UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

School of Nursing and Midwifery

Understanding the experience of developing and being diagnosed with lung cancer: Exploring the potential of narrative

by

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ABSTRACT

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES
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UNDERSTANDING THE EXPERIENCE OF DEVELOPING AND BEING DIAGNOSED WITH LUNG CANCER: EXPLORING THE POTENTIAL OF NARRATIVE

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Lung cancer is a significant issue within the United Kingdom and in countries around the world. Many individuals are diagnosed with late stage disease which is not amenable to potentially curative surgical resection. This has led to calls for the disease's earlier diagnosis. Individuals facilitate diagnosis by consulting a GP but much time can elapse between the initial symptomatic experience and presentation for medical advice. Related to this, individuals often do not interpret their experience as related to the disease with which they are subsequently diagnosed. The purpose of this study was to make a contribution to the earlier diagnosis of lung cancer through seeking to understand the experience of developing and being diagnosed with the disease. Of particular interest was how individuals interpret the symptomatic experiences associated with lung cancer and why individuals may not interpret them as related to it.

Situated within the interpretive paradigm and adopting a case study approach, this study sought to develop an understanding of the pre-diagnosis experience of lung cancer. The principal data were illness narratives generated in interviews with 33 individuals who had been diagnosed with the disease, though other data were also drawn upon to facilitate the understanding. Techniques of 'narrative analysis' and 'analysis of narrative' (Polkinghorne 1995) were applied to the illness narratives.

Of the 33 participants, only two had interpreted their symptomatic experience as related to lung cancer prior to presenting for medical advice. Many of the remaining participants interpreted their symptomatic experiences as related to normal life or normal illness. These and other study findings highlight the significance of narrative for how individuals interpret and respond to symptomatic experiences. Indeed, it is proposed that individuals interpret their symptomatic experiences through drawing upon storied meaning and emplotting their experience into a narrative plot in a process of experiential emplotment. This positions interpretation as an active and creative process and acknowledges that any interpretation occurs within a particular social context. Narratives of specific diseases are just one type of plot which an individual can draw upon to bring meaning to their experience. However many individuals who develop lung cancer cannot see themselves in the disease's narrative and therefore cannot interpret their experience as related to it. Health education interventions based on this understanding would strive to construct and communicate narratives of lung cancer which are faithful to how the disease is experienced and in whom so as to influence the availability, visibility and acceptability of the narrative plot. With this, the interpretation of lung cancer would be accessible to those who may need to draw upon it and the potential for the earlier diagnosis of lung cancer would become a distinct possibility.

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Acknowledgements

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1 Introducing the study and the thesis

1.1 Introducing the study

Lung cancer is a disease which is responsible for a great deal of morbidity and mortality within the United Kingdom (UK). Furthermore, the disease has a huge personal impact on the 35,000 individuals who are diagnosed with it each year (Cancer Research UK [CRUK] 2007a). Many of these individuals will die from their disease within one year of diagnosis. Surgical resection offers the best hope of cure but only a small percentage of individuals are diagnosed with early stage disease and are suitable for this intervention (Moghissi and Connolly 1996; Laroche *et al* 1998). If one can expedite the process of diagnosis, it might be possible to diagnose individuals at an earlier stage of disease and to increase the percentage of those undergoing surgical resection. With this, many more individuals might be cured from the disease or, at the very least, have a longer period of disease-free survival.

Mechanisms to facilitate speedier diagnosis have been developed but most are contingent upon the individual presenting for medical advice. However the seeking of medical advice is far from straightforward and recent work by Jessica Corner and colleagues has suggested that individuals diagnosed with lung cancer experience symptoms for a significant period of time prior to presentation, thus delaying the point of diagnosis (Corner *et al* 2003; 2005). Why this should be the case is uncertain, but it does suggest that there is potentially much to be gained from a detailed understanding of the experience of developing and being diagnosed with lung cancer. Indeed the most recent paper by Corner and colleagues ends with the following statement:

> 'The complex processes by which individuals become diagnosed with lung cancer are at present poorly understood and warrant further detailed investigation as part of broader investigation into the 'sociology of diagnosis'' (Corner *et al* 2006, p1390).

The study at the centre of this thesis was devised to develop such an understanding. Of particular interest was how individuals interpret the symptomatic experiences associated with the development of lung cancer and why they may not interpret them as related to the disease. This is important because how an individual interprets an experience influences how they respond to it. If individuals recognise the significance of their experience they may present for medical advice sooner than would otherwise be the case. This could expedite the process of diagnosis and lead to the disease being diagnosed at an earlier stage.

Within this study, the potential of narrative was explored as a mechanism for coming to know the experience of developing and being diagnosed with the disease, and as a framework for understanding it. This has, of course, imposed a very particular stance upon the study, upon its form and upon its findings, but it is a stance which is both insightful and useful. The narrative perspective affords opportunity for alternative conceptualisations and in this the study is about possibilities; thinking of things in a different way and seeing where that takes you. In so doing, the study and its findings are part of the puzzle; a contribution to understanding how individuals interpret symptomatic experiences and, it is hoped, a contribution to the earlier diagnosis of lung cancer.

1.1.1 Situating me as researcher and author

The opportunity for me to conduct the study arose because I responded to a notice in a national newspaper which advertised several PhD studentships, including one within the arena of promoting the earlier diagnosis of lung cancer. I applied for the studentship and was very fortunate to be accepted onto it. I resigned from my role as a therapy radiographer to pursue the study under the supervision of Professor Jessica Corner and Dr. Jane Hopkinson.

When writing this thesis, I experienced some of the 'trouble' that Mattingly (1998) talks of in terms of how to situate myself within it. I chose to write this thesis in the first person, though there are occasions when my presence is more explicit than at others. To use Mattingly's (1998) words, I 'flit in and out of the pages of this text' (pvii). At times, for example, I have included excerpts from my research log[1] because I am keen that

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[1] I started a research log on the first day of my studentship. I used it as a scrap book for the sources which have informed my understandings and in it I wrote my thoughts and ideas relating to the development and conduct of the study.

you, as reader, have a real sense of not only what the study was about but also of what it was like to do it. In doing this, my intention is to present the study as the challenging and complex process that it was and, through this faithful reflection, make a contribution to the rigour of the work. However at other times within this thesis I am much more in the background. But regardless of this, within the text I am always partial; I never fully exist within this thesis though I have been so central for what it is that you read. It is because of this that I have appended a short autobiographical statement (Appendix 1) to allow you, should you choose, to learn a little more about me.

1.1.2 Situating the others

This study could not have taken place without the input of a number of people, not least those who had been diagnosed with lung cancer and who subsequently agreed to take part. Throughout this thesis I refer to such people as individuals or as participants. I have avoided the term 'patient' because I feel strongly that patienthood is only ever one aspect of what it is to be a person[2]. Furthermore, I did not come to know these individuals as patients and I did not meet them in my capacity as a health professional.

1.1.3 A comment on terminology

Throughout this thesis I employ the term 'symptomatic experience' liberally. When doing so, I am referring to what a biomedical practitioner might refer to as a symptom, what Corner *et al* (2006) refer to as a health change and what Locker (1981) refers to as a problematic experience. Indeed, when using the term 'symptomatic experience' I am referring to 'events, situations, or states of affairs which disturb the taken-for-granted attitude towards the world and call for interpretive and explanatory activity' (Locker 1981, p49). This is Locker's definition of a problematic experience but I prefer the term symptomatic experience for two reasons. Firstly, the problematic experience is not always considered to be, or interpreted as, problematic by the individual. Secondly, the experiences which are of principal interest within this thesis are those which can be, and indeed have been, associated with the development of lung cancer and are in this way a symptom of disease.

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[2] However I do employ the term when describing the work of others who have used it.

1.2 Overview of the thesis

There are seven chapters within the thesis, this is the first. **Chapter 2** is titled 'Situating the study' and its purpose is to provide an overview of the existing literature and context for the study's central themes. In addition, it signals my journey through the literature and my shifting interest from patient delay and medical advice seeking to the process of interpretation. This journey culminated in my unanswered questions which are presented at the end of the chapter.

Chapter 3 is titled 'Describing the study' and it is in two parts: research in theory and research in practice. In the first part (research in theory) I present my unanswered questions as research questions, drawn on so as to provide focus and direction for the study. I then discuss the theoretical position of the study, moving from an interpretive paradigm, to a case study approach, to narrative and narrative research. I consider a number of definitions of narrative, the distinction between narrative and story and narrative as a mechanism for constructing and communicating experience. This leads me on to discuss illness narratives and the mechanisms for the generation of narratives and the approaches to their analysis. I conclude the first part of the chapter by discussing the issue of how studies in general, and this study in particular, could be appraised. Within this I outline the steps which I took in order to facilitate my understanding of the experience of developing and being diagnosed with lung cancer.

In the second part of the chapter (research in practice) I describe the actual process of conducting the study, paying particular attention to generation of the illness narratives, and include excerpts from my research log to illustrate the process. I then outline a distinction that I drew within the illness narrative data between narratives of personal experience and narratives of genesis. I consider the value of this distinction and propose a role for each in terms of answering a different research question. I conclude this second part, and the chapter as a whole, with a consideration of the factors which may have influenced the nature of the illness narrative data.

Chapter 4 is titled 'Drawing upon the narratives of personal experience' and within it I present my analytic approach to the narratives of personal experience whereby I drew upon the data to develop narrative case studies, in a process of 'narrative analysis'. I attempt to outline the process of development and then present the twelve narrative case studies each followed by a short commentary. I end the chapter with a brief response to the first research question.

Chapter 5 is titled 'Exploring the narratives of genesis' and within it I present my analytic approach to the narratives of genesis which was in line with an 'analysis of narrative' approach. I draw upon Bal's (1985) elements of events, actors, time and location to facilitate the presentation of the exploration and end the chapter with a brief summary.

Chapter 6 is titled 'Developing understanding: Data and insight' and within it I try to give a sense of my journey through the data and my shifting understandings. I continue to draw upon data from the illness narratives to illustrate these understandings. I present my initial understanding of why many of the individuals did not interpret their experience as related to lung cancer, emphasising the significance of genesis and biography. This leads me to discuss and expand on the narrative structure of disease such that a disease has a beginning, a middle and an end. I situate the narrative structure of disease within the concept of 'experiential emplotment', which I propose to be a potentially useful way of conceptualising the interpretation of symptomatic experiences. The premise of this concept is that individuals draw upon storied meaning and create sense out of their symptomatic experience through instilling it into a narrative plot. The narrative plot gives meaning to the past and to the present but also looks forward and provides a template for future action, positioning steps and events as next in the sequence. I ground the concept of experiential emplotment within the data and provide excerpts from the illness narratives to illustrate it. That one of the participants was not able to sustain the interpretation that he may have lung cancer leads me to explore the illness narratives for the narrative of lung cancer beyond the issue of genesis. I then describe how this renewed exploration led me to reconsider my previous understanding and offer a revised conceptualisation of the narrative structure of specific diseases.

Chapter 7 is titled 'Discussing the study: Implications, limitations and future directions' and within it I highlight the implications of this study which I discuss in relation to the existing literature. I suggest how my understanding of interpretation is different to that within the existing literature and outline the impact that this would have on any health education intervention developed to influence the processes of interpretation and presentation. I then consider some of the limitations of the study and outline the lessons that I have learnt. From this I consider potential future directions.

2 Situating the study

2.1 Introduction to the chapter

As I briefly mentioned in the previous chapter, I was awarded a studentship on the condition that I developed my PhD within the remit of promoting the earlier diagnosis of lung cancer. Though I encountered individuals with lung cancer on an almost daily basis in my clinical role and had theoretical knowledge of health education and related interventions, I could not begin to think how one might go about achieving such an enormous task. It was vital, then, that I reviewed some of the most related literature and fortunately I had access to the report which my supervisors had written (Corner *et al* 2003) and a large amount of literature sourced for the report. This literature, which focused on the area of delay and particularly patient delay, started the process and acted as the springboard for my own literature searches. This chapter is thus about the existing literature but it is also about my journey, and my shift in interest from patient delay and medical advice seeking to the process of interpretation. On this journey, I was able to establish what I thought was understood, but more importantly, what I thought was yet to understand. The literature generated three unanswered questions and these provided the stimulus and direction for the study at the centre of this thesis.

The purpose of this chapter is thus to attempt to situate the study within the arena of existing research and to give background information and context to its central themes. I begin by introducing the topic of cancer in general and lung cancer in particular. I then move on to consider the issue of patient delay, particularly in relation to cancer and as a component of the study of illness behaviour. I consider some of the individualistic approaches to the study of illness behaviour and this leads me to discuss a model of patient delay. From here, I describe the existing literature which has sought to investigate the extent of patient delay in lung cancer. Whilst mainly concerned with quantification this literature often recommends that members of the general population, or individuals at increased risk of developing the disease, be educated as to the symptoms associated with it. In light of this I consider health education as a mechanism for influencing passive detection and reducing delay. This leads me to return to lung cancer and to consider the work of Jessica Corner and colleagues which highlights that the majority of individuals who develop lung cancer do not interpret their experience as related to the disease. From here I consider the evolution of the study of illness behaviour which is less driven by medical rationality and more by the logic and cohesiveness of an individual's interpretation and management sequence. Following from this, I comment on the critique of symptom-based health education interventions, position delay as an inappropriate construct and seek to explore the process of interpretation in more detail. I consider a number of factors which have been identified in the literature as influencing interpretation, particularly in terms of whether an individual interprets their experience as related to a specific disease. I note that the understanding of interpretation within the existing literature places the emphasis on the individual and does not consider the potential impact of the immediate and wider social context. This leads me to discuss the social context as it relates to cancer in general and lung cancer in particular, outlining the social processes which may influence interpretation and the legitimacy attached to specific diagnoses. I end the chapter with an outline of my unanswered questions.

2.2 Cancer

Cancer is a generic term applied to a collection of more than 100 distinct disease types (Cooper 1993; Hanahan and Weinberg 2000; King and Robins 2006). Indeed, King and Robins (2006) suggest that cancer can be broadly defined as

> 'a set of diseases characterised by unregulated cell growth leading to invasion of surrounding tissues and spread (metastasis) to other parts of the body' (p1).

Each of the distinct disease types is further characterised according to the cell that it originates from and the tissue in which it develops (King and Robins 2006). Most cancers, approximately 90 per cent, are carcinomas which develop from the epithelial cells that line internal organs, such as the lung, or form glands, such as the breast and the prostate (Cooper 1993). Lung cancer, then, is a carcinoma which arises in the lung, whereas, for example, breast cancer is a carcinoma which arises in the breast. Other types of cancer develop out of muscle and connective tissue, as is the case for sarcomas, or the blood or lymphatic system, as do leukaemias and lymphomas respectively.

The steps through which a particular cell becomes cancerous are thought to vary between each distinct type. However Hanahan and Weinberg (2000) have identified a number of occurrences which they propose are a feature of most, if not all, cancers:

1. 'Self-sufficiency in growth signals' (p57) – A cell becomes able to control the production of growth factors on which its development depends.

2. 'Insensitivity to growth-inhibitory (antigrowth) signals' (*ibid*) – A cell becomes unaffected by the usual mechanisms designed to limit division and proliferation.

3. 'Evasion of programmed cell death (apoptosis)' (*ibid*) – A cell becomes able to resist the programmed instruction to destroy itself.

4. 'Limitless replicative potential' (*ibid*) – The previous three steps, in addition to a cell's ability to move beyond its usual potential to proliferate, enable the cell to proliferate indefinitely.

5. 'Sustained angiogenesis' (*ibid*) – In order to survive, the growing collection of cells must be able to supply itself with oxygen and nutrients, which it does through the creation of new blood vessels.

6. 'Tissue invasion and metastasis' (*ibid*) – A cell or small collection of cells from the growing mass are able to move to other locations. In new locations, the cells continue to follow the steps outlined previously, become imbedded in tissues and cause disruption to the usual physiological processes.

It is the ability to invade and metastasise which distinguishes malignant cancer from a benign tumour or growth and it is the mechanism of metastasis which is most often the cause of death in individuals diagnosed with cancer.

The development of a normal cell into a cancerous one and the continued cell proliferation and metastases, as the steps suggest, is highly complex and requires the accumulation of a number of errors. It is because this process, often referred to as carcinogenesis, requires time that the incidence of cancer increases with age (King and Robins 2006). In addition to the passage of time (ageing), a range of alternative factors have been identified as initiating the process of carcinogenesis including exposure to tobacco smoke, diet, sex hormones and genetics/family history, though the mechanisms through which each factor exerts an influence is variable.

2.3 Lung cancer

2.3.1 Aetiological factors and lung cancer

The development of lung cancer has been linked to a number of aetiological factors including exposure to radon, occupational hazards and pollutants (Souhami and Tobias 2003). However the factor which is of by far the greatest significance is exposure to tobacco smoke and sources suggest that approximately 90 per cent of all lung cancer diagnoses are caused by smoking (Tyczynski *et al* 2003). Tobacco smoke exposure is thought to initiate the development of lung cancer through exerting damage on the DNA[3] within the nucleus of the cell. Each cell has a nucleus which acts as a control centre and damage to the DNA has implications for cell functioning (King and Robins 2006).

Since the association between tobacco smoke exposure and lung cancer was first suggested in the early to mid half of the 20th century, subsequent studies have identified a number of factors linked to an increased risk of developing the disease. These include age of 55 years and over (Peto *et al* 2000), current smoking status (Doll *et al* 2004) and the cessation of smoking in the previous 12 months (Doll *et al* 2004).

2.3.1.1 Preventing lung cancer

The association between the development of lung cancer and tobacco smoke exposure has led to efforts to reduce the incidence of the disease through a number of tobacco related measures. Indeed, prevention is considered to be more appropriate for lung cancer than for most other types of cancer (McLaughlin and Boyd 1998). The primary approach has been in terms of decreasing the number of individuals who smoke, specifically through promoting cessation and abstention[4]. Various approaches including educational, fiscal and legislative measures have been employed to this end.

2.3.2 Incidence, mortality and survival in lung cancer

Lung cancer is a disease which is diagnosed in more than 35,000 individuals each year in the UK and accounts for 13 per cent of the total incidence of cancer (CRUK 2007a). The disease most commonly affects those in the sixth and seventh decades of life but the increasingly young age at which individuals begin to smoke is thought to be

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[3] DNA is an acronym for deoxyribonucleic acid.
[4] This shall be discussed further in section 2.4.7.1.

contributing to the raised incidence of the disease in lower age groups (McManus 2001). The distribution of the disease according to sex is also thought to reflect trends in smoking and though the incidence in males has reached a plateau, the incidence in females is increasing (McManus 2001). The ratio for male: female incidence within the UK is currently 3:2 (CRUK 2007a).

The mortality impact of lung cancer on individuals is high and in 2005 more than 33,000 individuals died from the disease (CRUK 2007a). As the figures illustrate, the incidence and mortality rates for lung cancer follow a similar trend since many affected individuals die relatively quickly after diagnosis (Payne 2001; Hamilton and Sharp 2004). A typical mechanism for comparing the impact of different diagnoses of cancer is through their average survival rates. Lung cancer has one of the lowest survival rates of all cancers, with just approximately 25 per cent of individuals alive one year after diagnosis (CRUK 2007a). This falls to seven per cent five years after diagnosis, a level that has been fairly constant in the UK since the 1970s (CRUK 2007a). To bring context to this figure, the five year survival rates of the cancers with the highest UK incidence[5] are given in Table 1.

Cancer type	**Years of diagnosis**	**Five year survival rates expressed as a percentage (CRUK 2007a)**
Breast carcinoma	2001-2003	80
Lung carcinoma	2000-2001	7
Large bowel carcinoma	2000-2001	50
Prostate carcinoma	1996-1999	65

Table 1: A table of the five year survival rates of the cancers with the highest UK incidence, excluding non-melanoma skin cancer.

2.3.3 Morbidity and lung cancer

The significant level of mortality associated with lung cancer is, rather unsurprisingly, associated with a great deal of morbidity. The majority of individuals who are diagnosed with lung cancer experience multiple symptoms at the time of diagnosis (Buccheri and Ferrigno 2004; Corner *et al* 2005). The most common symptom label reported is cough (Beckles *et al* 2003), with between 50 and 68 per cent of individuals reporting the experience at diagnosis (Buccheri and Ferrigno 2004; Corner *et al* 2005;

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[5] In 2003, breast carcinoma accounted for 16% of cancer incidence, bowel carcinoma for 13% and prostate carcinoma for 12% (CRUK 2007a). Basal cell and squamous cell skin carcinomas (non-melanoma) have been excluded because, though they have a high incidence within the UK (estimated at 100,000 occurrences), their impact on mortality is negligible.

Hamilton *et al* 2005). Systemic symptoms such as fatigue and weakness are also common, as are dyspnoea[6] and chest pain. That many individuals with lung cancer die within one year of diagnosis means that issues of palliation become relevant early in the disease trajectory (Tishelman *et al* 2005). If not effectively controlled, individuals are likely to experience increased morbidity as the disease progresses (Cooley 2000). In addition, the morbidity impact of treatment options can be pronounced. Indeed, studies have suggested that the symptom distress associated with lung cancer is higher than that experienced by individuals with other types of cancer (Degner and Sloan 1995).

2.3.4 Diagnosing lung cancer

On the basis of the symptomatic experiences associated with the development of lung cancer, the National Institute of Health and Clinical Excellence (NICE 2005) recommend that an individual should be referred for urgent chest x-ray in the event that they experience, and necessarily present with,

'Any episode of:
- haemoptysis[7], or

Unexplained or persistent (lasts more than three weeks)
- Cough
- Chest/shoulder pain
- Dyspnoea
- Weight loss
- Chest signs
- Hoarseness
- Finger clubbing[8]
- Features suggestive of metastases
- Cervical/supraclavicular lymphadenopathy[9]' (p3).

Chest x-rays are then the first investigative procedure when lung cancer is suspected. However, the nature of the technology is such that cancerous tumours below a minimal size will not be visible. Moreover, the reading of chest x-rays is contingent upon professional judgement and studies have indicated that visible lesions can be missed, thus delaying the point of diagnosis (Quekel *et al* 1999; Turkington *et al* 2002). In light of this, the referral guidelines suggest that if high suspicions remain in the face of a normal chest x-ray, urgent referral should be considered (see also The National Collaborating Centre for Primary Care 2005).

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[6] Dyspnoea is the biomedical term for difficulty breathing.
[7] Haemoptysis is the biomedical term for coughing or spitting up blood.
[8] Finger clubbing refers to 'thickening and broadening of the finger tips' (Havard 1987).
[9] Lymphadenopathy refers to swelling/enlargement of the lymph nodes.

The firm diagnosis of lung cancer is usually made when suspect tissue is analysed and assessed for its histology[10]. However, there are occasions when this is not possible, for example, when the condition of the individual does not allow it or when the position of the tissue growth means that access is problematic. In these instances, the diagnosis is made on the basis of other evidence, such as radiological examination, but there remains the possibility that the diagnosis of lung cancer is an incorrect one.

2.3.4.1 Histology

As discussed previously, lung cancer refers to a carcinoma which develops within the lung. Subsumed in this categorisation are four distinct types which vary according to histology: squamous cell carcinoma, adenocarcinoma, large cell carcinoma and small cell carcinoma. The first three of these types are included within the category of non-small cell lung cancer (NSCLC), whilst the last type exists within its own category of small cell lung cancer (SCLC) (McManus 2001). Within the UK, NSCLC accounts for approximately 80 per cent of all cases of lung cancer, whilst 20 per cent of the cases are SCLC (Summerton 1999).

2.3.5 Disease staging and treatment modalities

The distinction between NSCLC and SCLC is important because it impacts on the modalities of treatment available to the diagnosed individual. The options are also influenced by the stage of the disease, particularly in NSCLC. The stage of the disease refers to the size and distribution of the cancer within the individual and is often described by way of the TNM classification system[11]. Intensive follow-up of individuals who have been classified according to the TNM system has led to the development of stage categories which draw together those TNM classifications which have similar survival expectations (see Mountain 1997). To illustrate, the disease is labelled as Stage I if the TNM classification is T1N0 or T2N0, Stage II if the TNM classification is T1N1, T2N1 and T3N0, and so on. According to British Thoracic Society (2001) recommendations, Stage I and Stage II lung cancer should be considered operable, whilst the later stages (III and IV) of more advanced disease are considered inoperable.

SCLC has often metastasised outside of the lung at the time of diagnosis and because of this the TNM classification is considered to be inappropriate. Instead, the disease is

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[10] Histology is the 'study of the structure of tissues' (Oxford 1998).

[11] 'T' refers to the size of the tumour, 'N' to the presence and extent of lymph node involvement and 'M' to the presence and extent of metastases (Wittekind *et al* 2005).

staged as either limited or extensive and systemic management options, specifically chemotherapy, are the treatment of choice. A small proportion of individuals with limited disease might be suitable for surgical intervention followed by chemotherapy (McManus 2001).

Management options other than surgical intervention and chemotherapy include radiotherapy and a policy of 'watch and wait'. The significance of treatment modality should not be underestimated, since surgical intervention offers the only real chance of cure[12]. Whilst complete cure may not be achieved in those who undergo surgical resection, five year survival rates of 75-80 per cent have been reported (Deslauriers 2002). Indeed, individuals with Stage I disease who have had their disease completely excised through surgical resection have a five year survival rate of 80 per cent, which falls to 40 per cent when the individuals have Stage II disease (McManus 2001). The figure of 80 per cent, and even the figure of 40 per cent, compares favourably with the average five year survival rate of just seven per cent across all cases of lung cancer and highlights the potential gain to be made from increasing the proportion of individuals who undergo surgical intervention.

2.3.6 The imperative of early diagnosis

The surgical resection rate for lung cancer within the UK is approximately ten per cent (Moghissi and Connolly 1996; Laroche *et al* 1998) which means that a substantial percentage of the diagnosed population are not receiving potentially curative treatment. Several reasons for this surgical resection rate, which is lower than that found in many comparable countries, have been offered such as the tendency of UK surgeons towards a more conservative approach and the higher levels of co-morbidity within the UK population (Imperatori *et al* 2006). An alternative reason which has received much currency within the literature is that many individuals within the UK are diagnosed with late stage disease and so are not amenable to surgical intervention. This has led to calls for efforts to increase the proportion of individuals diagnosed with early stage disease (Imperatori *et al* 2006). Though there is no definitive evidence that earlier diagnosis leads to improved survival, it seems a reasonable assumption, given the availability of potentially curative management options (Allgar and Neal 2005). Earlier diagnosis of

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[12] In individuals who have been diagnosed with localised disease but are not appropriate for surgical resection, radical radiotherapy is often considered to be the next best treatment. Continuous accelerated hyperfractionated radiotherapy (CHART) has demonstrated improved survival (29% at 2 years) compared to the standard radiotherapy treatment (20% at 2 years) (Saunders *et al* 1997) but is only available in a small number of centres (Hatton and Stephens 2005).

lung cancer, then, may lead to reductions in levels of mortality and morbidity and improved personal outcomes for the individuals and their families (Allgar and Neal 2005; Neal and Allgar 2005).

2.3.6.1 Influencing diagnosis

One route for influencing the timeliness of the diagnosis of cancer and the subsequent disease outcomes has involved efforts to increase the efficiency and effectiveness of the pathway from the individual's initial presentation at the general practitioner (GP) through to their referral to secondary services for diagnosis and management. In doing this, a reduction in referral, diagnostic and treatment delays is anticipated[13] (Allgar and Neal 2005). The implementation of polices outlined in the NHS[14] Plan (Department of Health 2000a) and the NHS Cancer Plan (Department of Health 2000b) has been central to this approach and there is evidence to suggest that improvements have been made in reducing the waits for diagnosis and treatment (National Audit Office 2005; House of Commons Committee of Public Accounts 2006). An alternative mechanism, pertinent to the issue of improving early diagnosis, is directed at the role of the individual and specifically their role in facilitating diagnosis through presenting for medical advice. In this approach, the focus is on delay attributable to the individual and there is evidence to suggest that patient delay is an important issue for lung cancer (Corner *et al* 2003; 2005) and that it can make a significant impact on the timeliness of diagnosis[15].

2.4 Patient delay

2.4.1 Defining patient delay

Delay has been investigated in relation to a range of disease types but arguably the largest amount of enquiry has been conducted within the field of cancer[16]. As early as 1938 a paper was published titled 'The culpability for delay in the treatment of cancer' (Pack and Gallo 1938). The article draws a distinction between delay caused by the individual patient and delay caused by the health professional (specifically the doctor).

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[13] GP delay and service delay are alternative terms encountered within this literature.

[14] NHS is the acronym for the National Health Service.

[15] This approach assumes that an individual has developed the symptomatic experiences associated with lung cancer which can then be presented for medical advice. An alternative approach to fostering earlier diagnosis would be to screen those at risk of developing the disease (Mulshine and Smith 2002). Though the feasibility of this approach within the UK context is being investigated, its current unavailability positions prompt recognition of, and response to, symptomatic disease as the principal mechanism for facilitating early diagnosis (Hamilton *et al* 2005).

[16] Beyond the cancer literature, a range of disease types have been investigated, for example there is a great deal of investigation into delay and myocardial infarction (MI).

Within patient delay, the authors distinguish what they consider to be a reasonable delay, when an individual presents for medical advice within three months of the initial symptomatic experience, from undue delay, when a period of three or more months elapses between the initial symptomatic experience and presentation (Pack and Gallo 1938). Since the publication of this article, its definition of patient delay has been adopted in several studies (for example Burgess *et al* 1998; Burgess *et al* 2000; Burgess *et al* 2001). In addition, a range of alternative periods of time have been conceptualised as reflecting patient delay. Nosarti *et al* (2000), for example, consider that an individual has delayed if more than 27 days elapses between the initial symptomatic experience and presentation for medical advice. Further still, patient delay has been defined without reference to the passing of a particular length of time as reflected in the definition offered by de Nooijer *et al* (2001):

> [Patient delay is] 'the interval between the day someone first becomes aware of an unexplained symptom and the day they seek medical consultation' (p145).

2.4.2 Patient delay and cancer

The authors cited previously have operated within the field of cancer and patient delay. Indeed, patient delay has been investigated in relation to a range of different types of cancer including breast cancer (Nosarti *et al* 2000; Burgess *et al* 2001; Meechan *et al* 2003; Bish *et al* 2005), testicular cancer (Gascoigne *et al* 1999; Gascoigne and Whitear 1999), head and neck cancer (Pitiphat *et al* 2002; Rozniatowski *et al* 2005; Tromp *et al* 2005; Scott *et al* 2006) and colorectal cancer (Kocher and Saunders 1999; Wheeler *et al* 1999; Ristvedt and Trinkaus 2005). Macdonald *et al* (2004) conducted a systematic review of the world literature relating to patient and primary care delay in the diagnosis of cancer. The authors chose to exclude breast cancer from their review on the basis that it had been widely investigated (see for example Ramirez *et al* 1999) and found that the most represented cancer types were gastrointestinal, skin and head and neck. Only nine papers which related to lung cancer were included in the review and indeed the authors comment on the dearth of literature relating to patient delay and lung cancer[17]. I shall discuss the patient delay and lung cancer literature later in this chapter (section 2.4.6 and section 2.4.8) but for now I shall consider patient delay as an area of investigation in broad terms.

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[17] The authors make a similar comment in relation to prostate cancer.

2.4.3 Patient delay as a component of illness behaviour

The literature which has sought to investigate patient delay is a component of a broad area of investigation into the study of illness behaviour (Morgan *et al* 1985). The interest in illness behaviour arose out of an intention to account for, and to manage, the demand on health care services. Within the UK, the National Health Service was developed as a 'free at the point of use' service and was based on the assumption that an individual would know whether or not he or she was ill and in need of medical attention (Calnan 1987; Hardey 1998). However, the frequent use of the services by those often termed hypochondriacs or the 'worried well', and the lack of attendance at services by those whose condition necessitated such behaviour, questioned this assumption. Indeed, investigation of symptom prevalence has suggested that the morbidity reported to a medical professional is only a small proportion of the amount experienced and therefore represents the tip of the 'illness iceberg' (Wadsworth *et al* 1971; Scambler and Scambler 1984). It was acknowledgement of this which provided the justification for the developing field of study into illness behaviour (Armstrong 2003). One of the earliest protagonists in the field was David Mechanic who positions illness behaviour as a dynamic process referring to

> 'the manner in which a person monitors his body, defines and interprets his symptoms, takes remedial actions, and utilizes the health-care system' (Mechanic 1979, p148).

2.4.4 Deciding when to present for medical advice

Much effort has been directed towards investigating how individuals respond to the symptomatic experiences associated with disease particularly in terms of understanding the decision to present for medical advice. Mechanic initially sought to specify the relationship between the variables which influenced presentation for medical advice, specifically the propensity towards the experience of stress and the adoption of the sick role (see Mechanic and Volkart 1961). However, in a more recent publication, Mechanic (1968) lists and expands on ten variables that have been raised by the existing literature as being associated with seeking medical advice[18]. Mechanic's perspective is

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[18] '1. Visibility, recognizability, or perceptual salience of deviant signs and symptoms, 2. The extent to which the symptoms are perceived as serious, 3. The extent to which symptoms disrupt family, work, and other social activities, 4. The frequency of the appearance of the deviant signs or symptoms, their persistence, or their frequency of recurrence, 5. The tolerance threshold of those who are exposed to and evaluate the deviant signs and symptoms, 6. Available information, knowledge, and cultural assumptions

(predominantly) in line with an individualistic approach[19] to the study of illness behaviour and it is this perspective which has received a great deal of investigation. Within this approach, investigation has often sought to establish how individuals cognitively represent, and thereby attach meaning to, the experiences associated with disease and illness and how individuals act on the basis of this representation. In these instances, whether an individual presents for medical advice is positioned as a coping behaviour determined by their individual interpretations and representations. The role of the social context and the influence of social relationships are largely ignored within this approach. One area of investigation which falls within the individualistic approach, and which has received much attention, is guided by Leventhal and colleagues' work on illness representations and common sense models of illness (related to cancer, see for example Savage and Clarke 1998; Anagnostopoulos and Spanea 2005).

2.4.4.1 Common sense (self-regulatory) model of illness

Leventhal *et al* (1980) have developed a self-regulatory model of illness in which the cognitive representation of a health threat and the emotional response to the threat influences the appraisal of, and coping with, the threat. The representation is said to constitute a theory of illness, the content of which is derived from bodily experience, information from the external environment and past experience with illness and with threats to health (Leventhal *et al* 1980). The authors provisionally identify four attributes of the illness representation: identity; consequences; cause and time line (Leventhal *et al* 1980) and further work by Lau and Hartman (1983) led to the proposal of a fifth, curability/controllability, though this has been cautiously received by the original investigators (see Leventhal *et al* 1985). Generated through a process of interpretation the representation then acts as a guide for coping behaviour, for example presentation for medical advice. The effectiveness of the coping behaviour can be appraised in terms of the outcomes achieved, and it is this mechanism of representation, coping and appraisal of outcomes which is referred to as the common sense or self-regulatory model of illness.

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and understandings of the evaluator, 7. Basic needs which lead to autistic psychological processes, 8. Needs competing with illness responses, 9. Competing possible interpretations that can be assigned to the symptoms once they are recognized, 10. Availability of treatment resources, physical proximity, and psychological and monetary costs of taking action (pp130-131).

[19] Morgan *et al* (1985) draw a distinction between individualistic and collectivist approaches to the study of illness behaviour. A collectivist approach investigates the role of cultural values and significant others in the decision to consult for medical advice, examples of which include Zola (1973) and McKinlay (1973).

2.4.5 A model of patient delay

In generating the common sense model and in seeking to investigate how individuals cognitively represent illness threats, Leventhal and colleagues drew upon data from a number of studies. One such study was conducted by Safer *et al* (1979) in which patient delay was investigated in a sample of individuals presenting for medical advice at a hospital in America. Rather than conceptualise delay as the homogeneous period of time between the initial symptom and presentation for medical advice, the authors propose a three stage model of delay in seeking medical advice. The first stage of the model is appraisal delay defined as

> 'the number of days that elapsed from the day the patient first noticed his symptom up until the day he concluded he was ill' (Safer *et al* 1979, p13).

The second stage is termed illness delay defined as 'the number of days from the end of appraisal delay up to the day when the patient' decides to seek medical advice followed by utilisation delay defined as 'the number of days from the end of illness delay' until the individual is seen in the clinic (*ibid*). In drawing these distinctions, the authors suggest that one is able to establish and investigate the multiple factors that may affect delay across the pathway to presentation.

Later work by Andersen *et al* (1995) has developed the model to incorporate the additional stages of behavioural delay, defined as the number of days which 'elapses between the decision to seek medical attention and the person acting on this decision by making an appointment' and scheduling delay as 'the time that elapsed between the person making an appointment and first receiving medical attention' (p36)[20]. In this model, as in the original, delay is viewed as comprising a 'series of stages, each governed by a conceptually distinct set of decisional and appraisal processes' (Andersen *et al* 1995, p34). The work of both Safer *et al* (1979) and Andersen *et al* (1995) has highlighted the significant contribution of appraisal delay to the pathway to presentation. Indeed, it is on this component of delay that the paper by Andersen *et al* (1995) focuses, yet it has been suggested that there is still much to understand about how individuals interpret the symptoms of disease (Petrie and Weinman 2003).

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[20] Andersen *et al* (1995) also identify a final stage termed 'treatment delay' which refers to the period of time between seeking advice and receiving treatment. Recent work by Evans *et al* (2007) has expanded this final stage into a number of categories: non-investigation of symptoms, treatment for non-cancer causes, lack of follow-up, referral delays and system delays' (p54).

Despite Safer *et al*'s (1979, p11) criticism that an undifferentiated, homogeneous conception of patient delay 'simply confounds the effects of the multiple factors that affect delay', Andersen *et al*'s (1995) criticism that much of the existing literature does not incorporate a model of delay seems to be as much the case now as before[21]. Certainly the literature which relates to patient delay and lung cancer adopts a broad conceptualisation of patient delay as encompassing the time interval between the initial symptomatic experience and presentation for medical advice.

2.4.6 Existing literature on patient delay and lung cancer

I found little literature that relates to patient delay and lung cancer, a situation which has also been noted by Macdonald *et al* (2004). Some of which I describe in the following sections was identified in the literature review prepared for the study conducted by Corner and colleagues (Corner *et al* 2003). The remainder was identified through my own searches to locate the more recent literature, drawing on key terms such as delay, patient delay and lung cancer[22]. A breakdown of the search terms and databases can be found in Appendix 2. The dearth of literature relating to patient delay and lung cancer suggests that it is appropriate to give a brief description of each of the studies that I accessed. However I shall not consider the work of Corner and colleagues at this stage (Corner *et al* 2003; 2005; 2006). Instead I shall turn to it in section 2.4.8. I have chosen to do this because the work is in contrast to much of that which has been conducted in relation to patient delay and lung cancer both before and since, for it seeks to explain and explore delay in presenting for medical advice.

