told — it was ovarian cancer but it had spread to the border line of my bowel — I was not told how severe it was or anything like that, ... it was just borderline. And I kept asking, "What's the meaning of borderline?" ... they kept saying, "It's borderline". No one saying — no explanation ... they kept telling me, "But we have explained when you came out of the operation and out of the anaesthetic" and I said, "No, I don't remember at all", because I'm a car accident victim; I had a head injury and so on, but they didn't want to know They wouldn't answer ... they kept saying "Oh you want miracle answers." "No, I don't want miracle answers, I just want you to know what's going on — explain step by step." They never explained! "You want miracle answers." 'Cause they knew I was a nurse and so [they thought] that's what I wanted

Every time we [family] tried to ask them the only thing we got thrown in our faces was “miracle answers” .. they know something that I don’t know — they know — they don’t want to answer — there must be something wrong. (Martha, I 3-25; 156-170; 844-866)

This informant symbolically designates many elements of the medical discourse, and certain sections of health care professionals, as unhelpful and as actively trying to avoid her and the issues she wishes to discuss. In general, she perceives the medical discourse as failing to focus on patients needs and the ‘real’ issues for patients:

6.5 You go to a doctor and you say, “I need to talk to someone” and they say, “See a psychiatrist”, or “You’re having a panic attack. Look, I can’t do anything about it.” “But, I want to talk --” ... nobody understood. Doesn’t matter who it was I was put on Prozac — I was put on anti-anxiety pills — I was put on Valium — I was put on Serapax — they think that the pills are going to solve something — they won’t. Pills never solve anything. It’s taking time and sitting with the person — and talk to them. (Martha, I 353-361; 1269-1272; 1371-1374)

A second informant recounts what she considers to be a negative experience with a medical specialist who did not answer her questions adequately. During the diagnostic process that extended over several months this individual was referred to a medical specialist. She states:

6.6 I was referred to a back specialist and it [the pain] was actually getting steadily worse. I was getting referred pain down the side [of my leg]. And I was referred to — God, when I think of this I still feel anger over this — ... he started treating me for what he said was just a, you know, a normal level back problem and that I’d snap out of it pretty quickly ... anyway it got steadily worse and this Dr M... kept saying to me, “You’ll be alright”, you know, —. I’d say to him, you know, “I’ve got pain down her [pointing to leg] and maybe it’s not to do with the back. Maybe it’s to do with the hip?” “Oh that’s just referred pain. Just forget about it”, you know, just give you another pain killer and all the rest of it, ... I very clearly got the impression from, always through his treating me, that he was treating me like a neurotic, overweight woman — oh, you know, like so many doctors do. If you’re a problem, you know, you’re not a person, you’re a problem. (Jan, I 379-418)

Some informants do not seek details of the disease or treatment, appeared not to be interested in knowing these details and, apparently, were only interested in being ‘cured’. For example, one informant states:

6.7 I don’t want it to sink in. It goes in one ear and out the other what the doctors tell me, ‘cause I don’t want to hear about it. I just want to block it out ‘cause I was going to be told I was going to get better and that’s — I don’t want to hear

nothing [sic] else And I said, “Am I going to die?” and they [doctors] said, “No.” So I said, “Oh well that’s all right. That’s all I wanted to know.” (Sue, 1 704-721; 884-886)

This latter group, despite being informed by both doctors and nurses what was likely to happen, have no real understanding of any aspects of the medical discourse nor an apparent desire to become actively involved with it. This behaviour is in keeping with the common sense discourse about medicine that perceives doctors as institutionalised experts on matters relating to health and are able to take care of all health related matters.

Passive engagement

Patients who have already been through some form of treatment are sometimes ‘recruited’ by medical staff to act as ‘treatment ambassadors’. That is, they are requested by medical staff to talk about their treatment experiences to other patients who have a similar disease and may have not yet decided to agree to further treatment (e.g., surgery, chemotherapy or radiotherapy) or who may be deciding to rely on ‘alternative’ therapies. Such patients appear to be selected on the basis of their ‘good’ personal reactions to their own treatment, their apparent compliance with treatment decisions and the similarity of their disease and symptoms to those of other patients. In talking to other patients these treatment ambassadors reinforce the medical discourse in two ways. Firstly, they ‘teach’ the medical discourse to fellow patients, particularly the positive aspects concerning treatment. Secondly, they also reinforce elements of the medical discourse for themselves. Several informants in the current study were engaged in this activity. For example, one informant states:

6.8 But a doctor down there, he got me to go and talk to some of the patients there, that had had operations and were a bit ‘ify’ of the chemotherapy. This is when I went back for the treatments, you know, and I said to him, “What do you want me to tell them?” I said, you know, “I don’t want to intrude on them.” He said, “Oh no. No, just go have a talk.” — ‘cause by this stage I had no hair, and I had a wig, And he said, “Just tell them how chemotherapy effected you, and what you thought about it.” — And I’d go along and sit on the bed — have a chat to them — show them my baldy head — show them my wig And I said to her, “Well I can’t advise you to have it or not have it.” I said, “Look you can see me. This is what happened to me.” And I told her what happened to me. I said, “Your hair falls out.” And she had this beautiful black, curly hair, and she said, “Oh no, I don’t want to lose my hair.” I said, “Well, I didn’t want to lose mine either, but that’s what happened.” And — she was — she was a health freak. She was one of these ones that was into natural remedies and such like and so on, and her — the cancer she had, had gone through to her bowel and that —

and she was in a much worse state than I was. So whether chemotherapy would have helped her or not, I don't know, but — you know, she was pleased to talk to me but she wasn't in a very good state for strangers, I didn't think, to go talking to her, so whether ... [doctor's name] thought well maybe it might have made her feel a little better — and they try and convince you that you should have it. And I thought, “Well really it's not for me to tell anybody whether they should or shouldn't”. And because I was one of the lucky ones that didn't get ill I wasn't really a good person to talk to them about the pros and cons of chemotherapy ... and yet, if I was as sick as a dog I wouldn't have been the one to go and sit there and be ... [vomiting noise] all the time. (Dulcie, l 405-445)

From this narrative extract it is evident that Dulcie is aware of her 'suitability' to fulfil the treatment ambassador role. It is obvious that one reason she was chosen was because she was able to honestly say that she did not experience nausea as a side effect of chemotherapy and she had apparently accepted her hair loss with equanimity. It also demonstrates that fulfilling this role creates some dissonance for Dulcie. She realises that since she did not experience nausea, as did many of the other patients she observed in the oncology ward, her experience is not routine. Therefore she thinks that she may not be the best person for other patients to talk to as her experience was out of the ordinary.

Dulcie was also requested to undertake this task again with another patient:

6.9 One of the doctors down there had said to me, “Mary's got a clot in her leg the same as you, and she's a little . . . [overseas born] lady,” you know, “Have a talk to her.” And I kind of got a little bit close to her and she sort of told me that there was nothing they could do for her and — the day I left I called — they'd shifted her into another room, you know, and — she was on morphine — like she was not a well girl — and she had her rosary beads and everything and she said to me, “I don't want to live like this.” (Dulcie, l 364-380)

Despite being requested by medical staff to become involved with this patient in the role of treatment ambassador Dulcie's continued interest in the patient was later discouraged. On a follow-up visit to hospital Dulcie's inquiries concerning Mary's progress were rebuffed (see extract **6.52** page 170).