2.4.6.1 Existing literature on patient delay and lung cancer with the exception of the work of Corner and colleagues

Dische *et al* (1996) recruited individuals diagnosed with NSCLC and referred for radiotherapy treatment from ten sites in the UK over a three month period. A total of 524 patients were referred for radiotherapy at the sites but the authors chose to exclude the data relating to those who had undergone successful tumour resection, leaving 484 participant cases. Trial co-ordinators at the sites collected information from the participants' hospital medical records. In addition, the attendance of the participants at the radiotherapy department allowed for the cross checking of dates, though it is unclear

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[21] There are examples of studies which have incorporated the model of patient delay, for example de Nooijer *et al* (2001).

[22] Any literature published after 2004 did not inform the development of my study but it did influence my perspective and understandings as I moved into data generation and analysis.

as to how often this 'checking' occurred and the manner in which it was conducted. The key points in the patients' disease pathways were identified and the intervals between them assessed. Relevant to this discussion of patient delay, the authors report that there was a median interval of three weeks between the participant's first symptom and presentation to their GP.

Christensen *et al* (1997) conducted a study in Denmark whereby the hospital medical records of 172 patients admitted for surgery were retrospectively reviewed. The medical record data were used to identify the time intervals between a number of key points, beginning with the patient's perception of the symptom which prompted their presentation and ending with the date on which the patient was operated, or considered to be inoperable. Unfortunately, the data presented in the article is in a format which makes it difficult to translate the actual lengths of time involved, yet the authors report that the individual patient is responsible for the longest delay in the pathway to diagnosis and management. In light of this, a recommendation is made that action be taken to educate the general population of the early symptoms of lung cancer.

Koyi *et al* (2002) identified 134 individuals with lung cancer over a 13 month period in Sweden. Six cases of pleural mesothelioma and bronchial carcinoid[23] were included in this sample. All participants had attended the respiratory department of the hospital or had been selected from the cancer registry. The authors write that the aim of the study

> 'was to prospectively investigate a material of lung cancer patients in order to measure the delays, both by the patient and by the doctors' (Koyi *et al* 2002, p53).

However, a questionnaire was used to collect information relating to the types of symptoms experienced and when they had occurred, and so the data relating to patient delay (and GP delay) were collected retrospectively. From the questionnaires, the authors report that the mean patient delay was 43 days (median 21), though 'Nine patients were not included because they were asymptomatic and the tumor accidentally discovered or discovered first at autopsy' (Koyi *et al* 2002, p54). Of the seven months total delay between the initial symptom and treatment, the patient was deemed

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[23] Pleural mesothelioma is a tumour of the lining surrounding the lungs, the development of which is largely associated with exposure to asbestos, and bronchial carcinoid is a tumour of argentaffin cells which is associated with the production of excess hormones (Oxford 1998). Both of these diseases are distinct from lung carcinoma/cancer.

responsible for one and a half months, whilst the doctors were held responsible for the remainder. In regards to patient delay, the authors recommend that the public be educated as to the risks of smoking and the symptoms associated with lung cancer.

Bowen and Rayner (2002), in a letter to the editor prompted by the article published by Koyi *et al* (2002), report their study which had identified individuals with lung cancer presenting to two rapid access clinics in the UK. Prior to them seeing a physician, the participants completed a questionnaire which was designed to identify the length of the time interval between the initial symptom and presentation for medical advice and in total 37 questionnaires were completed. The authors report that the mean length of the interval was 3.2 weeks. However, when asked

> 'about cough 29 (78%) responded that they had had a new cough for a mean 14.8 weeks but this was not always the symptom that prompted a visit to their GP' (Bowen and Rayner 2002, p227).

Related to this, 75 per cent did not recognise their experience as significant and had not seen or heard any information relating to the potential significance of their symptoms. The authors recommend the development of public education initiatives to inform smokers of the symptoms which require attention.

Salomaa *et al* (2005) reviewed the hospital medical records of 132 individuals diagnosed with lung cancer from one Finnish department in the year 2001. The authors identified a number of time periods, and report that the median patient's delay was 14 days (mean of 41 days). They do, however, recommend that caution is exercised since there was a relatively high proportion of data missing from the records and so the patient delay figures are based on data from 101 participant cases. In regards to patient delay, the authors write that it was 'quite long in some cases, but it may be the one delay time that is the most difficult to shorten' (Salomaa *et al* 2005, p2287). Stemming from this, the authors support investment in services in order to improve diagnosis and treatment times.

Taggart *et al* (2005) invited 47 UK individuals newly diagnosed with lung cancer to participate in an interview study over the summer months of 2004, as reported in an abstract for the British Thoracic Society Winter Meeting 2005. Of the 47 invited, 29 agreed to be interviewed by the clinical nurse specialist. The medical records, specifically any CT scans and bronchoscopy reports, were used to establish whether the individual had experienced symptoms related to the cancer at the time of presentation (n=21) or whether the symptoms at this time were non-cancer related (n=8). The authors report that of those whose symptoms were cancer-related, the median time interval between initial symptom and presentation to the GP was 29.0 days compared to 49.0 days for those whose symptoms at presentation were non-cancer related. In addition, the authors report that none of the 29 participants had knowledge of the symptoms of lung cancer which leads them to recommend that 'a large and concerted effort is required to increase public awareness' of the symptoms of lung cancer within their locality (Taggart *et al* 2005, pii53).

I have summarised the literature described in this section in Table 2.

Study authors and country in which the study was conducted	**Number of cases on which patient delay data were based**	**Principal method**	**Length of time between first symptom and presentation for medical advice**	**Recommendations relevant to influencing patient delay**
Dische *et al* (1996) UK	484	Examination of medical records	3 weeks – median	
Christensen *et al* (1997) Denmark	172	Examination of medical records	(patient responsible for longest delay)	Educate the population as to the early symptoms
Koyi *et al* (2002) Sweden	134	Questionnaire	21 days – median 43 days – mean	Educate the population as to the early symptoms and risks of smoking
Bowen and Rayner (2002) UK	37	Questionnaire	3.2 weeks – mean	Educate smokers as to the symptoms
Salomaa *et al* (2005) Finland	101	Examination of medical records	14 days – median 41 days – mean	
Taggart *et al* (2005) UK	29 (n= 21) (n= 8)	Interview	29.0 days – median cancer related symptoms 49.0 days – median non-cancer related symptoms	Educate the population as to the early symptoms

Table 2: A table to summarise the patient delay and lung cancer literature.

2.4.6.2 Critique of the patient delay and lung cancer literature

The existing literature in the field of lung cancer and patient delay is particularly notable for one reason; it seeks quantification above explanation or exploration. The principal concern is to establish the length of time between the initial symptomatic experience and presentation for medical advice. Moreover, it is important to recognise that several of the studies have restricted their sample to those with a particular histology (Dische *et al* 1996), those undergoing a particular management option (Dische *et al* 1996; Christensen *et al 1997*) and only those experiencing symptoms (Koyi *et al* 2002). In this way, the figures given for patient delay may not reflect the wider lung cancer population.

The lack of intention to explain or account for why an individual may or may not have delayed is reflected in the preponderance towards the examination of medical records (Dische *et al* 1996; Christensen *et al* 1997; Salomaa *et al* 2005) and questionnaires (Koyi *et al* 2002; Bowen and Rayner 2002) as methods of data generation. I use the term generation as opposed to collection because it is my understanding that the methods generate the findings, rather than act as a vessel for their collection. This is a position which has been adopted within existing literature and May (2001), for example, writes that 'Data are not collected, but produced' (p28).

To be more explicit about this point, the examination of medical records, for example, is reliant on accurate record keeping and it may be that some of the symptomatic experiences relevant to developing lung cancer were either not conveyed to a medical professional by the individual concerned or not written into the records by those whose task it was to obtain the appropriate medical history. In either of these cases, the date of the initial symptomatic experience does not reflect the experience of the individual. Similarly, questionnaires are reliant upon a consistency of meaning as generated and communicated by language such that a particular question means the same to all who are asked it. This consistency is often not achieved and moreover a question which seeks to establish the time of the initial experience relevant to a diagnosis of lung cancer is reliant upon the individual making the appropriate connection between their diagnosed disease and their symptomatic experiences. In addition, the analysis of medical records and questionnaires are restricted by pre-defined categories of interest which dictate the data that can be generated. The use of tick boxes on medical record pro formas or questionnaires, for example, limits the extent to which an area can be investigated beyond what is already thought to be significant[24]. The opportunity for the generation of new knowledge and understanding can be difficult to achieve in these circumstances.

Though the majority of the literature has sought to quantify patient delay in lung cancer and not to investigate why it should occur, many of the authors recommend that members of the general public, or individuals at increased risk of developing the disease, be educated as to the symptom labels associated with it (Christensen *et al* 1997; Koyi *et al* 2002; Bowen and Rayner 2002). Taggart *et al* (2005) also make this recommendation but this is in light of their efforts to understand and to explain patient delay in lung cancer. For the study, individuals who had been diagnosed with lung cancer were engaged in an interview though the constraints of the abstract do not permit the disclosure of further information relating to the nature of data generation and analysis. In particular there is no access to any of the data generated and it is not possible to see the link between the data and the recommendation.

2.4.7 Health education as a mechanism for influencing interpretation and presentation

Naidoo and Wills (2000) write that

> 'Health education may be defined as planned opportunities for people to learn about health and make changes in their behaviour' (p81).

Health, or perhaps more fittingly disease, education is seen as a means of influencing individuals to behave inline with prescribed courses of action. Through disseminating the symptom labels associated with lung cancer one is attempting to increase awareness and knowledge and to facilitate passive detection, whereby an individual 'becomes aware of a cancer symptom without a conscious action' (de Nooijer *et al* 2002, p362). Passive detection is presented in contrast to active detection which involves an individual attending screening appointments or actively monitoring for disease through self-examination techniques. In seeking to influence, and thereby actively encouraging, passive detection the health education intervention is directed towards what has been variously referred to as secondary health education (Naidoo and Wills 2000; Ewles and

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[24] It is possible to include open sections within questionnaires which allow individuals opportunity to offer an extended answer to a particular question or to make further comments. Such data could potentially broaden the focus of the study but there is nothing to suggest that the studies which employed questionnaires utilised open questions.

Simnett 2003), secondary prevention (Jones and Douglas 2000) and secondary health promotion (Corner 1993). Though the precise terminology varies, the prefix 'secondary' is consistently applied to the same point of reference whereby efforts are directed towards the early detection of disease in individuals for whom the disease process has initiated.

In terms of facilitating passive detection, much importance is attached to awareness and knowledge of specific disease-related symptom labels within the general population or those most at risk of developing the disease. In relation to cancer, leading organisations have identified and publicised seven key warning signs and these have been used as a measure against which knowledge has been assessed (see for example Sheikh and Ogden 1998; Brunswick *et al* 2001; Waller *et al* 2004). In addition to general cancer warning signs, researchers have attempted to assess levels of awareness and knowledge in relation to specific types of cancer (see for example Grunfeld *et al* 2002; Miles *et al* 2005). At this level, risk factors for the disease are often addressed alongside its associated symptom labels as the interest broadens to include those who have the theoretical knowledge to reduce their personal risk of developing the disease as well as those in a position to make the correct interpretations should they have particular symptomatic experiences. This investigation reflects a key position:

> 'Improvements in cancer knowledge could potentially lead to improved survival, particularly if adverse risk factors are avoided, and cancer symptoms are recognized earlier' (Adlard and Hume 2003, p179).

Though much value is attached to health education for influencing interpretation and presentation in cancer, very little material has been published which describes such efforts or evaluates its impact. This may be because, at least in the UK, existing efforts have been driven by non-governmental organisations. Baird (2003), for example, gives a brief report on the campaign organised by Macmillan Cancer Relief (known as Macmillan Cancer Support since April 2006) and The Roy Castle Lung Cancer Foundation to coincide with global lung cancer awareness month in 2002. Two[25] of the aims of the campaign were 'to raise public awareness of lung cancer' and 'to help people at risk, recognise the symptoms and present early to their doctor' (Baird 2003, p119). Baird (2003) reports that substantially more telephone calls were made to the

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[25] The additional aims were to 'direct sufferers to sources of help' and to 'highlight to politicians and health planners, the desperate lack of thoracic surgeons in the UK' (Baird 2003, p119).

organisations' telephone lines but these would seem to have been made by people who had already been diagnosed with the disease and there is no evidence to suggest that the campaign influenced passive detection or presentation in those yet to be diagnosed.

A different mechanism was employed in a Swedish study to influence patient and GP delay in the detection of cancer (Mansson *et al* 1999). 32,627 individuals aged 40 years and over were sent a letter detailing the study which also included information relating to the symptom labels associated lung, colorectal, breast, prostate and skin cancer[26]. The recipients were asked to visit the primary health services if they were experiencing any of the symptom labels listed. Of those who received a letter, 234 visits were made to the services. The authors attempted to reduce GP delay through improving a standardised protocol for health professionals to draw upon. From the 234 visits, 15 cancers were diagnosed, one of which was lung cancer. The authors suggest that the educational programme reduced patient delay, though the authors were not able to assess if the disease had been diagnosed at an earlier stage than might have otherwise been the case.

In comparison to the prefix of secondary, tertiary health education (Naidoo and Wills 2000; Ewles and Simnett 2003), tertiary prevention (Jones and Douglas 2000) and tertiary health promotion (Corner 1993) are concerned with the control of established disease and maximising the potential for quality of life throughout the course of the disease process. Where secondary and tertiary interventions are contingent upon the existence of disease, primary health education (Naidoo and Wills 2000; Ewles and Simnett 2003), primary prevention (Jones and Douglas 2000) and primary health promotion (Corner 1993) are concerned with the prevention of disease and the maximisation of perceived health. In light of this, Jones and Douglas (2000) suggest that only primary strategies have a clear health promoting role.

2.4.7.1 Health promotion

What constitutes health promotion is a contested domain and this is reflected in the multiplicity of definitions. One of the definitions most frequently cited is that offered by the World Health Organization (WHO) and agreed upon at the First International

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[26] The lung cancer symptom labels identified were: cough which had lasted for more than one month, shortness of breath the reason for which was unknown, coughing up blood and chest pain on inhalation (Mansson *et al* 1999).

Conference on Health Promotion, Ottawa 1986[27]: 'Health promotion is the process of enabling people to increase control over, and to improve, their health' (WHO 1986). Within the field there is a general consensus of opinion that health promotion is concerned with raising the health status of individuals and their wider communities through addressing, indeed targeting, a range of different levels and factors (Macdonald and Bunton 1992; Ewles and Simnett 2003). In line with this, health promotion is widely considered to be an umbrella term encompassing a range of strategies to improve health and reduce disease, including, but not limited to, health education[28].

One of the most visible health promotion initiatives developed so as to increase health and reduce disease centres on smoking. Within England, approximately 27 per cent of the adult population are classified as smokers (Twigg *et al* 2004) and efforts directed towards reducing this figure are seen as a key mechanism for reducing the associated disease burden, including the incidence of lung cancer. Such efforts consist of health educational interventions designed to raise awareness of the health-damaging effects of tobacco exposure alongside other activities such as fiscal measures and legislation to restrict smoking in public places. The limitations of a health education approach to increasing the proportion of individuals who abstain from and who stop smoking have been recognised since many individuals continue to smoke despite being fully aware of the health-damaging consequences (Myatt and Treasure 2002). Such approaches are reliant upon the notion of the rational actor and often fail to consider the complexity of why an individual decides to initiate or continue to smoke. Graham (1993), for example, has highlighted the rationale for smoking among young, working class mothers. These mothers were aware of the potential health-risks associated with smoking but within their material and social circumstances smoking was a habit to which they turned 'when the demands of their everyday lives left them feeling on edge' (Graham 1993, p99). In this and similar situations concern for health may be much further down the list of priorities than health educationalists and government officers would like. Indeed, Calnan (1987, p26) suggests that it should be borne in mind that health is not a 'major concern for most people' and if it is, it is only to the extent that it allows individuals to continue their usual, daily activities. Related to this, Lawton (2002) suggests that individuals who do not experience ill health are in the position of taking health for

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[27] The Ottawa charter produced at the end of the conference identified five core areas to which health promotion action should be directed: building healthy public policy, creating supportive environments, strengthening community action, developing personal skills and reorientating health services.

[28] Though it has been noted that the terms health education and health promotion are often used synonymously (Cribb and Dines 1993).

granted and so perceive little need for lifestyle change as a component of health promotion. Moreover, those who do engage in health-related changes do so as a reactive measure in response to ill health and not as a proactive measure to avoid or defer the development of ill health.

2.4.8 The work of Corner and colleagues

To return to the issue of health education, Corner *et al* (2006) have also proposed that there may be value in publicising the symptom labels associated with lung cancer. This followed from a study conducted on behalf of the Department of Health (Corner *et al* 2003). When the study began its aim was to

> 'Develop and evaluate a method for gathering information about the symptom history of patients prior to a diagnosis of lung cancer and the health professional and system response to patients following presentation with symptoms using interviews with patients' (Corner *et al* 2003, pi).

For the purposes of the study, 22 participants were recruited from two hospitals, one in the north of England and the main recruiting centre in the south of England. Of those who took part, seven were considered to have operable disease at the time of diagnosis and were awaiting surgery whilst the remaining 15 were considered inoperable in view of their late stage disease. The participants were interviewed using a directed format consisting of three sections. In the first section a 'journey map' was used to guide the interview in terms of allowing the participant to consider the key events and tell the story of their experience. The second section took the form of structured questions focused around the symptomatic experiences identified with the aid of the journey map and the final section was used to record demographic details.

The findings of the study were such that individuals across both the operable and inoperable groups had experienced symptomatic experiences for many months prior to diagnosis. Indeed all of the participants in the study had experienced symptoms for at least four months prior to diagnosis and there were no differences between those who had operable disease and those who had inoperable disease (Corner *et al* 2003). One of the main contributions of this work has been to question the historic assumption that the experience of symptomatic experiences in lung cancer indicates advanced disease (see for example Putnam *et al* 2003), thereby raising the possibility that such experiences could be used to facilitate earlier presentation and diagnosis. The work of Corner *et al*

(2003) has also been important for highlighting the ubiquity of patient delay in lung cancer since all of the participants could be considered to have delayed presenting for medical advice[29].

2.4.8.1 Explaining patient delay in lung cancer

In a departure from the trend in the existing lung cancer and patient delay literature, Corner *et al* (2006) have sought to explain why individuals did not present for medical advice as promptly as they might. A thematic analysis of the interview data identified six themes which are potentially useful for understanding the concept of patient delay in lung cancer and I shall briefly discuss each in turn.

- 'Experiencing uncertainty over what was 'normal' and being slow to go to a doctor for help' (Corner *et al* 2006, p1384).

Many of the participants in the study were unsure whether to interpret their symptomatic experience as being within or beyond the realm of normality. In light of this, symptomatic experiences were often interpreted as being caused by everyday, non-disease related factors, thereby not necessitating presentation for medical advice. The symptomatic experiences were usually not considered to be serious and therefore as requiring medical attention until such time as they became more severe or an additional experience developed.

- 'Health changes as part of 'everyday' fluctuations of bodily functioning' (*ibid*).

A degree of daily fluctuation in health status was considered to be expected and therefore did not lead the individuals to interpret the symptomatic experiences as being abnormal or as requiring medical advice. In line with this, advancing age was considered to initiate the development of symptomatic experiences and this led many of the participants to interpret their symptomatic experiences as being par for the course.

- 'Disconnected interpretations of bodily changes' (*ibid*).

Though individuals often experienced more than one symptomatic experience, each experience was subject to a separate interpretation and attribution as to cause. The

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[29] If one draws upon the definition that patient delay is a period of more than three months between initial symptom and presentation for medical advice.

symptomatic experiences were not considered as a collective potentially indicative of a disease state but as separate, unrelated phenomena.

- 'The problem of co-morbidity' (*ibid*).

Eleven of the 22 participants in the study had been diagnosed with chronic conditions such as asthma and cardiac diseases. The pre-existence of symptomatic experiences made it harder for the individuals to identify new or changed experiences and to consider that such an experience was related to anything other than the pre-existing disease label.

- 'Not associating health changes with lung cancer' (*ibid*).

None of the individuals in the study seemed to have considered that their symptomatic experiences could be related to lung cancer, with the exception of one participant in whom the possibility had occurred, though she thought her symptoms to be too minor. This is despite the fact that most of the individuals had 'knowingly put themselves at risk by smoking' (Corner *et al* 2006, p1387). Related to this, the participants seemed to be unsure as to the form that symptomatic experiences associated with lung cancer could take.

- 'Feeling unworthy of treatment' (Corner *et al* 2006, p1384).

One of the participants suggested that her current smoking status could lead health professionals to withhold the necessary care and management and that this may deter individuals who smoke from presenting for medical advice.

Though these themes outlined are presented as discreet, separate categories there is a great deal of overlap and it may be more appropriate to consider there to be two distinct strands – making sense out of a symptomatic experience (interpretation) and deciding what to do and whether to do it on the basis of the interpretation (presentation). The first five themes relate to interpretation and could be summarised into one significant feature; the individuals in the study did not interpret their symptomatic experiences as related to lung cancer. Indeed, it is on these issues of interpretation and misinterpretation that Corner *et al* (2006) focus:

> 'Participants did not appear to have consciously 'delayed' seeking help for symptoms through fear, neither did we find obvious evidence of 'denial' among

> participants who were smokers or former smokers that the symptoms they were experiencing might be due to cancer, although this warrants further study. Participants more closely resembled individuals identified in other studies who 'minimise', 'normalise', or wrongly attribute their symptoms' (p1388).

2.4.9 The evolution of the study of illness behaviour

In this way, the symptomatic experiences that the participants experienced were not inherently meaningful; rather their significance was constructed through a process of interpretation. This position is upheld by those who have been influenced by the interpretive paradigm and have subsequently instigated the evolution of the study of illness behaviour (Morgan *et al* 1985). The earlier approach to the study of illness behaviour was concerned with investigating the decision to seek medical advice, a course of action which was positioned as the only appropriate response to a symptom (see section 2.4.3). However this approach was criticised for its reliance upon the socio-demographic and psychological characteristics of individuals who do and do not present (Locker 1981). Later approaches to the study of illness behaviour have acknowledged individuals as active and as seeking to make sense of their own experience through the employment of complex theories, which may or may not reflect biomedical understandings (Morgan *et al* 1985). Related to this, Locker (1981) adopts the term 'management sequence' in preference to illness behaviour, so as not to discount from enquiry those who do not present for medical advice and to acknowledge the many interpretations and courses of action that a particular experience can evoke. In line with this position, Locker (1981), employing a term originally coined by Dingwall (1976), refers to problematic experiences as

> 'events, situations, or states of affairs which disturb the taken-for-granted attitude towards the world and call for interpretive and explanatory activity' (Locker 1981, p49).

In this way, a problematic experience only becomes a symptom when, as a result of interpretive and explanatory activity (or medical investigation), it becomes associated with disease. Furthermore, the initial recognition of the experience is positioned as being the result of attentional, interpretive processes rather than a situation of passive registration (Cioffi 1991; Gijsbers van Wijk and Kolk 1997). As I introduced in section 1.1.3, when I employ the term symptomatic experience, I am drawing upon Locker's definition of a problematic experience, though I have replaced the word problematic with symptomatic. In referring to the experiences in this manner, I intend to highlight that whilst I and others (specifically health professionals) may associate the experiences with lung cancer, the individual whose experience it is may not interpret it as related to lung cancer or indeed any type of disease process. Thus, through the choice of terminology, it is emphasised that experiences are not inherently meaningful but are brought into significance through 'interpretive and explanatory activity' (Locker 1981, p49).

2.4.9.1 Limitations of symptom-based health education

The recommendations made by the existing literature that individuals be educated as to the symptom labels associated with specific diseases does not reflect the understanding that symptomatic experiences are not inherently meaningful. Indeed Zola (1966) has suggested that many of the interventions which rely upon the publication of symptom labels fail to meet their expectations of increasing disease recognition and influencing presentation because they are

> 'based on the assumption that a symptom or sign is fairly objective and recognizable and that it evokes similar levels of awareness and reaction' (pp629-630).

Though the limitations of symptom-based health education interventions have been recognised within the sociological literature for many years, this understanding has not transferred to the applied field and interventions often continue to employ this approach, as the previous discussion on health education suggests (section 2.4.7).

2.4.9.2 Delay as an inappropriate construct

That interpretation was significant for the participants in the study conducted by Corner *et al* (2006) is congruent with the existing literature which positions appraisal delay as fundamentally important to the pathway to presentation (Safer *et al* 1979; Andersen *et al* 1995). However, within the evolved study of illness behaviour, the notion that an individual delays interpreting or delays seeking medical advice is not acceptable. Presentation for medical advice is positioned as one of any number of possibilities for action and an experience can be interpreted in a range of ways. The length of time that this process of interpretation takes is not a failure or insufficiency on the part of the individual, but is testament to the complexity of the process. Whilst conceptualising the process of interpretation as a period of delay and a contributing factor to delay in presenting for medical advice may be inappropriate, it is recognised that the nature of the interpretation has implications for how the experience is responded to. In light of this, efforts have sought to investigate and explore the process of interpretation[30].

2.4.10 Interpretation

2.4.10.1 Normal, normality, normalisation

Interpreting a symptomatic experience as falling within the realm of normality is largely associated with no further action. Dingwall (1976), for example, has proposed an illness action model, part of which involves interpretive work in response to the disturbance (or symptomatic experience to adopt my terminology). Whilst the interpretive work remains implicit, the outcome of the interpretation is accorded great significance and Dingwall (1976) suggests three evaluations: normal, wait and see, and abnormal. If the experience is interpreted as normal, it is ignored, whilst an interpretation of abnormality leads to three potential courses of action: the experience can be ignored, the individual can adopt self-treatment to manage the experience, or the individual can seek help for the experience, either from significant others or from official services[31].

In a qualitative interview[32] study of individuals who had experienced a cough, those who had presented for medical advice had interpreted the cough as being abnormal, as interfering with social roles and as a cause for concern (Cornford 1998). A cough was interpreted as being abnormal if it lasted longer than expected, recurred, became worse or was more severe than previously experienced. An interpretation of normality was not associated with presentation since the cough was not deemed a cause for concern.

Freund and McGuire (1999) suggest that it is usual for individuals to interpret their experience as being ‘within the range of okay, or at least understandable’ (p147). Similarly, Locker (1981) employs the term ‘normalization’ to refer to the process whereby

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[30] Whilst my preference is for the ‘evolved’ study of illness behaviour and interpretation, I recognise that much of the literature which I draw on relating to the process of interpretation could be considered to fall within the original approach to the study of illness behaviour for which medical rationality is key. However this did not prevent me from gaining insight from it.

[31] ‘Wait and see’ feeds back into interpretive work until such time as an interpretation of normality or abnormality is reached.

[32] The person who conducted the interviews for the study was a practising GP, though not the GP of the individuals recruited. In light of this, the author recognises that the participants may have tried to justify their decision and suggests that a different researcher may have generated different findings.

> 'what is perceived as potentially problematic is explained in ways which show it to be normal, typical, or unworthy of further comment' (p88).

Andersen *et al* (1995) have identified eight principles which they propose govern the process of sign/symptom appraisal and interpretation[33]. Related to the concept of normalisation, the sixth principle concerns optimistic bias whereby the authors propose that an individual will prefer to make a benign interpretation over and above a disease-related, potentially threatening, interpretation. Certainly, the literature which has sought to explore the pathway to presentation reflects the position that interpretations often render symptomatic experiences as normal. Corner *et al* (2006), for example, report that the participants had interpreted their experiences as related to 'everyday causes rather than a health problem' (Corner *et al* 2006, p1385). Similarly, Gascoigne *et al* (1999) comment that, in a small qualitative interview study with individuals diagnosed with testicular cancer, the majority of the six participants had not interpreted their symptomatic experiences as related to the disease prior to diagnosis. Indeed 'some men attributed their symptoms to external causes such as back strain or injury from mowing the lawn' (Gascoigne *et al* 1999, p147) thus positioning them as normal.

Interpreting a symptomatic experience as within the realm of normality implies that it is unrelated to a disease process. The interpretation of a symptomatic experience as normal or as unrelated to a disease process can be a misinterpretation when, at some point in the future, the experience is associated with a disease category. The misinterpretation of symptomatic experiences has been reported across a range of disease types including colon cancer and melanoma skin cancer (de Nooijer *et al* 2001), breast cancer (Burgess *et al* 2001), ovarian cancer (Goff *et al* 2000), oral cancer (Scott *et al* 2006) and myocardial infarction (MI) (Ruston *et al* 1998; Horne *et al* 2000; Martin *et al* 2004).

2.4.10.2 Disease-specific interpretations

Whilst interpretations of symptomatic experiences often render that experience as normal and, implicitly, as unrelated to disease, there is evidence to suggest that individuals can, and do, make interpretations which confer categories of disease onto their experience. In the study conducted by Corner *et al* (2006), for example, one of the participants who had coughed up some blood interpreted his experience as related to

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[33] The process is described in section 2.4.10.3.

tuberculosis (TB). This was essentially, through a biomedical frame of reference, an incorrect self-diagnosis but there is much evidence to suggest that individuals can interpret their symptomatic experience as related to the specific disease with which they are subsequently diagnosed by a health professional. The breast cancer literature in particular is replete with examples of individuals who correctly self-diagnose breast cancer, and the MI literature has examples of individuals interpreting their experience as being of cardiac origin. It is because these correct self-diagnoses are widely considered to facilitate presentation for medical advice that it is deemed important and appropriate to influence interpretation. On what basis, then, do individuals come to interpret their symptomatic experience as related to a specific disease?

2.4.10.3 Disease and illness prototypes

Bishop and Converse (1986) have sought to address the issue of how individuals come to interpret a particular experience as related to a specific disease. Whilst supporting the significance of illness representations for behaviour, the authors believe there to be unanswered questions remaining as to how individuals come to make disease-specific associations. Bishop and Converse (1986) note that all of the participants in the studies conducted by Leventhal and colleagues had biomedically confirmed diagnoses and so it was not possible to establish whether, and how, they had engaged in the process of disease selection prior to biomedical diagnosis. Drawing on the earlier work of Rosch, Bishop and Converse (1986) have proposed the concept of disease prototypes which provide 'ready-made interpretations for given sets of symptoms' (p110). In their experimental work with undergraduate psychology students, the disease prototype was conceptualised in terms of symptom labels though the authors suggest that it also reflects the cause of the disease, its likely duration and what form treatment may take[34]. In this, as in Leventhal's model, a specific disease is understood in terms of a collection of categories.

Andersen *et al* (1995) have incorporated the prototype concept into their understanding of sign/symptom appraisal and interpretation. Indeed, the authors conceptualise the process

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[34] In addition to serving as a standard against which people match their experienced symptoms, Bishop (1991) suggests that the chosen prototype may influence communication with health professionals such that only those experiences consistent with the prototype are divulged.

> 'as one of psychophysiological comparison – a comparison of bodily symptoms with at least two types of circumstances: salient situational events and/or circumstances (e.g. nausea may be due to eating something 'bad', low back pain may be due to strenuous exercise) and/or those of known *illness prototypes* (e.g. acute abdominal pain may be appendicitis) (Andersen *et al* 1995, p36, my emphasis).

Furthermore, the fifth of the theory's eight principles posits that

> 'illness inferences result not because of the perception of physical symptoms *per se*, but because of the relative *match* between the symptoms and a prototype for a disease' (Andersen *et al* 1995, p44, emphasis in original).

2.4.10.4 The significance of the symptomatic experience for disease-specific interpretations

That a specific disease is associated with particular symptom labels and that it is this which influences interpretation is a conjecture supported by the existing literature. In the study reported by Gascoigne *et al* (1999), one of the six participants had interpreted their experience as related to cancer prior to diagnosis. This participant was the only one to have had a palpable, obvious lump on his testicle. The remaining participants had had a different experience and had made their interpretations on that basis.

The significance of the label of the symptomatic experience is supported within the breast cancer literature which reports that those who do not experience a breast lump delay presenting for medical advice for longer (Burgess *et al* 1998; Burgess *et al* 2001; Meechan *et al* 2003). It has been suggested that women have a 'lay perception or cognitive model[35]' (Meechan *et al* 2003, p377) of breast cancer which associates the disease with a breast lump such that those experiencing other symptomatic experiences related to the disease do not make the correct disease interpretations.

However, there is evidence to suggest that it is not just a case of certain symptomatic experiences, as expressed in symptom labels, being associated with particular diseases. The more subtle or descriptive characteristics of the symptomatic experience also seem to be significant for the interpretation. To illustrate, participants in the study conducted

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[35] Bishop and Converse (1986) would refer to this as the disease prototype, and Andersen *et al* (1995) as an illness prototype.

by Burgess *et al* (2001) who had experienced a breast lump but had not presented for medical advice as quickly as others had not interpreted the lump as related to breast cancer on the basis that it did not fulfil the criteria of size, for example the size of a pea, or sensation, specifically painless. The finer characteristics of the symptomatic experience, beyond the symptom label, may also be important for whether individuals interpret their experience as related to lung cancer. Though not explored in any detail, Corner *et al* (2006), for example, report that one of the participants had considered that her symptomatic experience was related to cancer but dismissed this interpretation on the basis that her symptoms were 'too minor' (p1387).

A similar thread runs through the MI literature as, O'Donnell *et al* (2006), for example, report that amongst their participants there was a

> 'common misperception that a 'heart attack would be much more dramatic' or 'I'd clutch my chest and fall to the ground'' (p273).

The idea that the symptomatic experience would have to reach a particular level of severity and impact is suggested as a reason for why many of the study participants did not interpret their experience as related to a heart attack.

2.4.10.5 The discrepancy between expectations and experience

The myocardial infarction literature accords great currency to the discrepancy between the expectations of what it would be like to have a heart attack and the individual's actual experience as a mechanism to account for incorrect interpretation. This is essentially in line with Bishop and Converse's (1986) disease prototype approach and Andersen *et al*'s (1995) psychophysiological comparison theory and it has been noted, too, in a recent paper exploring interpretation and patient delay in individuals with oral cancer:

> 'Patients talked of their expectations of symptoms and appearance of cancer and remarked how these did not match their own experiences. In turn, this deterred them from linking their own symptoms to cancer ... Patients also spoke of how they believed cancer to be a disease that displays itself with feelings of sickness and ill health yet expressed their feelings of physical fitness and well-being when the symptoms presented. In turn they experienced a mismatch between their expectations and their experiences' (Scott *et al* 2006, p478).

In this study, the actual experience of developing a disease is presented as different to the expectations of what the experience would be like in terms of the nature of the symptoms but also in terms of the impact on the individual. The notion that cancer is associated with feeling unwell was not congruent with the participants' perceptions of themselves as physically fit and well. The literature has also drawn attention to other factors which may be significant for whether a disease-specific interpretation is made.

2.4.10.6 Perceived personal risk and disease candidacy

The notion of risk is a complex one but the literature suggests that an individual's perceived personal risk of disease may influence the nature of their interpretation and particularly whether a specific disease interpretation is made. Within the myocardial infarction literature, for example, Ruston *et al* (1998), report that

> 'Patients' previous perceptions of their own risk varied among the three groups, with more than twice as many of the non-delayers considering themselves to be potentially at risk of a cardiac event compared with the other two groups [delayers and extended delayers.] In describing a typical potential victim of a heart attack, informants described a stereotype unlike themselves' (p1063).

Within the study, a typical victim of a heart attack was described as someone who ate unhealthy food, drank a lot of alcohol, was obese, led a sedentary lifestyle and smoked. Lockyer and Bury (2002) have related the image of an individual with coronary heart disease (CHD) to Davison *et al*'s (1991) notion of coronary candidacy. Candidacy for heart problems, generally interpreted as a heart attack, is suggested as being related to three areas: physical appearance, social information and personal information. Davison *et al* (1991, p11) report that the 'first and most common assessment' relates to physical appearance where those who are obese, flushed and who demonstrate lack of fitness are considered to be candidates for cardiac disease. Lockyer and Bury (2002) draw attention to the lack of consideration paid to gender within coronary candidacy and suggest that the typical CHD patient is viewed as male which has implications for the diagnosis and management of the disease in women. The same may also be the case for myocardial infarction and the perception of heart attack as a male disease may influence how women interpret the symptomatic experiences associated with it. This conjecture may be supported by Martin *et al*'s (2004) finding that the female participants in their study were less likely to consider their experiences to be of cardiac origin than were the male participants (see also Clark 2001).

Within the cancer literature, the notion of disease candidacy as significant for interpretation has not been widely explored despite some evidence to suggest that it may be a fruitful area of enquiry. The literature suggests, for example, that older women with breast symptoms tend to delay presenting for medical advice (see Ramirez *et al* 1999). Grunfeld *et al* (2002), in a structured interview administered as part of the Office for National Statistics (ONS) Omnibus survey, sought to establish the knowledge and beliefs relating to breast cancer held by members of the general UK population. According to the authors, approximately 25 per cent of the sample of 996 participants who positioned themselves as being at reduced risk of the disease believed that they were too old to develop it. The belief that breast cancer is not a disease of older women has also been highlighted by a recent survey carried out on behalf of Cancer Research UK (CRUK 2006). Of the 2, 289 women questioned, 77 per cent thought that a woman is at a greater risk of breast cancer if she is below 70 years of age when in actuality the risk of developing the disease increases with age (CRUK 2006). The finding is contextually grounded in terms of the 'Kylie effect' whereby the recent diagnosis of breast cancer in celebrity Kylie Minogue at the age of 36 and the subsequent media coverage has led to the presentation, and potentially the reinforcement, of the disease as one of young age[36].

The social context may, then, be significant for how individuals interpret and respond to symptomatic experiences but only to the extent that it influences how a specific disease is understood. Within the existing literature and its understanding of interpretation, the emphasis is on the correctness or the completeness of an individual's cognitive structure (i.e. prototype). Whilst it is recognised that such a structure may be informed by knowledge from outside, the interpretation is positioned as solely contingent upon the individual and entirely independent of the immediate and wider context[37]. In this way, a particular interpretation is value neutral, not being held in higher or lesser regard than another, such that an individual is at liberty to make any interpretation that his experience and his cognitive structures will allow.

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[36] Within the UK, the NHS Breast Screening Programme invites women aged 50-70 years for mammography screening. Any woman above this age can attend but has to instigate their own appointment. This situation may also serve to position breast cancer as a disease of younger women.

[37] The distinction between individualist and collectivist approaches to the study of illness behaviour is not then reflected in the study of interpretation, which is undertaken from an individualist position.

2.4.11 Cancer and the social context

The significance of the wider social context has been implied by Corner *et al* (2006). That all of the participants had experienced symptoms for at least four months prior to diagnosis led the authors to propose that the findings of their study

> 'point to the ways in which 'late' diagnosis of lung cancer may not only be a matter of the biomedical difficulties in detecting lung cancer, but that it may also be a socially produced phenomenon' (Corner *et al* 2006, p1390).

Indeed, when discussing the implications of their work the authors suggest that though there may be value in educating the general population as to the symptoms labels associated with lung cancer and encouraging them to seek early diagnosis, the nature of the social context may act as a barrier to the effectiveness of such interventions. Corner *et al* (2006) suggest that the social context as it relates to breast cancer facilitates the interpretation of particular symptomatic experiences as associated with the disease and furthermore encourages presentation for medical advice as a justified and appropriate response. However, the social context relating to lung cancer neither facilitates the correct interpretation of specific symptoms nor positions presentation for medical advice as an appropriate, indeed warranted, course of action since little is perceived to be gained from securing a diagnosis and initiating treatment options (Corner *et al* 2006). The authors report that the symptomatic experiences frequently described by the participants, such as cough, tiredness and weight loss, were not perceived to be symptoms of disease processes. This reflects the wider social context where such experiences are not considered to be significant indicators of disease and therefore as necessitating medical advice. Related to this, Zola (1966) suggests that there are at least two possible mechanisms through which a symptomatic experience, which he refers to as a sign, can be considered a cause for concern in one population but not in another. One such mechanism is 'related to the actual prevalence' of the experience whilst the other is determined by the experience's congruence with major value orientations (Zola 1966, p29). Though Zola (1966) is referring to cultural comparison, it does highlight the way in which what is considered to constitute a legitimate symptom is very much part of a social process.

2.4.11.1 The legitimacy of diagnoses

An additional aspect relevant to this discussion is the legitimacy of particular diagnoses. Cornwell (1984), drawing on a study of individuals living in the east end of London, has identified three categories of health problem: 'normal' illness, 'real' illness and 'health problems which are not illness' (pp130-131). Within the category of 'normal' illness, Cornwell (1984) places the infectious diseases, such as fever, flu and some common respiratory disorders. 'Real' illnesses correspond to diagnoses such as cancer and cardiovascular disease which are perceived as having a serious impact on the individual. Included within 'health problems which are not illness' are those associated with natural processes, such as ageing and menstruation, or individual factors, such as asthma and eczema. These problems are not considered to warrant medical attention, though efforts at self-care may be deemed appropriate. If interpreted as being a part of 'normal' illness, as with 'health problems which are not illness', recourse to a medical professional may not be the first course of action. Indeed, in an effort to manage demand on services, individuals interpreting a symptomatic experience as within the realms of 'normal' illness can be discouraged from seeking medical advice[38].

2.4.11.2 The 'double'

As well as the legitimacy of diagnoses and the implications that this may have for the management sequence, diagnoses also have social consequences. Writing in this vein, Scheper-Hughes and Lock (1986) refer to the 'double' which comprises the 'layers of stigma, rejection, fear, and exclusion that attend to particularly dreaded diseases' (p137). Cancer is associated with largely negative connotations and Susan Sontag's acclaimed collection of metaphors is a testament to this. The overwhelmingly negative perceptions with which cancer is endowed led Sontag (1983) to call for diseases to be reduced to their biological form, for cancer to be seen only as the uncontrolled proliferation of cells. Scheper-Hughes and Lock (1986), whilst recognising the negative impact of meanings attached to prominent diseases, disagree that disease should, or indeed could, be separated from its symbolic meaning, an opinion which is shared by others (see for example DiGiacomo 1992).

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[38] A leaflet which I picked up from a GP surgery within the geographical locality of the study advises readers to 'Think twice before calling your doctor if you have a cough, cold or flu'.

2.4.11.3 The social portrayal of lung cancer

Relating to the social consequences and legitimacy of particular diagnoses, others besides Corner *et al* (2006) have reflected on the social context relating to lung cancer as opposed to other types of cancer. An editorial in The Lancet (2000) wrote

> 'Is it far-fetched to suggest that some cancers are more fashionable than others, at least based on the attention they receive in the mass media? Breast cancer is an obvious example' (p1205).

The Lancet (2000) comments that lung cancer is largely perceived to be self-inflicted and thus preventable with unsatisfactory treatment options and few advancements in screening technologies, and suggests that increased awareness in these areas is needed if lung cancer is to be viewed on a par with breast cancer. Only then, the author proposes, will resources be dedicated to what is, at this time, a 'devastating disease' (The Lancet 2000, p1205). Similarly, Chapple *et al* (2004) suggest that the representation of lung cancer as a self-inflicted disease has led those diagnosed with the disease to experience a level of stigma not associated with other types of cancer. The authors highlight the media, including television programmes and newspaper articles, as contributing to the level of stigma through their depiction of the disease and those likely to develop it. Indeed, the information delivered through the media is both a potential source of knowledge and an influence on the definition and shape of 'societal attitudes and views concerning health and illness' (Lyons 2000, p350).

The tobacco control agenda is identified as a source of consistently negative portrayals of lung cancer (Chapple *et al* 2004), employed as a mechanism to promote smoking cessation and facilitate smoking abstention. The following is my textual representation of one of a series of television advertisements screened on UK television in 2004 as part of the NHS 'Giving up Smoking' campaign.

'Steve'

There is a gentleman sitting on a settee, the type you would find in an ordinary home. It certainly does not seem to be a hospital setting. The gentleman is Steve and he looks tired, thin and drawn. There is little hair on his head.

Steve's voice over: Basically it grabbed me and took hold of me

Steve speaking directly to camera: Cancer spreads and it develops fast. My lung was infested with a tumour. I was told that it was malignant. I've had to have a major operation and they've taken the lung away (camera shot of Steve's right hand under his shirt). And this is all due to smoking, ha (Steve smiles lightly). That white little stick that you put in your mouth and at thirty-four you're thinking, hhh, I shouldn't be going through this'.

Voiceover (not Steve): If you want to stop smoking call

The screen turns black, upon which is written 'The NHS Smoking Helpline 0800 169 0 169. Don't give up giving up'.

The series of television adverts from which I extracted Steve's representation was welcomed by those who felt that its emotive stance would enable the tobacco control agenda to attain its goals (see for example Myatt and Treasure 2002) whilst others, for example Chapple *et al* (2004) as discussed previously, warn that their impact may stretch beyond this remit. However, it is not only the interventions devised within the tobacco control agenda which present a particular view of lung cancer. The information produced by the general mass media is not without bias (Hoffman-Goetz 1999) and what is depicted is likely to have been influenced by a particular agenda (Seale 2003). Lung cancer is an oft-given example of a disease type which is under-reported, a situation which is inline with the interests of tobacco companies, many of whom have a stake in advertising and publishing (Seale 2002). When lung cancer does feature in the media, the discourse of hope which Lupton (1994) considers to surround the portrayal of cancer is not evident.

2.5 The existing literature and my unanswered questions

The literature, as reviewed in this chapter, was important for two reasons. Initially it allowed me to become familiar with an area that I knew little about. Then as I journeyed through it I became conscious of what I thought was understood and what I thought was yet to understand. I conceptualised this need for understanding in the form of unanswered questions and it is to these that I shall now turn.

2.5.1 First unanswered question

What is the experience of developing and being diagnosed with lung cancer?

Once I had reviewed the most relevant literature I felt strongly that I would only be in a position to make a contribution to the earlier diagnosis of lung cancer if I knew what the experience of developing and being diagnosed with the disease could be like. I was aware, for example, that not all individuals 'delay' presenting for medical advice, which is why the median values are often employed rather than the mean values. I understood too that some individuals are diagnosed incidentally and never see their GP. I wondered if these individuals have symptomatic experiences which they misinterpret or whether they do not experience anything at all.

The nature of the existing literature meant that I was not able to answer these sub-questions or even to answer the main question (what is the experience?). The concern with patient delay and its quantification has led to the utilisation of methods of data generation which are not able to explore the experience in any depth. The work of Corner and colleagues has been different in that through their choice of method they have been able to explore the experience more fully but one still gets a limited sense of a real experience in the published research texts (Corner *et al* 2005; 2006).

Whilst in this chapter I have referred solely to the unpublished report (Corner *et al* 2003) and the published research texts (Corner *et al* 2005; 2006), I want to make it clear that I was in the fortunate position of having access to the full interview transcripts generated in the study conducted by Corner and colleagues, which I took the opportunity to read. In addition to this, I listened to several of the interview recordings. Despite this, I was still left with the question of 'what is the experience?' Part of this may have been because the interviews were conducted to generate particular data to address the aims of the study and in this way were directed at the symptom experiences of the individuals and the service response to those experiences. But it may also have been because a transcript, even a recording, can only capture certain aspects of the data and there is much which cannot be heard or translated into written form. Similarly, the generated data are the outcome, the destination, but there is much to be gained from the journey itself and that I had not talked with the participants meant that I felt that there was much missing (Thorne 1998). I still, then, did not feel that I was in a position to understand the experience of developing and being diagnosed with lung cancer and therefore felt unable to respond to my second unanswered question.

2.5.2 Second unanswered question

Why may, or may not, individuals realise the significance of their symptomatic experiences? Specifically, why do individuals not seem to interpret their experience as related to lung cancer?

My initial entry into the existing literature concentrated on patient delay in presenting for medical advice. In this understanding, presentation for medical advice is positioned as the only response to disease and responsibility for failing to do so rests on the individual. Interpreting symptoms incorrectly is positioned as making a significant contribution to the duration of the pathway to the doctor, referred to as appraisal delay (Safer *et al* 1979; Andersen *et al* 1995). But in a different approach within the literature, these 'incorrect' interpretations are of interest in their own right, and whilst it is accepted that these interpretations influence the subsequent management sequence, they are positioned as arising from an individual who is actively responding to the complexity of the experience and discerning in their use of medical knowledge (Morgan *et al* 1985). In this way, patient delay is an inappropriate construct, though the significance of interpretation is acknowledged.

In the study conducted by Corner *et al* (2003; 2006), only one of the twenty-two participants had considered that they might have lung cancer, though this interpretation was not sustained. Many of the remaining participants had not interpreted their experience as related to ill health, not least as related to any type of disease. The existing literature suggests that interpretation can be understood as one of psychophysiological comparison (Andersen *et al* 1995) whereby an individual compares their experience with a disease prototype (Bishop and Converse 1996). Within the concept of a disease prototype, much emphasis is placed on the symptoms associated with a specific disease though, as the literature reviewed in this chapter has suggested, other aspects of how a disease is understood have been deemed to be important for whether a particular experience is associated with a specific disease. I wondered, then, how lung cancer is understood if many individuals do not interpret their experience as related to the disease[39]. Certainly, some of the literature suggests that it is because individuals do not have an understanding of lung cancer that they do not interpret their experience as related to the disease and it is this which has led to health education

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[39] Birring and Peake (2005) have also commented that the issue of why the participants had not interpreted their experience as serious or as a warrant for medical attention has not been reported by Corner *et al* (2005) (or, I suggest, by Corner *et al* 2006).

interventions which publicise the symptom labels associated with the disease. But the limitations of such an approach have been recognised within the sociological literature (Zola 1966) and Corner *et al* (2006) suggest that the social context may be a barrier to the success of the interventions. I began to think that there may be more to interpretation than the correctness or completeness of cognitive disease prototypes. I thought that if I could understand the process of interpretation, and potentially also the process of presentation, for individuals subsequently diagnosed with lung cancer, I would be in a position to suggest an answer to this, my second, unanswered question but also to my third.

2.5.3 Third unanswered question

How might the processes of interpretation and presentation in lung cancer be influenced so as to make a contribution to the earlier diagnosis of the disease?

In understanding interpretation more fully, particularly as it relates to lung cancer, I thought that I might have some 'actionable insights[40]' (NCC 2006) on which to build future interventions developed so as to influence interpretation and presentation in the disease. It was this insight which I felt would make a contribution to the earlier diagnosis of lung cancer, thereby fulfilling my commitment to promote its earlier diagnosis.

2.6 Chapter summary

The purpose of this chapter has been to situate the study at the centre of this thesis within the arena of existing research and to give background information and context to its central themes. I began by introducing the subject of cancer in general and then lung cancer in particular. I considered the study of patient delay, particularly in relation to cancer and as a component of the study of illness behaviour. I presented the common sense model of illness as an individualist approach to the study of illness behaviour. This led me to consider Safer's (1979) and Andersen's (1995) models of patient delay which considers the pathway to presentation to involve movement through a number of stages, each of which involves particular processes of appraisal and decision-making.

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[40] The term 'actionable insight' is presented by the National Consumer Council as an important component of social marketing approaches to influencing health-related behaviour. Drawing on marketing, the approach invests great significance in understanding 'why people act as they do' (NCC 2006, p3) so that interventions can be developed with this understanding in mind. The assumption is that the intervention will thus be more successful if it is informed by the perspective of the target.

From here, I described some of the existing literature relating to patient delay and lung cancer which has sought to quantify the extent of patient delay. Within this literature, educating members of the general population, or those at increased risk, of the symptom labels associated with a particular disease is recommended so as to reduce patient delay. This led me to briefly consider the literature relating to health education as a mechanism for influencing presentation behaviour and the arena of health promotion.

At this point I considered the work of Jessica Corner and colleagues which, though originally designed to establish the symptoms experienced by individuals prior to diagnosis, sought to explain the significant amount of delay in presenting for medical advice. A thematic analysis highlighted the role of interpretation, with the majority of the individuals not realising the significance of their experience. That symptomatic experiences are not inherently meaningful led me to consider the evolved study of illness behaviour. In this approach, individuals are positioned as actively seeking to make sense of their experience through the employment of complex theories and the discerning use of biomedical knowledge. From here I introduced Zola's (1966) critique of symptom-based health education and positioned delay as an inappropriate construct.

Whilst the evolved approach to the study of illness behaviour does not seek to evaluate the correctness of interpretations, it does recognise that the interpretation influences the management sequence. In light of this, I considered the factors which can influence the nature of interpretations, particularly with regards to whether a particular experience is interpreted as related to a specific disease. However, whilst much reference to interpretation is made within the literature, efforts to make this process explicit are often lacking. Furthermore, interpretation is presented as something which happens within the individual and there is no consideration as to the impact of the wider social context. Corner *et al* (2006) suggest that the social context positions the symptomatic experiences associated with lung cancer as not associated with disease processes and this led me to draw upon Cornwell's (1984) distinctions of the legitimacy of different diagnoses. From this point, I considered the notion of the 'double' and the portrayal of lung cancer within the wider social context. I ended the chapter with my unanswered questions as the culmination of my journey through a range of different literature.

3 Describing the study

3.1 Introduction to the chapter

The purpose of this chapter is to describe the study in theoretical and practical terms. It is for this reason that I have divided it into two parts: research in theory and research in practice. In the first part (research in theory) I position my unanswered questions as research questions followed by a consideration of the theoretical assumptions which are implicit in them. This leads me on to the topic of paradigms and to position myself within an interpretive paradigm. From this I consider research designs and outline the case study approach as one congruent with my position. Robert Stake's view of case study research, in which he draws attention to the prevalence of stories, leads me into narrative research where I discuss the relationship between narrative and experience and introduce illness narratives as a mechanism for constructing and communicating the experiences of illness. I introduce the interview as a method of data generation commonly employed within narrative research and outline a number of different approaches to narrative data. Following this I summarise the direction of the study such that I sought to understand the experience of developing and being diagnosed with lung cancer, principally through the generation of illness narratives with individuals who had been diagnosed with the disease. I end the first part of the chapter with a discussion of how the study might be appraised and the steps which I adopted in order to facilitate my understanding, including a consideration of the alternative sources of data which I drew upon in a process of extensive engagement.

In the second part of the chapter (research in practice), I discuss the actual process of generating the illness narratives with excerpts from my research log employed to illustrate what the research process was like for me as well as what I did. I then reflect on the illness narrative data and my decision to draw a distinction between two components: the narratives of personal experience and the narratives of genesis. I explore the value of the distinction in terms of the potential to contribute to the addressing of different research questions. I end the second part of the chapter by outlining a number of factors which may have influenced the nature of the illness narrative data, positioning the data as situated constructions. I consider my analytic approaches to the generated data in subsequent chapters.

Research in theory

3.2 Unanswered questions – research questions

At the end of the previous chapter I outlined a number of unanswered questions which I developed as I journeyed through the existing literature:

1. What is the experience of developing and being diagnosed with lung cancer?
2. Why may, or may not, individuals realise the significance of their symptomatic experiences? Specifically, why do individuals not seem to interpret their experience as related to lung cancer?
3. How might the processes of interpretation and presentation in lung cancer be influenced so as to make a contribution to the earlier diagnosis of the disease?

These unanswered questions became my research questions. The development of research questions is identified as one of the principle mechanisms for clarifying what it is that one wants to achieve and how one might go about achieving it (Gillham 2000). Indeed, the research questions provided the direction for the study because whatever I did and whatever decisions I made, I always sought to be in the best position to suggest possible answers.

3.2.1 Research questions and theoretical positions

All research questions are theoretical (Silverman 2000); they espouse positions on what the world is and how it can be known. The first question, for example, was concerned with experience. Through my question I revealed my position: there is such a thing as experience, it can be reflected upon by the individual at the centre of it and it can be communicated to others[41]. Furthermore, I assumed the existence of a biomedical disease category termed lung cancer. Within the second question I assumed that there is such a thing as a symptomatic experience which is open to interpretation. In this way, I did not

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[41] Though there is debate about how much of an experience can be communicated to others and I touch on this in section 3.5.1.2.

consider a symptomatic experience to be inherently meaningful and, moreover, I viewed the individual as central to the process of interpretation. Within the third question I assumed that, once the experience of developing and being diagnosed with lung cancer was understood, it would be possible to influence how individuals interpret the symptomatic experiences associated with the disease and how they act on them, particularly in terms of presenting for medical advice. Within this, as well as it being possible, I assumed that it would be right and justified to attempt to influence individuals to interpret and act in this way.

Though I thought of the research questions as unanswered and of myself as seeking to answer them, I had a particular position on this. I have tried to illustrate this in my choice of language since I have written of being in the 'best position to suggest possible answers' (section 3.2). This reflects my decision to align myself with a particular paradigm.

3.3 Paradigms

Patton (2002) defines a paradigm as 'a world view – a way of thinking about and making sense of the complexities of the real world' (p69). According to Denzin and Lincoln (2003) paradigms explicate first principles and encompass four concepts: ethics, epistemology, ontology and methodology[42]. It is because paradigms are human constructions (Guba 1990) that there is no consistency of opinion regarding what constitutes a paradigm or what the different types of paradigm might be. For illustration, Weaver and Olson (2006) suggest four distinct types of paradigm that are most often adopted in the conduct of research: positivist, postpositivist, interpretive and critical social theory, whilst Denzin and Lincoln (2003) identify four paradigms operating in qualitative research: positivistic and postpositivistic, constructivist-interpretive, critical and feminist-poststructural.

3.3.1 The distinction between qualitative and quantitative enquiry

Weaver and Olson (2006) apply their paradigmatic categories to all research, whereas Denzin and Lincoln (2003) limit their application of paradigms to qualitative research. Qualitative research, according to the authors, can be broadly defined as a 'situated

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[42] Ethics refers to the moral principles which inform conduct, epistemology is the branch of philosophy concerned with knowledge, ontology is the branch of philosophy concerned with the nature of being and methodology refers to a system of methods (Denzin and Lincoln 2003).

activity that locates the observer in the world' (Denzin and Lincoln 2003, p3). The authors suggest that qualitative researchers can draw upon language-based perspectives such as those encountered within semiotics, narrative, content and discourse as well as 'statistics, tables, graphs, and numbers' (Denzin and Lincoln 2003, p10). This is a somewhat different position to that which is often encountered within the literature and which defines qualitative research as emphasizing 'words rather than quantification in the collection and analysis of data' (Bryman 2001, p506) whilst quantitative research is used to refer to those approaches which emphasise 'quantification in the collection and analysis of data' (*ibid*). Bryman (2001) suggests that quantitative research is usually associated with positivism. Similarly, qualitative research is often viewed as synonymous with an interpretive paradigm (see for example Marshall and Rossman 1999). Rolfe (2006) highlights the variation of approaches usually included under the qualitative umbrella and disputes the correspondence between qualitative research and the interpretive paradigm. He suggests that Husserlian phenomenology, though qualitative in terms of the data generated, is more congruent with positivism/postpositivism than an interpretive paradigm. Whilst Green and Thorogood (2004) seem to suggest that there could be such a construction as a qualitative paradigm, Atkinson (1995) disagrees and comments that there 'is no single set of theoretical or methodological presuppositions to underpin a qualitative paradigm' (p119).

My position on this issue was that a) there are insufficient grounds for a qualitative paradigm and b) forms of data (language- or number-based) are not paradigm specific. Qualitative data can then be situated within a positivist/postpositivist paradigm and quantitative data can be situated within an interpretive paradigm.

3.3.2 Patient delay and lung cancer literature within a positivist paradigm

To be explicit, and to engage in the paradigm debate, I propose that much of the existing literature which I reviewed in order to prepare myself for this study is positioned within a positivist/postpositivistic paradigm. Guba (1990) outlines the basic foundations of positivism as a commitment to realist ontology, an objectivist epistemology and empirical experimentalism. He defines realist ontology as 'the belief that there exists a reality *out there*, driven by immutable natural laws' (Guba 1990, p19, emphasis in original) which it is possible to know through experimental and manipulative empirical design (methodology) so long as the researcher operates in a detached, objective manner (objectivist epistemology). Guba (1990) positions postpositivism as a 'modified version of positivism'[43] (p20).

To justify my proposal I shall comment on the research texts of Corner and colleagues (Corner *et al* 2005; 2006)[44]. I have chosen to do this because I think that it reinforces the notion that qualitative data can be drawn upon outside of an interpretive paradigm. Within both of the articles the retrospective character of the interviews is identified as a limitation of the work. Following from this, it is stated that a prospective design would have been more appropriate but was not feasible (Corner *et al* 2005). Implicit in this suggestion is that there is one truth which can be best known when the event of interest is in temporal unity with its enquiry. Tied in with this is the exercise of caution over the content of the participants' talk given its retrospective nature, and the quest to triangulate it with other data sources (GP and hospital records) so as to be sure that the correct version of events has been established. The use of alternative data sources is often referred to as between-method triangulation but researcher triangulation is also employed in the work. This is particularly explicit in the sections of text which describe the roles of three researchers in conducting sections of the analysis. The analytical discussion (Corner *et al* 2006) and the high level of agreement that is achieved (Corner *et al* 2005) are presented as enhancing the research through facilitating the correct understanding. Related to this, 'reveal' is employed within both of the research texts and implies that the truth is independent of the methods of investigation.

Within the existing research, language is widely viewed as a window onto reality and this is also the case within the work reported by Corner and colleagues. No consideration is given to the notion that language constitutes reality and is a tool which can be used creatively to effect different ends. In line with this, although the authors write of participant 'accounts' of experience (Corner *et al* 2006), the role of the participant in actively building their talk to suit the specific social occasion of the interview is not considered. The interview talk is viewed as a medium for transmitting 'how it was' and there is no acknowledgement of the impact of the immediate and wider social context on the nature of this talk. Similarly, the role of the researcher in co-constructing the interview talk is not acknowledged, and direct quotes from participants

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[43] Guba (1990) suggests that postpositivism is characterised by a commitment to a critical realist ontology, a modified objectivist epistemology and a modified objectivist methodology.

[44] I am conscious that in order to get a piece of work recognised and published in a particular journal it may be necessary to adopt specific language and draw attention to certain aspects of the research process. It is therefore the position of the research texts which I am commenting on and not that of the researchers.

when presented are done so in an extracted, context-free way removed from the interviewer's contribution.

3.3.3 Interpretive paradigm

Whilst I recognise the position of much of the existing relevant literature (as it was presented in the research texts), I conducted this research from within an interpretive paradigm, influenced by social constructionism. Guba (1990), who I have drawn on in this discussion, does not apply interpretive as a paradigm label, preferring instead to identify a constructivist paradigm. In his view, such a paradigm is characterised by a commitment to a relativist ontology, whereby realities exist as situated constructions, a subjectivist epistemology, such that any findings are the product of the interaction between the researcher and the researched, and a hermeneutic, dialectic methodology which is concerned with interpretation and the refinement of interpretations. Though my terminology differed, Guba's (1990) explication of the constructivist paradigm, which he aligns himself to, summarised aspects of my own position. However whilst I recognised that the encompassing nature of a paradigm leads to an inevitable choice of one over another (Lincoln 1990), I did not share Guba's (1990) opinion that any paradigm outside of constructivist/interpretivist is wrong and should be replaced. To replace or deny the existence of other ways of seeing would be to stymie what can be a stimulating debate.

Adopting a slightly different stance, Green and Thorogood (2004) write that the interpretive paradigm is focused on meaning and a quest to understand rather than to explain. Whilst I too think that there is much emphasis on understanding, I do not think that understanding is paradigm-specific or that one can separate understanding from explanation. In an interesting essay, Vendler (1984) draws a distinction between what it is to know and what it is to understand. To understand is positioned as far more demanding an enterprise than to know such that 'To understand, it may not be enough to know' (Vendler 1984, p204). Understanding, according to Vendler (1984), requires the ability to interpret and *explain* (my emphasis). To come to an understanding of an individual, one must imagine what it is like for the individual to be in that situation[45]. In this way:

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[45] See also Waller's (1934) notion of insight (understanding) through sympathetic imagination and Dilthey's notion of understanding through empathic imagination (see Ermarth 1978).

> 'understanding, unlike knowledge, is no mere passive state but a result of the mind's constructive labor. We try to understand, we speak of "flashes" of understanding, and, in difficult cases, our understanding may be only partial or incomplete' (Vendler 1984, p206).

When Green and Thorogood (2004) comment that research conducted from an interpretive perspective is not concerned with explanation, it is the explanation associated with positivist and postpositivist perspectives to which they are referring. From this perspective, explanations are positioned as referring to a reality outside of the study and therefore judgements as to their correctness can be made. Explanations generated from within the interpretive paradigm are understood as just that, generated, and claims to being right or correct in terms of reflecting an outside reality are not appropriate. In this way, explanations are positioned as historical and contextual.

3.3.3.1 Social constructionism

The type of explanations associated with positivism and postpositivism are developed so as to facilitate the prediction and control of the natural world. They are presented as being true and real to the extent that they reflect a reality which exists outside of them. However I held an alternative position and instead considered truth and facts to be socially constructed (Denzin 1997). Crotty (1998) defines constructionism as

> 'the view that *all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context'.* (p42, emphasis in original).

Green and Thorogood (2004) outline the social constructionist position with respect to health and disease:

> 'How we divide up the world (for instance, how we see the systems of the body, or how we classify diseases) is the result of historical, social and political processes, rather than an inevitable result of our greater understanding of the 'reality' of the body, or disease' (p13).

Medical diagnoses such as lung cancer are constituted through a process of social construction (Brown 1995; Bloor 2001). However, recognising that meaningful reality is created does not mean that it is not real (Crotty 1998). As I discussed in the previous chapter, lung cancer as a disease is associated with the experience of a number of symptoms. To say that these symptom labels are socially constructed does not mean to say that they are not really experienced (Freund and McGuire 1999).

From my position, knowledge, facts, interpretations and understandings are constructed and so it follows that the methods of research do not provide a way of accessing the world. Instead they provide a way of bringing meaning to and constructing what is under investigation. This is entirely congruent with my discussion in the previous chapter with regards to methods of data generation as opposed to data collection (section 2.4.6.2).

3.4 Research design

In section 3.3.2 I made a number of connections between particular paradigmatic positions and aspects of the actual research process as presented within the research texts. The link between the theoretical positions and the actual process of conducting the research is made more explicit through the concept of research design. Green and Thorogood (2004) write that 'research design refers to the logic of the study: the what, how and why of data production' and identify a typology of five: experiments, survey, observational studies, case studies and action research (p34). Alternatively, Denscombe (1998) employs the term research strategies and identifies five distinct types: experiments, surveys, case studies, ethnography and action research. The variation in these typologies serves to demonstrate the lack of consensus over what the different research designs are. Nonetheless, each particular research design is meaningful through its relationship to others and so it becomes possible to identify the key points of difference between the alternative research designs. It is these key points of difference which are potentially more useful than the category titles.

Lathlean (personal communication 9th June 2006) is in favour of a typology of four research designs (survey, experiment, case study and action research) but more significantly for the present discussion she suggests that each design differs in terms of how much it interferes and manipulates the focus of study and its claims to generalisation[46]. I found it helpful to draw on these key points and it was through

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[46] In a similar vein, Hammersley (1992) highlights the differences between case study, experiments and surveys so as to clarify the position of case study. Compared to survey, Hammersley (1992) proposes, case study allows for more depth of study but less generalisation to finite populations, whilst compared to experiment, case study does not permit such tight control of variables but does allow for a greater degree of naturalness (as opposed to artificiality).

considering them alongside my theoretical position that I came to consider that a case study approach provided the link to the actual research process and that it was well suited to addressing the research questions.

3.4.1 Case study approach

To link to the previous discussion, case study does not seek to manipulate that which is under study and its claims to generalisation are of a conceptual/theoretical, rather than statistical, nature. There are a number of key writers and thinkers in the field of case study but I found the work of Robert Stake most suited to my theoretical position[47]. Stake (1995) defines case study as 'the study of particularity and complexity of a single case, coming to understand its activity within important circumstances' (pxi). Within this, Stake makes a distinction between intrinsic case study, where the case is selected because of an intrinsic interest in it, instrumental case study, where the case is selected because an understanding of it will further the understanding of something else, and collective case study, where more than one case is explored. That case study typically focuses on single cases or small numbers of cases leads it to be subject to much derision but the criticisms levelled at it can be addressed in such a way so as to demonstrate the utility and worth of the approach (see Flyvbjerg 2006). Indeed, case study research has a long history within the social sciences and particularly education, and it has also secured a valued position within health research (Riessman 2003).

But what constitutes a case? A case is 'one among others' (Stake 1994, p236). It is 'a specific, a complex, functioning thing' (Stake 1995, p2). In this way Stake identifies people and (educational) programmes as potential cases but considers that events and processes are insufficiently bounded to be a case. In order to be in a position to address the research questions, I thought that an individual who had personal experience of developing and being diagnosed with lung cancer would be a suitable case, fulfilling as it does the requisite for boundedness. But more focused than that, I further defined the case as that experience. In making this decision I was influenced by Locker (1981) who, in a study exploring symptoms and illness in six participants, writes

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[47] I did consider the work of Robert Yin who suggests that case studies are well-suited to answering questions of how and why (as in my second and third research question). However, I found the rigidity of Yin's approach unhelpful and disengaging: 'investigating an empirical topic by following a set of prespecified procedures' (2003, p15).

> 'I did not conceive of the women I interviewed as 'cases'; they are not the unit of analysis. Nor as the thirty or so individuals about whom the women talked. The unit of analysis is what I have referred to as a management sequence' (p19).

Defining the case within a case in this way, I risked not complying with Stake's (1995) position that an event (or I assume events) is not sufficiently bound to be considered a case. However, when a person is defined as a case, what is of interest if it is not their experience, the events in their life[48]?

Though Locker (1981), in the previous quote, revealed that he had engaged his participants in interviews, a case study approach does not preclude the adoption of particular methods. However, the approach does attempt to select methods which limit intrusion and manipulation and there is a tendency towards the utilisation of multiple sources of data (Denscombe 1998). The intention is to come to understand the case, the focus being on particularisation rather than generalisation, and then to present the understanding to others:

> 'We seek to understand them (the cases). We would like to hear their stories... Much of our gathering of data from other people will take the form of stories they tell and much of what we can convey to our readers will preserve that form' (Stake 1995, p1).

Furthermore, the understanding generated through the research is always contingent, as Stake (1995) writes:

> 'Our observations cannot help but be interpretive, and our descriptive report is laced with and followed by interpretation. We offer opportunity for readers to make their own interpretations of the case, but we offer ours too' (p134).

Though the case study approach does not in itself obviate the adoption of particular methods, Stake's (1995) concern with stories, as both heard and presented, makes some methods of data generation and analysis more appropriate than others. Stories, for

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[48] In defining a case, and in making decisions relating to the selection of cases (i.e. atypical or extreme, multiple), the researcher makes explicit their implicit understandings and ideas since cases 'come wrapped in theories [and] are always hypotheses' (Walton 1992, p122). Indeed, it is because the definition and selection of cases connects evidence to ideas that 'what the case is a case of' can shift through the research process (Ragin 1992).

example, are central to a narrative approach to research[49], a perspective which has received much attention within the social sciences as signalled by the 'narrative turn' (Garro and Mattingly 2000; Atkinson and Delamont 2006).

3.5 Narrative research

Narrative research is predominantly presented as a qualitative approach but not all qualitative research is narrative (Overcash 2003). Similarly, Elliott (2005) has presented a case for the application of narrative within quantitative as well as qualitative fields of enquiry. What, then, is narrative and what is narrative research?

3.5.1 Defining narrative

The following quote is often drawn upon within the narrative literature to illustrate the ubiquity of narrative:

> 'Able to be carried by articulated language, spoken or written, fixed or moving images, gestures, and the ordered mixture of all these substances; narrative is present in myth, legend, fable, tale, novella, epic, history, tragedy, drama, comedy, mime, painting (think of Carpaccio's *Saint Ursula*[50]), stained glass windows, cinema, comics, news item, conversation. Moreover, under this almost infinite diversity of forms, narrative is present in every age, in every place, in every society; it begins with the very history of mankind and there nowhere is nor has been a people without narrative. All classes, all human groups, have their narratives, enjoyment of which is often shared by men with different, even opposing cultural backgrounds. Caring nothing for the division between good and bad literature, narrative is international. transhistorical (*sic*), transcultural: it is simply there, like life itself'. (Barthes 1977, p79, emphasis in original)

Whilst this extended quote may feature relatively often, the narrative front is far from a united one. Rather, there is much disagreement as to the definition of the term narrative[51] (Riessman 1993). Despite this variation, it is possible to identify from the existing literature what appear to be core elements of the definitions. Arguably the most

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[49] Narrative research/analysis has been positioned as a case study approach in itself by some researchers (see for example Edvardsson *et al* 2003; Riessman 2003).

[50] The artist Vittore Carpaccio painted a series of nine large canvasses between 1490 and 1496 depicting 'Stories from the Life of St Ursula'.

[51] The term 'narrative' derives from the Latin word '*narrare*' which means to tell or relate.

frequently occurring element is the notion of temporality, as illustrated in the following two quotes:

> 'Regardless of the contexts in which they emerge, the modalities through which they are expressed, and the genres laminated within them, all narratives *depict a temporal transition from one state of affairs to another* (Ochs 1997, p189, emphasis in original).

> 'In the context of narrative inquiry, narrative refers to a discourse form in which events and happenings are configured into a temporal unity by means of a plot' (Polkinghorne 1995, p5).

There is a general consensus, then, that narrative refers to the depiction of events over time. Related to this, it is often implied that the narrative, the depiction, has a beginning, a middle and an end (Hyden 1997) which serves to contain the events. Polkinghorne's (1995) definition also incorporates the term 'plot' which is widely encountered within the narrative literature. Paul Ricoeur utilises the concept of plot in his exploration of the connection between time, or temporality, and narrative and defines it as 'the intelligible whole that governs a succession of events in any story' (Ricoeur 1981, p167). The purpose of plot is to act as the connecting function between the events and the narrative. In this way, the plot is a non-chronological dimension which configures the chronological, episodic dimension of events such that a 'story is *made out of* events to the extent that plot *makes* events *into* a story' (Ricoeur 1981, p167, emphasis in original). Related to plot is the concept of emplotment which, according to Polkinghorne (1988),

> 'is a dialectic process that takes place between the events themselves and a theme which discloses their significance and allows them to be grasped together as parts of one story' (p20).

The depiction of events over time is central to Labov and Waletzky's (1967) definition that 'Any sequence of clauses which contains at least one temporal junction is a narrative' (p28). From their position, it is possible to identify narrative from non-narrative discourse. An interview response, for example, would contain stories or narratives which could be distinguished from the surrounding talk (Mishler 1986). Certainly, Labov and Waletzky's definition has been employed in a wide range of narrative research, though there has also been some resistance to it since many narratives are not thought to fit within its strict limits (Riessman 1993; Benwell and Stokoe 2006). An alternative position is to consider that the depiction of events over time need not be so bounded and may, for example, apply to the entire interview material (Mishler 1986; Bailey 2001).

3.5.1.1 Narrative and story

Those operating within, or influenced by, the structuralist tradition devote much time to the precise definition of narrative and this often leads them to view it as distinct from 'story'. Bal (1985), for example, distinguishes between a narrative text, a story and a fabula, where a narrative text 'is a text in which an agent relates a narrative', a story 'is a fabula that is presented in a certain manner' and a fabula 'is a series of logically and chronologically related events that are caused or experienced by actors' (p5). Whilst some within academic circles consider there to be clear differences between narrative and story, the terms are often used synonymously (Emden 1998) and indeed in general speech 'narrative' is frequently adopted as a synonym for 'account', 'story' and 'chronicle' (Williams 1984). Frank (2000), who employs the terms narrative and story interchangeably, comments that 'people do not tell narratives, they tell stories; "let me tell you a narrative" sounds strange[52]' (p354). In this way, the choice of terminology appears to be dictated by the context. In this thesis I too use the terms interchangeably since I consider each to refer to the same thing – the depiction of events over time. When I use one term instead of another it is because it seems more appropriate to the context rather than that I consider them to be referring to different things.

3.5.1.2 Narrative and experience

The temporal and sequential aspects of narrative, that it depicts events over time, positions it as a key mechanism for the communication of experiences (Coffey and Atkinson 1996; Cortazzi 2001). However, there is much debate as to the extent to which narrative can be used as a proxy measure for what has been. There are some who assume a correspondence position in regards to the association between narrative and the experience to which it refers. Others prefer to adopt an alternative position which views narrative as constituting the experience, such that through narrative experience is re-presented (Good 1994; Hyden 1997; Clandinin and Connelly 2000), constructed

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[52] Wiltshire (1995) would agree with Frank's statement because, for him, narrative is distinct from story since narrative is a written, considered form whilst story is a verbal, spontaneous form. This is not a distinction that I agree with.

(Bury 2001) and re-constructed (Bailey and Tilley 2002). Within this approach, the development of narrative is viewed as a 'sense-making activity' (Ochs 1997) and as a way of bringing 'a sense of order' to life as it has been experienced (Murray 2003, p98). In this way, the experience needs to end for it to be narrated since the act of narrating requires time for reflection (Sandelowski 1999). Meaning is brought to experience through the decisions concerning which aspects of experience to incorporate within the narrative (Elliott 2005) so that only those events which contribute to the advancement of the plot, to the ending, are incorporated into it. As Lawler (2002) writes,

> 'Within narratives, and through processes of emplotment, prior events seem *inevitably* to lead to later ones, and the end of the story is understood as the culmination and actualization of prior events. Significance is conferred on earlier events by what comes later' (p246, emphasis in original).

From this position, narratives are not viewed as in-tact phenomena existing within the minds of individuals (the narrators). Rather they are viewed as occasioned tellings for which interaction and performance are considered to be highly determining. The narrative generated is seen as being influenced by the narrator's perception of their audience (Cortazzi 2001). Minister (1991) adopts the term 'ghostly audience' to describe the way in which the audience, those immediately present or perceived as likely to be present in the future, influence the content and form of talk. Whilst I was of the opinion that narratives re-present, construct and re-construct experience, I also acknowledged that narratives are grounded in events. In so doing, I shared the opinion of Lieblich *et al* (1998) who write:

> 'We do not advocate total relativism that treats all narratives as texts of fiction. On the other hand, we do not take narratives at face value, as complete and accurate representations of reality. We believe that stories are usually constructed around a core of facts or life events, yet allow a wide periphery for the freedom of individuality and creativity in selection, addition to, emphasis on, and interpretation of these "remembered facts"' (p8).