A second informant appears to be less aware of the reasons why she was selected as a treatment ambassador and sees her involvement as simply helping others:

6.10 Every time I go into hospital the — ahhh — stomal therapist gets me to help other people — uhm — that are having — colostomies that don't understand them — she gets me to talk to them — uhm — show them my colostomy so

that they're not frightened — they will know what to expect afterwards — uhm — and I say to them, “Look, you know, what's a colostomy if it gives you life. And that's what it boils down to — it gives you quality of life. Just because you can't use your bowel the normal way — doesn't mean to say you're any less of a person.” ... I just feel if I can help other people to cope with it. (Josie, l 1119-1138)

She also appears to be more openly supportive of the medical discourse and readily reiterates its views:

6.11 As I've said, I like to help other people — I've said I've seen a lot of people die. The ones that I've seen die I — I feel so sad for because they're so young — and I think it's unnecessary that they die. The reason that — that they die is because — they haven't — been diagnosed early enough. So in actual fact the cancer has gone too far — for them to stop it — and once it gets that far it gets into the glands and things like that — well — there's just no stopping it — and I feel sad that women are silly — or so — not silly — so naïve that they won't go — they think that a smear test is going to hurt them — or they're ashamed — or embarrassed — or for other reasons. (Josie, l 1401-1421)

It is evident in this extract that Josie is reproducing an aspect of the medical discourse that is contradictory to her own action. It is not a belief that she acts on for herself. Josie's response to serious symptoms or medical information concerning her own health is to react with considerable fear. When she was originally diagnosed with cancer 28 years ago this fear prompted Josie to continue to avoid medical practitioners until her condition deteriorated to the point where she had to receive emergency treatment - she was taken to hospital haemorrhaging after collapsing and being found “in a pool of blood”. After 28 years of constantly having treatment for cancer, Josie's reactions to serious symptoms had not changed and she still ignored the symptoms until she was ‘forced’ into seeking medical assistance because of the severity of the symptoms – again collapsing in the street.

It appears that acting as a treatment ambassador supports established power relations within the area of health. By selectively recruiting patients to discuss their experiences with fellow patients both selected patient and medical staff reinforce the medical discourse by convincing other patients to comply with recommended treatment decisions. Patients are more likely to be swayed by hearing the experiences of other patients than the reassurances from medical staff: patients hear the ‘positive’ reasons for agreeing to treatment and ‘see’ the effect such treatment has on other individuals with cancer. As outlined in extract **6.8** (page 148) although Dulcie acknowledges to herself that her experience is different to

many other patients in that she was ‘one of the lucky ones that didn’t get ill’ she does not report this to other patients. Instead she relays to her fellow patients the medical discourse belief concerning the value of treatment and emphasises the positive outcome of such treatment.

A similar situation occurs with Josie. However, as indicated above, Josie continues to reinforce the beliefs of the medical discourse despite reacting in direct opposition to these expressed beliefs in respect to her own experiences. In Josie’s situation recruitment as a treatment ambassador has the overpowering effect of encouraging her to say one thing but continue to react in direct opposition to those beliefs. One reason for this conflicting behaviour may reside in the fact that as a treatment ambassador individuals may have a self-image of being included in the responsible, healthy, ‘normal’ group within the community rather than being perceived as the irresponsible, unhealthy other. In supporting the dominant beliefs of the medical discourse individuals may believe themselves to be part of the responsible community and not part of the unhealthy, irresponsible other.

Although the objectives of the medical discourse may be met by the recruiting of treatment ambassadors, the practice may not necessarily meet the needs of patients. As identified earlier, dissonance may be created for patients so recruited in that they may realise that their experiences are not the ‘norm’, yet they are being used to persuade other patients that their experience is, in fact, the norm. Furthermore, the needs of the patient being ‘targeted’ may not be best served by hearing only one version of treatment outcome. In order to make an informed decision about agreeing to undergo treatment, patients may need to have discussions with a number of different patients who demonstrate a range of treatment-related outcomes.

Effects of engagement of medical discourse

During interactions with health care professionals and other patients, individuals begin to perceive that the focus of the medical discourse is not always congruent with their specific needs or experience. Individuals begin to question the validity of the medical discourse to make sense of their specific experiences. Patients continue to construct their own interpretations of the language and practices of the medical discourse. Consequently, there is a range of patient interpretations of the medical discourse about life-threatening diseases.

As will be demonstrated in this chapter, some aspects of this medical discourse may support perspectives of the common sense discourse of life-threatening illnesses already known to the individual. Other aspects may be contradictory or incongruent with the common sense discourse. Furthermore, patients begin to perceive that some aspects of the medical discourse conflict with each other.

With the commencement of treatment individuals are drawn further into contact with the medical discourse, often becoming well acquainted with specific aspects of this medical discourse. For example, several informants in the current study are able to use appropriate medical terminology in discussing their disease and its treatment:

6.12 I had Bowen's disease It's like a wart virus — it's — they're like warts that grow but they're cancerous and they're malignant Now twenty eight years ago they didn't know what it was ... they took photos before they took them off — they painted them blue — then they painted them another colour — in the operation — and then they painted them again when they took them off. So there were three processes ... taking photos throughout the operation — they took before, through the operation, and after the operation — and that made the Medical Journal. (Josie, 1 1345-1372)

6.13 I was put on a research program. They were saying that the Canadians had had — tremendous results with MACOP-B with something like seventy percent — uhm with MACOP-B, which is one form of chemotherapy. CHOP is the usual. It's made up of the initials of the chemicals used ... and CHOP is the alternative, which again is made up of some pretty nasty chemicals ... so I pulled the straws and got on the MACOP-B program which I thought was pretty terrific which meant I was going to have treatment once a week for twelve weeks. It'd all be over in three months, whereas if I were on CHOP it would be nine months. (Jan, 1 892-919)

Jan developed a very good understanding of aspects of the medical discourse about cancer, particularly pain control. However, this knowledge is not recognised, nor appreciated by some medical staff. Jan recounts one of her experiences:

6.14 The people up in the orthopaedic ward at ... [hospital] were very bad at handling pain control ... I had specifically said to somebody, "Listen, I'm on this level of morphine and I have excruciating pain —". They found out later that the tumour was the full length of the femur and had broken out of it, which is the reason, I suppose, why the radiologist previously thought it was Paget's [disease] because it had left cracks on the bone. But, — I had specifically said, "Please wake me up when my next dose is due, which is two o'clock in the morning, because if you allow me to sleep, I will wake up in pain." And she didn't wake me up. I — was -- in — agony. And if you know anything about pain control it's got to be continuous, because if you allow it to come up to the

peak again it can make — it took me quite a while to actually come back down from that pain. Anyway, I lashed into the sister. I was really angry about it. And of course, the Matron came in and told me I was a problem, you know, that I was — uhm — aggressive — and all this crap. (Jan, l 619-638)

This is also an example of tension for patients being produced by the medical discourse. On the one hand patients are encouraged to take some responsibility for developing an understanding of the nature and treatment of the disease. They are encouraged to be active members of the 'team'. On the other hand patients are not encouraged to disagree with the treatment supported by the medical discourse.

Diagnosis

Individuals begin to construct aspects of the medical discourse through their interpretation of the language and practices of health care professionals during the diagnostic process. Aspects associated with diagnosis raised by current informants include the need for urgent follow-up action when a life-threatening form of cancer is suspected; diagnosis of cancer is not a death sentence; medical practitioners are the experts; doctors disregard patients' experiences; and the individual's opinions and choices are minimised.

Urgency for treatment

One of the first medical discourse beliefs perceived by patients is that urgent follow-up diagnostic action is necessary when a life-threatening form of cancer is suspected. This belief is linked to the medical discourse assumption that early detection of cancer means a better chance of cure (Lowenthal 1996). This perception can arise through what is actually said to the individual or, in the absence of any specific comments, through the practices of their doctor in responding to the presenting symptoms. For example, one informant recounts her doctor's comments during an incident twelve months prior to her current diagnosis:

6.15 I'd had a lump under my armpit and I rang the doctor in a panic and said, "I've got a lump under my armpit. For god's sake, what is it?" and he said, "I don't know. Does it move?" And I said, "Yes. It moves around with my finger" because I was feeling it. He said, "Well don't panic. It's fatty tissue or something." He said, "Now, if you ever find a lump and it doesn't move, *you panic*, you ring me, otherwise you just make an appointment and we'll double check it." I said, "OK". [Emphasis added] (Doris, l 81-100)

A number of issues are evident in this extract. Firstly, the practice of urgently ringing the doctor implies recognition of the expertise of the medical discourse: the doctor will know what to do and will be able to provide some diagnostic information over the telephone. Secondly, this belief is reinforced by the doctor's action in asking a simple question concerning the lump's movement. Thirdly, in reassuring the patient that this time the lump appears to be harmless and by prescribing the appropriate behaviour for the patient in specific future situations, the doctor is reinforcing the mutual belief in the expertise of the medical profession. This incident also reflects Foucault's concept of power relations: both the practitioner and the patient support the belief that the doctor possesses the specific knowledge to define situations as either routine or urgent and to identify the appropriate behaviour. However, despite this clearly stated need for urgency in specific circumstances, this particular informant exercised her freedom of choice and decided not to respond as advised. She did not immediately seek medical advice on self-identification of a new lump "that didn't move". Rather than making an urgent appointment, as advised, she waited for several days and visited her GP for a routine appointment that had been previously arranged for another condition. She comments that on discovering the second lump:

6.16 I thought, "That's not good, but I've got to come up to the doctor on the Thursday, because of my arm, so I won't panic or say anything to anyone, I'll ask him when I get up there." (Doris, l 108-113)

In attempting to control her panic Doris tries to act in accordance with the common sense discourse that supports the display of 'bravery' (see Chapter Five). She was also fearful of having her suspicions confirmed and thus delays consulting the doctor. This situation is also an example of the general common sense discourse about displaying strong emotions which supports the need for bravery in facing, and not giving in to, the fear she was feeling at the time. It is also evident that at this time Doris does not have a self-image as someone with a serious disease. However, Doris is so frightened about the possibility of the lump proving to be cancer that she could not contain her anxiety for more than a few days. She had to talk about her anxiety with someone on whom she could depend to provide her with support. She comments that:

6.17 I did tell my daughter. I thought I've got to tell somebody. (Doris, l 114-115)

At the same time, in discussing the issue with her daughter Doris is attempting to retain her self-image as a person who does not have a serious illness. Her daughter's joking response

that Doris probably had “vaginal warts” eased the tension and anxiety Doris was feeling in response to discovering the lump. The daughter’s humour enabled Doris to maintain her self-image as a healthy responsible person rather than a seriously ill other.

A number of informants, who did not respond immediately to unusual symptoms, report that the sense of medical urgency was communicated to them through their GP’s actions in urgently arranging, on their behalf, further diagnostic or treatment assessment consultations with specialist medical practitioners. The first informant indicates that during the initial consultation her general practitioner had attempted to get her an appointment with a specialist that same day:

6.18 So he [GP] referred me to Mr. ... [surgeon] immediately and I was there within, I suppose, two days, they couldn’t get me in that day. (Doris, l 147-150)

A second informant provides a detailed account of her experience with the initial consultation with her general practitioner who, on the day she consulted him, referred her for further investigative tests that confirmed his suspicions of a life-threatening form of cancer. Before she left the surgery the GP had made arrangements for her admission to a major metropolitan hospital at the first available opportunity the following Monday:

6.19 And from the time I went to him [general practitioner] — and then I went and had an ultrascan [sic] and all they said to me there, at this hospital here [local], they said, “Have you had an operation? We can’t find your left ovary.” I said, “No. I’ve had no operation.” So I went back to the local doctor [on the same day] and he said, “Oh, it’s [the scan] inconclusive.” So he sent me up to the clinic at the hospital and I had a CAT scan. Well, that was on the Friday. I was in Melbourne on the Monday and they operated on me on the Wednesday. Ovarian cancer! On the Friday I had the CAT scan — and it was — Anzac weekend — and the doctor up here said to me, “I hope you’ve got your bag packed, because you’re not coming back. And get to the shops and get your nighties or go ’round the neighbourhood and grab as many as you can, because you’re not going home to pack a bag” And that’s the guy that did the CAT scan ... I spent the whole day at the hospital up here [local] because they wanted me to stay there until they got the results of the CAT scan ... I was there ’til four o’clock, from about eleven in the morning. And my husband’s sitting here [at home] wondering where the hell I was. But, anyway, they got me a — copy of the x-rays — the CAT scan and the ultrasound and put that in an envelope, rang the hospital — the ... [named] Hospital — rang the hospital, organised everything, and told me to be down there on the Monday morning. (Dulcie, l 87-98; 547-575)

One informant speaks symbolically of this belief in the need for urgency, at the same time implying that he was not as concerned as the doctor was:

6.20 When we had the CAT scan, that proved that I had cancer on the oesophagus, or whatever you call it. You know, the tube you swallow — swallow through — ... *he* [doctor] *panicked a bit* — and we couldn't get into the ... [named] hospital because there was too much of a waiting list and apparently he didn't have as much pull there, so we shot out to the ... [named] hospital. [Emphasis added] (Fred, l 50-55)

Diagnosis of cancer does not mean certain death

Informants are reassured by the positive way in which medical practitioners speak about the future. At the same time informants begin to perceive that, within the medical discourse, there is a strong belief that diagnosis of cancer does not mean certain death: it can be treated successfully by surgery, chemotherapy or radiotherapy. This is in direct conflict with the common sense discourse. For example, one informant who was diagnosed with cancer of clitoris states:

6.21 I really thought they were going to find the answer to it. Because I can remember asking [surgeon] what were the chances of them getting ... He said, "We'll get it." He said, "*We'll get all of it anyway and you'll be OK. It's something that we can take out.*" [Emphasis added] (Doris, l 1298-1304)

This particular individual is so reassured by this interaction that "everything was going to be alright at the end" and so confident in the recommended treatment that she comments on how she felt prior to surgery:

6.22 I just accepted everything that happened and when they said they were going to have to operate [vulvectomy] and take it out, — I don't think I realised what the implications were. I knew part of me would disappear, but I didn't realise quite how much [begins to cry] and how much I'd be disfigured. Uhm, I thought, "Well that's OK. People lose their breast and live through it —." I mean you can't even see where I'm going to lose mine, and I've decided not to use it anyway, any more, so that will be all right. [said humorously] so that'll be all right. And that is how I sort of approached it. You do crumble after a while. (Doris, l 191-206)

In this extract Doris hints at the dissonance between the reassuring beliefs within the medical discourse and her personal post-operative experience. Her sense of reassurance 'crumbled' when she was 'assaulted' by her personal realisation of the extent of the surgical disfigurement that her body sustained and the impact that it had on her self-image. In clarifying what she meant by "crumble" Doris states:

6.23 Well, all your brave feelings that, you know, it's going to be alright and you're going to live, — when it actually happens and you've got to face the fact that you're not a woman anymore. — Well they tell me I am a woman, but I don't think that I am. Now that hurts. (tears begin to flow). (Doris, l 210-219)

In this situation the conflict for Doris arises from the disparity between the reassurances of the medical discourse and her emotional reaction. Although Doris acknowledges that she was informed of the consequences of surgery she comments that, at the time, she was not ready to discuss the issues:

6.24 They [people reassuring her] haven't lost it. And as yet there isn't a group of people [begins to cry] that I've got — that've got the same as me that can get together and talk about it. I wish there was. It would make it much easier. ... [name] at the ... [named] hospital was great. She took me through it — but I still didn't talk about things because I wasn't ready to. Now, perhaps two years later, I'd like to know how other people felt. (Doris, l 243-258)

It is clear that prior to surgery Doris was unable to conceptualise a self-image as surgically disfigured and what impact that might have on her perception of womanhood, despite the efforts of medical staff to adequately 'prepare' her for the consequences of surgery. Even after surgery Doris was unable to readjust her self-image. It is clear that Doris' perception of womanhood involves the capacity to engage in and maintain intimate relationships. Furthermore, it is clear that Doris believes that this capacity was dependent on possessing intact genitalia. Since her genitals were surgically mutilated Doris constructs a self-image as no longer being a complete woman. Although given reassurances by the medical profession that she is still a woman and capable of intimate relationships, Doris indicates in the above extract that she does not believe these reassurances and needs to discuss the effects of such surgery with other women who have had the same experience. Doris needs to 'test' the validity of her newly developed self-image against the experiences of other women who have had vulvectomies.