It is because narratives are grounded in life events and dependent on remembered facts that those telling their story would claim it to be true rather than fictional, false or a lie (Finnegan 1998). This is the case regardless that the narrative itself can be told in many ways. Whilst the individual narrator may be in a position to generate different narratives, for many different audiences and on many different occasions, all tellings are bounded by the social world. The social world shapes the telling and makes certain narratives more available or easier to tell (Coffey and Atkinson 1996; Murray 1999, 2000; Lawler 2002). And as Bury (2001) writes;

> 'When lay people construct and present narratives of their experience they do so within cultural settings which provide specific forms of language, clichés, motifs, references and other elements of linguistic and symbolic repertoires which allow and constrain what is said and how it is expressed' (p278).

3.5.1.3 Illness narratives

That narrative is seen as a key way in which experiences can be communicated and made meaningful has led to it being adopted as a mechanism to 'tap into' individual experiences of illness (McCance *et al* 2001). Whilst much of the existing literature focuses on the experiences post-diagnosis (see for example Mathews *et al* 1994; Bailey 2001; Gray *et al* 2005), narrative has also been drawn on to explore the experiences of individuals prior to biomedical diagnosis and to broaden the understanding of the pathway to the doctor (see for example Facione and Giancarlo 1998; Svedlund *et al* 2001). Through this interest the term illness narrative has become ubiquitous within the social science literature. Hyden (1997) writes that

> 'Illness narratives are concerned – in a broad sense – with illnesses, illness episodes, or illness experiences, and even with experiences considered to be unhealthy' (p53).

Frank (1995) suggests that becoming seriously ill is a prompt for the telling of narratives (stories) for at least two reasons; people want to know what is happening to the individual, be they health professionals, family or friends, and telling a narrative can be a way of repairing an individual's sense of self and position. Similarly, Mattingly (1998) writes that the

> 'need to narrate the strange experience of illness is part of the very human need to be understood by others, to be in communication even if from the margins' (p1).

Whilst Frank (1995) and Mattingly (1998) write from the perspective of serious illness, Mishler (2005) suggests that talk centred on the experience of illness is a common feature of our lives:

> 'Hardly a day goes by that we do not talk to each other and of each other about our aches, pains and illnesses, and also of treatments and our experiences with physicians and other health care providers. 'How are you feeling?' is our common greeting to a friend or co-worker' (p434).

It has been suggested that these stories and conversations expand individuals' knowledge of illness and influence how they conceptualise and interpret their illness experiences and those of others (Price 1987; Skott 2002).

In constructing and communicating the experiences of illness the narrator selects the events which contribute to the plot that they are creating and eliminates those which they perceive not to contribute to the ending (Mattingly 1994). Furthermore, for an illness narrative 'to be coherent, the narrator must at some point discuss cause' (Price 1987, p315). Williams (1984) too has commented on the significance of cause, though he prefers to adopt the term 'genesis'. Drawing on interview data generated with individuals who were chronically ill he developed the concept of narrative reconstruction as

> 'an attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society' (Williams 1984, p197).

Through narratives, then, the events associated with disease such as the symptomatic experiences and the management sequence, become contextualised within a biography: these things are happening, or have happened, to a real person (Hyden 1997). In this way narrative positions illness as 'present in a life' which is different to the biomedical conception of disease which locates it within a contained body (Good 1994, p157). In hearing the narratives we are invited into the experience of illness (Frank 2000) and in this way we can, in some sense, imagine what it is like to be that individual. It is because narratives allow us to enter into an experience, to creatively imagine what it must be like, that narratives are so absorbing (Greenhalgh and Hurwitz 1999).

3.5.2 Narrative research – interviewing as a method of data generation

Barthes' (1977) quote which I offered previously (section 3.5.1) gives a flavour of the ubiquity of narrative and from this it follows that narratives can be generated and sourced through a variety of media including verbal, written and visual (Bleakley 2005). However the interview is the most widely used method of data generation within social enquiry (Rubin and Rubin 1995; Seale 1998; Holstein and Gubrium 2002) and the most frequently adopted method when one is seeking to generate and utilise narratives (McCance *et al* 2001; Murray 2003). Interviews, as a mechanism for the generation of narrative, are often preferred to sourcing written narratives within the social sciences because their real-time nature allows the researcher to explore particular aspects of experience, as might be necessary to answer the research questions.

Within a narrative approach, interviews are geared towards the generation of narrative discourse. A key part of this is creating a situation and environment in which the telling of narrative is encouraged and permitted. Whilst Green and Thorogood (2004) suggest that most individuals are familiar with the 'rules of engagement' as they relate to interviews, the type of interview which seeks primarily to generate narrative may violate the 'role expectations' of both interviewer and interviewee (Flick 1998). Similarly, although narrative may be ubiquitous within our society and individuals may engage in the generation of it often, 'it is mastered to varying degrees' (Flick 1998, p103).

One of the most significant aspects of the narrative interview is its beginning. The question asked is crucial for whether a narrative is generated because, as Chase (1995) cautions, questions can be so abstract as to remove the participant from their experience and make it impossible for them to narrate it. Morse (2001) writes that the 'tell me about' question is often used in unstructured interviews with the ill and injured and 'in turn, the story of illness is typically delineated with a distinctive beginning, middle and end' (p324). That is, narrative is generated.

3.5.3 Narrative research – approaches to data analysis

Once narrative data have been generated or sourced, a decision has to be made in regards to how to approach it and its analysis. There are many different approaches described within the literature and various attempts have been made to categorise these approaches, a selection of which I shall now describe.

Langellier (1989) has proposed five different theoretical positions in personal narrative research. In personal narrative as story-text, there is an assumption that narrative discourse is bounded and can be distinguished from the surrounding discourse and there is emphasis on examining the structure of narrative segments, for example the work of Labov. When the interest is in personal narrative as storytelling performance, the focus is on how the story is told, whether it is performed, and how this impacts on the audience. Personal narrative as conversational interaction 'acknowledges how personal narratives occur in the ongoing stream of naturally-occurring talk' (Langellier 1989, p256) and explores them through structural and semantic analysis. When personal narratives are viewed as social process the focus of analysis moves 'beyond the immediate conversational setting to consider the social and cultural constraints on narrative use' (Langellier 1989, p261). And finally, personal narrative as political praxis focuses on the ideological implications of the narrative, who or what it legitimises or questions.

Lieblich *et al* (1998) draw distinctions between different approaches to narrative which are based upon how the narrative is accessed. The authors identify two dimensions: 1) holistic versus categorical and 2) content versus form, and this paves the way for four distinct approaches to narrative. The authors write that the holistic-content reading 'takes into consideration the entire story and focuses on its content' (Lieblich *et al* 1998, p15). The holistic-form reading likewise looks at the complete story but rather than content, the interest is in the form, for example, as in plot analysis (see Gergen 1988). Lieblich *et al* (1998) associate the categorical-content reading with traditional content analysis which 'focuses on the content of narratives as manifested in separate parts of the story, irrespective of the context of the complete story' (p16). The categorical-form reading attends to the formal aspects of discreet sections of the narrative. The authors refer mainly to life stories but their distinctions apply to a more general narrative approach, defined as such through its use or analysis of narrative material.

Mishler (1995) has proposed a typology of narrative approaches developed inductively from a review of the existing literature. The first set in the typology is titled 'Reference and temporal order' and researchers operating within this position are concerned with the temporal order of events and the accuracy of their representation within a narrative.

'Textual coherence and structure: narrative strategies' is the second set in the typology and within this the focus is on

> 'how narratives are constructed, on ways in which different resources of language are used to create a form that carries meaning' (Mishler 1995, p102).

The final set in the typology is titled 'Narrative functions: contexts and consequences' and within this the areas of interest are the settings in which the narratives are generated and the ends that their generation contributes to.

Writing from a psychological position Murray (2000) identifies four levels of illness narrative analysis. The first level is the personal level which is congruent with a phenomenological approach and views narrative as reflecting the inner thoughts and feelings of the narrator. The second, interpersonal level focuses on the way that the narrative is interactively produced, for example the role of the interviewer as well as the interviewee in the generation of a narrative. The third level is the positional level which, as an extension of the interpersonal level, seeks to explore the influence of social position on narrative production. The final level is the ideological level which seeks to explore narrative in relation to the beliefs and ideologies held within the wider society.

Polkinghorne (1995), drawing upon the work of Bruner and his distinction between paradigmatic and narrative cognition, identifies two approaches to narrative. In the paradigmatic analysis of narrative the researcher 'seeks to locate common themes or conceptual manifestations among the stories collected as data' (Polkinghorne 1995, p13). Alternatively, narrative analysis 'is the procedure through which the researcher organizes the data elements into a coherent developmental account' (Polkinghorne 1995, p15). The distinction between analysis of narrative and narrative analysis shares similarities with his earlier distinction between descriptive narrative research, which 'does not construct a new narrative; it merely reports already existing ones' (Polkinghorne 1988, p162), and explanatory narrative research, the purpose of which is to provide 'a narrative account' (Polkinghorne 1988, p173).

I have summarised these different approaches to narrative and its analysis in Table 3.

Author(s)	**Categories of approach to narrative and its analysis**
Langellier (1989)	**1.** Personal narrative as story-text **2.** Personal narrative as storytelling performance **3.** Personal narrative as conversational interaction **4.** Personal narratives as social process **5.** Personal narrative as political praxis
Lieblich *et al* 1998	**1.** Holistic content **2.** Holistic form **3.** Categorical content **4.** Categorical form
Mishler 1995	**1.** Reference and temporal order: The "telling" and the "told" **2.** Textual coherence and structure: Narrative strategies **3.** Narrative functions: Contexts and sequences
Murray 2000	**1.** Personal **2.** Interpersonal **3.** Positional **4.** Societal
Polkinghorne 1995	**1.** Analysis of narrative **2.** Narrative analysis

Table 3: A table to summarise the different categories of approach to narrative and its analysis.

3.5.4 Summarising the direction of the study

Through the study I sought to understand the experience of developing and being diagnosed with lung cancer. Indeed I chose to adopt a case study approach, defining the experience as the case. In seeking to understand the case I intended to make a contribution to the earlier diagnosis of lung cancer, thus bringing me within the realms of an instrumental case study approach.

The methods of data generation within a particular case study are chosen so as to develop the understanding of the case, and multiple sources and methods are often used (Denscombe 1998). Stake's (1995) comment that case study often involves stories, and the use of narrative to construct and communicate experience, led me to position the generation of illness narratives through interview as the principal method of data generation and source of data. In this, I sought to explore the potential of narrative for coming to know the experience. That said, I envisaged a need to draw upon alternative sources of data so as to develop my understanding, and I shall discuss this further in section 3.6.3.1. In terms of how I would approach the analysis of the illness narrative data, I was attracted to what Polkinghorne (1995) refers to as narrative analysis. The illness narratives, then, were at the centre of this study and were the main foundation of my understanding but before I describe the actual process of their generation, I shall first discuss the issue of appraising the study.

3.6 Appraising the study

3.6.1 Validity and reliability criteria within the literature

Qualitative approaches to research are often criticised for being anecdotal, highly determined by researcher bias and strongly impressionistic (Koch and Harrington 1998). Stemming from this, a great deal of attention has been directed at ensuring that qualitative research is of sufficiently high calibre and rigour that it may then be able to compete alongside its more traditional, quantitative counterpart[53]. Within this literature, the criteria of validity and reliability are frequently encountered, largely because they have been central to the notion of rigour within quantitative research for many years (Emden and Sandelowski 1998). Robson (2002) writes that 'Validity is concerned with whether the findings are 'really' about what they appear to be about' whilst reliability relates to the 'consistency or stability of a measure' (p93). Though the terms are frequently encountered, the literature is not always in their favour. Emden and Sandelowski (1998) suggest that these terms have been championed, translated, exiled, redeemed and surpassed at various times and by various writers within the qualitative field. Morse *et al* (2002), for example, argue that validity and reliability are important issues in qualitative as well as quantitative research and that their use must be maintained. Whilst others, for example Cutcliffe and McKenna (1999), suggest that only the terms and criteria which have been developed to specifically apply to qualitative research should be used.

Though these two groups of authors differ in their views as to the suitability and relevance of the terms and the concepts to which they relate, they do not appear to contest the existence of a qualitative research field. This is a point of discussion in which Rolfe (2006) engages and that leads him to argue that the

> 'failure to agree on universal criteria for judging quality in qualitative research is symptomatic of an inability to identify a coherent 'qualitative' research

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[53] The criticism of lack of rigour levied against qualitative research can also be levied against quantitative research (Strang 2000).

> paradigm and that, in effect, such a unified paradigm does not exist outside of research textbooks' (p308).

It is perhaps the acknowledgement of the heterogeneous field of qualitative research which has led proponents within the various approaches to suggest other criteria by which their research should be judged. Within narrative research, for example, a range of criteria have been proposed such as persuasiveness, correspondence, coherence and pragmatic use (Riessman 1993), width, coherence, insightfulness and parsimony (Lieblich *et al* 1998) and fidelity and believability (Blumenfeld-Jones 1995). Clearly there is no agreement as to how approaches within a particular area of qualitative research can be judged, which should come as no surprise as my previous consideration of the narrative literature revealed a multitude of approaches to narrative and to its analysis. But whilst no criteria exist which are deemed pertinent to all approaches, the use of criteria is in itself an issue. Specifically, criteria are employed to ensure that a particular (high) standard has been reached, but who is to say when the criterion has been met? These criteria often have no objective measurement and instead it is a call of judgment which decides whether the standard has been fulfilled (Hammersley 1992).

3.6.2 Criteria and theoretical underpinnings

Emden and Sandelowski (1999) suggest that the growing unease with criteria-based assessment reflects the changing philosophical perspectives. Though the authors acknowledge this argument, they still consider it appropriate to suggest criteria for judging the 'goodness' of qualitative research, one of which should be a 'criterion of uncertainty'. The embracing of uncertainty has its foundations in postmodern thought and leads them to state 'that to openly declare the uncertainty of one's work is to acknowledge the current state of play of knowledge development' (Emden and Sandelowski 1999, p5). This is a complex statement appropriate to the level of paradigms, which given that the title of their articles includes the term qualitative research, suggests that the authors consider quantitative and qualitative distinctions to operate at paradigm level. As I have previously discussed, this was not an opinion I shared. I, too, considered it important to recognise that this study and my understandings could have been otherwise but that is because I situated myself within an interpretive paradigm, not because I conducted qualitative research.

3.6.3 Tentative understandings, utility and doing 'one's best'

> 'Research is to see what everybody else has seen and to think what nobody else has thought'
>
> – Albert Szent-Gyorgyi (1893-1986)

This quote epitomises, for me, what it is to be engaged in the research process. In seeking to address the research questions I was involved in an active process whereby I developed my own understandings of the experience of developing and being diagnosed with lung cancer. The quote makes no reference to the right or wrong ways of thinking and neither do I. My interpretations and understandings are mine and so, for me at least and at this particular moment, they are not wrong. Indeed, as Crotty (1998) writes, 'What constructionism drives home unambiguously is that there is *no* true or valid interpretation' (p47, emphasis in original). However the principal intention of this study was to make a contribution to the earlier diagnosis of lung cancer, an area which is highly relevant[54] in the UK at this time, particularly to policy makers and practitioners[55], and so it is important that my understandings have utility[56] (Stake 1995; Sandelowski 2004). It is against this measure of utility that I wish this study and its contributions to be judged. As Crotty (1998) continues,

> 'There are useful interpretations, to be sure, and these stand over and against interpretations that appear to serve no useful purpose' (p47).

I believe that my understandings are useful and indeed are 'actionable insights' (NCC 2006) which can be drawn upon to influence how the symptomatic experiences associated with lung cancer are interpreted. Central to this, in chapter 7 I outline the implications of my understanding for health education interventions and in this way attempt to highlight the potential for instrumental utilisation (Estabrooks 1999, 2001; Kearney 2001), that is, 'a concrete application of research' (Estabrooks 2001, p282). It is entirely possible that my understandings, whilst proving useful for the development of health education interventions, serve no usefulness for influencing the interpretation of the symptomatic experiences associated with lung cancer and thereby are of no use

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[54] Hammersley (1992) suggests that social research should be appraised according to its validity and its relevance. He writes that an 'account is valid or true if it represents accurately those features of the phenomena that it is intended to describe, explain or theorise' (p69) whilst relevance 'concerns the importance of the research topic and the contribution to our knowledge made by the findings of the study' (Hammersley 1992, p78).

[55] And also to individuals who have yet to develop the disease, though they are unlikely to accord great value to the relevance of the topic until such time as they are diagnosed.

[56] I believe that the concept of relevance is implicit within the concept of utility.

for contributing to the earlier diagnosis of the disease. However, there is an alternative, more immediate, type of research utilisation which I hope will have been achieved by the time you have finished reading this thesis. In conceptual utilisation, research 'may change one's thinking but not necessarily one's particular action' (Estabrooks 2001, p284). It is my hope that you, as reader, will find this thesis useful; that it will facilitate your understanding of the experience of developing and being diagnosed with lung cancer, lead you to think about the interpretation of symptomatic experiences in an alternative way and allow you to consider your own 'intellectual puzzle' (Mason 2002) in a new light.

Whilst I do not claim that my understandings and interpretations are right, nor correct nor true, there were a number of steps which I took throughout the study to facilitate my understanding. As Clandinin and Connelly (2000) write in regards to narrative inquiry, the attitude

> 'is one of doing "one's best" under the circumstance, knowing all the while that other possibilities, other interpretations, other ways of explaining things are possible' (p31).

3.6.3.1 Extensive engagement

The period of generating the illness narratives took place over a period of 14 months. During these months I spent several hours a week in the outpatient clinics recruiting individuals who had been diagnosed with lung cancer. I spoke to many individuals who had been diagnosed with the disease, both those who fulfilled the study inclusion criteria and those who did not. I introduced the study to individuals who later declined to take part and in that first meeting they would often tell me a little about how they came to be where they now sat. I talked to the significant others who had accompanied the individual to the clinic. I stood at the nurses' station and watched everything happening around me, observing as much as I could of what was going on. When I arrived to conduct an interview the participant and I conversed, sometimes it was related to lung cancer, sometimes it was not. This was again the case once the formalities of the interview had ended.

Throughout this period of data generation, but also before and since, I was on a state of 'high alert', reaching out to and absorbing anything which I thought might help me to develop my understanding. In this way, I was operating in line with a case study approach, seeking to draw upon different sources of data so as to facilitate my understanding of the case. Indeed, as Denscombe (1998) writes, a case study approach not only allows the researcher to do this, 'it actually invites and encourages the researcher to do so' (p31). I collected newspaper and web-based articles which related to lung cancer. I collected leaflets from GP surgeries and pharmacies relating to health but more often to disease. I drew upon the resource that is the DIPEx website[57], watching and listening to the illness narratives of individuals with lung cancer whom I had never met. I went through the websites of the Department of Health and leading non-governmental organisations, focusing on what they wrote about lung cancer and how they positioned it in relation to other types of cancer. I drew upon these sources because they helped me to develop my understanding of the case, the experience of developing and being diagnosed with lung cancer, but in a way that is far beyond the scope of language and difficult for me to describe.

3.6.3.2 Examining and reflecting on my experience

Though I have not been diagnosed with lung cancer, I have on many occasions throughout my life experienced a symptomatic experience which has prompted me to engage in the process of interpretation. In this way, I did not consider myself to be very different from the participants in my study who had also sought to interpret their symptomatic experience. I thought about my last major symptomatic experience and how I had interpreted and responded to it. I wrote down what I had thought, what I had felt and what I had done (see Appendix 3). Examining myself in this way, and reflecting on my experience, drew attention to the similarities between myself and the participants and led me to acknowledge the complexity in all of us. I found this to be a very powerful exercise.

In addition to examining and reflecting on this particular personal experience, I also recorded many of my experiences throughout the research process within my research log. Through these entries I was transported into a different place, a place where I could critique what I had done and why I had done it, or into a different time, reminding myself of all the challenges and changes incumbent within the process. I draw on excerpts from my research log in this thesis, specifically within the second part of this

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[57] www.dipex.org.

chapter, to give you a sense of what it was like for me to conduct the study and in so doing I intend to make a contribution to its rigour[58].

3.6.3.3 Maintaining the links

Whilst I have offered a broad conceptualisation of extensive engagement and identified the alternative data which facilitated my understanding, my most sustained and intensive engagement was with the illness narratives. The understanding that I generated were grounded within these data and this was my intention; to maintain the links between the data and my understanding. In the chapters to follow I present extracts from the data to support and to illuminate my understandings. That said, my understanding, whilst having its origins in the data, may not be explicit within it: it may not be obvious to you how I came to hold it from the data that I present. But that is to be expected since understanding is interpretation and interpretation requires that you 'go beyond the words' (Cutcliffe and McKenna 2004, p130). Interpretation, to generate understanding, is an active and creative process and it is the data which triggered them rather than the data which delivered them, pre-formed and intact, to me.

Research in practice

3.7 Conducting the study and generating the data

I have now come to the second part of this chapter in which I attempt to describe the details of how the principal data drawn upon in this study were generated.

3.7.1 Access and sampling

Stake's (1995; 2005) concept of 'opportunity to learn' was significant for my selection of individuals with whom to generate illness narratives. I was mindful that some of the broadly relevant existing literature had only included participants who had been diagnosed with a particular histology or individuals who were undergoing a particular management option. I did not want to impose any such constraints and instead took the

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[58] The concept of the audit or decision trail is widely seen as making a contribution to the rigour of qualitative research (see Koch 1994) through contributing to its dependability. Within this, the assumption is often that the decision trail will allow another researcher to follow the same process and arrive at non-contradictory findings. I do not offer excerpts from my research log so that my study can be judged at some point in the future (dependability, reliability) but so that you are given additional grounds on which to judge it in the present.

lead from Corner *et al* (2003) to recruit individuals who had either operable or inoperable disease, NSCLC or SCLC. Moreover, I deemed it important to seek the participation of male and female individuals, individuals who were current smokers, former smokers and never smokers, individuals across a range of ages and individuals who had experienced a range of different symptomatic experiences. In this way, I sought not to reduce individuals to these characteristics, but to facilitate my understanding and to, potentially, seek a global property (Ragin 1992) of the experience.

Though I sought to engage a number of individuals in the study, it was important to stipulate inclusion criteria.

3.7.2 Inclusion criteria

In order to be approached to take part in the study, an individual had to satisfy several inclusion criteria which I have outlined in Table 4.

Inclusion criteria
Aged 18 years and over
Recent diagnosis of lung cancer
9 in 10 (90%) chance that diagnosis will be lung cancer
Comfortable speaking English or personal translator

Table 4: A table to summarise the study's inclusion criteria.

3.7.2.1 Age 18 years and over

Consent procedures and ethical considerations are more straightforward when the participant is an adult, as opposed to a child, and it was for this reason that I thought it appropriate to stipulate a minimum age level[59]. In the event, this criterion did not prevent any individual from being invited to participate in the study which was entirely expected since the incidence of lung cancer in individuals below 18 years of age is extremely low[60].

3.7.2.2 Recent diagnosis of lung cancer

I made the decision to recruit individuals recently diagnosed with lung cancer. In light of this, none of the participants had begun active management of their disease at the

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[59] Implicit in this statement is that, in order to be approached to participate, individuals needed to be in a position to give informed consent.
[60] In the UK in 2003, there were five new cases of lung cancer in individuals aged 19 years or under (CRUK 2007a).

time of recruitment[61]. I set the criterion of a recent diagnosis because I wanted to engage the individuals close in time to the experience that I wanted them to narrate. It was not that I thought that closer temporal proximity to the experience would generate a more truthful illness narrative but that I thought it would be easier for them to construct the narrative and to respond to my comments and questions which sought to explore that narrative. Fifty seven per cent (19) of the interviews were conducted within one month of the biopsy which had confirmed the diagnosis or within one month of being told that the diagnosis was likely to be lung cancer. Thirty nine per cent (13) were conducted within two months of this and I interviewed one participant between four and five months after biomedical diagnosis[62].

Within the study, I chose not to include individuals who had been diagnosed with pleural mesothelioma. Though in the chest cavity, mesothelioma is classed as a distinct disease originating from the lining surrounding the lungs rather than from the lungs themselves. Mesothelioma has a recognised aetiology, epidemiology and clinic features and is excluded from NICE Guidelines for the diagnosis and treatment of lung cancer (NICE 2005).

3.7.2.3 9 in 10 (90%) chance that diagnosis will be lung cancer

I included the criterion of 9 in 10 (90%) chance of developing lung cancer at the suggestion of the cardiothoracic nurse specialists. This was to ensure that those individuals who had not had a confirmed histological diagnosis prior to surgery, but were highly suspected of having lung cancer, would be approached[63].

3.7.2.4 Comfortable speaking English or personal translator

The narrative approach drawn upon within this study demanded quite detailed communication and given that the study was small and conducted without additional funding for translation services, it was important that myself and the participant could communicate reasonably easily in the same language. It was for this reason that this

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[61] Though recruited prior to treatment, several of the participants were interviewed once they had begun treatment. This was usually individuals who were receiving chemotherapy since the limited period of time (four days) between the consultation in the combined clinic and the appointment at the chemo clinic made it difficult to allow for the minimum 24 hours to consider the study and the arrangement of a convenient interview appointment.

[62] This period of time was slightly longer than I had envisaged accepting but the participant had not had any treatment at the time that I recruited her and I was keen to hear her story because she had presented with an unusual symptomatic experience (corneal metastases).

[63] In the event, all individuals who were suitable for surgical resection had a confirmed histological diagnosis of lung cancer at the time of recruitment.

criterion was established. Fortunately, the criterion did not preclude any individual from being asked to participate in the study.

3.7.3 Recruitment procedure

So as to engage individuals who had been recently diagnosed with lung cancer, I decided to recruit the participants through the outpatient clinics of a large hospital in the south of England[64]. I recruited the individuals who were suitable for surgical resection through the cardiothoracic outpatient clinics and those who were not to have surgery through the multidisciplinary combined lung clinic. I have summarised the steps of the recruitment procedure as follows:

1. The health professional[65] and I identified the individual as meeting the inclusion criteria
2. The health professional considered it appropriate that the individual be approached to participate in the study
3. The health professional broached the study to the potential participant and gave them the study paperwork
4. The health professional introduced me to the potential participant
5. I outlined the study to the potential participant and gave them the study paperwork if it had not already been given to them by the health professional
6. I asked the potential participant to consider taking part in the study and for their permission to contact them by telephone to hear their response. All potential participants gave permission for me to contact them in this way, though I did have a reply slip and stamped addressed envelope for any individuals who declined to be contacted by telephone
7. A minimum of 24 hours later I made telephone contact with the potential participant. If the individual had decided that they would like to take part in the study, we organised an interview appointment
8. At the interview appointment, I outlined the study again, asked if they had any questions or queries and together we completed the consent form[66]. In signing the consent form, the individual agreed to take part in the study and the interview was formally commenced

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[64] That my supervisors had conducted their previous work in the same hospital meant that they were in the position to provide me with the details of contacts within the clinical environment. This was a huge advantage to me in terms of securing access to the site and to the potential participants.

[65] The health professional was either the consultant or the clinical nurse specialist.

[66] I shall discuss informed consent in section 3.7.9.

The study paperwork consisted of the 'patient letter' and the 'information sheet'. The content and form of the paperwork was largely governed by the local research ethics committee (LREC) whose approval I had to gain before I was allowed to begin recruiting participants[67]. Copies of each can be found in Appendix 4.

3.7.4 My role in the clinic environment

According to the steps in the recruitment procedure outlined in section 3.7.3, my presence in the clinic was required so that I could meet with the potential participants and give them the study paperwork if the health professional had not already done so. In actuality, I had a significant presence within the clinics, particularly in the multidisciplinary combined lung clinic. The following is an excerpt from my research log which illustrates this situation.

> Jane[68] (clinical nurse specialist) was around briefly at the start of clinic and then went off to have her lunch. Sister came round and asked if I was okay to help out but I told her that there were no patients for me and that I would be leaving. She said thank you for my help last week. I stayed until 3.30pm and in that time I had identified patients who needed scan results requesting, liaised with the doctors about which patients to see next, weighted a patient, answered the telephone and passed a message to the consultant and brought patients round [to the consultation rooms].
> Research log 4th April 2006.

In many ways, I became an integral part of the workings of the clinic. This was not, of course, what I was there to do but slowly and surely I became a key member of the team. Though I did not have a problem with my additional roles, I was concerned that it would influence the recruitment of participants. The clinical nurse specialist, for example, once went out of her way to introduce me to a potential participant and in her own words: 'I wouldn't have done it for anyone else'. I spent a lot of time alongside this particular nurse and I feel sure that she would not have introduced me to someone who she did not consider appropriate but I was nevertheless wary that this could be the case[69].

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[67] The ethical implications of the study are considered throughout this chapter. As Holloway (2005) has commented, ethical issues are central to qualitative research and are considered throughout a well-written study.

[68] Pseudonym.

[69] See Seymour and Ingleton (1999) for similar comments/concerns.

3.7.5 Participant characteristics

I used the recruitment procedure outlined in section 3.7.3 to recruit 33 individuals (I shall discuss the rationale for this figure in section 3.7.7). This recruitment took place between the beginning of July 2005 and the end of August 2006. The characteristics of the participants are given in Table 5.

N = 33	*n* (%)
Sex	
Male	21 (64)
Female	12 (36)
Age	
Median (range)	69 (49-84)
41-50 years	2 (6)
51-60 years	6 (19)
61-70 years	11 (33)
71-80 years	9 (27)
81-90 years	5 (15)
Diagnosis	
NSCLC[70]	29 (88)
SCLC	2 (6)
No histological diagnosis	2 (6)
Disease status at diagnosis	
Operable	4 (12)
Inoperable	29 (88)
Smoking history	
Current (at interview)	6 (19)
Former smoker	
Gave up at diagnosis	2 (6)
Gave up in last 24 months	8 (24)
Gave up more than 24 months ago	15 (45)
Never smoker	2 (6)
Marital status	
Married	24 (73)
Living with partner	1 (3)
Widowed	7 (21)
Single	0 (0)
Separated/divorced	1 (3)
Housing tenure	
Owner-occupier	27 (82)
Council tenant	5 (15)
Private tenant	1 (3)

Table 5: A table to summarise the characteristics of the participants.

The histological diagnosis of the participants was extracted from their (hospital) medical records. Permission to do this was given as part of the consent procedure which

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[70] Of those with NSCLC, three male and two female participants received a diagnosis of adenocarcinoma, and three male participants received a diagnosis of squamous cell carcinoma. The actual histological diagnosis for the remaining participants was not further classified and was noted as NSCLC.

is to be discussed in section 3.7.9. Additional data extracted included the stage of the disease (though this was often lacking), the date of diagnosis, the date of the first appointment with the chest physician and the participant's recorded symptomatic experiences. The intention of doing this was not to corroborate the participants' narratives, but to attempt to place them within an alternative understanding.

3.7.6 Participation rate and individuals who declined

In addition to the 33 individuals who agreed to take part, I was introduced to 13 potential participants who later declined to participate. This translates into a participation rate of 72 per cent. Initially, many of those who declined said that they did not feel as though they had much to say, that their experience had been in the main uneventful. I responded to this by making sure that in my first meeting with the potential participants I made it clear that I was interested in their experience, irrespective of whether they considered that much had happened or not. I cannot say that this led individuals to take part who would otherwise have declined, but it brings to the fore the flexible nature of the research and the potential that there was to address challenges as they arose.

3.7.7 Rationale for the number of participants recruited

In terms of how many individuals to engage, I made the decision with a number of factors in mind. Driving the decision was my expectation that the experience of developing and being diagnosed with lung cancer would vary between individuals and so I thought it important to engage with as many individuals as was practicable to achieve since I thought this would aid my understanding of the case. The practicality issue related to the amount of time available to conduct the study over, bearing in mind that the studentship was funded for a limited period. In addition to this I was conscious of the vast amount of data likely to be generated through the interviews, particularly as I sought to generate narrative responses as opposed to categorical ones. With a large amount of data there are issues regarding data management but I was also wary that I should only generate that which I would be in a position to draw upon. Related to this was the principle of what I refer to as researcher saturation such that I gained less from each interview as I progressed through data generation and began to develop my understanding. The notion of researcher saturation shares similarities with a term that is often considered within qualitative research, that of data saturation. The term is frequently encountered in relation to grounded theory and Strauss and Corbin (1998), for example, write that saturation is

> 'reaching the point in the research where collecting additional data seems counterproductive; the "new" that is uncovered does not add that much more to the explanation at this time' (p136).

The notion of data saturation is frequently positioned as an appropriate rationale for ceasing data generation or data analysis. Though Strauss and Corbin (1998) recognise that additional observations or findings are always possible within the data, the term data saturation places the emphasis on the data and neglects the role of the researcher. Through the term researcher saturation, one explicitly allows for the continuing interest of the data but recognises that it is the researcher, and not the data, who makes the decisions. As I engaged in the interviews, I began to develop my understanding of the case to the extent that I felt in a position to respond to the research questions. In developing this understanding I reached a point where I was entirely saturated by the data and by my understandings of the data. It was this notion of researcher saturation[71] which led me to cease recruiting participants once I had engaged in 33 interviews.

Now that I have described who participated and in what circumstances[72], I would like to consider the actual process from the point of meeting the participants for the interview.

3.7.8 Interview contexts

Thirty-two of the 33 interviews were conducted in the participants' homes. The interview with the second participant took place in the chemotherapy clinic shortly before he was due to begin his treatment. I only had the first interview to compare to, which had taken place in the participant's home, but I decided then that if at all possible the interview should be conducted away from the hospital environment. It seemed as though just by being in the clinic the illness narratives were limited to a biomedical focus. There seemed little scope for moving the illness narrative beyond the tangible symptomatic experience and it seemed that this was the case because of where we were, rather than because of how we spoke and interacted with each other. This is something which Kleinman (1986) has commented on:

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[71] Seymour *et al* (2005) consider data overload but this is in relation to what could be termed 'emotional saturation' and not in relation to the analytic saturation which I am referring to.

[72] I shall consider the issues of how I introduced the study and myself to the potential participants in section 3.9.1 and section 3.9.2.

> 'Patients are quite aware of the "demand characteristics" of different settings – their homes, a neighbour's room, public clinic, private office, hospital room, factory clinic, courtroom – and these help to cast the story in a certain form' (p154).

Fortunately, it was convenient for the participants that all future interviews could be conducted in their own homes.

3.7.9 Informed consent

The issue of informed consent is seen as a significant component of ethical research practice. Ryen (2004) writes that informed consent

> 'means that research subjects have the right to know that they are being researched, the right to be informed about the nature of the research and the right to withdraw at any time' (p231).

The study paperwork which was given to the potential participants in the outpatient clinic attempted to convey the nature of the research and that it was possible, indeed acceptable, for them to withdraw at any time. By virtue of this, the individuals were entirely aware that, should they agree to participate, they would be involved in research. Prior to beginning the interview it was necessary to secure written confirmation of informed consent from the participant which involved them reading and signing a consent form, the content of which was highly determined by the local research ethics committee (please refer to Appendix 5 for a copy of the form). Though the consent form was designed to be clear and easy to understand, there was a particular statement which I found ambiguous: 'I understand that the information I give will be kept strictly confidential'. In light of this, I discussed with each of the participants that the data generated would not be kept confidential in the strict sense of the word because it was likely that I would use it within my thesis and within any additional publications. However I reassured the participants that from the point of signing the consent form that they would be referred to by a number and that it would not be possible for others to identify them in any data in the public domain[73].

Whilst the procedure of securing informed consent is viewed as a one-off situation, as the study moved forward and data generation progressed I became aware of the

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[73] I gave the first participant the number 101, the second participant the number 102 and so on ending with the 33rd participant who I referred to as 133.

limitations of such an approach. Rather than being something that is acquired at the beginning of data generation, I came to share the opinion of Estroff (1995) who writes:

> 'We have come to the view that consent is an ongoing process – never completed and seldom "truly informed" but a helpful framework and goal to keep always in mind' (p89).

That consent should not be viewed as a one-off event is in line with Clandinin and Connelly's (2000) position that the ethical concerns are central to the entire research enquiry and are not only of interest in the beginning when formal ethical approval is sought from research ethics committees. Consent, as an important part of ethical research practice, needs to be considered beyond the context of data generation when the data are being explored and drawn upon. Throughout the researcher must consider how they presented the study to the participants and the understanding that the participants would have of the study in light of this information. Always the researcher should ask themselves if, in their analysis, they are moving beyond this understanding and what the repercussions of that may be[74].

3.7.10 The presence of significant others and the issue of consent

There were occasions when the interview was conducted in the presence of significant others, principally spouses. In those interviews where others were present, they often made a contribution to the illness narrative. Indeed, there were occasions where the presence of another person was necessary since the condition of the participant made it difficult for them to communicate[75]. Though this contribution was interesting in itself, initially I did not hold it in as high a regard as the participant's talk and significantly I did not enter into a formal consent agreement with the others. As time progressed I felt that this was inappropriate and therefore from the twenty-first interview onwards I engaged all those in attendance in the formal consenting procedure and asked them to sign the consent form.

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[74] At one stage, once data generation had begun, I had thought that I would employ a discourse analysis approach to the data but as time moved on I became deeply uncomfortable because it would mean shifting my principal interest from what was said to how it was said, something which I did not believe the participants had consented to. Indeed, the shifting nature of qualitative research can mean that the consent given at the start of the study cannot always be assumed to stand at later stages (Holloway and Wheeler 1995). It is because of this that Munhall (1988) advocates the concept of process consenting, the negotiation and renegotiation of consent with the participants.

[75] One of participant 114's main symptoms was voice change, and this meant that he was unable to speak loudly, or for long periods of time and so his wife took the main lead in the generation of the illness narrative.

In the interview excerpts contained within future chapters, I have included talk which is the most illustrative. Predominantly, this is the participant's talk but there are occasions where I have included that of others who were present. I have done this whether or not they had signed the consent form. For those who had not signed the form, because I had not asked them to do so, I have applied an implied consent approach. The notion of implied consent is frequently encountered within the health services (Aveyard 2002). As Fleming (1998) writes,

> 'Consent may be given expressly, as when a patient authorises a surgeon to perform an operation, but it may just as well be implied: actions often speak louder than words. Holding up one's bare arm to a doctor at a vaccination point is as clear an assent as if it were expressed in words' (p87).

In this understanding, informed consent does not have to be written, or even verbal, but can also be non-verbal (Department of Health 2007). That the significant other had been present during the time that the participant and I engaged in the process of signing the consent form and that they sat in the room and indeed took an active part in the generation of the illness narratives implies their consent. This is because the person present was aware of the purpose of the study and its consequences and was capable of objecting to it should they have chosen to do so (Fleming 1998). It would have been different if the significant other was not privy to the consent procedure and so was not aware of the purposes of the study or its consequences. This is certainly a situation which I have learnt from and in any future work I shall ensure that a signed consent procedure is in place for all participants.