A second informant comments on the positive approach of the doctors:

6.25 The doctors talked to me yesterday. They were so positive about it — tapped me on the back and said, "We're going to beat it. We've beaten it so far." (Sue, l 874-876)

Another informant indicates that she is reassured by the 'news' give to her by the doctor despite the fact that some of the news is 'bad':

6.26 ... [the doctor] came in and he said that, “I’ve got some good news and some bad news” — he said, “I’ll give you the bad news first” — he said, “It is a malignant tumour. We didn’t have to whip your leg off because,” he said, “fortunately it’s a lymphoma not a sarcoma and that can be treated”. He said, “they have a very high success rate with chemotherapy”. — [deep sigh] — It was almost like a sense of relief, you know, it was quite amazing. It was still like I really don’t know what I’m quite in for. (Jan, l 711-720)

As indicated in the above extract, the doctor first relayed the bad news confirming Jan had a malignant tumour. Next came two pieces of good news. Jan did not have to have her leg amputated and the lymphoma was treatable. Despite not knowing what the future held for her, Jan felt relieved with this news. In a sense the doctor’s reassurances meant that, for the moment, Jan did not have to reconceptualise her self-image as a seriously ill ‘other’. Although she had a serious disease, with the information that it was considered treatable Jan perceives that it is not life-threatening and there is no need to reconceptualise her self-image.

Disregarding patients

Patients perceive that members of the medical community respond selectively to their comments about, or descriptions of, their symptoms or their personal reactions to medical intervention. Patients interpret this behaviour as indicating that the medical profession is not interested in their experience or those aspects that are important for the individual. Also, patients form the opinion that the medical discourse does not encompass the belief that patients are able to make an informed opinion about their symptoms or personal reactions to a range of other health related issues. In commenting on the gynaecologist’s reactions during the protracted diagnostic process, in which the doctor continued to ignore her concerns that there was something else more seriously wrong than cervical erosion, one informant makes the comment:

6.27 Sometimes they [doctors] disregard what you feel is wrong and they think, then, “I wish these people wouldn’t diagnose themselves. I wish they’d leave it to us. (Betty, l 255-256)

This same informant’s comments were ignored during radiotherapy when she tried to explain that she had difficulty remaining flat on her back for long periods of time:

6.28 They put these three tubes into — big thick tubes — and they were sort of in the vagina, on either side and then one right up into the uterus — and they were stitched into place on the legs so that they wouldn’t fall out ... It was so

uncomfortable because you had to lie flat. You weren't allowed to move; like for goodness sake don't dislodge those tubes [laughs] or we're in trouble — and I had to lie like that with just being rolled on my side — or on my back ... feeling as sick as a dog the whole time. *I was nauseous because I can't stand lying flat, it makes me sick* — I was throwing up the whole time for twenty-two and a half hours ... I kept saying, "Can't I just sit up a little bit, you know, ... give me two pillows instead of one", but they just kept saying, "No you can't do that because if you sit up the tubes might fall out." So I just had to lie there. [Emphasis added] (Betty, 1 375-465)

As a result of this interaction with medical staff Betty concluded that there was inconsistency between medical procedures and reasons given for practices. Betty was informed that the tubes were stitched into place on her legs so that "they wouldn't fall out". However, she was also informed that she could not move to ease her nausea because "the tubes might fall out". Furthermore, Betty was informed that she could not have two pillows or move but was rolled over by the nursing staff every two hours. Betty perception was that the medical staff dismissed her concerns and that the treatment was more important than she was as an individual. Furthermore, Betty perceived that medical opinion was dominant and she was not able to effectively have her concerns heard. This perceived failure to heed individuals' emotional responses may result from the way that patients' responses are defined by the medical discourse. Perhaps Betty's responses were classified as 'routine' for patients undertaking a course of uncomfortable treatment and, consequently, ignored or taken lightly. The important point is that Betty perceived that her emotional responses were not heard and so she believed that the staff were not interested in her personal experience or understanding that she might know her bodily responses.

However, she felt vindicated when, the following morning, she overheard the specialist censuring the staff:

6.29 So ... [specialist] came in and went mad on the staff for not giving me something or ringing him up and asking him — so they ended up giving me Valium I could hear him — going mad at them for not ringing him up and getting an order for something else besides pain-killers, like there's sedatives that could have knocked me out — there's anaesthetics they could have given me to keep me sedated so that I wouldn't have to go through it all. He was really mad. They didn't ring him up — and when he came in the next morning he was — you know, like — I must have looked terrible 'cause he took one look at me and that was it — he walked out of the room and started — in this very low voice, telling staff off. Then the next thing I know I'm having a shot of Valium; IV [intravenous] Valium and — uhm — that sort of knocked me out

until nearly about the time when it was time to get off the machine. I wished to goodness they'd put me on it — right through Monday night, 'cause that was the worst night of my life. (Betty, l 495-520)

Betty interpreted the different practices of the radiotherapy staff and the specialist as demonstrating inconsistencies within the medical discourse.

Another informant also concluded that there was inconsistency, within the medical discourse, in relation to pain control. Jan had been misdiagnosed with, and treated for, a “normal level back problem”. However, the pain steadily increased and she was admitted to hospital for further diagnostic tests. By this time she was on morphine for severe pain control and had informed the staff in the orthopaedic ward about her pain control regime and requested that she be woken for her regular pain medication. The ward staff ignored Jan's request and she was woken in the morning by severe pain (see extract 6.14 page 152). Jan was later diagnosed with cancer and was immediately transferred to the oncology ward where she received adequate pain control. In response to her experience Jan makes the comment:

6.30 I felt ... ‘How could they do this to someone who's obviously so ill?’ It was like not being able to put yourself in somebody else's shoes ... I say in the orthopaedic ward they were lacking. They weren't in the cancer ward but they were in the orthopaedic. Of course, admittedly they have a lot of problems there ... people who have mental illnesses who commit — try to commit suicide with broken bones ... and I know the sisters have to put up with a lot, but I consider that when a patient makes a request like I do, to not carry it out, that is just — well, I — you know, — I can't even use words to describe what I think about that. I'm still angry. I'm angry about that ... ever since those issues I have spoken to people about —, you know, — how I feel nursing staff should listen to patients. (Jan, l 647-689)

This extract also demonstrates the distance between the ‘normal’ healthy staff and the diseased, other. Jan identifies what she perceives as the nursing staff's inability to comprehend the experiences of the seriously ill other.

One informant made the comment that medical staff do not appear interested in important medical information and not only ignore her constant reminders but also considered her to be ‘difficult’:

6.31 I kept saying to them — “I'm allergic to Retromycin.” Do you know that every time I went in [to hospital] I had to say, “Did you read the file? I'm allergic to

Retromycin.” ... They couldn't be bothered reading the files ... she [nurse] wouldn't listen to me — and this particular day I had my arm swell up, swell up, swell up, — I said, “I'm going to pull this IV out if the doctors won't come up and pull it out.” “He's busy. He's in theatre.” “Get somebody else. My arm is swelling up. I'm allergic — I'm going to pull it out” — they wouldn't listen “Did you read the file that I'm allergic?” “No. We have to give you the IV in this arm, we can't give it to you in the other.” ... they wouldn't take no for an answer. (Martha, 1896-905; 1562-1578)

This perceived practice of ignoring or dismissing patients' comments also extends to the process of treatment. Josie's complaints about her colostomy leaking led to it being refashioned. However, it continued to leak fecal material but her protestations were met with what she perceived as dismissive comments from the surgeon. Despite her continued assertiveness Josie's opinions were met with more dismissive comments. The surgeon was not able to deal with Josie's emotional response or acknowledge that her assessment was accurate when he returned some time later. Josie describes the incident as follows:

6.32 I wasn't happy when they did the — colostomy — the colostomy collapsed ... the bowel turned sideways — and I had a dished out part underneath that was leaking ... and I said something's got to be done about it. So I went back in and they did a re-fashioning of the stoma — it lasted five days — it turned sideways again — and the dished out part leaked — I said to ... [surgeon], “I've got another fifty seven years of this. I want some quality of life, I mean, this has given me nothing, I — I go home, I've got to sit at home, I can't go out until I go to the toilet, it leaks all over my clothes. I want to go and play lawn bowls. I want to live a normal life. I don't want this to stop me. I mean, I've got to have it for the rest of my life, so I want some quality of life. This has given me nothing.” And he said, “You're expecting too much of it.” And I said, “I beg your pardon?” He said, “You're expecting too much of it.” I said, “No, I'm expecting it to be right. Just because you did the operation — and it's gone wrong doesn't mean to say I expect too much of it. I expect things to be — to be right — I expect it to work. I expect it to go in this bag.” “Well,” he said, “You've got to have a two piece.” I said, “I don't care what I've got to have, just so long as it works.” I said, “It's my body — and I want it to work, and I want it to function properly. Anyway we had a disagreement. The first time I've ever had a disagreement with him, but — I wanted my point put across. *So I ended up in tears and crying and carrying on and he went away* and one of the other doctors had a talk to me and he [surgeon] came around later on in the morning, about two hours later, and he said, “Now, let me have a look at this.” And he had a look at it and he said, “Oh it has turned again.” Not — not ‘I'm sorry’ — but he said, “Oh it has turned. Yes. Right. We can't do anything at the moment, we have to wait six to eight weeks for it to heal and then we'll have another look at it.” And I said to him, “*I told you it had and you wouldn't listen to me*”, and he just patted me on the leg and smiled, you know, that's the sort of apology you got. But — when I went back in again this time — well I've been on the 'phone to them quite a few times because the skins escoriated — it was

just no good and they were going to pull it out again and I said, “Look you’ve had two goes at it and I don’t feel that pulling it out any further — is going to stop my problem.” I said, “It’s my body and I understand my body a little bit more than you understand it. You can do a hundred operations on it — but you’re still not going to understand it the way — I do. I live with it every day.” — So I went back in early and they looked at it and they decided to resite — this time — so by resiting at least — uhm — it gives me a chance for it to work properly — once it heals — and — I was happier with the resiting than what I was with them pulling it out again. [Emphasis added] (Josie, l 1935-2009)

In this example Josie was adamant that she wanted her opinions accepted. In response to her sense of frustration at not being heard Josie “ended up in tears”. Josie interprets the oncologist’s reaction in walking away from her at that moment as his not being able to cope with patients’ emotional responses. Furthermore, Josie interpreted the oncologist’s later reaction, when challenged to accept that she had been correct originally, as being unable to acknowledge her claim or even offer an appropriate apology for his behaviour.

Doctors as experts

The perceived authority of the medical discourse is also acknowledged within the common sense discourse in a variety of ways. Individuals refer to members of the medical profession as experts and defer to their opinions

6.33 When it comes down to the nitty gritty they’re the experts and — you go by what they say. (Josie, l 1217-1219)

6.34 They [doctors] know what they’re doing. (Dulcie, l 1725)

6.35 Well it’s a case of have to [accept the doctors’ decisions] I mean, they were throwing me around, and I couldn’t do much about it. I couldn’t say no, I don’t want to do that — *they were the bosses*. [Emphasis added] (Fred, l 846-853)

This expertise is reinforced by patients’ perception that the practices of the medical discourse define the boundaries of issues for discussion in medical consultations concerning life-threatening diseases. A further patient perception is that only issues concerning the disease and its cure are legitimised by the medical discourse and that patient issues, concerning living with the effects of treatment or disease, are marginalised by being ignored, dismissed or trivialised by members of the medical community. For example, Betty, a former nurse, was referred to a gynaecologist one March after receiving inconclusive results from several Pap smears. The gynaecologist diagnosed, and treated

Betty for cervical erosion despite the continuation of unusual symptoms and Betty's protestations that she was beginning to believe that something serious was wrong:

6.36 I had a really horrific discharge that smelt terrible. I mean, it was embarrassing to go out. You couldn't go anywhere because this thing just stunk. It was gross. And he [gynaecologist] kept saying it was cervical erosion. So I put up with it for a while but then in December it just got worse, and I thought, "Oh no, there's definitely something wrong", you know, "this just can't be real." And I kept hounding him. I kept going back to him every week and saying to him, you know, like, "Do something. I mean, this is driving me crazy." ... I kept saying to him, you know, "If I didn't know better I'd say I had cancer." And he kept saying, "No, no, it's just cervical erosion. They're similar." And I'd say to him, "Let's do a biopsy and make sure." And — I don't know how but he just kept fobbing it off, you know, "Oh well," you know, "we'll try this first and see if it works." (Betty, 154-276)

Although Betty appeared to be assertive and tried to change the diagnostic focus she was not successful and alludes to her sense of powerlessness in the final sentence of this extract. Despite her suspicions and, as a former nurse, her belief in patients' rights to seek a second opinion if not satisfied with any medical consultation, Betty stayed with this gynaecologist. Betty was subjected to medical authority from two sources. Firstly, as a patient, her concerns were continually marginalised by being ignored. Despite her apparent assertiveness and persistence Betty was unable to change the medical discourse practices and have the consultation focus on her concerns. Secondly, as a former nurse Betty was also influenced by the secondary socialisation of professional nursing education that also supported the dominance and authority of the medical discourse and of doctors over nurses. The dissonance between Betty's self-images as a former nurse and as a probable cancer patient also caused problems for her. Betty's emotional response to the vaginal discharge was that of a frightened lay person and resulted in her not seeking a second medical opinion. She was very frightened of having her suspicions about cancer confirmed – a fact that she was only able to discuss with a fellow patient during one of her stays in hospital (see 7.3 page 181). Betty's perception that her concerns were being dismissed lent support to the authority of the medical discourse being reinforced and the diagnostic focus being effectively maintained on the original diagnosis rather than considering further diagnostic investigation. After eleven months of constant "hounding", the gynaecologist finally agreed to Betty's requests:

6.37 He didn't do anything until February when I really did my cruet and I said, "Look we're doing a biopsy and we're going to do something about it. We're

going to cauterise the cervix. Even if you have to amputate the cervix”, I said, “I’m sick and tired of this. Get rid of it. Even if you have to do a hysterectomy. I don’t care. And he said, “Oh we’ll cauterise the cervix.” And I said, “Fine! Anything! Just get rid of this discharge.” And I’d been on Flagil and Bactrim and antibiotics galore ’cause he, you know, it was just cervical erosion that’s infected. (Betty, 165-73)

However, the proposed surgical intervention was too late and Betty’s suspicions concerning cancer were confirmed:

6.38 I went into ... hospital to have the D&C and cauterisation of the cervix — ahhh — he didn’t even bother — doing anything. They just woke me up. When I got back to the ward, I thought, “That’s strange, I’m really wide awake here. That’s never happened to me before” and — they had the forms just sitting on the bench, so I thought, “Oh, I’ll just have a sticky.” So I had a look and — the prognosis, on the opposite side of the page was “Cancer of the cervix”; “Viable cancer of the cervix” which means you can already see it. (Betty, 174-79)

Other informants also speak about how they perceived that their concerns were marginalised by the practices of the medical discourse. For example, another informant was concerned about aspects of her health that arose after surgery and chemotherapy. She was not sure of the origins of these symptoms: were they the result of pre-cancer surgical treatment for thrombosis in her legs: were they the side effects of chemotherapy; or were they new symptoms indicating progression of the disease? This informant was also interested in clarifying whether anything could be done to alleviate her problems. She describes her experiences in raising these issues with her oncologist during a follow-up consultation:

6.39 And I said to him, “What am I going to do about all this weight?” and he says, “Eat less.” — I said, “Eat less? If I eat less I’ll die of malnutrition. I’ll starve to death.” He said, “Oh well, at your age you’ve got to expect to put on weight.” Well I didn’t need that! I didn’t need that. And I said to him, “Well — why do I get puffed walking up a slope like that?” I said, “I can walk on the flat,” I said, “I can walk down hill, but I can’t walk up steps and I can’t go up a hill.” ... He said, “Oh you’ll have to do more exercise.” I said, “I would if I could, but I can’t walk. I can just not get my legs going.” And I think it’s probably the fluid or what — or whether it was the circulation problems I had, or whether the neuritis in my feet, I don’t know. And I’ve got arthritis in my ankles now because of chemotherapy, I think it dries up all the — whatever — so I’ve got constantly burning ankles and they say there’s nothing they can do about that. So, you know, if I could exercise I would — I do as much as I can — but you feel as though, well, why didn’t somebody warn me about this — does it happen to everybody or is it just me? Is it because I had the — thrombosis in the legs — and they tied off my blood flow? Is it because I’m not getting

enough blood flown up and down my legs to make them work? (Dulcie, l 1090-1116)