3.7.11 The interview in action

The purpose of the interview was to generate narrative data relevant to the experience of developing and being diagnosed with lung cancer. As I discussed previously, Morse (2001) writes that the 'tell me about' question is often used within interviews with the ill and injured to initiate the generation of their illness narrative. Indeed, as Hyden (1997) writes, 'To tell something means to relate an ordered sequence of events' (p60). In light of this I chose to initiate the interview with the following question: **'Can you tell me about how you came to be at the clinic appointment where I met you last week/on Monday/on Friday?** In the event, I asked the question in a variety of different ways, as illustrated in the following examples:

- So I was wondering if you could just tell me about the chain of events that led up to you being in (consultant's) clinic? (105)
- So I briefly just explained how it's going to go and you started off telling me about, about your experience and I was just wondering if you could just try and recap on what you've just said I'm interested in how you came to be in, in the clinic a couple of weeks ago? (115)
- I was, met you in clinic um a week ago last, on Monday a week ago and I was just wondering if you could tell me about how you came to be at that clinic appointment? (129)

Though the specific wording was liable to change, the feature of the majority of the questions was my request for them to 'tell me'. It was an appeal for them to tell me about their experience, and in the majority of cases the participant responded with a long narrative sequence. However the question did not always unproblematically translate as a request for a narrative. At times, for example, an illness narrative could not be generated until the participant had sought clarification for how to proceed. The following extracts are from the very beginning of two interviews which illustrate the negotiation that was sometimes required before an illness narrative could be generated.

I[76]: I was just wondering if you could tell me about how you came to be in clinic last week when I saw you?
P: um, what do you want me to go back from the beginning how I got to the hospital, you know
I: yeah what, whatever you can remember
P: about three months ago I had a pain... (112)

I: So we met in clinic on Monday
P: right
I: and I just really wondered if you could tell me about how you came to be at that, at that clinic appointment?
P: that specific one?
I: yeah um
P: well that specific clinic appointment was just planning for um treatment for my cancer um that's it yeah, that's the reason I was at that clinic
I: okay
P: or do you want any?
I: can you go back um telling me as much or as little as you want about how this has all come about?
P: (deep breath in)
I: why, you know why, what, why you were getting
P: okay um started off with... (126)

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[76] 'I' is me, the interviewer and 'P' is the participant. In later excerpts, 'H' is the husband and 'W' is the wife.

Whilst for the majority of the initial questions I had asked the participant to 'tell me', there was an exception, notably the question which I asked the final participant: 'So I just wanted to ask you about why you were in the clinic appointment when I met you on Monday? (133). I re-worded the question in response to the participant and the following extract, taken from my research log, explains why.

He said that I couldn't do no harm asking any questions and that he was happy to go ahead, but not before I explained what questions I was going to ask him because he didn't want to produce a dodgy recording. So I told him the original narrative question, that I wanted him to tell me about how he had come to be at the clinic appointment, that I wanted to know about his experience, but he was struggling to clarify my intentions and exasperatedly he said 'yes but what do you want to know?!'. So then I said 'why were you at the clinic?' and he told the story from there.
Research log 17th August 2006.

3.7.11.1 Layers of the illness narrative

Irrespective of the exact wording or whether negotiation was required, my first question was successful in terms of leading to the generation of illness narrative. However this was not all of the narrative data generated, indeed it was only the first layer. The second layer of the illness narrative was generated through my efforts to explore the experience further and was prompted by my exploratory questions or comments. This is a distinction that has not been explicitly addressed within the narrative literature but I think that it is an important one. Whilst I do share the opinion that narratives are co-authored (Williams 1984; Ochs 1997) and generated within a social context, I think that the extent to which the audience influences the narrative is variable. With regards to the first layer, for example, I had set the scene for the interview and I had asked a question but then what was incorporated into the narrative was largely down to the narrator, the study participant in this instance. In the second layer, however, my role as interviewer was more explicitly directing the content and form of the narrative as I sought to explore the narrative, and the experience, further. Mishler (1986) remarks that the

> 'interviewer's presence and form of involvement – how she or he listens, attends, encourages, interrupts, digresses, initiates topics, and terminates response – is integral to a respondent's account' (p82).

It is to this which I am trying to draw attention in making the distinction between the first and second layers.

Common to all but one of the interviews within the generation of the second layer of illness narrative was when I asked if the individual had considered that they might have lung cancer prior to the diagnosis of the disease. I felt that it was important to ask this question since I believed that the response would be valuable in my efforts to offer an answer to the second research question. Furthermore it was an area which Corner *et al* (2003) had not addressed. Once I felt that the second layer had been generated as far as was possible, I moved the interview onto the final section in which I collected some specific socio-demographic information. These data included details of the participant's smoking history and smoking status (if not previously discussed), occupation and housing status. Whilst not an angle that I have explored as yet, studies of illness experiences and illness narratives within the existing literature have sought to associate their content and form with the particular social and demographic positions of the individual. Age (Pound *et al* 1998), socio-economic position (Riessman 2003) and sexual orientation (Klawiter 2004) have been suggested as influencing, indeed limiting, the possibilities of the illness experience and the illness narrative.

- The newsletter

In the final section of the interview, I also asked the participant if they would like to receive a newsletter in two to three months time[77]. I explained that the purpose of the newsletter was to update them on the progress of the study. All but one of the participants readily accepted the offer of the newsletter and those who did accept were very enthusiastic about receiving it (an example of a newsletter can be found in Appendix 6). Indeed, one participant telephoned me, once he had received his newsletter, to request another one. I sent the newsletter to the home address of the participant accompanied by a compliment slip on which I thanked the participant again for their participation.

3.7.11.2 The issues of harm and loss

One of the most significant ethical aspects of the research process for me personally was to try to ensure that the participant did not suffer or lose through their participation. I stipulated this in the form completed as part of the process of securing ethical approval. However it must be recognised that it is not always possible to anticipate the full

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[77] I chose the period of two to three months post interview because I believed that many of the participants would still be alive at this time, and was aware that if I left it much longer than that an increasing proportion of the individuals would not be able to receive the newsletter.

implications of participation (Ryen 2004). Inviting someone to engage in the telling of their illness narrative may, for example, be a beneficial experience, but the act of telling can also be a negative experience. Indeed, McLeod (1997) suggests that all therapies could be considered to be narrative therapies, involving the telling and re-telling of stories it is hoped for good but also, potentially, for bad. Telling and re-telling, even if an individual perceives it to be beneficial, can be challenging. This may particularly be the case for illness narratives since the lack of a known ending can make it difficult to know what to tell (Hyden 1997). This ambiguity can be difficult for the narrator but it can also be difficult for the audience.

Within the clinical context, working as a therapy radiographer, I became accustomed to difficult stories, stories which were either difficult to tell or difficult to hear, indeed stories that were both difficult to tell and difficult to hear. But it is not just within the clinical context that such encounters happen. Within everyday social life one becomes familiar with reading the cues which identify a difficult story and which suggest that the story will not be told, or that more time is needed for the telling. Within the interview interaction I allowed myself to read the signals that are part of everyday life.

There was one particular occasion within an interview when I relied on my instincts for how to manage a situation. The following is an excerpt from my research log which describes the situation.

> At one time in the interview I could see that he had tears in his eyes and asked if he was okay to continue, and then further on he started to cry. I did not say anything to him, I felt that it was appropriate to let him be. His wife was at the other end of the table and she began to cry also. We sat there, each of us in contemplation, for a minute or so and then he said that he was okay to carry on.
> Research log 23rd August 2005.

The interview was being recorded at the time[78] but the general consensus seems to be that if as an interviewer one encounters such an emotional situation, the recorder should be switched off. I did not do this, I left the recorder running and I just sat at the table in a state of being with the participant and his wife. I felt that if I was to turn the recorder off I was signalling that I was not interested in this aspect of his experience and potentially denying him the right to feel as he did. I believed that it was important to

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[78] I address the issue of recording in section 3.7.13.

recognise his anguish and distress, not act so as to reject it[79]. I did not think that it was the interview that was causing the participant distress or that I was. He was distressed because he was living through a horrible experience and contemplating how his illness narrative might end.

The following is another extract from my research log which illustrates a tension that I experienced when conducting the interviews, relating to the issues of harm and loss.

> So far I have done 16 interviews – today's was by far the shortest. The participant was a lady who started chemo last Friday and today she was feeling a bit queasy and was having stomach cramps. I asked her if she wanted to postpone but she said she was fine to do it as long as it wasn't too long. I was therefore conscious of her ease and comfort, as I am with everyone I meet in the interview situation. Obviously I have come away with gaps and areas that warranted further exploration but in the real time interview situation I was one human being who could feel the anguish and suffering of another. Whether as explicit as in this case or not, I am interacting with people who are, by and large, going through a horrible time in their lives. I can sense this, and at times I feel uncomfortable about putting them in the research position, and I am definitely uncomfortable with the notion of a researcher interviewing an informant regardless of the details, coming away with what they want to achieve with little regard for the other. I cannot and will not interview in such a manner.
> Research log 30th November 2005.

In an alternative approach to interviewing, the interviewer is armed with a schedule of questions which need to be asked in order to generate the most relevant, indeed the correct, information. However this was not the case in my interviews; I had no real schedule to speak of, I only sought for them to tell me about their experience and ask if they had considered that they might have lung cancer. The remaining questions which I asked or exploratory comments that I made were developed within the interview situation so as to generate the second layer of the illness narrative and were not stipulated in advance. And at all times when making these contributions, I tried to be as sensitive to the participant as I could be, whilst always acknowledging the research questions to be addressed.

3.7.12 Interview notes

As soon as was practical after the end of the interview I typed no more than one side of A4 paper describing the physical environment in which the interview had taken place, how I felt about the interview, how I thought the participant felt about the interview and

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[79] Kavanaugh has noted that when crying, a participant does not always want the interviewer to intervene (Kavanaugh and Ayres 1998).

any other comments related to it (please refer to Appendix 7 for an example). Jones (1985) is in favour of this type of interview note since it is

> 'all too easy to forget these additional contextual data which can so importantly affect the interpretation of the interview content' (p58).

Often reading through the description I was able to answer a query that I had about what was said and why it was said that way.

3.7.13 Recording, transcribing and listening

As part of the process of securing consent, the participant was asked to provide permission for the interview to be recorded. Two of the participants declined to have the interview recorded. An excerpt from my research log illustrates how I found that situation problematic.

Today I did an interview and the participant did not want it to be recorded. This was really hard for me, I struggled to note things down, listen to what she was saying and develop further questions. I decided that I would only write down key things which I considered to be relevant to symptom interpretation – but of course this was entirely selective. Since I was only writing occasionally, it was obvious to the participant what my notes were related to. On several occasions she commented on my taking notes in response to a certain topic and I feel able to assume that taking notes influenced the structure and content of the interview beyond my usual presence. At the end of the interview the participant read through my notes – she was concerned that I should only write down what was true.
Research log 29th September 2005.

Of the interviews which were recorded[80], the mean length was 54 minutes, with a range of 16 minutes to three hours and two minutes. I made a verbatim transcript as soon as possible after the interview had been completed[81]. This was an incredibly time-consuming feature of the study and it took on average one hour to transcribe 15 minutes of recording. Within the transcript, I was keen to preserve some of the nuance of meaning that operated within the actual interaction. However it is widely recognised that it is impossible to capture the interaction in its entirety, and that any transcription is only a partial representation (Elliott 2005). It is also a theoretical and interpretive feat which has an impact on the type of analysis that the text can be subject to (Riessman 1993; Elliott 2005). A detailed transcription notation, such as Jefferson (2004), seeks to

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[80] I used an Olympus DM-20 digital voice recorder. The recorder was small and discreet and I was impressed by the quality of the recording.
[81] I used an Olympus AS-4000 PC transcription kit.

provide as accurate a representation of the interaction as possible through capturing tone, volume, emphasis and speed of speech amongst other features. But as Watson (2006) writes,

> 'An ironic feature of transcription is that the greater the attempt to convey nuance through transcription conventions the less natural the transcription appears' (p374).

The extremely annotated transcriptions can be difficult to read, especially for someone who is not familiar with reading a text where the symbols do not represent punctuation but some feature of the talk. As I had thought that I would approach the generated data through a process of narrative analysis, I considered it appropriate to only include the conventions and features outlined in Table 6.

Conventions	Feature
(1)	Indicates length of pause in seconds
bold	Indicates emphasis
[ ]	Indicates overlapping speech
(laugh/cough)	Indicates non-verbal action

Table 6: A table to summarise the transcription conventions employed in the study.

Recording and transcribing are key components of the research process when a narrative is the main interest (Riessman 1993) because it allows the (albeit partial) transformation of the aural into a written form which is a more manageable format for analysis. Transcription is also suggested as an important way in which the researcher becomes familiar with the generated data (Atkinson 1981; Riessman 1993). True to this I did find that through transcribing the interviews myself I was able to hear things that I had not heard before. Once the data had been transcribed, I reviewed the recording alongside the transcription to check for accuracy and often this allowed me to fill in the blanks where I had previously been unable to make out what had been said. In addition, I listened to all of the interviews again once I had decided not to conduct any more. I found this difficult, as illustrated in the following excerpt from my research log, because I knew that many of the participants were no longer alive.

Today Dr (name) came into the office to download some interviews. She's been conducting a longitudinal study with individuals diagnosed with (disease). I'm not quite sure how we got onto it but she said that she's finding it hard to analyse the interviews because she can hear pain and suffering, but that it's easier once the participant has died. I told her that I'm finding it harder – that I hear ghosts.
Research log 7th September 2006.

During the course of data generation I had attended sessions with my reflective supervisor[82] to discuss any issues that arose during the research process but I did not foresee the impact that hearing the interviews again would have. In working to resolve the tensions, I found the words of Copp (1999) a helpful reminder that others, too, have experienced similar feelings:

> 'in the research I found myself having to resurrect the patients who had died, and relive and re-engage in their experiences weeks and months later. Often this involved listening to their voices from the tape-recordings and reading their experiences on transcripts, and I found this emotionally extremely hard going' (p239).

Whilst I was worried about being overly melodramatic, for example through employing the term 'ghosts', I was reassured to see that this was not unjustified, as Copp (1999) goes on to write:

> 'With the help of my counsellor I was able to make some sense of my experiences. For instance, my counsellor would explain that, having asked the patients for their experiences, it was not inconceivable that I should carry their 'ghosts' at certain times' (p240).

Whilst I did find it difficult, immersing myself within the data was extremely beneficial in terms of allowing me time to hear anew and think afresh. It was at this time that I really began to think seriously about the potential significance of a particular aspect of the illness narratives.

3.8 Drawing a distinction between components of the illness narratives

3.8.1 Narratives of personal experience

I had expected that the interview situation would allow for the generation of illness narratives relating to developing and being diagnosed with lung cancer and indeed this was the case. Much of the content of the illness narratives was composed of narratives of personal experience. These were presented by the narrator as corresponding to a 'remembered fact' (Lieblich *et al* 1998) that was tangible but had now passed. Primarily

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[82] My reflective supervisor was not one of my academic supervisors but a trained counsellor employed by the research group.

they described symptomatic experiences and their interpretation of, and response to, these experiences alongside the responses of those also involved such as family members and health professionals. In addition to those relating to lung cancer, a range of other narratives of personal experience were generated which re-created their experience, or those of others, with alternative disease types or non-cancer related symptomatic experiences.

3.8.2 Narratives of genesis

Whilst the narratives of personal experience did constitute a large part of the illness narratives there was also another significant component which related to how and why lung cancer develops. These narratives were explanatory in tone, rather than the descriptive tone associated with the narratives of personal experience. I termed these narratives the narratives of genesis, drawing upon the terminology used by Williams[83] (1984) and Frank (1995) who asserts that 'part of any story of illness is genesis: what caused the disease; why did it happen to me?' (p72). Indeed, as discussed in section 3.5.1.3, for an illness narrative to be coherent, the issue of cause or genesis has to be addressed (Price 1987). Despite this, I had not anticipated that the participants would so readily tell me their narratives of genesis.

In the interviews with the participants such narratives were often raised spontaneously[84]. As the number of participants accumulated, I began to prompt for the narratives of genesis to be generated once I had felt that they were unlikely to be raised without my intervention[85].

3.8.3 Assessing the value of the distinction

The distinction between the two components of the illness narratives seemed a very obvious one as I thought about all that had been generated within the interview but it was important for me to appraise the value of this distinction. In order to do this I returned to the first two research questions:

1. What is the experience of developing and being diagnosed with lung cancer?

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[83] The paper is titled 'The genesis of chronic illness: narrative reconstruction'.

[84] By spontaneous I mean that I had not asked them any direct question, but of course the whole interview interaction had set the scene, as Williams (1984) has noted, for such narratives to be told.

[85] This demanded much sensitivity as the issues surrounding the cause of lung cancer are complex and have potential ramifications for the individual's identity.

2. Why may, or may not, individuals realise the significance of their symptomatic experiences? Specifically, why do individuals not seem to interpret their experience as related to lung cancer?

The narratives of personal experience which related to the experience of developing and being diagnosed with lung cancer were, then, fundamentally important in terms of me being in a position to suggest an answer to the first research question. And I began to consider that the narratives of genesis were insightful for suggesting an answer to the second research question. At this time it felt very much as though I was following a feeling or a hunch but it was incredibly thrilling to be considering possibilities that had not occurred to me prior to hearing the data.

3.8.4 Schematic representation of the distinction within the illness narratives

So as to attempt to make the distinction clearer, I developed a schematic representation (Figure 1).

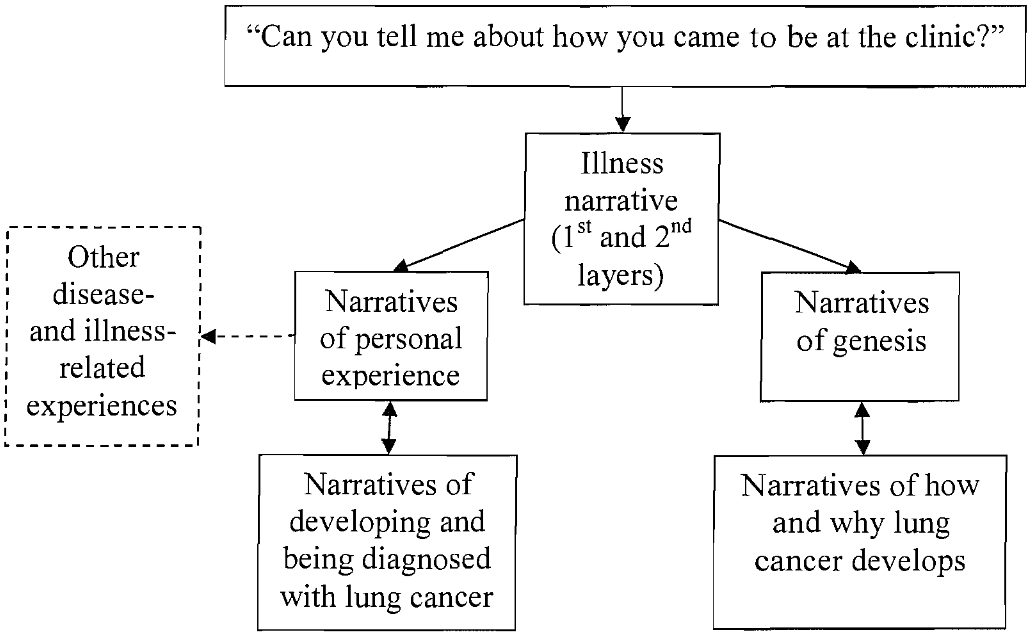

Figure 1: A schematic representation of the distinction within the illness narratives.

In assessing the value of my distinction[86] between the narratives of personal experience and the narratives of genesis I felt that their contribution was different in so much as each addressed a different research question. In light of this it felt appropriate, indeed necessary, to retain the distinction in terms of how I approached their analysis. It is the analysis and generated understandings which are to be the focus of the remaining chapters but given that the illness narrative data are so central, I should first like to consider some of the factors which may have influenced their content and form.

3.9 Narrative data as situated constructions

3.9.1 The study that the participants had agreed to take part in

The process of constructing meaning out of experience comes from deciding which events or situations to emplot within a particular narrative (Elliott 2005). It is likely that this decision is influenced by the perceived justification for the telling. I introduced the study to the potential participants at our first meeting as a study to explore their experience of the things which had led to them being at the clinic. I gave a slightly different presentation of the study in the paperwork: 'A study to explore the experience of developing chest problems'. As may be evident, I chose not to mention cancer or lung cancer either in the first meeting or anywhere on the paperwork. I did this because I was conscious that the individual's understanding of their disease situation might be quite different to the one that I knew them to be in by virtue of their attendance in the clinic. In retrospect I think that this was a wise decision since there were participants who chose not to refer to themselves as having cancer in any of our interactions, preferring instead to adopt terms such as the 'nasty' or the 'problem'.

In linking the study to a disease-related experience, albeit implicitly through adopting the phrase 'chest problems', I influenced the participants to hold expectations of the types of narratives that it would be appropriate to tell. In this way, the content of the narratives could have been similar to what one might expect a patient to tell a doctor[87].

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[86] Reflecting back on this thesis, it seems as though the distinction that I made within the illness narratives is a distinction which I have applied to my thesis. There are my narratives of personal experience of conducting the study, interlaced with descriptions from my research log, and then there are my narratives of genesis, my narratives of understanding the experience of developing and being diagnosed with lung cancer and proposed explanations of why individuals do not, indeed cannot, interpret their experience as related to the disease.

[87] It was not uncommon, when I asked a question relating a particular symptomatic experience, for the participant to respond that a doctor had asked them the same thing.

Indeed, Coffey and Atkinson (1996) draw attention to the way in which narratives can be told and re-told in this way:

> '[narratives] are worked up and recounted on repeated occasions. Often the research interview provides an additional situation for their telling rather than a uniquely novel encounter' (p78).

Related to this, Williams (1984) comments that any illness narrative must acknowledge the biomedical context in which the experience receives its official definition. This may have influenced the terminology used within the narratives but it also may have influenced the events emplotted into a particular narrative. That the individual had been given a diagnosis of lung cancer gave them an end-point from which to construct their narrative, including those events which they thought had contributed to the advancement of the narrative and leaving out those which did not. An alternative approach could have been to involve individuals who had yet to be diagnosed with lung cancer, for example those attending a chest clinic prior to confirmed diagnosis, and then to exclude those who were not actually diagnosed with the disease. Such a procedure was undertaken by Bankhead *et al* (2006) in a study which investigated the experience of symptoms in individuals diagnosed with ovarian cancer. Whilst this would certainly have been a possibility in this study, the narrative would still have been narrated from a particular perspective. The individuals, for example, would have been aware that they were undergoing further investigation of their symptomatic experiences and this could lead them to confer significance onto the experience differently to how they had done previously. A narrative will always be constructed from a particular position and experience will always be more than can be narrated (Good 1994).

3.9.2 My biography and role

> 'We suggest that who respondents *think* you are affects what you get told' (Richards and Emslie 2000, p75, emphasis in original).

Whilst Richards and Emslie (2000) were referring to data generated through more structured interviews than the ones I undertook, I do feel that how the participants perceived me influenced the nature of the data. I was given or adopted a range of different personas within the course of data generation. One of the consultants within the combined lung clinic introduced me as a radiographer doing a research study, which gave me a particular storied history. He introduced me in this way because we had worked together clinically and so he knew me in my capacity as a radiographer. The remaining health professionals referred to me as someone from the university. When I was in the actual presence of the potential participant I continued the university theme but I added a supplement of information; I would say that I was someone who had worked in the NHS but was now based at the university and working on a research project. I felt that it was important for me to say that I had worked in the NHS because I thought that it would give me a favourable identity. In truth, I thought that they would be more likely to consider taking part if I offered this information than if I did not. In the study paperwork I gave alternative identities:

- 'I am a research worker with experience of caring for people with chest problems'
- 'Researcher'
- 'I have experience of working in the NHS but I am currently studying for a higher degree in the School []. This study is being conducted as part of my studies'

Whilst I had introduced myself to the potential participants as someone who had worked in the NHS, there were occasions within different interview situations when I lived this aspect of my background. The following is an excerpt from my research log which I wrote after an interview with a participant who was shortly to start radiotherapy treatment.

> I was able to answer some questions that the participant had about radiotherapy treatment and drew a simple picture to illustrate the linac[88] as he asked if it was like a scanner. I enjoyed doing that, being of assistance, but I was careful to be as general as possible so that they are not concerned if it does not happen exactly the way that I described.
> Research log 29th July 2005.

This situation was just one example of when I acted upon my history and volunteered the knowledge that I have based on my clinical background. The tension between researcher and professional (clinical) role has been discussed within the literature (see for example Holloway and Wheeler 1995; Colbourne and Sque 2004). Similarly, as the previous excerpt illustrates, I found that I was unable to separate myself as health professional from myself as researcher. Moreover, since I never sought to position

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[88] Linac is short for linear accelerator, the machine which generates the high voltage x-rays used in radiotherapy.

myself as only a researcher when I introduced the study to the participants it did not seem fair for me to avoid my clinical background when they appealed to it or when I thought I may be of some use. My feeling was that as long as I did not seek to provide answers that I did not have, it was appropriate for me to be a radiographer-researcher amalgam, rather than just a researcher[89]. To guard against me being in the position of offering answers without substance, I encouraged any participant who asked me a question which I could not answer to speak to their clinical nurse specialist.

Through volunteering information relating to my clinical background, I espoused a particular position in the debate about how much the interviewer should reveal of themselves within the interview. Within the existing literature, for example, there are those who consider that a researcher's role is to remain impartial and to facilitate the participant's narrative but not to unduly influence it. At the other end of the spectrum, the feminist approach in particular advocates the interviewer's disclosure as a route to relationship building (Rubin and Rubin 1995). The narrative approach, to my mind, does not consider that a true or unbiased narrative telling is possible and so does not consider that any disclosure on the part of the interviewer is damaging because it obstructs the truth. Nor does it consider that exhaustive revelation is the way to a more truthful narrative. Both of these positions miss the point: 'Whatever ideals are practised, no single practice will gain 'better data' than the other practices' (Rapley 2001, p307). In light of this, I presented myself in different ways and to different extents depending on the specific interview interaction. There were times when I found myself offering many snippets of detail about my life and others where I remained relatively silent. How I acted and what I said was as much about the other person as it was about me. I responded to them, and sometimes I did not sense that they wanted to know anything about me whilst I felt that others did.

In addition to the potential impact of how much information I volunteered about myself within the interview, there was another aspect of my presence and conduct which influenced the illness narratives in a more explicit way. I am referring to the notion of the first and second layers of the illness narrative, a distinction I discussed previously in section 3.7.11.1. The first layer of the illness narrative was the one that was generated in response to my request for the participant to tell me about how they came to be at the clinic appointment. The second layer refers to the illness narratives that were generated

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[89] Indeed, Reinharz (1997) comments that '"being a researcher" is only one aspect of the researcher's self in the field' (p3).

after this, principally in response to my exploratory comments and requests for further information. In this way, I consider my role in the generation of the second layer of illness narrative to be greater than that for the first layer. Later in this thesis I present a range of excerpts from the interviews and in these I have tried to give a sense of the two layers. If I have abstracted the excerpt from the first layer of the illness narrative then I annotate the excerpt as such. Similarly, when the excerpt has been abstracted from the second layer it is clear, often because the excerpt features the participant's speech as well as my own. In giving a flavour of the immediate context in which particular talk was generated, I am attempting to emphasise that the data are situated constructions and that they, and ultimately the findings, could have been otherwise[90].

3.9.3 The wider context

Much is written within the existing literature about the social nature of narrative and how the content and form of narrative is limited by what is available within the wider social context (see Coffey and Atkinson 1996; Murray 1999, 2000; Lawler 2002). The social climate as it relates to health and illness may have influenced the content and form of the illness narratives. Within the western world, for example, health is seen as a moral issue and an individual has a responsibility and a duty to maintain themselves as a healthy member of society (Crawford 1984; Blaxter 1990). When unhealthy or diseased, Blaxter (1990) suggests that an individual may be viewed as immoral. To be diagnosed with lung cancer, then, as well as being a period of personal crisis, is also likely to have implications for how the individual is perceived by others. This is because the individual has been diagnosed with a disease but also because lung cancer is associated with a particular aetiological factor, exposure to tobacco smoke, which may mean that the individual is held more responsible for the development of their disease than is the case with other cancers. In addressing the issue of why they have developed lung cancer, the participants were doing so within a social context which does, in effect, hold them responsible for their situation (Freund and McGuire 1999). If they could present alternative factors or problematise the significance of tobacco exposure, the view of themselves as being solely responsible for their situation would be questioned. This may be why the component of data which I referred to as narratives of genesis seemed so integral to the illness narratives.

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[90] In offering so much of the interview interaction, I feel that I may show the weaknesses of my interviewing skills but conducting the study, and the interviews in particular, was a huge learning curve for me and I am happy to make public any deficiencies since there is a larger point that I am trying to make.

Related to this issue is the potential influence of the moral context surrounding health, and by default disease, on the content and form of the narratives of personal experience. If health is considered a state preferable to disease and illness, and if disease and illness are associated with symptomatic experiences, it may be more appropriate to construct a narrative which underplays the significance of any such experiences (see also Pollock 1993). The symptomatic experiences incorporated into the narratives of personal experience may reflect only a proportion of the actual experiences and moreover they may be presented as having little impact on the daily life of the individual. Tied in with this is the concept of embodied health and embodied disease such that as well as having to tell a narrative which presents themselves as not too ill, an individual may also have to try to ensure that their body does not betray them and denounce them as a person in dis-ease. As Radley (1999) writes:

> 'For an ill person, being interviewed is more than being asked to 'tell one's story' or to give an account of events surrounding one's treatment. It also means having to display one's condition to the interviewer, a meeting which is invariably conducted by a healthy other' (p23).

Also related to this issue of health as a moral concept, if one is not able to maintain oneself as healthy one at least has to behave appropriately when disease is experienced. Behaving appropriately entails presenting for medical advice at the earliest opportunity (Pill and Stott 1982). In this way, the individual is acting responsibly and playing an active role in regaining their health. The notion that there are right and wrong courses of action to take in the event of disease and illness may have influenced the participants in the study to present themselves, through their narratives, as seeking medical advice sooner than was actually the case or as taking any other action which they perceived would be positively judged.

In this section I have tried to consider some of the factors which may have influenced the illness narratives generated within the interviews. I do not know if these factors did exert an influence and I cannot say what the impact has been. My intention in this section has only been to dispel the notion that the content and form of the data were inevitable. The participant, me as researcher and the social context, all constructed the data into the shape they have. Because my efforts at understanding the experience of developing and being diagnosed with lung cancer were so dependent on these data I feel it only right that I should make this clear before I describe my analytic approach to the illness narratives.

3.10 Chapter summary

This chapter has had two main parts: research in theory and research in practice. In the first part of this chapter I positioned my unanswered questions as research questions which provided the focus for this study. I followed this with a discussion of the theoretical positions of research generally and this study in particular, specifically in relation to paradigms. I identified the case study approach as a research design best suited to my position and defined the case as the experience of developing and being diagnosed with lung cancer. From this I moved on to discuss narrative as an approach to research. I identified the core features of narrative and highlighted it as a mechanism for communicating and bringing meaning to experience. I discussed illness narratives as a mechanism for communicating and constructing the experience of illness. I identified the interview as one of the main methods through which narratives are generated and outlined a number of approaches to narratives and their analysis. Following this I summarised this study. The generation of illness narratives through interviews with individuals who had been diagnosed with lung cancer was positioned as the principal method of data generation and source of data, with the acknowledgement that additional data would also be drawn upon as necessary to facilitate my understanding of the case. I then turned to the issue of how this study might be appraised, discussing the lack of consensus over how to judge the quality of qualitative or narrative research and critiquing the value of criteria. Stemming from this, I considered how important it is that this study has utility and outlined a number of steps which I took during the research process to facilitate my understanding.

In the second part of this chapter I described the actual process of data generation and sought to describe what I did and what it was actually like for me as the researcher, often drawing upon excerpts from my research log to illustrate this. Towards the end of the section I described a distinction that I made within the illness narrative data between narratives of personal experience and narratives of genesis. I briefly discussed the relevance of this distinction and then moved on to consider some of the factors which may have influenced the content and form of the illness narratives as situated constructions.

4 Drawing upon the narratives of personal experience

4.1 Introduction to the chapter

In this chapter I present my analytic approach to the narratives of personal experience which took the form of 'narrative analysis' (Polkinghorne 1995). I present the narrative case studies which I developed through this process, each followed by a short commentary. I end the chapter with a brief response to the first research question.

4.2 Addressing the first research question – What is the experience of developing and being diagnosed with lung cancer?

As I discussed towards the end of the previous chapter, I drew a distinction within the illness narratives between the narratives of personal experience and the narratives of genesis. It was the narratives of personal experience which I felt would allow me to respond to the question 'What is the experience of developing and being diagnosed with lung cancer?'

This question arose because the existing literature had made it difficult for me to come to know, let alone understand, what the pre-diagnosis experience of the disease could be. The lung cancer literature which is broadly relevant focuses on patient delay and its quantification and does not permit the exploration and presentation of an experience. A limited exception within this field is the work of Corner *et al* (2003) which presents two case exemplars of particular participant's experiences of developing lung cancer. The exemplars are written in the third person and as well as documenting experience, each has theoretical content written by the authors in an effort to explain why the participants had not sought prompt medical advice. Though these exemplars give a flavour of what the experience of developing lung cancer can be like, the emphasis is on delay since both of the participants at their centre of the exemplars had experienced symptomatic experiences for at least four months prior to diagnosis. Moreover, it is interesting to note that the exemplars are not included in the more recent publications (Corner *et al* 2005; 2006) which instead draw upon thematic analysis to present features of the experience (Corner *et al* 2006). In this analysis, the experience is presented as static since it is not possible to portray the experience over time and indeed it is difficult to establish the implications of a particular situation or event for a particular experience. The authors may well be aware of the possibilities of experience but a wider audience is not.

An example whereby a limited portrayal of the experience of developing and being diagnosed with lung cancer is available to a wider readership is in Anne-Mei The's (2002) book titled 'Palliative Care and Communication'. The (2002) adopted the role of participant observer within a clinical setting and through observation and interviewing came to an understanding of the pathway of fluctuating optimism and hope that the participants with small cell lung cancer experienced, even though they were to die from their disease. The author has developed a number of characters and, writing in the third person, tells her story of interactions with them, and therefore their experience, at regular intervals throughout the book. Within this book, narratives of developing and being diagnosed with lung cancer are presented but they are not the core interest of the author and so are not subjected to further interpretation[91].

4.2.1 'Narrative analysis'

In the illness experience literature more generally, the approaches to analysis have tended to simplify and reduce the complexity of the experience. Within the qualitative arena, content and thematic analytic techniques are often used as a funnel through which the participant's experience is filtered and diluted by the analyst's extrapolation. Such analysis is concerned with the identification of categories and themes but it is difficult to develop an understanding of the where these themes may fit within an experience and the implications that they may have for an individual. As Ayres and Poirier (2003) write about the presentation of such analysis, 'these decontextualized segments, compared only with one another and not returned to their original context, may oversimplify informants' stories' (p117). Certainly, the nature of these approaches infers that the experience is static and the presentation of isolated excerpts means that it is often not possible to capture the temporal dimension of the experience.

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[91] Other examples which share this feature are Kendall and Murray (2005) and Levealahti *et al* (2007).

I had sought to generate illness narratives with individuals who had been diagnosed with lung cancer because I thought that it would allow me to come to know the experience but also so that I could develop my understanding of it. I was uncomfortable with separating these stories of experience into excerpts and drawing on these excerpts to illustrate themes and instead wanted to retain a sense of a whole experience over time. In light of this I was drawn to Polkinghorne's distinction of 'narrative analysis' which he defines as 'the procedure through which the researcher organizes the data elements into a coherent developmental account' (Polkinghorne 1995, p15) and importantly

> 'the process of narrative analysis is actually a synthesizing of the data rather than a separation of it into its constituent parts' (*ibid*).

The end product of narrative analysis is a narrative (Polkinghorne 1995). The data elements brought together through the analysis could be many and varied but Polkinghorne (1995) suggests that any data would need to be diachronic in nature as opposed to synchronic, whereby diachronic data have a temporal dimension. However, he also suggests that the data drawn upon in narrative analysis are usually not in storied form. This is perhaps why McCance *et al* (2001) found the process of narrative analysis so challenging since they had used as their main data personal narratives of a caring experience. In this way, it was important to be aware of the need to 'not simply recount the events in the story' (McCance *et al* 2001, p355). But the feature of the narratives of personal experience in this study was their diachronic nature, and not their boundedness, and it was this which positioned them as an appropriate foundation for narrative analysis.

In developing a narrative or a series of narratives, the researcher draws upon the notion of plot. Indeed, Oliver (1998) writes that the

> 'centerpiece of the narrative analysis is the plot. It is the integration of various events, happenings, and actions of human life woven into a whole' (p253).

The researcher selects events and experiences from within the diachronic data which support the development of the plot. In generating a plot the researcher is engaging in an active and creative process, making constant interpretations about the significance of the events for the experience as it was narrated. Through developing the narrative or narratives the researcher intends to understand the complex actions of an individual and in generating and presenting a narrative, the opportunity for others to formulate their own understanding is made available[92].

In making the narrative, and implicitly the experience, of individuals available to others, there is an opportunity for the experience of those often not heard to be rendered accessible. Cortazzi (2001), for example, suggests that one of the reasons[93] for conducting narrative analysis as a contribution to ethnography is that it gives voice, it shares the 'experience of particular groups, so that others may know life as they know it' (p386). However, others think that it is never possible to give voice for the voice of the researcher enters at all points of the research process (see for example Riessman 1993). Certainly, in narrative analysis, the voice read is the voice of the researcher since it is she who develops the narratives. But the researcher has an ethical duty to remain faithful to the data (Munhall 1988; Kvale 1996) and in this the narrative of the participant, the experience of the participant, will be the foundation and others will be able to know and to understand the possibilities.

4.2.2 Developing the narratives

4.2.2.1 Individual narrative case studies

My initial thoughts led me to devise narrative case studies which reflected each participant's experience of developing and being diagnosed with lung cancer. Polkinghorne (1995) identifies four steps which I found to be a useful guide: 1) the experiences are ordered chronologically, 2) the experiences relevant to the outcome are identified through a process of interpretation, 3) relations of cause and influence are explored, and 4) the story is written. As I have written of previously, there were two layers of illness narrative within the interview interaction; one which was generated with minimal intervention from me and one that was generated through my exploration and questioning. This meant that the interview did not progress chronologically; instead facets of the experience of developing and being diagnosed with lung cancer were frequently discussed out of temporal order. The first task for developing the individual narrative case studies was therefore to restructure the content of the talk so that it followed in a chronological sequence. Once I had identified and ordered the aspects of experience, I interpreted and extracted those which, in my opinion, had contributed to

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[92] Polkinghorne (1995) writes that the 'storied analysis is an attempt to understand individual persons, including their spontaneity and responsibility, as they have acted in the concrete social world' (p19).

[93] The three remaining reasons explored by Cortazzi (2001) are that it is 'concerned with the meaning of experience, ...human qualities ...and research as a story' (p385).

the outcome, specifically the diagnosis of lung cancer. I synthesised these excerpts into an individual case study excerpt, retaining the original spoken words where possible. I developed an individual narrative case study for each participant though this was harder to achieve when I did not have recordings to refer to, as was the case in two instances. The following is an example of such a case study[94].