Again, although she was assertive in her attempts to obtain satisfactory answers, Dulcie perceived that she was not successful in having her concerns addressed. In attributing her weight gain to the process of aging Dulcie's concerns were trivialised and, consequently, marginalised. This is an example of patients' emotional responses not being clarified within the medical consultation. It is clear that Dulcie is concerned about the post chemotherapy symptoms she is experiencing. It is understandable that she is concerned whether her current symptoms might be symbols that the cancer has returned or might be spreading to other parts of her body. She is also concerned that she may be experiencing the side-effects of chemotherapy and that she may have these symptoms for the rest of her life. Despite the perceived dismissive response Dulcie tries again to raise another personal issue: her inability to walk without difficulty. This too, she perceives as being trivialised by the medical practitioner's response. However, this was not an isolated incident for Dulcie. She describes another example of raising different concerns, about possible side effects, with another oncologist during a follow-up consultation. Again her issues were minimised. Even raising the issue with her GP does not result in having Dulcie's concerns addressed:

6.40 When you go down there [for follow up visits] you want to have a couple of answers ... I said to him [another doctor] over this neuritis and he said to me, "Oh well, you'd be one of the unlucky ones," he said, "one in every two thousand, perhaps would get that." And I said to him, "You've got to be joking," I said, "three people that I know that were in hospital at the same time with me have got the same thing as me. Now where's this one in two thousand business?" And I said to my doctor down here [local GP] and he says, "If they told you everything that could happen to you, from chemotherapy," he said, "they would frighten you to death. So they tell you only the major ones like your hair falling out and going deaf, but the other things you just cope with it as it happens." But I thought, 'Well these blokes are supposed to know that they're doing on that oncology section', whether they're new at it or interns or whatever they are. But for them to turn around and say "Oh well, you're just one of the unlucky ones," I think — I don't think that's a very nice attitude. I think they could be a little bit more — well — sensitive — like if you ask a question — like if you ask a reasonable question I think you need a reasonable answer. I mean, after what you've been through you're not going to break down and cry over — what can't be changed, you know. (Dulcie, l 1871-1896)

There are a number of issues raised in this extract. Firstly, there is evidence for the patients' perception that the medical discourse has expertise and knowledge about all aspects of the

disease and the side effects of treatment and that it is not interested in the concerns of patients. Secondly, there is the perception that the medical discourse is only interested in focusing on saving life rather than dealing with side effects of treatment. Thirdly, tension is evident between the interests of the medical discourse and patients' concerns with living with the effects of treatment. Fourthly, Dulcie by suggesting that patients are not going to become emotional over "what can't be changed" implies that the medical discourse is not able to respond effectively to emotional issues: a point also taken up by other informants. Finally, the patient practice of discussing their experiences among themselves is alluded to. Dulcie perceived that the medical discourse was more interested in the disease rather than any individual's psychosocial experience and meaning associated with the consequences of living with the disease. She also gives her opinion of why the medical discourse does not address the issues raised by patients:

6.41 But some of them sort of — push you aside, you know. *You're cancer's gone — that's major — these little tingling nonsense — and — maybe a bit of deafness in one ear — that's only secondary — can't change it.* They're kind of very matter of factish ... you ask questions, they kind of sidestep the issues, I feel. Kind of skirt around it -- 'cause they're not — I feel they don't really know — the proper answer. [Emphasis added] (Dulcie, 1 1897-1921)

The perceived focus of the medical discourse on saving life rather than treating symptoms was reinforced for Dulcie when she consulted a locum GP whom she described as providing "very patronising" responses:

6.42 I said, "I've got this little bit of a problem and that bit of a problem", and he says, leans over his desk at me, and says, "You're still with us though, aren't you!", and I said to him, "That's poor consolation some days when I get up and wish I wasn't with us!" (Dulcie, 1 2001-2003)

This extract also exemplifies the dissonance between what patients perceive as the focus of the medical discourse on curing the disease and the aspects of the illness experience that individuals consider as important. This perceived authority of the medical discourse is also associated with informants' perception that they had no choice in what was happening to them.

Minimising lay opinion and choices

Despite the medical discourse use of inclusive language (e.g., "we'll try this first" or "we'll do ...") that gives the impression of the 'fight against cancer' being considered a team

approach, informants perceive that the medical discourse does not seriously consider lay opinions or give them choices. Although their questions may be answered and, in most situations, they were given information on request, many informants believe they had no input into decisions concerning their treatment. For example, one informant who states she asked a lot of questions comments that she was not given any options concerning treatment and eventually came to the conclusion that:

6.43 I, sort of, had to come to grips with having this operation — and them — deciding for me and me not being able to sort of say — well — you know, I don't want it that way I want it so and so — but — you don't have a choice really — they [doctors] take you as you have cancer — uhm — it's a life-threatening disease — you have to have treatment — uhm — whether you want to have chemotherapy or whether you want to have radiotherapy that's — insignificant — you have to have it — like you don't have a choice in the matter — if they say you've got to have it — you've got to have it. (Josie, 1212-1216; 1862-1867)

This perception of minimising lay opinions and choices is reinforced by previously cited examples. In extract **6.8** (page 148) Dulcie recounts the story of being recruited as a treatment ambassador to a patient who was a “health freak, she was into natural remedies and such like”. It is clear from this account that the patient's choices regarding “natural remedies” were being minimised by the medical profession. They were using another patient to reinforce the dominance of medical opinion. Similarly, in extract **6.28** (page 158) Betty identifies how her opinions about her own physical reactions were minimised by nursing staff and she was not given the option of another pillow to ease her physical reaction during a lengthy radiotherapy treatment.

Treatment

Hospitals serve as multifunctional venues for patients. Although they are primarily places of treatment they also act as a ‘clearing house’ for the transfer of knowledge about treatment, prognosis and the progress of friends. As individuals progress through treatment they come into contact with a variety of health care professionals and other patients. Within the hospital setting patients learn more about the medical discourse. Patients perceive that cases are treated rather than people; there are topics that are avoided or marginalised; and there are significant variations, contradictions and inconsistencies within the medical discourse. These aspects of the medical discourse create dilemmas for patients as they attempt to cope with living with a life-threatening illness.

Treating cases rather than people

Patients quickly perceive that the medical discourse does not treat individuals but rather 'cases', diseases or abnormal cells. A number of informants speak about this belief either openly or implicitly. One informant makes the clear statement:

6.44 I think each person is an individual but — they [doctors] don't, sort of, take you as an individual — they take you as you have cancer — it's a life-threatening disease — you have to have treatment — whether you want chemotherapy or whether you want to have radiotherapy, that's — insignificant — you have to have it — like you don't have a choice in the matter — if they say you've got to have it — you have to have it. (Josie, l 1860-1867)

Implicit in this statement are two important perceptions about the medical discourse. The disease is being treated rather than the person and the patient is not included in the decision making process. In discussing how decisions are made about treatment, this informant also states that a team of medical staff made decisions on her behalf. For example, the decision to operate was:

6.45 ... decided by — four doctors — it wasn't one doctor's decision — apparently — I was told by ... [social worker] that they had other *cases* to discuss but mine was the most discussed — because it was the biggest — they wanted to do what was right for me — so they decided that [operation] was the best way to go for me. (Josie, l 1189-1196)

Another informant also implies that, on entering hospital to undergo treatment, she was no longer an individual:

6.46 They operate down there on a Wednesday — and you just line up — and you take your turn It's like going on a treadmill and once you're on it — you can't get off ... you sort of get carried away — with things that happen — in order of happening. (Dulcie, l 594-596; 916-923)

Furthermore, she also reports that she was not involved in decision making concerning treatment:

6.47 They [doctors] all consult on it — you know, they have their round table conference, they all decide — and — what they're going to do and what they're not going to do. (Dulcie, l 1046-1049)

This informant goes on to explain that after recovering from surgery she felt as though the staff were no longer as concerned about her. When she returned for follow-up consultations in the out patient department she again thought that patients were treated as though they were on a treadmill:

6.48 ... and you go to the clinic downstairs [out patients] — and you sit there for hour upon hour waiting for these dudes to come down from wherever they come from — and — you've got all these questions that you want to ask — and you get in there — and before you know where you are you're back out again — because they've got stacks of people there — you know — and it's kind of — in and out, in and out — and you think, 'Well, I don't need this.' (Dulcie, l 1067-1074)

Another informant is angry that the practices of the medical discourse appear not to be treating patients as individuals:

6.49 They [medical staff] don't care. You are a number. They don't give a shit. They don't give a fuck who you are No matter how many text books they read — and no matter how much treatment they're going to give — if they're not there ... and explain and talk to them [the patient] and not be in a hurry to say "Hey, next!" and you're just a number. (Martha, l 911; 1055-1058)

Another informant describes an experience, concerning pain, where she was not treated like an individual. Although she had what she described as a very good relationship with the oncologist his response to her statements about where she felt pain implied he was treating her as just another case. Since the pain did not correspond with the oncologist's expectations following recently performed surgery he dismissed the informant's comments and informed her that everything was fine. Her response was:

6.50 I hit him, and he said "What did you do that for?" 'Cause he was sitting on the bed and I thumped him one. I said, "Don't ever say that to me again." I said, "Or you can go somewhere else." I said, "Or I'll get someone else to look after me." I said, "That's *how* I am. It's what I *feel*." I said, "You don't feel what I feel." I said, "If you ever tell me again 'That can't be right'." I said, "Not only will I hit you but I'll thump you stupid." I said, "Don't ever say that to me again." He said, "What, you really feel that particular pain?" and I said, "Yes ...[name], I just told you I did." I said, "It's my body. I know what it feels like, you don't." I said, you know, 'Don't *ever* say that to a patient in my hearing that it's all in her imagination or it's not — and 'Oh no, it can't possibly be there because that isn't where I did the operation.' [Emphasis in narrative] (Betty, l 1207-1230)

Marginalised issues

During treatment individuals learn more about the expectations of the medical discourse and how to respond as a 'patient'. This includes identifying which issues are legitimised and which are marginalised. That is, which issues can be openly discussed with health care professionals and which issues can not be discussed. Patients learn in a variety of ways that issues that are perceived by members of the medical profession as too emotional, too

irrational or subjective are marginalised. For example, one informant speaks in general terms about her experiences of trying to raise emotional issues:

6.51 You go to a doctor and you say, “I need to talk to someone” and they say, “See a psychiatrist”, or “You’re having a panic attack. Look, I can’t do anything about it.” “But, I want to talk --” ... nobody understood. Doesn’t matter who it was About three months ago I went to ... [named] hospital — I said, “I’m having a breakdown.” — They couldn’t give a fuck [begins to cry] — about me having a breakdown ... I was put on Prozac — I was put on anti-anxiety pills — I was put on Valium — I was put on Serapax — They got no time to talk even to the sick and dying — I’m bitter at the whole medical field, because I never expected this as a nurse they think that the pills are going to solve something — they won’t. Pills never solve anything. It’s taking time and sitting with the person — and talk to them. (Martha, 1 353-361; 404-406; 1269-1272; 1304-1306; 1371-1374)

This particular informant experienced considerable difficulty in having her concerns heard by health care professionals. She eventually turns to physical forms of enticement when her verbal symbols are not acknowledged or acted upon. (see discussion of extract **7.32** page 197).

Another informant perceives that the medical discourse does not deal effectively with discussion of dying and death. She also believes that the practices of the medical discourse are inconsistent. Under some circumstances patients were encouraged to be actively involved in supporting and encouraging fellow patients (see Passive engagement discussion on page 148). However, patients are not encouraged to make follow-up inquiries regarding the progress of individuals with whom they had been requested to support. For example, Dulcie, through her role as treatment ambassador, became friendly with a fellow patient. On her return to hospital for further treatment she inquired about her friend’s condition but was met with an indeterminate answer:

6.52 One poor lady down there [in hospital], they couldn’t do anything for her and I’m sure she died when I wasn’t there. But of course they [health care professionals] don’t talk about that, you know. “So where’s Mary? What happened to Mary?” “Oh, don’t know!” And I thought, “Oh no, I know where Mary is. She’s gone to God.” ... Like they won’t tell you anything about any of the other patients. (Dulcie, 1 346-352; 403)

Dulcie interpreted the medical staff’s non-committal response to her request for information about her friend’s progress as tacit confirmation of her friend’s death. This type of interaction has important consequences for patient/medical discourse interactions. It

reinforces the message that only certain topics of conversation are acceptable within the medical discourse: dying and death not being among them.

Patients also perceive that the practices of the medical discourse signify that emotional issues are to be avoided. For example, one informant, who had been receiving various forms of treatment over several months and was informed that the cancer had metastasized, describes her experience at the time she was informed by the oncologist that no further acute treatment could be given:

6.53 Betty: I said, “Well, will I survive?” and he said, “I can’t even tell you that.”

Interviewer: So how was that for you when he told you that?

Betty: Well poor old — I mean — I don’t know ’cause at the time I was having to pacify ... [husband] who was about to lose his bundle and the kids were there — and — I had to ask the kids to go somewhere else — you know, it was like — it was all happening to somebody else — after a while — it wasn’t happening to me — ’cause I had to be brave and sort of shoo the kids off and I got one of the nurses to take the kids down stairs, and then — uhm — ... [husband] couldn’t take it and he took off. Just left me sitting there by myself — and then ... [oncologist] nicked off ’cause he couldn’t cope — so I was just sitting there all by my lonesome feeling like — ‘Gee, you know, like — it’s happening to me people. You’re supposed to be here holding my hand [laughs]. I’m the patient — get back here — somebody hold my hand — I need somebody to hold my hand.’ [stops laughing] *Nobody came — not even the nursing staff — it was like they knew — that really bad news had been told and they didn’t want to get involved ’cause they can’t cope either* [spoken softly]. [Emphasis added] (Betty, 1926-954)

In this example the patient is not supported effectively either by her family or the medical staff. As discussed in Chapter Five, it is the healthy members of the community who are unable to effectively engage in social interaction with individuals facing death. It is the patient who, in a reversal of roles, takes care of others during such particularly stressful situation. This informant’s initial method of coping with her difficult experiences was to laugh and joke about her situation. This may have given the medical staff the wrong idea that she was coping well with her illness experience. However, in recounting this incident she stops laughing, lowers her voice and sheds some tears as she speaks of her need for support and the failure of staff to provide it.

Other perceived inconsistencies within the medical discourse

Through contact with a variety of health care professionals, who focus on different aspects of the medical discourse, patients are introduced to what they perceive as a range of

apparent inconsistencies. This perception of conflicting information creates dilemmas for patients who also perceive the medical discourse as providing minimal support or opportunity for them to discuss these uncertainties and their emotional reactions. In particular, patients perceive that the medical discourse contains conflicting information about treatment and prognosis. The dilemma for patients is whom and what to believe when they perceive the existence of inconsistencies within and between discourses.

Growth of cancer cells

As indicated earlier in this chapter, patients perceive that the medical discourse supports the belief that urgent medical attention is needed when a life-threatening form of cancer is suspected. Patients believe that this urgent action is necessary because of the rapid growth of cancer cells. For example, several informants describe the size of the cancer at initial diagnosis and a short time later during further diagnostic tests or treatment:

6.54 It was the size of a — my little finger nail when he [specialist] saw it. Three weeks later, when they operated, it was the size of a golf ball. (Doris, l 151-158)

6.55 In the afternoon he [oncologist] came up and he said — that it was a lot bigger than Dr ... [gynaecologist] said — that it was, you know, about the size of a golf ball and ... [gynaecologist] said it was only the size of my fingernail —, you know, your thumbnail — and it wasn't. (Betty, l 156-159)

The belief that cancer grows rapidly is implied in these extracts. Doris underwent immediate surgery but Betty, an ex-nurse, was told that surgery was not possible at that point in time. Betty recalls her experience at the time and the oncologist's explanation:

6.56 He said, "It's spread and I can't take it out. I can't do a hysterectomy because I'm not too sure where else it's gone — whether it's in the bladder or whether it's in the bowel or in the soft tissues or where it is." He said, "So, we'll have to do radiation therapy first. That's sixty days of radiation therapy, and then we'll see where we go from there." And I thought 'OK' — so we set up a date to go and see ... [radiologist] and had a simulated one, that's another day out, and — ahhh — *all the while I was sitting there thinking 'the more time these people spend — mucking about, the more time this thing's got to grow', you know? "Oh no," says ... [oncologist], "it doesn't grow like that. It takes the cells a while to grow."* And I thought 'Oh yeah!?' [Emphasis added] (Betty, l 160-173)

As is evident in the final line of the above extract, Betty does not believe the oncologist's comments and is not reassured by him. Betty's tension is increased when the oncologist supports his initial comments with further argument:

6.57 He said that it couldn't possibly be the size of a thumbnail on the 25 February then on the 12 March it's the size of a golf ball. (Betty, l 178)

Implicit in these statements is the view that, as a cancer specialist, the oncologist's statements have a greater validity than the statements of the gynaecologist. This situation leaves the patient trying to interpret this conflicting information between two aspects of the medical discourse. Since the oncologist is now treating her the patient believes that she had no other recourse but to accept his statements and disregard those of the gynaecologist. Betty's expresses her tension by directing her anger at the gynaecologist:

6.58 I got so mad with Dr ... [gynaecologist]. I could have cheerfully strangled the man, you know, and probably felt no compunction [laughs] I could sit there and strangle him. (Betty, l 183-185)

Prognosis

Patients perceive that the medical discourse contains conflicting beliefs about prognosis. Different information comes from different groups within the medical profession. For example, one informant describes her experience with two different doctors providing different information:

6.59 When I first went to ... [specialist hospital], before the radiation, I met this doctor there, and I don't know how old he was or [whether] he was just an intern or had any idea about patients with cancer, the one I got, — and I said, "What's the successful rate — rating on each patient that's got what I had?" and he said to me, "Oh the successful rate is — your kind of cancer survival is two years." — so I went back to Dr ... [oncologist] ... and he said, "Who was he to tell you that kind of answer?" He said, "You could get hit by a car tomorrow — How would he know? And I'm the specialist." (Martha, l 788-806)

The first doctor's response supports the common sense discourse belief that cancer is a death sentence. In an attempt to gain reassurance and maintain hope that she may be cured the informant sought the oncologist's opinion. His vague response is not reassuring to the patient. It adds to this person's tension as she perceives that he was actually avoiding a direct response to her query. He did not provide information concerning her chances of surviving the cancer experience but responds with a platitude concerning death from other causes. At the same time he cast doubt on another medical opinion. She is left feeling more confused. More importantly, she comes to the conclusion that not only is the medical discourse not interested about her as an individual but also that they are withholding information about her condition:

6.60 They know something that I don't know — they know — they don't want to answer — there must be something wrong. (Martha, l 863-866)

This perception of Martha's influenced all of her interactions with medical staff. She believes that she can no longer trust any of the medical profession. In turn, members of the medical profession label Martha as 'difficult', 'uncooperative', 'aggressive' and requiring tranquilisers because she is not coping adequately with her illness experience. That is, she is not coping in the way prescribed by the medical discourse as being within acceptable boundaries.

Other sources of information about the medical discourse

During treatment individuals interact with other patients who are at different stages of living with a life-threatening form of cancer and who have also been drawn into contact with the medical discourse. Some patients form a strong bond with those individuals who had surgery on the same day. For example, one informant describes the bonding she felt with fellow patients:

6.61 I was operated on, on Wednesday. There were five of us went through. And we all had different cancers. But we all went through — the preparations and all the things that happened. It was — actually it was a lovely group. Some of us have kept in touch; some have died. Uhm — but I think we were lucky, we had such a lovely group, and we all went through together. I mean we were all facing — death, and some of us did die there's a very close kinship — especially the ones that have lived through it and have fought back and are getting better. Perhaps it's because the ones — we had two that got better very quickly and we were all very, not jealous, but "Oooh that's terrific. I wish that was us," — one dropped back and I haven't heard anymore about her and as far as I know she's gone [died]. She was lovely. It was sad seeing her go backwards. But — the other one, no! She's doing well. There's two of us. One doesn't talk to us — now — she's got better and she's gone off to live her own life, obviously she wants to forget that we all went through it, and that's OK, that's her way of — coping with life. (Doris, l 479-492; 1680-1704)

A second informant reinforces this belief that through their common experience of living with the effects of cancer strong friendship bonds developed:

6.62 I've made a lot of friends — from the hospital — and I ring those people and I keep in touch with them — and I do write to them and I've had friends for what, four and a half years — from the cancer ward. (Josie, l 1734-1739)

It is during this interaction that individuals discuss their experiences and compare them with other patients' experiences. Some patients are going through the same stage of

treatment (e.g., surgery, chemotherapy or outpatient check-ups), while others have progressed further with treatment and may be returning for various forms of follow-up treatment, including corrective surgery (e.g., repairing or resiting colostomy). They also observe what happens to other patients within the ward. For example, one informant recalls her experiences with one of her “group of five” who subsequently died:

6.63 She'd had cancer for years — and when the doctor came around, and they were coming around with our results, which was three days later [after surgery] I think it was, ... and she was in bed — and she broke down, and that for me was worse than my news, than waiting to find out mine. I thought she'd got bad news and hers wasn't going to get any better, and that for me was worse, and they told me I was fine and that made me feel even more miserable because I thought hers was bad and mine was good, and that didn't seem fair, and everybody else, all of ours was good. And then I found out later that they'd told her she was all right. They thought she was going to be fine. That's what they [health care professionals] told us all, and she was dead two months later. (Doris, 1366-1391)

This extract also demonstrates patients' implied questioning of the medical profession. Although members of the medical profession provide reassurance that the patient is going to be fine, and implied that her tears were of relief or happiness rather than in response to bad news, fellow patients eventually found out that she was dead within a short time. This inconsistency and contradiction make it difficult for patients. They want to believe the medical discourse that provides hope for survival but 'evidence' begins to accumulate the medical discourse may not be as 'powerful' or accurate as first thought.

Summary

Individuals living with a life-threatening form of cancer come into close contact with the medical discourse through interaction with members of the medical community during the diagnostic and treatment processes. As diagnosis and treatment proceeds patients interact with a range of medical professionals who introduce them to the diversity and scope of the medical discourse. Although this interaction introduces individuals to different ways of interpreting cancer-related social objects, patients perceive that the medical community have different 'facts' or 'truths' about cancer. Since these facts or truths differ to those provided by the common sense discourse individuals are faced with two major dilemmas. The first involves deciding whom and what to believe about cancer: the common sense discourse or the medical community. Since patients are not initially aware of the definition of the situation or configuration of meaning provided by the medical discourse, they must

rely on their common sense discourse understanding of cancer. This leads directly into the second dilemma: how to interpret the actions of medical staff. In making these interpretations individuals rely on the perspective of the common sense discourse of cancer and its definition of the situation and configuration of meaning. Hence, for individuals the actions of health care professionals symbolise having patient concerns disregarded; being treated as a case rather than as a person; not being included in decision making; and, some sensitive, emotional issues are not to be discussed. Furthermore, patients perceive that contradictions and inconsistencies exist within this medical 'truth' and between medical truth and the truth of the common sense discourse. These perceived contradictions and inconsistencies are important in that they open up questions about what other discourses are at work (Parker 1992).

During hospitalisation for their treatment individuals develop friendships with other patients and, in discussing their common experiences, learn more 'truths' about cancer. They also observe what occurs to other patients and how they react to the disease and illness experience. This inter-patient interaction raises a number of important questions, for patients, concerning the adequacy of others (i.e., healthy family members and medical staff) to 'understand' the patient experience.

A number of important questions arise from patients' questioning of the adequacy of both the common sense and medical discourses to accurately reflect patients' subjective experience of cancer-related illness: How do patients react to these perceived contradictions and inconsistencies of the medical discourse? How do patients react to issues that are marginalised by the medical discourse? How do patients make meaning of their illness experience? How do patients talk about their experience of living with a life-threatening form of cancer? What reaction do patients have to thoughts about their future? These questions are the focus of discussion in the following chapter.