> 'It started off several months, maybe up to four months ago. I found that um, my legs became quite uh, tired' and 'I found that by about the sixteenth hole out of the eighteen I was quite tired in the legs and this got progressively worse until I could only do nine holes' and 'I thought I might have taken on a bit more than I should have done out of myself'. 'At the same time, um, I experienced quite a bit of congestion in my throat' which 'I thought it may have been an infection of some kind and that was the only thoughts I had about it as a matter of fact' and 'I think I bought some throat lozenges and uh, they would ease it sometimes, but um, I didn't do anything at all really'. In addition to this the gentleman coughed up a 'fleck of blood now and again' and 'that's when I began to think it might be more than just a throat infection' and 'I would think something like two or three weeks before I went and saw the GP'. The GP 'thought it may have been a thyroid problem and uh, I took blood tests and what not and it wasn't a thyroid problem or kidneys or anything like that and uh, during the conversation he suggested that um, I have a chest x-ray because I have a history of um asbestos in the lung'. 'Anyway um he told me that yes I had a lot of asbestos and one thing led to another and he sent me to the um, chest clinic and I saw a doctor there and he suggested that, well he didn't suggest he advised that I have a scan' 'and that's when all the fun started' and 'it seems that I've got uh, small cell lung cancer'.

The individual narrative case studies represented my interpretation of each individual's experience of developing and being diagnosed with lung cancer, as communicated and constructed through their narrative. The participants had not told their narrative as I now displayed it in the case study; I had interpreted the significance of particular events and depicted them over time differently to how the participants had done in their telling. I had foregrounded their interpretation of their symptomatic experiences and their response to that experience, as well as the responses of others. But I employed the individual's own words wherever possible, and where that could not happen, I made my own contribution, written in the third person. However I was disappointed since I felt that this served to distance the reader from what was written and therefore from the experience. The use of the participant's and my words together also made the excerpt clumsy and difficult to read and it lacked the natural rhythm that many of the narratives seemed to have in their real-time telling.

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[94] Quotation marks are used to distinguish the participant's actual words from mine.

4.2.2.2 Rethinking the individual narrative case studies – developing narrative case studies

In my opinion, the individual narrative case studies needed to be re-worked because they were not able to convey the experience of developing and being diagnosed with lung cancer in the way that I had imagined. In addition to this, there were practical issues associated with presenting 33 individual case studies, specifically the sheer amount of space that would be required. I questioned whether there was value in making all of the individual studies available and I decided that there was not. I therefore needed an alternative strategy which would allow me to both come to develop my understanding and to manage the voluminous amount of data. I needed a way to enter the data and it was for this reason that I chose to make a distinction between the participants' narratives of personal experience on the basis of a particular event. I was aware that the events in the narratives varied between individuals particularly in regards to the experience of different symptomatic experiences. It was for this reason that I decided to use the symptomatic experience as the organising framework in the first instance.

The majority of the individuals had narrated the experience of more than one symptomatic experience but there was always one which they positioned as more significant for the diagnosis of lung cancer, one which they emphasised more than any other. I identified this symptomatic experience as the one which dominated the narrative and formulated a matrix (Table 7) detailing which participant had constructed a narrative around each of the particular symptomatic experiences described.

Dominating symptomatic experience	**Participant**								
Cough	101	106	110	115	119	120	121	128	129
Shortness of breath (SOB)	104	107	111	117	123	125	131		
Coughing up blood	103	(101)	(108)	(110)	(118)	(126)			
Chest infection	105	126							
Pain in chest/ shoulder	112	118	122	127	130	132			
Voice change	114	124							
Weight loss	116								
Miscellaneous	102	108	109	113	133				

Table 7: A matrix of dominating symptomatic experiences experienced by the study's participants.

Whilst I found that organising the participants according to the symptomatic experience which dominated their narrative was a useful heuristic device for managing the data, it did not sufficiently allow me to explore the range of different experiences. The individuals who had narrated a particular symptomatic experience as dominating their experience often interpreted it differently from each other, with an associated variation in how they responded to that experience. Moreover, other individuals also narrated that particular symptomatic experience, though it was not positioned as dominating and was interpreted differently further still.

Related to this, a situation which I had not expected occurred on several occasions whereby the experience of coughing up blood did not dominate the narratives of all of the participants who had experienced it. This was somewhat different to the finding of Corner *et al* (2006, p1387) who report that this particular symptomatic experience was so 'out of the ordinary' that it prompted immediate action in participants. I therefore chose to identify the participants who had narrated the experience of coughing up blood but had not positioned it as dominating. The bracketed participant numbers within the matrix represent this situation (Table 7).

In light of this complexity and variation, rather than develop seven narrative case studies reflecting the dominating symptomatic experiences[95], I felt it important to develop as many narrative case studies as I could ground within the data. To this end, I employed the matrix as the guiding framework; I drew upon it to decide which narratives to generate and what their form would be. I developed at least one, but often two, case studies which reflected the varying interpretations and management sequences relevant to each symptomatic experience. I developed the case studies to highlight how the individuals actually interpreted their experience and the implications that this had for the management sequence. On occasion, I chose to develop a case study which was based on the narrative and, to my understanding, the experience of one participant, whilst at others I drew upon the narratives and the experiences of more than one participant. When I decided to develop a composite narrative, based on the narratives of more than one participant, I drew upon the individual narrative case studies. The different, yet similar, aspects of interpretation and management sequence provided a

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[95] Cough, shortness of breath, coughing up blood, chest infection, pain in chest/shoulder, voice change, weight loss. I chose not to develop a narrative case study relating to the miscellaneous symptomatic experiences which dominated the narratives of participant 102, 108,109, 113 and 133 since they had experienced other, more common, symptomatic experiences reflected in the other case studies.

foundation for synthesising these composite narratives[96]. The creation of composite narratives is not an original concept and there are references to it within the existing literature. Oliver (1998), for example, presents three fictionalised stories which are 'composites of some of the stories from the students I visited in a middle school gymnasium' (p246).

Regardless of whether I had drawn on the experience of one participant or more than one[97], I developed the narrative case studies so that they were written in the first person. I chose to do this because I was unhappy with the way that my initial individual narrative case studies conveyed the experience of developing and being diagnosed with lung cancer. The case studies are rooted in the narratives, and experiences, of real people and I want you, as reader, to feel close to the experience that you are reading about. Newman (2004) suggests that stories are powerful when the experience happened to the person telling the story and that this can facilitate more of a connection than if the experience and the story are re-told by someone with less personal involvement and investment in the story. First person, rather than third person, is thus likely to foster more connection which may be important for engaging readers and for allowing them to creatively imagine what an experience is like (Vendler 1984).

Like the individual narrative case studies, I used the participants' own words wherever possible but I took care to retain the naturalness and the rhythm of the narratives as they were originally generated. Writing the narratives entirely in the first person helped to achieve this. Though I did incorporate actual spoken words wherever possible, I must be clear that the narrative case studies are my interpretations. I extracted the spoken words out of the context in which they were generated, I imposed a different order on them and I made my own contribution.

I recognise that it may seem odd that I chose to impose a biomedical frame of reference (the symptomatic experiences) onto the illness narratives and the development of the narrative case studies. However I thought it necessary, and ultimately useful, since the primary intention of this study was to make a contribution to the earlier diagnosis of lung cancer. With the benefit of biomedical intervention and hindsight, the experiences

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[96] When I present the narrative case studies, I make it clear if it is a composite narrative, based on the narratives and experiences of more than one participant.

[97] There are a small number of participants whose experience, as constructed through their illness narrative, does not explicitly feature in a narrative case study. This is because whilst I wanted to illustrate a range of experiences, some shared similarities with others and in this way could be considered 'typical'.

which the individuals narrated, and which I incorporated into the narrative case studies, could all be associated with lung cancer, though they were interpreted and responded to in a range of different ways by the individuals. It was this which I found most interesting and wanted to understand as well as draw attention to. Interpreting particular symptomatic experiences as related to a specific disease is key to diagnosis, whether the interpretation is made by the individual with the experience or by someone else, for example a health professional. Hearing the illness narratives, it was clear to me that the majority of the participants had not interpreted their symptomatic experience as related to lung cancer. This reinforced my existing unanswered/research question of why do individuals not seem to interpret their experience as related to lung cancer, but it also raised another question: how do individuals interpret the symptomatic experiences associated with lung cancer if they do not interpret them as related to the disease? I thought an understanding of this would be beneficial for my answering of the research questions but also for my more general understanding of the case, the experience of developing and being diagnosed with lung cancer.

Whilst I had drawn upon a biomedical frame of reference to develop the narrative case studies, I wanted to be faithful to how the individuals had interpreted their symptomatic experiences and chose to assign a title to each of the case studies which was drawn from the actual words of a participant. The title draws attention to the way in which an individual made sense of their experience and the biomedical frame of reference through which I organised the development of the case studies becomes less obvious. In this way, the narrative case studies signal the interface between the imperative to make a contribution to a disease's earlier diagnosis and the insight afforded by sociological and narrative perspectives.

4.3 Presenting the narrative case studies

In the remainder of this chapter I shall present the twelve narrative case studies. Polkinghorne (1995) writes that in a narrative analysis approach, the narrative case studies are presented often followed by a chapter which seeks to interpret the meaning of the experience and which discusses the similarities and differences. This commentary is 'essentially a description of what can be learnt from the reported case studies' (Polkinghorne, quoted in McCance *et al* 2001, p355). In light of this, I shall present each case study followed by a brief commentary. The commentary is in no way exhaustive, and indeed it seems odd to highlight similarities and differences which I have constructed and emphasised, but my intention is that it 'sets the scene' for what follows in the later chapters.

4.3.1 'I never have a cough other than like that'

> Well it all started off with a cold and my cold pattern usually is a streaming nose for about a day and a half and then it dries up and then it goes onto the chest as a cough and then take the cough mixture and within a week it's virtually on its way out. That's the only time I have a cough, I never have a cough other than like that.
>
> But this time, I should say it was about March, early April something like that, I thought the cough was starting but it didn't it developed into a dry cough so I wasn't coughing all the time but it was irritating periodically. But I think this sort of thing is all down to knowing your own body, how do you normally react to illness and suddenly if there's something different, you can ignore it if you want but I didn't want to ignore it and so after about two weeks I went to the doctor. He said I think you've got a viral cough, he says come back in two or three weeks which I did and it was still the same. Now I can't remember exactly what happened on that occasion whether he said give it more time or not, he must have done because the next time I went back she sounded me chest and she thought there might have been some wheezing there so she gave me an inhaler. I did used to have inhalers about ten years ago, that was when they said I had asthma but after about nine months I threw the inhalers away cos I was swimming and I was diving and it just wasn't there. So anyhow she gave me the inhaler and it didn't seem to work very well and then I went back, I think it was every other week then 'til I got the x-ray sorted and they found this.

Individuals can interpret their symptomatic experience as related to a disease process but when this is within the realms of normal illness, for example a cold, presentation for medical advice is not needed and the experience resolves over time and through self-medication. The typicality of such an experience for a particular individual can act as a benchmark from which to make judgments of abnormality – 'I never have a cough other than like that' – and so when a different, though similar, experience occurs the usual interpretation is questioned and alternative interpretations are considered. As the existing literature suggests, the interpretation of an experience as abnormal positions the seeking of medical advice as a potential course of action, an action not associated with interpretations which evaluate the experience as normal (see for example Dingwall 1976). Once presented, symptomatic experiences such as a cough are associated with a range of differential diagnoses and there is a process of elimination which takes place before the ultimate diagnosis is made.

4.3.2 'Several people have said to me'

I smoked a long time I know and I never had a cough, never had chest infections, never had any problems over the years and then last year I thought I could do with giving up smoking and so I did and immediately I started coughing. Several people have said to me that this is a common thing, you give up smoking and you start to cough but the cough did ease off and I actually went back to smoking. But it wasn't a smoker's cough it was a dry cough and you couldn't stop it, you know what I mean, you weren't bringing nothing up it was just like a dry cough. And then I found that, I was doing a lot of work at this one place and to get to it I had to travel and going through particular airports I found it was more difficult to carry my suitcases through the airport but you don't know whether to put it down to pure ageing or deterioration or some other thing and I thought no more of it.

Then in January I started going to the GP cos I was coughing a lot and I was so fed up with it I thought I'd better go and see the doctor about this. I think my wife thought that I had a chest infection and she kept on telling me to go and see them so that I could get some antibiotics and they sent me for an x-ray in January and they found no problems with it and I was diagnosed as having COPD and they prescribed me inhalers. Not long after I started this steroid inhalers I started losing my voice and actually it's still not right even though I don't use them inhalers anymore but I didn't think much of it at the time but then I still continued with the coughing so I went back to the doctor again and was sent for another x-ray which they found a problem with this time. When I went to the chest clinic the doctor asked me what I thought might be wrong, well I said I might have tuberculosis, I might have asbestosis, I said I might have lung cancer she said yes that's what you have.

Composite

A smoker's cough is not deemed to be the result of underlying disease processes and is not considered a cause for concern. However, a change in the cough can prompt interpretations from significant others, as well as the individual themselves – 'people have said to me'. These interpretations can act to reinforce or question original interpretations and may subsequently influence the management sequence. Associating the cough with smoking cessation, for example, does not mean that medical advice needs to be sought but associating it with an disease process, for example a chest infection, makes presentation for medical advice an available and appropriate course of action. Once presented, the process of biomedical diagnosis is not straightforward and a negative chest x-ray serves to remove suspicion from the possibility of lung cancer. Only after the persistence of the symptomatic experiences, and the continued presentation for advice, is lung cancer diagnosed.

4.3.3 'It was so unusual for me'

> I think it was about March time that I noticed that I was getting out of breath going up the stairs, I mean I wasn't really concerned by it but I've never been one for getting out of breath, it was so unusual for me that I decided to go round and see the doctor, that was end of March I went there. I thought that it was most likely cos what with my accident you know I'm putting on the weight cos I'm not doing the exercise and I thought that's got to have some effect on breathing and when I went round I said to him you're gonna tell me to lose weight, you know, I think I thought he was gonna confirm what I thought it was. But then when I was there he listened to my lungs and he said there wasn't enough air going through one of my lungs and so he sent me off for all sorts of tests and that's when they confirmed that they found out I had lung cancer.
> But I couldn't have gone to the doctor any sooner cos I had no symptoms did I?, I mean I get pain in me shoulder but I put that down to me accident, you know this is where I find it difficult to, you know because having the accident different aches and pains I don't know whether it's to do with that or whether it's pain from the cancer. But, you know, I hope I've caught it pretty quick.

The development of one symptomatic experience can be interpreted as abnormal – 'It was so unusual for me' – whilst a different symptomatic experience may not be interpreted in this way. Experiencing symptomatic experiences in the presence of pre-existing morbidity presents difficulties in terms of how to interpret the new experience – as linked to the original disorder or a new one[98]? Certain experiences are more easily interpreted as related to the pre-existing condition than others and so the nature and origin of the experience is highlighted as significant for the interpretation.

4.3.4 'I wasn't the only one there who suffered that problem'

> Months back, I guess as many as twelve months back I noticed that I was getting a bit short of breath, you know there's this path outside the house and it's quite steep and it felt like a struggle to get up it. And at work I'd often have to go up three flights of stairs and I was gasping a bit when we got to the top but I wasn't the only one there who suffered that problem so I just palmed it off, I thought oh you're getting old, and also cos I smoked I knew my lungs weren't in the best condition.
> Then, I'd say, back three, four, five months ago it started to hit me harder, it started to get worse and I found I had to then start slowing myself down which was difficult. We'd not long got back from being away and I thought I'd picked up a bug or something off the recycled air or you know you get all sorts of peculiar things and that is obviously what I thought I had but the wife had been on to me all this time, all the twelve months, and then when I had to change, do things slower than I usually do because it had got that much worse, I decided to go and see the doctor and see if there's somethin' wrong.
> The doctor took a look at me and things and decided to order some tests and it went from there and that's when they told me that I had this nasty, you know,

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[98] This has been noted by Corner *et al* (2006)

twelve months ago I never dreamt that it could be this it's only in the last few months that I began to think that it could be something more serious. But I don't feel ill at all, in fact life now is almost as good as what it was previous except that I know I've got this waiting for me.

Composite

A particular level of symptomatic experience can be interpreted as within the realms of normality, principally if an individual is not 'the only one there who suffered that problem'. Related to this, expectations of ill health, for example related to age or smoking status, influence how symptomatic experiences are interpreted, typically rendering them as within the realms of 'anticipated'. The existence of the symptomatic experience can be demonstrated by its impact on the life of the individual, for example in the course of their daily activity. Limiting that activity because of a perceived worsening of the symptomatic experience moves the interpretation from one of normal, or at least anticipated, to one of abnormal. Abnormal in this instance is related to the perception of an underlying serious disease which makes presentation for medical advice a legitimate course of action.

4.3.5 'My make-up in me is not like that'

I'd say it was about August last year that I noticed, on a night I'd curl up in these chairs like this cos I like to watch the television like this and every time I did this I used to wheeze. I used to think well this is odd and if I went over to the other side it didn't. Well anyhow I went down to two of the doctors at our practice last August and I told them about all this you see, one of them sent me for an x-ray which came back alright. I went back again because I said it hadn't cleared up and he said they thought it was something that I was breathing in the air that was causing it and I do get very bad hay fever and allergies you know so really after that last time I was at my doctors last year I just thought it's just um, allergies really and that's what I thought this last time.

I had been wheezing a little bit and this particular night I started to cough because the wheezing was making me cough and one of the times I coughed up some blood in my handkerchief then I coughed up some more and so my husband rang the out of hours doctor. He told me cos it was a weekend there was nothing much could be done but to go down to my own doctor on the Monday morning which I did. I know that say on Sunday night I might have thought oh well don't really need to make this appointment but my make-up in me is not like that I've got to get things sorted you see.

So I went to the GP and she sent me for blood tests and an x-ray which came back in ten days and seemingly everything seemed to be alright but the GP thought that I should see the chest doctor and she thought seeing I coughed up the blood to make absolutely sure there was nothing wrong she wanted me to have some more tests and then a few days later she told me the bad news that she'd found a tumour in me lungs and now I'm just anxious cos I'm waiting for them to tell me when I can go in for the operation.

The existence of a symptomatic experience necessitates interpretation, even if that interpretation renders it unproblematic and does not position presentation for medical advice as warranted. If an experience is interpreted as a cause for concern and presented for medical advice, the subsequent diagnosis can act as a template which can be drawn on to account for the symptomatic experience on all further occasions. In light of this, repeated medical consultation is often not required. When an additional experience develops and is not interpreted as congruent with the understanding of the original diagnosis, presentation for medical advice becomes available – 'my make up in me is not like that'.

4.3.6 'It was obvious that something had to come up'

About a year ago, maybe more, I started getting this real hacky cough and I had it a long, long time before I went to the doctors because it wasn't all the time, you know I'd just take a drop of cough mixture or something like that. Even when I was at the surgery I didn't think anything of it because everyone else seemed to have the same as me, I thought oh well I'm not the only one am I? Anyhow, the GP gave me antibiotics but quite a while went by and the coughing was still there and occasionally, not very often, I was bringing up a bit of blood, not a lot just a little bit. But I didn't think much of that cos the amount I was coughing it was obvious that something had to come up. Well so cos the coughing was still there I went and saw the GP and they gave me another course of antibiotics and some steroids but the cough kept on and to me it seemed to have got worse and so I went back again and this time they sent me for an x-ray.

When they done the x-ray, you know you have an ordinary chest x-ray she called me in again could I have a sideways view? I thought 'ello I don't like the idea of this and then it's from then that they've said I've got cancer. I mean I knew that something was wrong but I didn't think it was a cancer, you know, I mean I've always tried to help people where it's possible to help so why do I keep getting all these bloody illnesses?

The interpretation of a symptomatic experience influences the subsequent management sequence and the use of cough medicines or similar preparations becomes an appropriate course of action. Additional symptomatic experiences may not lead to a revised interpretation of cause if it is congruent with the expectations surrounding the original interpretation – 'it was obvious that something had to come up'. In this situation, the experience is not considered to require the seeking of medical advice and may not be communicated to a health professional once consultations are in place.

4.3.7 'I thought it was coming back the same'

About every year I get a cold and it goes straight to my chest. Two years ago I had to send for the doctor because I couldn't get my breath and she brought a nebuliser out here for me to use and after about a week I got over it okay. This year, 'bout January time, I couldn't breathe properly and I kept bringing stuff up but not very much but I just couldn't get my breath and it left me with a pain in the back. So after about three days I sent for her to come up, you know, which wasn't very long because of the experience I had two years ago I thought it was coming back the same.

She gave me antibiotics, I can't remember now whether I had two courses or just the one, but this time it just didn't clear up so good. I do remember one time I said to her when it was so painful I said I do worry about my chest because my father died of TB and my two brothers died of lung cancer and she didn't pass any comment and I forgot all about it then next time I knew she sent me for an x-ray.

I went up there to have this x-ray done, and they put me on the scales and that's when I realised that I'd lost nearly a stone but you know I hadn't realised it before that. But then I went home and I forgot all about the x-ray because I wasn't worried about it you see, you know I didn't think anything really was wrong because I felt better but then she phoned me up and said I'd like you to go for a scan she said they'd found something and after that they told me that I had a serious cancer but you know I don't look at myself as ill at all, I'm no different now to what I was a year ago it seems to me, or two years ago.

Previous symptomatic experiences and sanctioned biomedical diagnoses facilitates interpretation and influences the management sequence when faced with a similar experience – 'I thought it was coming back the same'. Perceptions of personal risk and candidacy can influence interpretations and decisions to present for medical advice, and may also influence the decisions made by the health professionals. Whilst some symptomatic experiences are perceived and interpreted, others are not and only come to light at a later stage, for example when medical investigations have been initiated.

4.3.8 'I've had problems with me chest all me life'

Last year I seemed to go about three chest infections in a period of about nine months and each time I was prescribed antibiotics and steroids and it cleared up then this particular bout started off just after Christmas, constant chest infections, couldn't get rid of 'em. I mean I've had problems with me chest all me life ever since I was a little boy um every, not so much this time of year but especially round like Christmas time I'll always get chest infections or have breathing problems, it's a chest weakness really.

And this time then I was wheezy, getting short of breath, coughing all the time, sometimes coughing uncontrollably so me family would have to come and bang me on the back really hard to be able to get me breath back. I was being seen by my own family doctor and I was being filled up with antibiotics nothing much was happening. In about February I coughed up and you could just see a trace of blood in there and I thought oh crumbs and then I thought I better go and see

the doctor about this and then I thought nah it's only once. This went on, though I never coughed up no more blood, and then I'd walk over the shops or somein like that and as I was walking it'd feel like me lungs were filling up so that by the time I got over the shop I couldn't hardly breathe.
That was a new thing that I hadn't experienced before and without a doubt it was that which made me wanna go to my doctor and I said you know enough's enough you know I've gotta get rid of this chest infection and she sent me for an x-ray and the following day she called me back in and said they'd found a mass on me lung. So that's where I'm at now.
Composite

Though a particular symptomatic experience may occur and be consistently interpreted as relating to a disease process, for example a chest infection, it is not automatically viewed as a cause for concern. Expectations as to vulnerability to ill health can influence individuals to interpret particular symptomatic experiences as being within their personal range of normality – 'I've had problems with me chest all me life'. The perceptions of normality can be disrupted by the experience of a new symptomatic experience but this is not necessarily the case, particularly if an event happens on just one occasion.

4.3.9 'I'd never had anything like this pain before 'cept...'

It was about three months ago now that I got this pain, Saturday morning this was, and by Monday I was a bit worse like you know so I went straight over to my GP. You see I'd never had anything like this pain before 'cept when I broke a couple of ribs in me back a couple of years ago but the doctor she thought it was probably muscular and told me to take co-codamol and to go back in a month if it hadn't got better.
As time went by the pain was getting worse and worse and near the end of the month I thought well it should've eased off a bit by now like and so I went back and seen her, you know I just got thinking there's got to be something more than what the doctor said like.
When I went back this time I saw another GP and they asked what the first doctor had said and so I told them and they thought I ought to go for a chest x-ray and it's all come about from there. But what I can't understand is that at the chest clinic they told me that there'd been something on my chest x-ray I'd had done in 1995 but if they had told me that in 1995 I'd have packed up smoking in 95 I know I would.

Previous experience of a symptomatic experience can facilitate interpretation and the subsequent management sequence – 'I'd never had anything like this pain before 'cept...'. The health professionals may not hold the same interpretation as the participants and there can be a sense that an individual has to fight hard to secure a diagnosis which can account for their experience.

4.3.10 'In fact the pain went away'

I s'pose I sort of have a history of having a bad back and I also for the previous two years I s'pose I've been having what I thought was sort of you know trapped nerves, frozen shoulder basically um 'ticularly when I was doing sort of physical things, pulling boats in and out and that sort of thing and whenever it caught me I'd just take a painkiller or something.

Then, nearly a year ago now, I started having chest pains and I felt it was that, the frozen shoulder, to start with really it was sort of up in the shoulder. And, you know, I do aqua classes each week at the gym and that means a lot of moving about and I thought maybe I'd hurt myself doing that but then as it got worse it sort of also was in the front bit of the chest. The pain was waking me up at night which was boring if nothing else and so I wanted to have some form of painkiller that would sort of see me through the night and so I went along to my doctor.

It's going back a bit now but I think she probably gave me some painkillers and then when it persisted she said come on let's have an x-ray but the result seemed okay and in fact the pain went away during the summer then towards the end of the year I started getting the same chest pains and I went to my GP who said they thought I ought to have another chest x-ray and that came back and showed up that there definitely was a cancer there.

Composite

The symptomatic experiences associated with the development of lung cancer are complex whilst at the same time associated with a range of differential diagnoses. The context in which the experience is recognised furnishes a range of interpretations which can be drawn on to account for it. Indeed, it may be the impact on the life of the individual which draws the existence of the symptomatic experience into consciousness. When a particular experience changes or becomes more severe the interpretation may shift to account for it but if that experience ends – 'in fact the pain went away' – the concern for underlying disease processes also ends. The existence of disease is associated with the existence of symptomatic experiences.

4.3.11 'I thought that she would maybe give me some nerve tablets'

About three or four months ago, yes that's right just as the New Year began, I started to lose my voice. It was weird, it just wasn't as good as it was before, all croaky and I had to put a lot of air behind it to give it any sort of volume. My husband kept saying to me 'is it sore' but it, there was no pain, no soreness and I could swallow perfectly alright. I let it go on for a couple of weeks swallowing throat tablets but they didn't clear it up. Then I started to think that because I was under such a great deal of stress maybe it was another sign of that so I went round to my GP.

I thought that she would maybe give me some nerve tablets or something but the first one I saw thought it might be reflux that had burned the back of me

throat so she give me indigestion tablets and away I went. Then when that didn't get any better I went back and saw another GP and she thought it might be good to sign me off work and at first I had one week off and it did seem a little bit better cos I was more relaxed and I was at home and because I'd started to feel better she said we'll give it another go so I had another week off. By the end of the second week I was no better so she referred me to ENT and they did some tests and it was them who diagnosed what I got.
Composite

Individuals attempt to make sense out of a particular symptomatic experience by associating it with other events. That an individual has a change of voice but not a sore throat creates difficulties for interpretation for the change of voice cannot be attributed to the sore throat. The symptomatic experience is associated with alternative interpretations and these render particular courses of action and outcome available – 'I thought that she would maybe give me some nerve tablets'.

4.3.12 'But then again I did wonder why?'

It was about three or four months ago that I noticed that my trousers were a bit large, you know they didn't fit as well. We don't have any scales in the house but my daughter-in-law does and the next time I was round there I stepped on them. I got a bit of a surprise cos I've been on the ten stone mark for as long as I can remember and on that day I was nine. I had been suffering from a bit of constipation at the time and I thought oh it's probably because I'm constipated I'm not eating so much that I've lost the weight. I mentioned it to the family and they said that I ought to go and see the GP and I wasn't so sure but then again I did wonder why you know cos I have lost the weight, why have I lost the weight?
He said that as I was a smoker and had lost weight that I'd need to have a chest x-ray which I had and a week later he phoned me up and said there was an abnormality there and when they say that you sort of think let's hope I've had bronchitis in the past and it's a scar on it and, anything but cancer. But the tests revealed that yes it is cancer, lung cancer. I mean I smoke, or at least I did, when you smoke you know that you can get cancer but you never think it's gonna happen to you.

A certain level of variation in weight is expected and not considered a cause for concern, rather it can be interpreted as related to diet, for example. But there is a point at which such an experience can transcend the boundaries of what is normal and becomes worrisome and potentially linked to underlying disease – 'but then again I did wonder why?'. Interpretations of abnormality and disease can be reinforced by others who notice and comment on the situation, positioning presentation for medical advice as a legitimate course of action. Once investigations are initiated, the individual can identify a number of potential self-diagnoses to account for their experiences and the continued interest of the medical profession.

4.4 Responding to the first research question

The existing literature made it difficult for me to know what the experience of developing and being diagnosed with lung cancer could be like. This led me to my first unanswered/research question. On one level, the process of generating the illness narratives allowed me to come to know the experience but I also wanted to develop my understanding and to make the experiences available to others who may not have the opportunity to know through my analytic approach. Much of the existing literature which has sought to explore the experience of illness conducts thematic analysis of the data. The implication of this is that it is often not possible for the reader to know what the repercussions of a particular situation or event may be for a particular individual. Indeed, the nature of thematic analysis means that an experience is often presented as static and there is little sense of an individual's experience changing over time. But experience does change and this is no less the case for the experience of developing and being diagnosed with lung cancer.

I viewed narrative analysis (Polkinghorne 1995) as a way of facilitating my understanding and of making the unfolding nature of the experience a central feature. My theoretical interest led me to develop twelve narrative case studies, each constructed around a particular symptomatic experience but reflecting the range of ways in which they were interpreted and the different management sequences prompted. In this, I highlighted the complexity and the variation associated with the experience of developing and being diagnosed with lung cancer[99].

Corner *et al* (2006) report that the participants in their study largely did not interpret the symptomatic experiences associated with lung cancer as indicative of ill health or as a warrant for medical attention. Often the experiences were attributed to ageing and were seen as a normal part of everyday life. Certainly, some of the participants within this study interpreted their symptomatic experience as part of normal life and as unrelated to ill health. But there were also many individuals who did interpret their experience as

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[99] This, particularly the variation, was only at the level of actual interpretation and response. Beyond this there was a great deal of similarity across the illness narratives and the narrative case studies as individuals consistently experienced difficultly in interpreting the significance of their symptomatic experiences.

related to disease processes, though this often fell within the category of 'normal' illness (Cornwell 1984). Interpretations relating the experiences to 'real' (Cornwell 1984) types of illness were also evoked but only a minority of the individuals interpreted their experience as related to lung cancer prior to presenting for medical advice[100]. Though I believe that it is useful to know how the symptomatic experiences associated with lung cancer can be interpreted, to talk of them in this way is to imply that they were static. But interpretations did shift as the individual's experience changed and this is clear when one reads the narrative case studies. In this way, each of the narrative case studies is a response to the question of 'what is the experience of developing and being diagnosed with lung cancer?'

4.5 Chapter summary

In this chapter I have presented my analytic approach to the narratives of personal experience whereby I developed narrative case studies in a process of narrative analysis (Polkinghorne 1995). I presented the twelve narrative case studies, each followed by a short commentary. I ended this chapter by suggesting that each of the narrative case studies is a response to the first research question.

4.5.1 Key points to take away from this chapter

I have suggested that

- the experience of developing and being diagnosed with lung cancer is complex and variable
- at the most basic level, individuals experience different symptomatic experiences
- the interpretation of the symptomatic experiences and the subsequent management sequence varies between individuals but also, the narratives highlight, within the same individual over time
- seldom do individuals interpret their symptomatic experience as related to lung cancer

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[100] I explore this further in chapter 6.

5 Exploring the narratives of genesis

5.1 Introduction to the chapter

In this chapter I present my analytic approach to the narratives of genesis – the narratives of how and why lung cancer develops. In contrast to the narratives of personal experience, my approach to the narratives of genesis was in line with a categorisation and separation approach. I drew on Bal's (1985) elements (events, actors, time and location) to structure the search which I present followed by a brief summary.

5.2 Addressing the second research question – Specifically, why do individuals not seem to interpret their experience as related to lung cancer?

The distinction within the illness narratives between the narratives of personal experience and the narratives of genesis seemed to me, at the time, to be an obvious one. Furthermore, I thought that each of the distinctions could make a contribution to the addressing of a different research question and specifically that through exploring the narratives of genesis I would be in a position to suggest why individuals did not realise the significance of their experience and did not interpret it as related to lung cancer[101].

5.2.1 'Analysis of narrative'

Rather than synthesise the data as I had done for the narratives of personal experience, I felt that there was much to be gained from extracting the content of the narratives of genesis. I felt comfortable with this approach as the narratives of genesis did not construct or communicate experience in the way that the narratives of personal experience did. Instead, the narratives had an explanatory bias; they sought to account for how and why the disease had developed. It was this that I felt to be significant for

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[101] This is something which I explore further in the following chapter.

my understanding of why individuals did or did not consider that their experiences might be associated with lung cancer. Was there anything about their ideas of how and why lung cancer develops that led them away from interpreting their experience as related to the disease? This was the theoretical position driving the exploration of the narrative data and in adopting it I was influenced by the existing literature around the notions of perceived personal risk and disease candidacy (Davison *et al* 1991; Ruston *et al* 1998; Martin *et al* 2004) and the literature which suggests that older women do not perceive themselves to be at risk of developing breast cancer (see Grunfeld *et al* 2002).

In reducing and distilling the narrative data I did what Polkinghorne (1995) would refer to as 'analysis of narrative'. Polkinghorne (1995) writes that

> 'analysis of narrative seeks to locate common themes or conceptual manifestations among the stories collected as data ...The researcher inspects the different stories to discover which notions appear across them' (p13).

He suggests that there are two mechanisms for searching the narratives. In the first, theoretical categories and notions are brought from outside the data and the researcher seeks to determine if these pre-existing possibilities are found within the narratives. In the second, the researcher approaches the narrative with no pre-existing categories and notions and so draws heavily on an inductive process to derive concepts from the data (Polkinghorne 1995). My approach to the analysis of the narratives of genesis was a combination of the two mechanisms: I used Bal's (1985) elemental distinctions to structure the search but I derived the substance of the search from the narrative data. Bal's (1985) distinctions are events, actors, time and location and she describes them as the elements of the fabula, the deep structure within the narrative. Bal (1985) proposes that her theory of narrative, resting as it does on a distinction between text, story and fabula, can facilitate the description of a narrative text. Furthermore, the 'textual description that results provides the bases for an eventual interpretation' though the interpretation 'is never anything more than a proposal' (Bal 1985, p10).

I found the air of tentativeness with which Bal (1985) writes engaging and I believed it to be congruent with my theoretical position within the interpretive paradigm. To illustrate, in the initial pages of her book she writes:

> 'Conceived as a set of tools, as a means to express and specify one's interpretative reactions to a text, the theory presented here *holds no claims to certainty*' (Bal 1985, px, my emphasis).

It was as a set of tools that I drew on Bal's (1985) formulation. I viewed it as a heuristic device, a way of accessing the narratives and of presenting their content. Bal's (1985) terminology facilitated the search of the narratives of genesis because it provided a framework. I made the link between the framework and the actual analytic process through the following questions:

Events:

- What mechanisms do the narratives of genesis offer for how and why lung cancer (and cancer in general) develops?
- How might the mechanisms for developing lung cancer influence the interpretation of the symptomatic experiences associated with the disease?

Actors:

- What actors feature in the narratives of genesis?
- How might the actors, and their characteristics, influence the interpretation of the symptomatic experiences associated with the lung cancer?

Time:

- How does time feature in the narratives of genesis?
- How might explicit references to time influence the interpretation of the symptomatic experiences associated with lung cancer?

Location:

- What locations feature in the narratives of genesis?
- How might location influence the interpretation of the symptomatic experiences associated with lung cancer?

5.3 Presenting the exploration

5.3.1 Events

The topics of smoking and tobacco exposure were often referred to in relation to how and why lung cancer develops, reflecting awareness of the reported association between exposure and the disease. Often the topic was raised by participants without it being in response to a direct question. At times, the raising of the issue created tension and I sensed a feeling of defensiveness since the reported association suggests that individuals with lung cancer may be responsible for their diseased status. Such a situation is illustrated in the following excerpt.

P: (at the end of a turn of talk) if I could cough up my lung now I'd be more than happy to give it to you you know. It's, it really is that bad at that time wasn't it?
W: it was that was yeah. But no [touch wood there's
P: it's all] I knew it, you know, as soon as you start, getting a little bit shall we say down. No, but it didn't last. And yes I did used to smoke but you're tal-, talking about many, many years ago. I haven't smoked for years (110)

In one notable interview, the issue of smoking was raised by the participant's wife. This was potentially problematic for the participant since he had spent a significant part of the interview offering reasons for why he had developed lung cancer, going back as far as to his time in the Second World War. In this talk the individual had not once mentioned smoking or that he had smoked. As illustrated in the following excerpt, he was able to present the role of tobacco exposure in the development of his disease in such a way as to dispel any suggestion that he was responsible for his status as an individual with lung cancer.

P: (at the end of an extended turn of talk) but **how** the lung problem **developed**, I haven't the faintest idea. I mean I, I, as I said I did a lot of exercise. I was able to take **normal** breaths. I was never **restricted** by my breathing, and. Now did I have any other problem with, with?
W: well you never smoked did you from, for the last
P: no, I, I tell you
W: since after the war then he wasn't a heavy smoker
P: no th-, the only other thing that **may** have had some bearing on it, um. I used to have to attend a lot of meetings at work. In conference rooms some of them were very large rooms, one or two were quite small and in those days of course people were still allowed to **smoke** and it used to be **choking** in at times in these, at these conferences and I, I uh, I may have taken in a lot of smoke, passive smoking that sort of thing but, I can't think of anything else (113)

That the participant had smoked or was a smoker was presented as having led participants to suspect that they might be suffering from cancer once further investigations had been initiated, as illustrated in the following excerpt.

I: and, once you had, once you'd been to your GP and she sent you for [a chest x-ray
P: an x-ray] yeah
I: what happened after that?
P: (3 second pause) in respect of what?
I: (2 second pause) what, how did you?
P: how did I feel?
I: yeah, how did you feel, yeah

P: I had a feeling it was going to be cancer
I: did you?
P: yeah
I: do you know why that was?
P: don't know just one of those things in it
I: hm
P: heavy smoker (106)

This excerpt continued in a way that was a feature of a number of the interviews; those also present raised alternative suggestions for how and why lung cancer develops.

W: it's in the family
P: in the family. **That don't count** so they say but, you know just, just thought it w-was somehow (106)

The introduction of hereditary/genetic factors in the development of the participant's lung cancer was a natural one for his wife to make since both his mother and father had died of lung cancer. However it seems as though the familial situation did not lead the participant to interpret his experience of a cough as related to lung cancer prior to presenting for medical advice. The participant had perceived himself to be a candidate for an alternative disease type, as illustrated in the following excerpt.

I: if you could just try and think a bit more generally about did you know any of the, any of the symptoms that are related to the disease or the type of person that develops the disease or any risk factors or anything like that?
P: no, not really no. I mean if anything I was more concerned about getting um, uh, what-do-you-call-it arteries (106)

Other notable[102] examples of significant others introducing alternative factors occurred, such as in the following excerpt.

W: (in the middle of a long turn of talk about smoking, 2nd layer of illness narrative) but every doctor that we've talked to has said to him, 'have you been working around asbestos?' Yeah. Ask me if I've been round asbestos? Oh yes (101)

After the participant's wife had finished talking about asbestos, I validated it as an important concern.

I: It's a major issue isn't it, the asbestos?
P: hm

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[102] I consider the occasions notable because of the way that the suggestions were made and because of the influence on the direction of the narratives of genesis.

W: so, yeah I think, half the people or three quarter of the families that worked in this town that worked down the dock, their families have got it. So what do you do?
P: I was in the navy many years, every ship is full of asbestos (101)

This was the first time that participant 101 had suggested a role for any factors other than exposure to tobacco smoke in his narratives of genesis, and it serves to illustrate the impact that other people can have on the content of the generated narrative. Aetiological factors relating to occupational exposure were often introduced to account for the development of lung cancer. The following excerpt is another example of an occasion when both myself and the participant's wife influenced the narrative and offered alternative ways to tell the narrative of genesis.

P: all smokers?
I: um, so far everybody has been but it's varied. Some people gave up you know as soon as they found out. Some people like last year, some people, multiple years ago.
P: yeah
I: and a lot of people like yourself working in industry that might have had something to do with it as well. It's so, there's so many things we don't know
P: as I say with, with the pipe it was, virtually a comfort blanket
W: you sucked it more than you smoked [it
P: yeah]
W: didn't you?
P: it was just, there, no, it was just luck of the draw
W: born in you
P: eh?
W: born in you (111)

Whilst the majority of the participants implicitly or explicitly acknowledged that exposure to tobacco smoke can be associated with the development of cancer, the inclusion of other factors presented the development of lung cancer as a complex and contentious issue. Drawing on interview data generated with 23 individuals diagnosed with advanced non-small cell lung cancer, Salander (2007) comments that the

> 'causal relationship between smoking and cancer is a statistical fact, but it is not a fact when transferred to the individual case. Lung cancer patients take advantage of this truth by disregarding their own responsibility for contracting an illness' (p591).

Though I agree that the association between lung cancer and tobacco exposure occurs on a population, rather than an individual level, I do not feel that the participants were taking 'advantage' when presenting a range of potential aetiological factors as much as reflecting the current state of knowledge, both their personal knowledge and that of 'experts'.

5.3.2 Actors

The complex and contentious issue surrounding the development of lung cancer, and of cancer more generally, was reinforced with the use of actors. Many of the narratives of genesis incorporated actors as a means of questioning the asserted causal relationship between smoking and cancer. Drawing on lay epidemiological (Davison *et al* 1991) principles participants talked of individuals who had died young or of respiratory disease but who had never smoked and of individuals who had smoked all of their lives but had lived for many years without suffering (serious) ill health. To illustrate, the preceding interview excerpt continued in the following way.

P: yeah
W: wonder if it is, that'd be interesting (laughs) **well it's supposed to be isn't it**, it's supposed to be some. You're supposed to everybody's supposed to have a cancer, somewhere, and it's just something that triggers it off
P: the thing that amazes me is. That they take so much **trouble** over us old ones. **No it really does**
I: does it?
W: some, you know somebody your age, **yes**.
P: we're living on borrowed time. Anyhow
W: you've had your three score years and ten haven't you (laughs)
P: yeah well you haven't
W: this is true, not quite
P: I have (4 second pause). And yet there's old (name) a mate of mine he's eighty
W: he still smokes like a chimney
P: still smokes like a ruddy chimney (laughs)
W: he's nearly **ninety**
P: yeah nearly **ninety**
I: [oh gosh
W: nearly ninety] he's ten years older than you
P: yeah
W: **still**
P: yeah
W: yes you went out to see him the other day and he lost his hearing aid
P: oh god
W: and it was awful (laughs) 'so you're seeing your daughter?' 'yes that's right thank you' (laughs) right
P: um, few years back he had, chest pains his doctor says to him 'well, you'd better give up smoking' so he gave up smoking. Three or four months after he went back to the doctor he said 'I don't know what you've done' he says 'but it's gone'. Continued smoking (laughs) carried on smoking, still smoking. Ah it's lu- luck of the draw (111)

The old man who smoked 'like a ruddy chimney' and yet was still alive at nearly ninety years old, was used to illustrate the complexity of cancer development and implicitly to question the association between smoking and cancer. In these extracts, the participant drew upon the turn of phrase 'luck of the draw' on two occasions. The first time that I encountered this phrase in an illness narrative was during the interview with the third participant. She drew upon it in the same context as participant 111 had, as illustrated in the following excerpt.

P: (at end of a turn of talk about stopping smoking, 2nd layer of illness narrative) it's not a good thing to be a smoker is it, not really? But I stopped smoking so easily
I: did you?
P: I don't know. I can't explain it any more than that I just think I'd made up my mind come what may that cigarettes was not going to **get me** in the end and I'm still fighting the things aren't I? Even though I stopped all these years ago. But, I don't know Jodie, do you **think** that it could have been connected with smoking? Cos some people don't even smoke and they get cancers don't they?
I: um, I wouldn't really like to say but it's very true what you say that, that people who have never smoked do get lung cancer and people that do smoke may never develop [the disease
P: exactly]
I: so I mean I can't say but
P: it's the luck of the draw hm, cos there was a dear little man in the next bed to me in (town) hospital when I had this, brontoscope? I know I'm pronouncing this wrong (laughs)
I: I think it's bronchoscope but I know what you mean
P: anyhow um, he said he had two shadows on **both** lungs and he said he'd **never ever** in the whole of his life touched a cigarette. It's just weird really (103)

Within these, and other, interview excerpts the development of lung cancer was presented as the 'luck of the draw'. I was fascinated by the use of this phrase as a way of reconciling the tensions between the participant's understanding of disease, the experience of others and their own experience. Indeed, as Hardey (1998) writes,

> ''Fate' or 'luck' may provide an adequate explanation for observations about ill health that appear to contradict official or scientific evidence' (p38).

Whilst the understanding that the development of lung cancer is associated with (bad) luck was presented by individuals who had been diagnosed with lung cancer, the experiences of others may have influenced their own perception of personal risk of the disease prior to diagnosis. As Bury (2001) writes,

> 'stories of individuals within the family or community who live high-risk lives and are clearly 'candidates' for the disease, but who do not succumb, abound, and provide lay correctives to mechanistic views of risk' (p271).

A compelling excerpt of narrative relating to the complexity of perceived personal risk follows, generated in an interview with participant 115. It illustrates the triad of positions implicit in much of the talk around the development of cancer and of lung cancer; everything causes cancer, no one knows what causes cancer and what we think causes cancer does not always cause cancer (see also Balshem 1991). A number of actors feature in the excerpt including family members and medical professionals.

I: and you said that you had your suspicions?
P: well, because it's in the f-, my father died of lung cancer and it's always been, you know I wonder if I'm going to turn out, is it, is **me** or my brother gonna get it. You know because most, well they do say cancer's in the family don't they? So, I'm just trying to make my daughter pack up smoking, my oldest, but I've had the odd fag because I know when I've, I've thought 'oohh shouldn't' I'm packing it up, you know obviously this, what's the point in smoking but I said to him 'I should never have smoked' and he said 'not necessarily it's there' I said but I did ask how long it had been there and the one down (hospital) reckoned like a **month** but it's most probably always been there but lay dormant maybe where I've passed out and fell on my back, juggled it? (115)

Participant 115 did not find it problematic to present multiple aetiological factors and positioned roles for genetics and tobacco exposure in the first part of the excerpt. The response of the doctor who suggested[103] that her disease had only been present for a month led her to propose an alternative factor, since she considered genetics and tobacco exposure to operate over an extended period of time. The participant searched her biography for a situation which could account for why she had lung cancer in light of this new information and a recent fall was employed to make the link. Genetics, tobacco smoke exposure and dormancy all represent a particular take on the initiation and development of disease and it has been commented that

> 'Most people appear to be quite capable of holding a number of apparently contradictory general theories of causation at the same time which are brought forward in various combinations depending on the situation and the nature of the question asked' (Pill and Stott 1985, p983).

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[103] Salander (2007) has also noted the role of the medical professional in questioning the asserted relationship between an individual's smoking history/status and their diagnosis of lung cancer.

As well as the incorporation of actors such as family members and medical professionals, an actor who was present in all of the narratives was the participant as the actor-narrator. A feature of narrative, even first person narratives, is that the narrator or teller of the story is distinct from the actor in the story even if they are the same person (Bal 1985; Finnegan 1998). One of the aspects of the actor-narrator that was often referred to was smoking status and level of smoking. When an individual was a current or former smoker, much of the time the actor-narrator was presented as a 'good class of smoker'. Part of being a good class of smoker related to being a healthy smoker, being a responsible smoker, and not being a heavy smoker as illustrated in the following excerpt.

I: how, how many did you used to smoke a day, can you remember?
P: well if I had a heav-, heavy day I'd smoke twelve. I used to buy twenty packet, and, yes, habitually that would do two days, so ten a day so I didn't count myself as heavy smoking but thinking **now**, money wise, I'm glad I stopped cos now they're over five **pound** a pack (107)

Only two participants chose not to present themselves in a qualified light.

I: no, no (6 second pause) and you mentioned about um, going to see your practice nurse for the spirometry test
P: yeah
I: the Thursday before then, can you rem-, can you tell me a bit more about that and how that came about an-?
P: **well basically because I was**, you know I mean **I was a heavy smoker**, I was fifty a day, forty, fifty a day (118)

I: hm (3 second pause) have you given any thought to what caused it to develop?
P: phwor I could smoke for England
H: smoke, used to smoke like mad
P: I could smoke for England. If I wasn't working I was smoking wan I? (121)

The significance attached to smoking history and smoking status, and particularly to the amount of tobacco exposure, is illustrated in the following excerpt.

P: and then on and off through life I've given it up for huge periods of time and then gone back to it um. I didn't smoke when I was expecting the children, gave up for a long period of time, started it again when they told me I had (type of cancer) funnily enough
I: did you?
P: yeah and um, but never a heavy smoker, my husband would agree and I said to doctor (name) it's always been, five or under because also the asthma wouldn't allow me to smoke too many so I just had, you know, if we went out socially I'd have a couple so and **now** I've only been smoking now only **again** since I was diagnosed

(indistinct) it's done for me anyway so I might as well have one so um, but yeah. If I was a sixty a day smoker I would have expected this do you know what I mean um, but because I've gone long periods of time, as I say ten years sometimes (124)

The participant at the centre of this excerpt presented herself as a light rather than a heavy smoker but potentially more significant, she suggested that she would have expected to develop lung cancer if she 'was a sixty a day smoker'. The excerpt which follows also illustrates the significance attached to the level of smoking.

P: (towards end of turn of talk) do you want to know um Jodie how I think this was brought to light? How, you know cos I don't, apart from coughing up the blood I would never of **known** I had cancer of the lungs you know. Do you want to know how I think it happened?
I: yep, I'm interested in [anything
P: really]
I: yeah
P: I think I might have told you this last week but you mean you couldn't write it down. Um, yes I **smoked** but eight years ago but I was **never** a heavy smoker **ever**, you know I used to smoke maybe five a day, sometimes not even that so I was never a heavy smoker and I stopped **completely** eight years ago and I just **hate** the smell of it now. Uh, but I never ever thought I would hear anybody saying you've got lung cancer, I know it's probably a daft thing to say cos even five was probably wrong I don't know but anyhow (103)

Further on in the interview the following exchange occurred.

I: can you, are you able to tell me anything that you knew about this disease before all of this happened. Did you know, the sorts of symptoms somebody might have or the sort of person it affects or anything like that?
P: yeah I do you see **both** the people were heavy smokers though Jodie (103)

That both of the individuals known to the participant and had developed lung cancer were not just smokers but heavy smokers positioned the disease as one of current, heavy smokers prior to the participant's own personal experience with the disease. After her diagnosis of lung cancer the participant drew upon the notion of 'luck of the draw', as discussed in the previous section, as a mechanism for accounting for her situation, and that of the person she had met in the hospital, in light of her pre-existing understanding that she was not a candidate for the disease.

An additional aspect of the actor-narrator which was referred to by one participant was age, as illustrated in the following excerpt.

I: and did you know anything about, I mean you mentioned about people that you've known that have had it. Did you know anything about this particular type of cancer, that happens in the lungs?
P: um, no. Didn't thi-, didn't even suspect it. I knew I'd get it eventually but not this early, you know in the late sixties, sixty five like that, retirement age (132)

The participant thought that he would develop lung cancer 'eventually' but not at his current age (he was in his mid fifties). In this participant's understanding, lung cancer was positioned as a disease of individuals older than himself.

5.3.3 Time

The concept of time was an implicit feature of the narratives of genesis, essentially because temporality is a feature of narrative. However, there were explicit referrals to time which tended to relate to the participant's smoking history. The first extract from participant 103 given previously points to the significance of time ('I stopped **completely** eight years ago') and the second extract presented towards the end of the previous section continued in the following way (once she had gone into more detail about the first of the two people known to her).

P: And then the other was this person I worked with but there again she was a real heavy smoker and **she** had this terrible cough as well. That's why you see I, I just thought 'no I haven't got lung cancer' I thought 'no they're saying it to somebody else it's not me' (laughs). You know and uh, but it does happen doesn't it? It doesn't just happen to other people. So I am going round and saying, not to people I don't know, but I say to them 'put that cigarette out' (laughs). But I don't know whether it. You see um, Mr (name) he, I think my husband said to him 'how long do you think my wife's **had** this?' and he said six months to a year. I can't quite grasp that cos it was years before that I **stopped** smoking **unless**, if you stop smoking it can still gradually **build up** in you. I, I'm not quite **sure** about that (103)

As with the participant's previous excerpts, her understanding of lung cancer was of a disease of current, heavy smokers such that those who no longer smoked were not in a position to develop the disease. Time featured in a similar way in the following extracts taken from two different points in the same interview.

I: yes. And I mean the diagnosis was it something that was, expected or was it a shock, how have you?
P: it was a shock really because uh, in my earlier days I had, I had smoked uh, but three years ago I had the x-ray and um, it was clear and my wife said to me you've, you've got it clear now, now stay clear so um, I stopped smoking

P: (towards end of talk about smoking) it was a social thing you know that uh, most of the people that I seemed to be having lunches or dinners with um, smoked to some extent and I s'pose stupidly I joined them (laughs). But no I never, I never really suffered from it and the thing is that when I had the x-ray three years ago nothing showed up so it wouldn't seem to have stemmed from that. Uh, so I was a bit puzzled really as to why it should have come **after** I'd given up (laughs) (117)

For these individuals, then, the length of time that they had not smoked for led them away from associating their symptomatic experience with lung cancer. Alternatively, the length of time that the participant had smoked for seemed to be a reason why the development of lung cancer was not unanticipated at the time of diagnosis. This is related to the discussion in section 5.3.1 whereby the diagnosis of lung cancer was considered once investigations had begun in view of the participant's smoking status/history. This is illustrated in the following excerpt.

I: how have you responded to the diagnosis if that's not too much of a strange question?
P: no that's a fair question I think. It's a thing, as I said I smoked for many years and anybody who denies they know the risks is fooling themselves (101)

5.3.4 Location

Location was seldom explicitly referred to within the narratives of genesis. When it did feature, it was usually in reference to physical location and in terms of the environment in which individuals were exposed to occupational pollutants, as illustrated by the following excerpt.

W: and then they told us that he had emphysema and asbestos plaque
P: asbestos plaque, so I've worked with asbestos you see
I: right
P: I worked in a workshop with wood and um, it was a dusty shop really so and we cut up asbestos on the saw ...in those early days I was, I was on caravan production and uh, for insulation we used to use a lot of fibreglass and in the workshop there was no, no um, mask or anything in those days the early post-war years and uh, on a sunny day when they, the operators were pulling the fibreglass in between the, the uh caravan inner and outer shell, you could see that it was a very dusty thing, and as the light shone through the workshop you could see **all**, the dust all glittering of the fibreglass, I mean we were breathing that in (104)

The descriptions of the physical locations were drawn upon to reinforce the credibility of occupational exposure as having a significant role to play in the development of lung cancer by several of the participants.

5.4 Summarising the exploration of the narratives of genesis

The ubiquity, and often the spontaneity, of the narratives of genesis within the illness narratives was a surprise to me. However, it should not have been since, as Price (1987) has commented, for an illness narrative to be coherent the narrator must address the issue of cause or genesis. All but one of the participants proposed ideas relating to how and why they had developed lung cancer thereby considering the genesis of the disease. At times explicit, and at others implicit, these narratives suggested who develops lung cancer; what such an individual would have to be like or to have done. For many of the participants, their understanding of lung cancer positioned it as developing in a certain way; to current, heavy smokers of a certain age with the notion of the luck of the draw featuring also. For some individuals, the diagnosis of lung cancer was suspected once investigations had been initiated because they considered themselves to be a heavy smoker. Similarly, the diagnosis was not a surprise for those who understood the development of the disease as related to smoking and considered that they had smoked for many years. But for other individuals, this understanding of lung cancer positioned the disease as unavailable to them, even once they had presented for medical advice and investigations had been initiated. Indeed, there was a suggestion that you cannot get lung cancer if you are not a current, heavy smoker or if you are young. I thought that this understanding of how and why lung cancer develops could be leading individuals away from interpreting their experience as related to the disease prior to presenting for medical advice. This is an understanding which I developed throughout the study and which I explore further in the following chapter.

5.5 Chapter summary

In this chapter I have presented my analytic approach to the narratives of genesis, an 'analysis of narrative' (Polkinghorne 1995) drawing on Bal's (1985) elemental terms: events, actors, time and location. Through this and in summarising the exploration I suggested that lung cancer was understood as a disease of current, heavy smokers of a certain age[104], though its development was also influenced by luck. This understanding of lung cancer ensured that, for some individuals, the diagnosis of the disease was not

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[104] I am cautious that this was only mentioned by one of the participants but it is important to recognise that the majority of the participants were several years older than this participant.

unexpected. But for others, this understanding ensured that lung cancer was not an option for them.

5.5.1 Key points to take away from this chapter

I have suggested that

- lung cancer is understood as developing in particular circumstances – genesis
- understandings of how and why lung cancer develops implicitly suggest who develops the disease
- lung cancer is understood as a disease of current, heavy smokers of a certain age, whilst at the same time its development is associated with the 'luck of the draw'

6 Developing understanding: Data and insight

6.1 Introduction to the chapter

In this chapter I try to give you, the reader, a sense of my journey through the data and my shifting understandings, thereby highlighting the tentative nature of all understandings. I continue to draw upon data from the illness narratives and explore the potential of narrative as an analytic frame for understanding the experience of developing and being diagnosed with lung cancer.

To begin, I present my initial understanding and response to the second research question, emphasising the significance of genesis and biography. This leads me to discuss the narrative structure of disease such that specific diseases are understood in terms of a beginning, a middle and an end. This narrative structure extends both forwards and backwards in time giving meaning to the past, the present and the future. Understanding disease in this way leads me to propose 'experiential emplotment', informed by Mattingly's (1994; 1998) concept of therapeutic emplotment, as a potentially useful way of conceptualising how individuals interpret their symptomatic experiences. In this conceptualisation, individuals draw upon storied meaning and actively and creatively emplot their experience into a narrative plot. The narrative plot brings meaning to their experience and provides a template for the future. I draw on excerpts from the illness narratives to illustrate the significance of storied meaning for interpretation and the management sequence. I introduce the narrative of lung cancer as a potential plot and identify the two participants who had interpreted their symptomatic experience as related to lung cancer prior to presenting for medical advice. That one of the participants was not able to sustain the interpretation that he may have lung cancer leads me to explore the illness narratives for the narrative of lung cancer beyond the issue of genesis and I present this exploration, again drawing upon Bal's (1985) elements of events, actors, time and location. In light of this exploration I present my revised response to the second research question and my revised understanding of the narrative structure of specific diseases.

6.2 The study so far

In chapters four and five I presented my analytic approach to the two components of the illness narratives generated with individuals recently diagnosed with lung cancer. One component was the narratives of personal experience and it was my expectation that through their analysis I could address the first research question. I approached the narratives of personal experience according to a 'narrative analysis' approach (Polkinghorne 1995). To this end, I developed twelve narrative case studies in an effort to retain a sense of experience over time and these drew attention to the complexity and variability of the experience. Different individuals developed different symptomatic experiences which were subsequently interpreted in different ways and, if brought to the attention of medical professionals, were interpreted differently further still. Within this variation, the majority of the participants did not interpret their experience as related to lung cancer and alternative interpretations which related the experience to normal life or normal illness were more readily evoked. It was in regards to this situation that I approached the narratives of genesis.

My approach to the narratives of genesis was in keeping with what Polkinghorne (1995) would refer to as 'analysis of narrative'. I used Bal's (1985) terminology of events, actors, time and location to structure the exploration and presentation of the narratives of how and why lung cancer develops. It was my expectation that through this I would be in a position to suggest an answer to the second research question and specifically to propose why individuals seem not to interpret their experience as related to lung cancer. It is to this which I shall now turn.

6.3 Responding to the second research question – initial understanding

The understanding of how and why lung cancer develops within the narratives of genesis outlined the mechanisms of genesis for the disease and implicitly implied who develops lung cancer. Indeed, the disease was principally positioned as one of current, heavy smokers of a certain age. My initial thoughts were that this understanding was leading many of the participants away from interpreting their experience as related to lung cancer since they did not see who they were, their biography, in their understanding of the disease's genesis. Biography in this regard is not synonymous with the dictionary definition[105], but with the work of Bury (1982) and Williams (1984). To quote Williams (1984)

> ''biography' connotes the indeterminate, reciprocal relationships between individuals and their settings or milieux and between those milieux and the history and society of which they are part' (p178).

I thought, then, that many of the individuals were not in a position to interpret their experience as related to lung cancer because, though they may have considered themselves to be experiencing the symptoms associated with the disease, their understanding of the disease's genesis did not reflect their biography. I have illustrated this proposal in Figure 2.

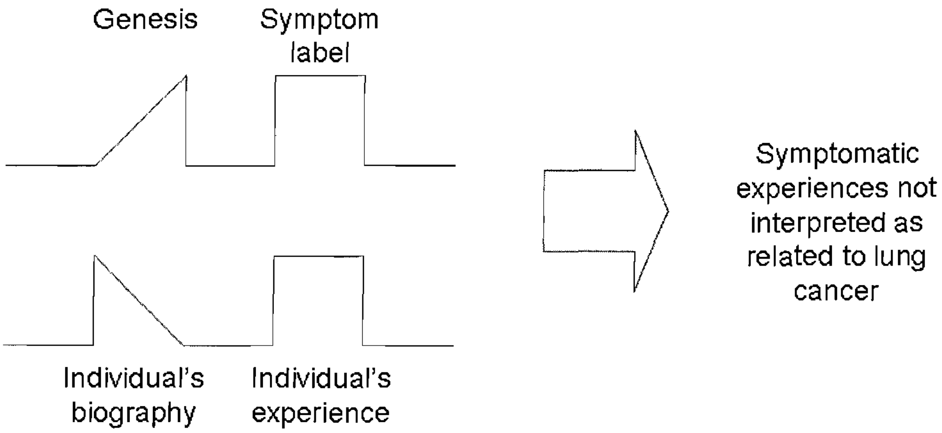

Figure 2: A schematic representation of my initial understanding of why individuals did not interpret their symptomatic experience as related to lung cancer.

The main components of the figure are the two lines. The bottom line represents the individual; their biography and their experience. The top line represents the understanding of lung cancer; its genesis and the symptom labels that it is associated with. In one part of the figure, the bottom line follows the path of the top line, but in the other part the shape of the bottom line does not correspond to that of the top line. This was my area of focus. Individuals could not interpret their symptomatic experiences as related to lung cancer if they could not see their biography in their understanding of the disease's genesis.

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[105] 'Biography': 'an account of a person's life written by someone else' (Oxford English Dictionary [OED] 2001)

Whilst the majority of the participants did not seem to interpret their experience as related to lung cancer, two of the participants had considered that their experience was caused by the disease prior to presenting for medical advice[106]. In addition, other participants suggested that they were anticipating the diagnosis once investigations had been initiated or were not surprised by the outcome of medical enquiry. Figure 3 illustrates my initial understanding of why this interpretation was available to these individuals.

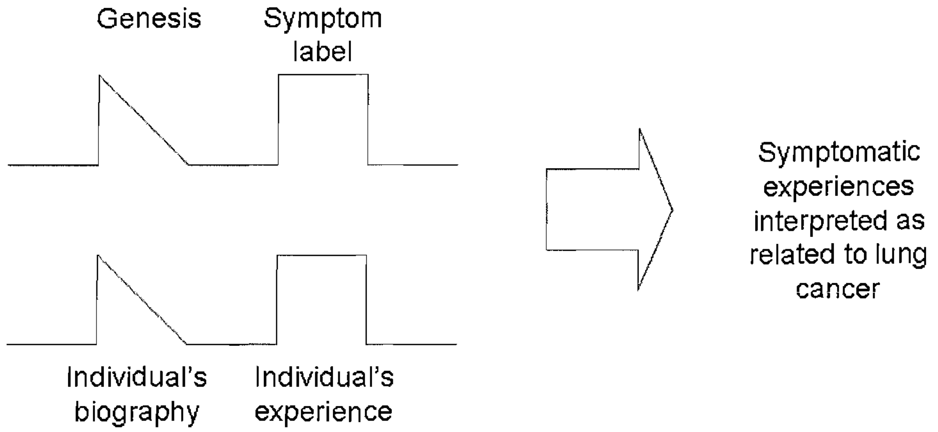

Figure 3: A schematic representation of my initial understanding of why individuals did interpret their symptomatic experience as related to lung cancer.

As with Figure 2, the main components of Figure 3 are the two lines, but in this instance the shape of the bottom line follows that of the top line. My initial understanding was that those individuals who had interpreted their experience as related to lung cancer were able to do so because they experienced the symptom labels that they associated with the disease *and* because their understanding of the disease's genesis was congruent with their biography.

6.4 The narrative structure of specific diseases – initial understanding

Through the issue of genesis, a specific disease is understood to develop in a particular way and in particular circumstances. In this, a specific disease is understood to have a particular beginning which introduces who will develop the disease, and equally significant, who will not. That a specific disease is understood to have a beginning, I wondered that it might also be understood to have a middle and an end and, in this way,

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[106] I explore this more fully in section 6.5.3.1.

take on a narrative structure[107]. Mogensen (1997) uses the term narrative structure in an anthropological discussion of why particular residents of Zambia, in the early part of the 1990s, associated AIDS with a local, pollution-initiated disease called *kahungo*. She writes:

> 'It is clearly not possible to classify either of the two diseases according to symptom, cause or treatment, and this is obviously not what people are trying to do either. Rather, they are juxtaposing disparate elements in a way which makes them contribute to a certain plot, a certain narrative structure' (Mogensen 1997, p435).

According to those living within the Zambian locality at the time of the study, the two diseases were related, even the same, because of their mechanism of genesis – they had the same beginning. Mogensen's (1997) discussion of the narrative structure of disease is limited and much remains implicit and theoretically driven, whilst I began to consider it to be of applied significance.

My understanding was that specific diseases, such as lung cancer, are understood in terms of a narrative structure which provides sequence and connection between distinct happenings. Though this understanding had been driven by my exploration of the illness narratives relating to lung cancer, my reflection on the way in which other diseases had been presented within the narratives and on my own experience of illness (see Appendix 3) permitted this generalisation to all types of specific disease. The beginning of the narrative structure refers to the issue of genesis and outlines who the disease will affect and under what circumstances, thereby introducing the actors of the disease's narrative. The middle of the narrative structure refers to the main action, the experience of the symptom labels associated with the disease and the next steps in the sequence in light of this experience. The end of the narrative structure refers to how the disease will end, for example in cure and recovery, chronicity, or death. This was my initial understanding and I have represented it in Figure 4.

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[107] As discussed in section 3.5.1, narrative is widely perceived to have a beginning, a middle and an end (Hyden 1997).

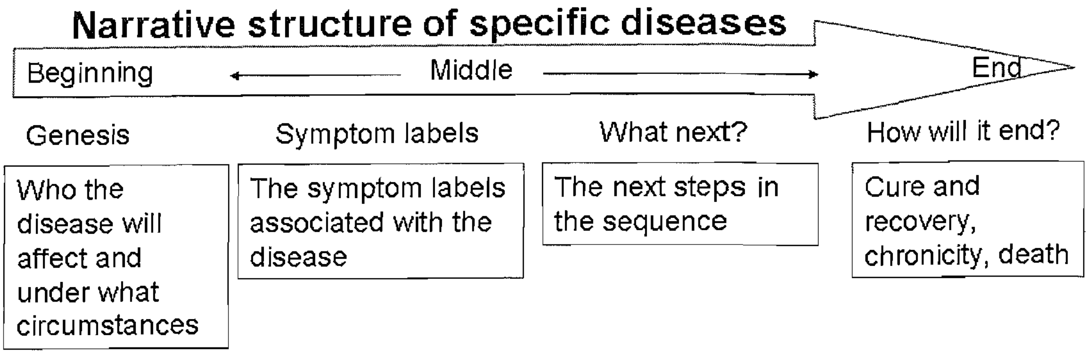

Figure 4: A schematic representation of my initial understanding of the narrative structure of specific diseases.

Conceptualising a specific disease as being understood in terms of a narrative structure and sequence is different to the existing formulations which emphasise categorical, rather than storied, meaning. Bishop and Converse (1986), for example, suggest that a specific disease is understood in terms of a prototype which is composed of a collection of categories. Similarly, the frameworks of Leventhal *et al* (1980) and Kleinman[108] (1980) focus much attention on categories and the content of categories, though the relationship between the categories is not explored and remains a-temporal. Leventhal *et al* (1980), for illustration, suggest that the representation of a threat to health is composed of categories: identity, consequences, causes and time line. In an actual experience, these categories are separated by time, a threat, for example, has to be caused before it has consequences, but there is no suggestion that temporality is important for understanding or for the representation. In suggesting that specific diseases are understood in terms of a beginning, a middle and an end emphasises temporality and whilst the components of the narrative are important, the sequence is also highly meaningful.

Conceptualising lung cancer in this way led me to situate the narrative structure of disease within a concept which proposes that storied meaning is significant for how individuals interpret and respond to symptomatic experiences. Significantly, I suggest that the interpretation of symptomatic experiences is driven by narrative and by the creation of narrative.

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[108] Kleinman (1980) writes of explanatory models which 'are the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process' (p105). Moreover, the explanatory models seek to address five key areas for each episode: aetiology, time and mode of onset of symptoms, pathophysiology, course of sickness and treatment.

6.5 'Experiential emplotment'

'Experiential emplotment' is a potentially useful way of conceptualising how individuals interpret and respond to symptomatic experiences. Within this concept, the emphasis is on making sense, indeed 'creating sense' (Mattingly 1994), out of an experience. The dictionary definition of experiential is 'having to do with experience' (OED 2001) whilst the term emplotment was first used by Northrop Frye, a literary critic, to describe four plot structures; romance, tragedy, comedy and satire (Mattingly 1994). Murray (1999) writes that

> 'Emplotment provides order and meaning to the previous chaotic flow of events. Emplotment is not a finished event but an ongoing process. As new information arises the plot is accordingly adjusted' (p48).

Good (1994) defines emplotment as 'the activity of a reader or a hearer of a story who engages imaginatively in making sense of the story' (p144) but it also relates to the creator of the story (see Good *et al* 1994). Drawing upon this, the main premise of experiential emplotment is that individuals draw upon storied meaning and actively 'story' or 'emplot' their symptomatic experience. In this way, the story of another time or of another person becomes their story. Furthermore, this emplotment is an active and creative process[109].

6.5.1 Exploring the origins of experiential emplotment

In developing the concept of experiential emplotment I was greatly influenced by Cheryl Mattingly and her work on 'therapeutic emplotment' (1994; 1998). Mattingly's context for therapeutic emplotment is the occupational therapy consultation in which therapists actively create sense out of clinical experiences through emplotting them into a story, often of recovery[110]. Whilst this context is different to that of an individual prior to the diagnosis of lung cancer, it is the significance of storied meaning and the aspect of ongoing emplotment which I found most appealing. Because of the influence, I feel it appropriate to quote Mattingly at some length.

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[109] By active I do not mean that the individual is necessarily conscious of the process, but I employ it as the antonym of passive, as in the process of passive detection (de Nooijer *et al* 2002). Interpreting an experience as related to a specific disease requires effort (conscious or otherwise), and the term 'creative' reflects that, for to create means to 'bring into existence, cause to happen' (OED 2001).

[110] The concept has also been explored within the oncology clinic (Good *et al* 1994).

> 'Narrative, I will argue in this book, not only functions as a form of talk; it also serves as an aesthetic and moral form underlying clinical action. That is, therapists and patients not only tell stories, sometimes they create story-like structures through their interactions. Furthermore, this effort at story-making, which I will refer to as *therapeutic emplotment*, is integral to the healing power of this practice' (Mattingly 1998, p2, emphasis in original).

In addition,

> 'The basic argument of this book, elaborated in the context of occupational therapy, is that narratives are not just about experiences. Experiences are, in a sense, about narratives. That is, narratives are not primarily after-the-fact imitations of the experiences they recount. Rather, the intimate connection between story and experience results from the structure of action itself. Many kinds of social actions (including many therapeutic interactions) are organized and shaped by actors so that they take on narrative form. Thus narrative and experience are bound in a homologous relationship, not merely a referential one' (Mattingly 1998, p19).

Envisaged in this way, the construction of narrative is not a retrospective endeavour needed to bring meaning and significance to events that otherwise would have no meaning or connection. Rather, experience can be constructed and communicated through narrative because, at the time it is experienced, it is guided by narrative. As Mattingly (1994) writes,

> 'We are motivated, as actors, to create stories whilst in the midst of acting. Locating ourselves within an intelligible story is essential to our sense that life is meaningful' (p812).

This is where the concept of therapeutic emplotment informs the concept of experiential emplotment. The symptomatic experience is actively and creatively emplotted into a narrative plot at the time that it is experienced, and not just retrospectively when the individual has the vantage point of an ending (see also Wikan 2000). The sequential and temporal features of narrative, this happened then this happened then this happened to this person, positions it is a valuable resource on which individuals can draw to create sense out of their own experience. Storied meaning within the social context furnishes a range of emplotments, disease and non-disease related, and the choice is influenced, indeed limited, by those visible and acceptable within the social context and by the biography and the experience of the individual (availability). For an individual to draw upon a narrative plot and emplot their experience into it, they must be able to see themselves in it so that it can then become their story. When an individual interprets their experience as related to a specific disease, it is because the narrative plot is visible and because they can see themselves in its narrative structure.

Within narrative theory, the social context is thought to limit the narratives which an individual can retrospectively create to bring meaning to their experience (Coffey and Atkinson 1996; Murray 1999, 2000; Lawler 2002). Whilst in experiential emplotment the creation of narrative is positioned as a prospective endeavour, the social context similarly restricts which narrative plots are available to be drawn on. Furthermore, of all of the narrative plots available, certain emplotments are more visible or more acceptable than others. The influence of the social context in this way is not recognised in existing understandings whereby an interpretation is solely dependent on the cognitive structures within an individual (see for example Bishop and Converse 1986; Andersen *et al* 1995). In experiential emplotment, the storied social context constructs value-judgments on the available interpretations and is not an un-influenced or un-influential source of knowledge.

6.5.2 Grounding experiential emplotment in the illness narrative data

The nature of the narrative plot drawn on, and which an experience becomes emplotted in to, has significant implications for the management sequence. The narrative plot extends forward in time and outlines the next steps in the sequence and how the story might end. The narrative plot may immediately position medical advice seeking as the next step in the sequence, or that course of action may only become available with alternative emplotments. Significantly, the narrative plot may never position medical advice seeking as the next step in the sequence. It is to these three scenarios which I shall now turn as I attempt to draw attention to the ways in which the symptomatic experiences associated with lung cancer can be interpreted and responded to and the significance of storied meaning. In order to achieve this, I have identified a number of excerpts from within the illness narratives through a process akin to that of over-reading (Poirier and Ayres 1997), seeing more than the literal meaning in the data. I completed a pro forma for each participant to facilitate this and an example can be found in Appendix 8[111].

6.5.2.1 Experience immediately emplotted into a narrative which positions presentation for medical advice as the next step in the sequence

In the event of a symptomatic experience, an individual draws upon storied meaning to create sense of it and the experience becomes incorporated into a narrative plot. On occasion, this initial interpretation and narrative plot positions presentation for medical advice as the next step in the sequence. I have represented this situation in Figure 5.

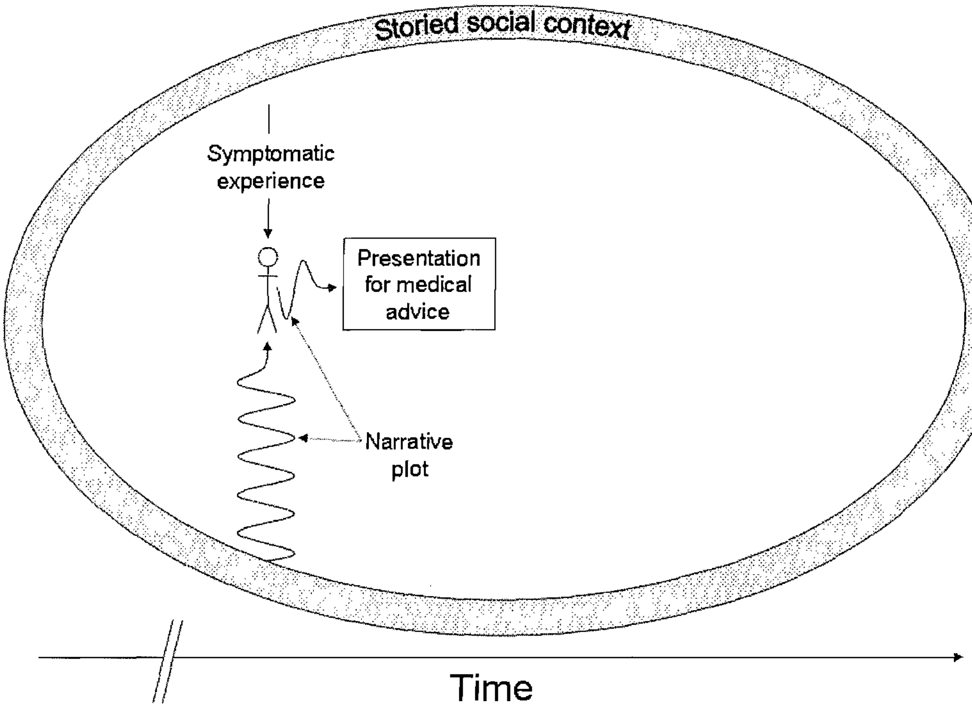

Figure 5: A schematic representation of experiential emplotment – a symptomatic experience is immediately emplotted into a narrative which positions presentation for medical advice as the next step in the sequence.

The large oval represents the storied social context. The stick diagram represents the individual who is located within that context. In the event of a symptomatic experience, the individual draws upon a narrative plot from the storied social context to create sense out of what is happening. The nature of the narrative plot is dependent upon those visible and acceptable within the storied social context and on the biography and experience of the individual. The individual emplots their symptomatic experience into

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[111] As well as facilitating my development of experiential emplotment, I also used the pro forma to facilitate my additional exploration of the illness narratives (to be discussed in section 6.6) and to record my previous exploration of the narratives of personal experience and the narratives of genesis.

that plot and the story of another time or another person becomes their story of the present. The narrative plot is one which positions presentation for medical advice as the next step in the sequence.

The interview excerpts which follow illustrate such a situation.

I: so I was wondering if you could just tell me about the chain of events that led up to you being in Mr (name) clinic?
P: well it started off, um, about every year I get, get a cold and it goes straight to my chest. Two years ago I had to send for the doctor because I couldn't get my breath and she brought a nebulizer, lent me her machine and after about a week I got over it o-, okay. This year I did the same thing but it didn't seem to ease at all very much (105)

Later I sought to clarify the narrative.

I: how long did you have the symptoms before you went to your GP, can you remember?
P: not very long because of the experience I had two years ago I thought it was coming back the same. So I sent for her after about three days I suppose (105)

For this participant, the experience and narrative of a previous time provided a narrative plot which she could draw on to create sense out of her experience of breathlessness in the present. The story of her past then became the story of her present and the narrative of chest infection positioned prompt medical attention as the next step in the sequence. The participant had expected the experience to end, as it had in her previous story, in complete recovery, but this was not to be the case and she was diagnosed with operable lung cancer.

For the participant in the following excerpt, the story of others became her story as she attempted to create sense out of her experience of breathlessness through emplotting it into a narrative of inactivity and weight gain.

I: right, and are you able to go back um, further to how this all began?
P: yes
I: what would you say?
P: I've never been one for getting out of breath so I went and saw my GP and I said about getting our of breath every so often I said 'I expect you're gonna tell me to lose weight' but then he listened to my lungs and he said there wasn't enough air going through my left lung (125)

To this participant, the narrative of inactivity and weight gain, connecting as it does the happenings of change in situation, difficulty exercising, weight gain and repercussions for the body, was a narrative plot which she could draw on to bring meaning to her own experience. Though this narrative plot did not relate the experience of breathlessness to disease processes, and whilst I would not consider presenting for medical advice to be the next step in the sequence for such an emplotment, the participant presented this course of action as the only appropriate response. In retrospect, I wonder whether the narrative of inactivity and weight gain was only one possible plot and that perhaps she had emplotted her experience into an additional narrative which was influencing the management sequence, though she preferred not to share it with me.

6.5.2.2 Emplotted narrative shifts over time

It has been noted within the existing literature that the interpretations that individuals make of their experiences can change over time. Indeed, this situation was narrated by many of the participants as their initial interpretation of their experience did not incorporate it into a narrative plot which positioned presentation for medical advice as the next step in the sequence. Ultimately, however, presentation for medical advice did become the next step. Conceptualising interpretation in terms of drawing on storied meaning to create a narrative plot allows one to understand this dynamic process since the process of emplotment is an on-going one, never fully finished (Murray 1999), responsive to an ever-changing situation. I have represented this situation in Figure 6.

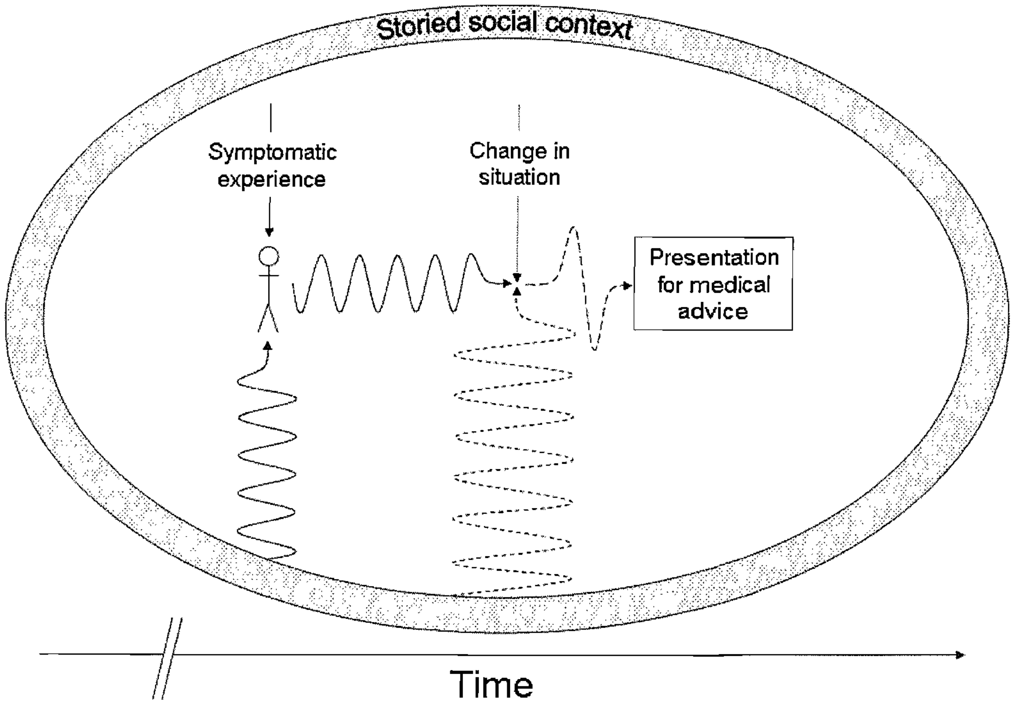

Figure 6: A schematic representation of experiential emplotment – the emplotted narrative shifts over time.

The individual, located within the storied social context, draws on a narrative plot to bring meaning to their experience and emplots their experience into that plot. The nature of this plot does not position presentation for medical advice as a step in the sequence. However when there is a change in the situation, the individual is faced with a different experience to create sense out of and draws on a different narrative plot to do this. The individual emplots their symptomatic experience into this plot and presentation for medical advice is positioned as a step in the sequence. Alternatively, the temporal notion of the original plot may position alternative courses of action as next in the sequence and it is only once these have been passed through that presentation for medical advice becomes an available step.

The interview excerpt which follows illustrates the notion of narrative plots shifting over time.

I: and it was the numbness that sort of started [that ball rolling?
P: yeah the numbness] yeah the sen-, sensitive round the nipple that's all, ju-, ju-, just felt like you, you know um some t-shirts you have these badges sewn on and they got the, the stitching felt like, felt that was scratching me nipple and making it irritable you know I, cos I wear a lot of [football] tops with the badge emblem an' that on it. I thought it was that catching it, irritating it or her washing powder she bin using making me, skin change, using, change of washing powder a few times didn't you, for sensitive skin
W: bought a sensitive one
P: I was still getting it (132)

This participant drew on the narrative plot of allergy to create meaning out of his experience of an irritable sensation on his nipple and it illustrates the active and creative ways in which individuals are able to bring significance to their symptomatic experiences. Because the participant had drawn upon this narrative plot and emplotted his experience into it, the next step in the sequence was a change of washing powder. When the irritation persisted despite the attempts to resolve it, the narrative of allergy could not be upheld and so he had to create another plot in which his experience would become meaningful. The revised narrative meant that presentation for medical advice was an available next step in the sequence and after a period of prolonged investigation during which he was suspected of having a minor stroke, the participant was diagnosed with inoperable lung cancer.

Similarly for the participant in the following excerpt, the narrative plot drawn on to bring meaning to the experience of breathlessness changed over time.

I: did you, when you were having the shortness of breath, say going back beyond five or six months and you had the shortness of breath, but it, was it that it wasn't really affecting you or, you know?
P: no so I just palmed it off, I thought 'oh you're getting old'
I: and then more recently it, did it change, how did it, what happened?
P: well it got worse. Whereas before I'd just walked a few steps and a few pants, uh it got worse than that and I found I had to then start slowing myself down which was difficult having walked a measured pace for so many years it's a habit you get into and it's difficult to make yourself slow down but **then** I realised well there's something wrong there and I then shouted help with the doctor. But as I say before that it just hit me occasionally and I just passed it off as getting old (107)

Initially, the participant drew upon the narrative of ageing in order to create sense out of his symptomatic experience. His biography, as an individual in the eighth decade of life, and the nature of the experience positioned this interpretation as available to him. Interpreting his experience as related to ageing did not require that medical advice be sought. Indeed, as Cornwell (1984) writes, when attributed to ageing, a symptomatic experience becomes a health problem which is not illness. However, the experience of the breathlessness changed, it worsened, and the individual was faced with a different experience to create sense out of. The narrative of ageing was no longer able to contain his actual experience and so he was forced to draw upon a different plot. Though not explicit in this excerpt, the experience was emplotted into a narrative of serious disease and presentation for medical advice was positioned as the next step in the sequence.

For participant 107, it was a worsening of the experience which prompted the emplotment to shift but for many of the participants it was the development of an additional symptomatic experience. Participant 126, for example, initially created sense out of his experience through instilling it into a narrative of a chest infection. Though associated with a disease process, this interpretation rendered the experience normal for the participant, as illustrated in the following excerpt.

I: were you concerned by it?
P: um, I've had problems with me chest all me life, ever since I was a little boy um, every. Not so much this time of year it has, you know this time of year things generally, generally calm down and I'm alright but especially round like Christmas time I'll always, always get chest infections or have breathing problems or, you know something like that and I have done ever since I was tiny (126)

The narrative of chest infections made presentation for medical advice a natural and available step in the sequence, though the participant's visits to his GP and specialist to secure antibiotics were at lengthy intervals since he wanted to give the antibiotics sufficient time to have an effect. Several months after the chest infection had begun, a different symptomatic experience occurred.

P: (2nd layer of illness narrative) as I say when I did experience something that was, like out of the ordinary that happened more than once and as I said I was walking, doing some exercise and it felt like me lungs were filling up, then I went an' you know, started the ball rolling but apart from that, apart from that because of the way it happened, and like the time of year that it happened (126)

The feeling that his 'lungs were filling up' was an unusual one for the participant and prompted him to reconsider his emplotment. However, had this different symptomatic experience occurred earlier in the year the participant may not have thought much of it since he expected respiratory symptoms during the winter months. It was the strangeness of the experience combined with 'the time of year that it happened' (in the summer months) which shifted his previous emplotment of chest infections. But the potential for a problematic emplotment was available earlier in the participant's pre-diagnosis experience. The following excerpt, generated before the one given previously, suggests why it was important for the participant to say 'like out of the ordinary that happened more than once' in the previous excerpt.

I: have you ever coughed anything up?
P: no my dad used to he used to cough up green stuff, horrible it was but mine's never been anything, anything like that, it seemed clear, you know
I: have you ever coughed any blood up?
P: yes um, that was in about February, that was outside on me dinner break I coughed up and I, I spit onto the ground and it was just a trace, you could just see a trace of blood in there. I thought 'oh crumbs' and then I thought shall I go, I better go and see the doctor about this and I thought 'nah it's only once'. The next time it happened it was clear so (126)

The experience of coughing up a 'trace of blood', on just one occasion, was not enough to shift the narrative plot. Furthermore, that the experience had occurred during the winter months allowed him to, unproblematically, subsume it within the narrative plot of a chest infection. Implicit in this is the notion that persistence over time would have been a cause for concern and would have led to a shift in the plot. The notion of temporality and persistence over time seems to have been noteworthy in the experience related to in the following excerpts.

P: (1st layer of illness narrative) 'bout, only about two months ago I come down with a cough, kept coughing, and then it hurt me under the chest so I thought, oh I just went to the pharmacy and he thought oh where you keep coughing you're bruised so I just took paracetamols for about three weeks, ibubrufen and that (coughs), felt fine generally and then um noticed that my breathing was getting a bit, I was getting out of breath and then one, one week I thought 'I've had enough of this I think I'll better go to the doctor' so I went to the GP (115)

Initially, the participant created sense out of her symptomatic experience through emplotting it into a narrative of the common cold. As the coughing continued, the participant began to experience discomfort in the chest. This experience was not congruent with her understanding of the common cold and she shifted her emplotment to render the experience problematic. Rather than present for medical advice at the GP, the participant consulted a pharmacist. The pharmacist then proceeded to emplot the experience into a narrative which rendered it unproblematic since the symptomatic experiences of cough and discomfort were not considered to have their origin in one disease. In light of this, the individual was advised to take painkillers and was reassured that her experience was not a cause for concern, or significantly, a prompt for medical consultation. As time moved forward, the individual experienced an additional symptomatic experience (shortness of breath) which brought into question the initial emplotment of the common cold, and the pharmacist's subsequent emplotment of common cold plus expected complication. The revised narrative plot positioned presentation for medical advice as the next step in the sequence. Later in the interview, I sought to clarify the narrative and the experience to which it referred.

I: um, when you, before you, I just need to sort this out in my mind, before you went to your GP about, what was it that, that made you go to your GP?
P: couldn't breathe
I: that was the main?
P: well the cough and then I started I just thought I had a chest infection that's why I went, cos my neighbour had a chest infection and I said 'I reckon I've got a chest infection I'm going to GP' and that was it just general, you know you ain't gonna stop and think oh you've got cancer are you? (115)

Like participant 126 quoted previously, the revised emplotment into a narrative of a chest infection made presentation for medical advice an available and natural next step in the sequence, though this course of action may have occurred earlier if the pharmacist had interpreted the participant's symptomatic experiences differently.

6.5.2.3 Presentation for medical advice is never the next step

The participants discussed in this chapter up until this point have ultimately presented for medical advice prior to their diagnosis of lung cancer. However, lung cancer can be diagnosed incidentally without an individual presenting the symptomatic experiences associated with the disease for medical advice. I have represented this situation in Figure 7.

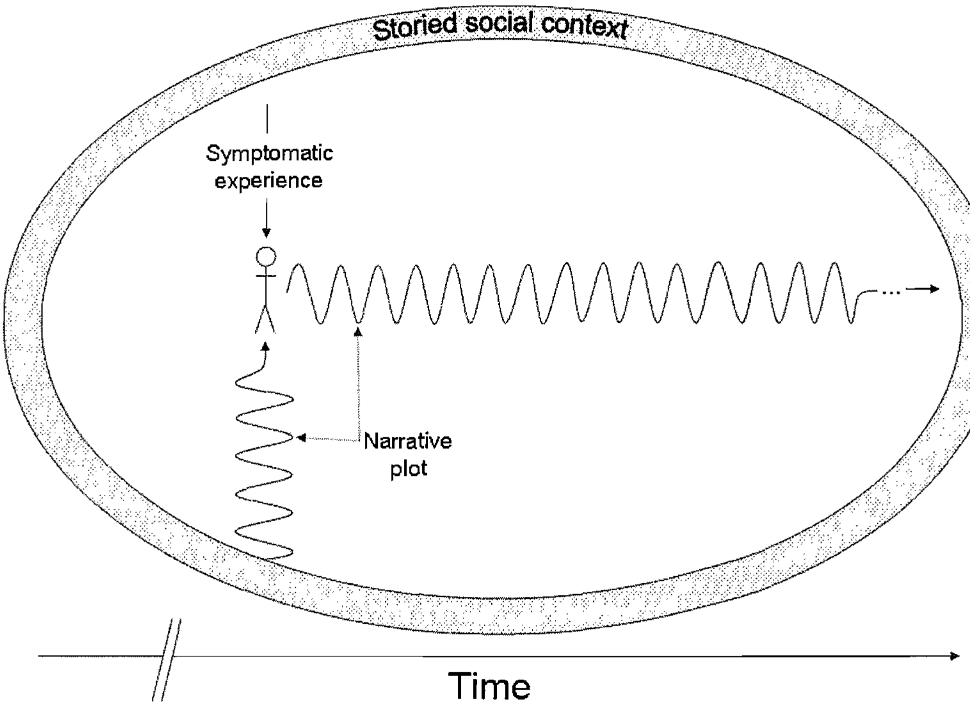

Figure 7: A schematic representation of experiential emplotment – presentation for medical advice is never positioned as the next step in the sequence.

The individual creates sense out of their symptomatic experience through drawing on a narrative plot from the storied social context and emplotting their experience into it. The narrative plot does not position presentation for medical advice as an available next step in the sequence and the individual never consults a GP with the symptomatic experiences associated with lung cancer.

Two of the participants had experienced symptomatic experiences associated with lung cancer but had not presented for medical advice with those experiences[112]. The existing literature does not consider individuals who are diagnosed with lung cancer incidentally[113] but I thought that it was important to understand how the symptomatic experiences associated with lung cancer can be interpreted so that presentation for

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[112] One participant was diagnosed after a routine x-ray requested following a myocardial infarction whilst the other was diagnosed following a chest x-ray requested for an un-related disease.

[113] Though where it does there is an assumption that individuals diagnosed with lung cancer incidentally, as a result of investigations for another issue, have yet to develop symptomatic experiences associated with the disease.

medical advice never becomes the next step in the sequence. The first of the two participants had experienced a cough but had emplotted it into a narrative of stress.

P: (1st layer of illness narrative) the only thing I did have when my husband was here I had a bad cough but I put that all down to stress I put it, and he used to say oh you know go and find something to suck and it will get better. It used to be mostly in the mornings this cough but it wasn't a cough that I kept on all day it was just once (120)

Through drawing on the narrative plot of stress and emplotting her experience of a cough into it, presentation for medical advice was not positioned as a next step in the sequence. Furthermore, the nature of the symptomatic experience, the fact that it just happened at certain times of the day, deterred the individual from associating it with a disease and the individual's narrative of stress was sufficiently flexible to accommodate this feature of the symptomatic experience[114].

The following excerpt is from the second individual who was diagnosed incidentally without prior presentation of the symptomatic experiences associated with lung cancer.

I: (laughs) something goes on behind the scenes.
P: yeah, yeah. As I say as far as I was concerned if I hadn't gone with the shakes nobody would know anything (laughs). Cos I certainly haven't had enough chest pain to think 'oh I just go to the doctor' you know it's, it's just been a, I don't know, sort of perhaps I've got indigestion or something and it's gone away. Certainly I wouldn't have gone to the doctor with it, so you've picked it up before me (laughs) (123)

In drawing upon the narrative of indigestion to create sense out of his experience, the continuation of the experience over time did not cause concern or prompt the narrative to shift. In line with the previous participant, the symptomatic experience did not have the qualities to warrant a shift. Through this process of interpretation, the individual had rendered presentation for medical advice unnecessary.

6.5.3 Disease-specific emplotments

6.5.3.1 Lung cancer emplotments

As I have tried to illustrate, the narrative plot drawn upon to give meaning to the symptomatic experience influenced how the individual responded to it in terms of the management sequence. The excerpts presented previously, and the narrative case studies in chapter four, suggest that the symptomatic experiences associated with lung cancer

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[114] That the participant's husband had advised her to use a medicinal preparation suggests that he interpreted the cough as related to an underlying, normal, disease process.

can be incorporated into a range of different plots, some of which relate to a specific disease. Whilst the diagnosis of lung cancer was anticipated by some of the participants once medical investigations had been initiated, two of the participants had emplotted their experience into a narrative of lung cancer prior to presenting for medical advice[115], though this interpretation could not be sustained by one of the participants. Both of these participants were men and were current smokers at the times that they interpreted their symptomatic experience, presented for medical advice, and were diagnosed with inoperable lung cancer. Prior to presenting for medical advice, the participant quoted in the following excerpt had drawn upon the narrative of lung cancer and had emplotted his experience into it.

I: was there ever a time when you started to consider that this, that you might, that um, the cancer might be what the problem was before somebody actually told you was, did it ever cross your mind at any time?
P: I guess it was one of various possibilities yeah
I: did, was that something that you would have had in mind before you went to your GP or once?
P: yeah I think you've got to have the pain in the first place, you then sort of think 'urrgghh' you know, 'could it be?' um, you know and then you go and see the GP and she pokes around and says well you know 'maybe it's muscular' or this and that and the other and you know and then. I mean in a way it was sort of that first x-ray **not** being positive that, in a way surprised me um, one sort of thought 'ah what a relief' (laughs) and uh, so it was a bit of a blow when it came back again really (122)

This participant was in a position to draw upon the narrative of lung cancer to create sense out of his experience because he could see himself in it: his biography was reflected in the beginning of the disease's narrative structure and his experience in its middle. In this way, the story of others became his story. In light of this emplotment, presentation for medical advice was positioned as the natural next step in the sequence. However it seems that the participant did not raise the possibility of lung cancer with his GP, who proceeded to emplot the pain into a narrative of muscular trouble. As time moved on and the pain continued the participant maintained contact with the GP and was referred for a chest x-ray. No abnormality was detected on the x-ray and this came as both a surprise and a relief to the participant. The pain eased for several months, but when it returned the participant again sought medical advice and further investigations revealed that he did indeed have lung cancer.

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[115] I recognise that other participants may have interpreted their experience as related to lung cancer prior to presenting for medical advice but preferred not to share this with me, for whatever reason. However the nature of the interaction and the coherence and ease with which people narrated their experience led me to believe that this was not the case.

The participant quoted in the following excerpt had also considered emplotting his experience into a narrative of lung cancer, though this interpretation was not one that he was able to sustain.

I: was there ever a time before you were in the clinic and they told you what the diagnosis was, was there ever a time bef-, you know before then that you suspected that it might have been, that you actually thought oh 'maybe it might be this?'
P: yes bu-. Yes but did I mean it that's, that's um. It has crossed my mind a few times but, you know. I think I've dismissed it and say 'no, no, no Christ you've got (disease) you've got your heart no you ain't gonna get, you ain't gonna get that as well' you know. Um, but it did cross me mind once or twice but I didn't dwell on it too much sort of thing you know
I: was that sort of um, once your GP had referred you on or was that possibly before that, when
P: oh no that was before I even, that was before that was um, only this year it has to be said but since like January this year I've wondered a couple of times and you know when um, when um the GP called me in and said you know they've found a mass on your lung then I knew what it was, you know, we went through the motions just to see whether it was, you know, um benign or not or anything else but yeah as, as soon as um, as soon as my doctor said you know 'we've found a mass on your lung' and that, I knew that's it
I: hm, an', did you, when you, it had crossed your mind did you ever voice it to anybody else or was it just something that you kept with you?
P: no, no I've ne-, never told anybody else that
I: and why do you think it, why do you think it did cross your mind?
P: well pos-, possibly because of all the ingredients smoking, chest infections um, yeah. You're thinking about it you know, while you're having a fag you're thinking about it and you just 'I wonder if it's cancer?' (126)

I presented excerpts from the interview with this participant to illustrate the shifting of the narrative plot over time (section 6.5.2.2). For this participant, a one-off experience of coughing up a small amount of blood was not enough to shift the experiential emplotment from that of chest infections to that of something more serious necessitating prompt medical attention[116] and the interpretation of lung cancer could not be sustained. Moreover, the notion of luck which was significant within several of the narratives of genesis seemed to be important for this individual for he did not think it possible that he could have more bad luck, that is be developing lung cancer, since he considered himself to have had his fair share.

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[116] It was the feeling that his 'lungs were filling up' which prompted the shift in emplotment from a narrative of chest infection to that which rendered the experience more problematic.

6.5.3.2 Breast cancer emplotments

Within the illness narratives as a whole there were sections of data which reinforced the significance of emplotting an experience into a narrative of a specific disease and which suggested that such interpretations could be made relatively easily. Two of the participants talked about a personal experience in which they had considered that they might have breast cancer.

> P: frightened the living daylights out of me mind you cos my mum died from breast cancer
> I: did she?
> P: yeah. When they sent me, my sister and I go for the mammograms you see, I'm too old now but we did, and uh when they phoned me up it was Christmas eve wan it lover something like that wan it?
> H: (indistinct)
> P: Christmas week and asked me if I'd go back and have another mammogram done I thought 'cor flippin hell'. Puts the fear of god up you (121)

Participant 121 had not responded promptly to the cough and the weight loss, which once presented and investigated, led to the diagnosis of lung cancer. Indeed, in the husband's words:

> H: I kept on long before she went round the doctor to go round and see him then she finally ga-, give in one day she said 'oh you make an appointment I'll go round and see him' and that's how it all started

However, it did not seem as though the participant was complacent about her health since the story that she told towards the end of the interview suggested that she attended mammography screening when called to do so and furthermore that she consented to the investigation of the radiological abnormalities.

When hearing participant 121's narrative I was struck by the story of a hard life which brought to mind Pound *et al*'s (1998) notion of stroke as a 'normal crisis'. In this way, her experience of cough, and weight loss in the first instance, was an expected part of normal life and 'normal' illness (Cornwell 1984) and was not a cause for concern, much less a reason to seek medical advice. Indeed, the narratives of normal life and normal illness are freely available within the storied social context for individuals to draw upon and have a higher profile than the narrative of lung cancer. It was only once the weight loss became more pronounced and she began to lose more than she thought was normal that the narrative plots which rendered it a symptom of serious disease became available to her.

The following excerpt of interview was again generated towards the end of the interview. The context was such that the participant was suggesting a role for stress in the genesis of her cancer, and she told the following story to illustrate her tendency to keep things to herself.

> P: um, probably if you shared it. I don't tell anybody you see. A couple of years ago I found a lump in my breast um, and that was pretty scary. Well the first time I went for a mammogram. They said there was something and I got referred but it turned out to be a cyst. And then the second time I found the lump myself so I went straight down the doctor and then I got referred and then it was a fortnight wait so for that whole two weeks you're a bit 'oh it's probably just another cyst' um and then I was okay til the day I went to the hospital and I said 'oh I've got', she put me in for another mammogram, 'oh I've got a cyst in there anyway' and she said 'that's not the side your cyst was in the other side' and then I thought 'god this is gonna be um' but it turned out to be another cyst that needed draining but what I'm saying is in that whole fortnight I told not a soul (124)

What the narrative relays is that the participant was conscious of her health, had attended mammography screening and had acted accordingly in response to a symptomatic experience which was suggestive of breast cancer. The participant could see herself in the narrative of breast cancer and when she experienced a lump in her breast, she immediately emplotted it into the narrative of the disease and this positioned prompt medical attention as the next step in the sequence.

The stories told by participants 121 and 124 present a social context in which breast cancer is widely recognised and a justified cause for concern. The symptomatic experiences associated with breast cancer are perceived to be significant and as necessitating medical attention which is a different situation to lung cancer whereby most of the symptomatic experiences are positioned within the realm of normal. That participants 121 and 124 had reacted similarly in response to the threat of breast cancer but differently in response to the experiences associated with lung cancer supports Corner *et al*'s (2006) conjecture that interpretation and delay are not solely influenced by individual and cognitive factors but also by the wider social context. Certainly the concept of experiential emplotment accords great significance to the storied social context for the way in which it makes certain narrative plots more visible, more available and more acceptable than others.

The concept of experiential emplotment draws attention to the active and creative ways in which individuals interpret and respond to symptomatic experiences. Storied meaning, connecting as it does distinct happenings into a coherent sequence, is an important resource from which individuals can draw to create sense out of their own experience. For an individual to be in a position to draw on a narrative plot, it must be visible and acceptable within the storied social context and the individual must be able to see their biography and their experience in it. The individual can then emplot their experience into this narrative plot so that the story of another person or of another time becomes their story. In becoming the narrative, a template for the future is provided; the end can be imagined and the individual is in a position to follow the next steps in the sequence.

To return to the interpretation of an experience as related to lung cancer, very seldom did the participants emplot their symptomatic experiences into the narrative of the disease. My initial understanding was that the individuals were not in a position to make this interpretation, to draw upon the narrative of lung cancer, because they could not see their biography in the beginning of the disease's narrative structure. However, that one of the two individuals was not able to sustain his self-diagnosis of lung cancer led me to consider that the nature of the symptomatic experience was also significant for whether it could be interpreted as related to the disease. Specifically, I thought that the middle of the narrative structure of lung cancer may refer to more than just the symptom labels associated with the disease. This led me to ask of the data, what were the features of the narrative of lung cancer, beyond the issue of genesis, if the majority of the participants did not see their experience in it?

6.6 Exploring the narrative of lung cancer beyond the issue of genesis

I adopted Bal's (1985) framework of events, actors, time and location to facilitate the exploration of the illness narratives as a whole, beyond the issue of how and why the disease develops, focusing upon other aspects of how the disease was understood within the interviews.

6.6.1 Events

The significance of the nature of the symptomatic experiences for the interpretations made has been highlighted within the existing literature (see for example Burgess *et al*

1998; Gascoigne *et al* 1999; Burgess *et al* 2001; Meechan *et al* 2003; Scott *et al* 2006). Within many of the illness narratives it was assumed that the presence of lung cancer would mean that certain symptom labels would be experienced, and particularly that the symptom labels would be respiratory related. This information was generated in a particular context, usually as grounding for the participant's experience, and not in response to a specific question that I had asked. This is illustrated in the following excerpt.

> I: and did you, were you given antibiotics?
> P: steroids, antibiotics. Um, they always seemed to kick in and work so it was never a problem. Um, as for my chest, for every infection I've had I've never, ever brought up any phlegm or coughed up anything nasty. No it's always been a clear chest, even now I don't bring up anything. You know, you thought you might get a bit phlegmy or cough up stuff but no, never brought up anything (102)

Participant 102 had 'thought you might get a bit phlegmy or cough stuff up' but he had had no such experience. Similarly, participant 113 and his wife implicitly suggested that the narrative of lung cancer is associated with the experience of a cough and difficulty breathing, as illustrated in the following excerpt.

> P: (partway through a turn of talk, 2nd layer of illness narrative) I thought I, when I went to see him I was talking to him about my lower back and this pain which was giving me a lot of trouble at the, that time in the buttock but after the x-rays it then appeared that I'd got a lung problem which I don't quite know anything about, didn't have a **clue** so it was great, a great shock when she told me
> W: well you didn't have a cough did you?
> P: I don't no and I can breathe
> W: you can breathe better than I can breathe (113)

Within the interview, participant 117 conveyed his thoughts about being diagnosed with lung cancer despite not experiencing any pain, thereby suggesting that the experience of pain is a feature of the narrative of lung cancer.

> P: (towards the end of a turn of talk referring to how his wife had died, 2nd layer of illness narrative) as for myself I've no, I've had no, no pains but I have seen pain in a person. So I was a little bit surprised when I saw the uh, that there was this thing on the x-ray (117)

That this participant had not experienced any pain led him to be surprised at his diagnosis of lung cancer. In a similar vein, the symptomatic experience at the centre of participant 130's illness narrative had been pain in the chest which she emplotted into a narrative of shingles. The participant presents the level of pain as congruent with this interpretation, as illustrated by the following excerpt.

> I: and you sort of mentioned that before that pain, before the pain started you wouldn't have thought that there was anything?
> P: no. Even when I did have the pain I wouldn't have thought it was bad enough to be serious. But I think this is a thing about um cancer, it does creep up on you, not like other ones (130)

For this participant, a disease as serious as lung cancer would be associated with a particular, specifically high, level of pain. Similarly, the story within a story (Price 1987) featured in the excerpt below presents lung cancer in a particularly negative and serious light.

> P: (towards the end of an extended turn of talk, 2nd layer of illness narrative) anyhow how, you know, it's just um, cos how do you know cos most people I've found in the past that have cancer of the lungs they're in a terrible state, you know I mean I'm supposing years ago, going back what, twenty years or less, people didn't survive it did they, you know if you had cancer of the lungs it was curtains really wasn't it cos there wasn't the CT scan or nothing was there so how would anybody know? So, you know I just feel that mine could have gone on and I would never have known cos I certainly, I mean I used, I had someone a friend of mine who had lung cancer and she had the most dreadful cough and she could hardly breathe and of course she did die, but um, I think with my case and I don't know how I would have known if it hadn't been for that blood coming up (103)

The participant had associated lung cancer with a 'dreadful cough' and being hardly able to breathe, and whilst she had experienced difficulty breathing, it had not been to the degree that she associated with the disease. In this way, participants 103 and 130 considered their own experience to be too minor to be associated with lung cancer. This is a similar situation to that reported by Corner *et al* (2006) whereby the possibility of lung cancer had crossed the mind of one of the participants but 'she thought her symptoms were too minor'[117] (p1387).

In addition to reaching a threshold level of severity, there was an implied suggestion within several of the illness narratives that a disease such as lung cancer would be associated with more than one symptom label. This is explicitly referred to in the following excerpt.

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[117] This situation was not commented on any further by Corner and colleagues.

P: (1st layer of illness narrative) I still get the cough and it's very bad sometimes, takes it out of me. I get it about, sometimes once a day sometimes twice a day. But that's really, if that is a symptom that's, that is all I've had or got. At the moment I'm very much under the weather cos I've picked up this cold um, which last night and the night before I had very bad nights because of the cough but normally I sleep quite well (4 second pause). For, for, for it to have got that size I would have thought that I would have had some sort of um, some other sort of symptom (120)

Related to the expectations of particular symptomatic experiences of particular severity, the development of lung cancer was associated with feeling ill, as illustrated in the following excerpts.

W: the (hospital) ordered the x-ray
P: yes it sort of came out of the blue rather sudden you know cos I wasn't feeling, you know it wasn't as though I've been feeling ill or anything (104)

I: uh huh. Have you ever felt a bit poorly or a bit unwell sort of since Christmas or, or before that?
P: not really
W: no not really
P: no not really no. That's what, that's what surprised me about having this like, getting this cancer
I: hm
P: like, and surprised everyone I'm talking to. Like for example you see me now you say 'he haven't got no bloody cancer'. That's true really in it? (129)

6.6.2 Actors

The preceding excerpt demonstrates the importance of embodiment for conveying and constructing health and illness states. The body acts as an important medium through which individuals and their significant others can judge health and illness status. This relates to the suggestion that individuals with lung cancer, or cancer more generally, would have a particular 'look'. Actors were brought into the narratives to illustrate this, as highlighted in the following excerpts[118].

P: wait for the next twelve weeks see what happens
I: take it from there
P: yeah. But I don't (cough). Although I've still got a cough, yeah, I, it, it's almost as if you're tryin' a put a label on it but you're not but I don't feel like a man whose got cancer, you know. um, I don't think I **look** like a man that's got cancer so you know, whether that means I'll be in for an easier ride or whatever I don't know but you know at the moment um, at the moment I've got a lot of fight in me so, you know, get the

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[118] In participant 126's extract, I influenced the incorporation of actors through my questioning which I developed in response to the participant's comment that he did not think that he looked like a man who had got cancer.

thing gone as much as we can and get on with it so. That's not to say I don't believe I've got cancer an' I haven't accepted it I **have**, fully, but you know um
I: did you think that some of the people you saw today looked like people with cancer?
P: yeah, yeah
I: what was it about them?
P: um, people I mean I was down near the ra-, radiotherapy centre cos I had to go for the, for the chest x-ray um. And there, there was a couple of people there all waiting to co-, go in or waiting to um, waiting for transport home or whatever I don't know but they looked, a couple of 'em looked really ashened you know. Um, the way they got up and walked, you know it was obviously painful an' a, an' a trial to do it. (identifiable information). And I say them people sat **there**, and I see that they were grey and, you know sitting there head down and everything you know so, it, pretty much I, as I thought it would you know (126)

P: (towards the end of a long turn of talk, 2nd layer of illness narrative) when I see people in that hospital, when was it, Tuesday wasn't it, there was a couple of people there and I thought 'god', you know, you could tell the look. You know how thin they were, the gauntness of them. You know this is how it's gonna be I suppose (127)

Participant 127's observations showed her 'how it's gonna be' but actors were also brought in to suggest that individuals with lung cancer do not always have the look of an ill person or experience severe and debilitating symptomatic experiences. This is illustrated in the following excerpt.

I: yeah. And did, did, did you know anything about lung cancer before all of this started?
P: not really uh. I mean a lady I used to work with a few years ago in a shop her husband had it and he did die of it after a couple of years I think but he never looked any different to be quite honest even though he had all his treatment um, he never looked ill or you know it was unbelievable to, to see him wandering round like it. I mean he never seemed out of breath he never seemed to be coughing because he used to pick her up everyday from work um, so yeah I got used to seeing him coming in and out but other than that haven't known many people with it really um, so (124)

In this excerpt I had asked the participant if she knew anything about lung cancer before she was diagnosed with the disease and she responded by telling me the story of an individual known to her who had been diagnosed with it, implicitly emphasising the significance of storied meaning[119]. The gentleman whose experience she was constructing and communicating did not experience the symptomatic experiences which she, the narrator, would associate with lung cancer (shortness of breath and cough) nor had he looked ill when she had seen him. The gentleman did, however, die of the

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[119] Frequently when I met someone for the first time, beyond the boundaries of the study, and was asked what I did, I told them that I was researching the experience of lung cancer. In response I was often told the story of an individual known to them who had, if not developed lung cancer, developed cancer of some type. As part of my extensive engagement, I recorded such situations within my research log.

disease and this was a feature of the majority of the stories within stories (Price 1987) which constructed and communicated the experiences of other individuals with lung cancer. In this way, the narrative of lung cancer was largely positioned as ending in death.

6.6.3 Time

Explicit referrals to time in relation to the narrative of lung cancer concerned the expectation that any experiences related to the disease would happen on more than one occasion and would be continuous. It was important, for example, that participant 126's experience of coughing up a trace of blood, though out of the ordinary, had not happened more than once (section 6.5.2.2). Related to this, there was an implicit expectation that lung cancer would develop insidiously over an extended period of time during which symptomatic experiences would become more pronounced and increasingly debilitating, as highlighted in the following excerpt.

P: yeah that's what made us think, you know, that there was nothing wrong cos my symptoms weren't like my dads you know. It's a shock cos it just hit me, that's what he said it just come on and that's it
I: no time, no
P: no, no, no. I mean I wasn't ill for a couple of months, you know, there wasn't no build up it just hit me, **wham** (115)

6.6.4 Location

In my exploration of the narratives of genesis I briefly discussed physical location[120] but within the illness narratives as a whole social location was significant for lung cancer and how it was understood. The key feature of the social location was the link between smoking and lung cancer, as illustrated in the following excerpt.

I: and um (cough) 'scuse me. Um, did you know anything about this type of problem before it was diagnosed?
P: did I know anything about it?
I: yeah
P: only what I read in newspapers and conversations with people. No I didn't, I've never taken any notice of it or studied it so to speak
I: what sort of thing have you read in the newspaper about it or, can you think?
P: um, things in general smo-, you know smoking always comes into it. I suppose what's where I became conscious of it with the amount of stuff you see written about smokers (108)

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[120] I presented an interview excerpt describing the physical location of occupational exposure to potential carcinogens.

For participant 108, the media, and more particularly newspapers, were a source of his understanding of lung cancer which associated the genesis of the disease with smoking. The role of the mass media in constructing and communicating aspects of the social world as they relate to health and disease was reinforced by participant 125.

P: I know my grandmother had cancer when she died, I'm not sure what cancer she had cos she didn't live near. I think that might have been lung cancer my grandmother, but it was many years ago that was back in the sixties
I: hm
P: do-, I don't really know
I: no
P: it's frightening because I think, you know it's all getting out of breath and you see all the adverts with all this breathing, that's what frightens me, I don't want my family to see if it does get like that
I: right, what do you mean like the smoking, non-smoking adverts?
P: hm, and I think if I get like that I don't want my family to see me like it (125)

The smoking cessation advertisements, as discussed in section 2.4.11.3, were designed to deter individuals from smoking and to encourage smokers to stop[121]. Fear and scare tactics were viewed as conducive to this and so the end of the narrative of lung cancer was presented as death, and an unpleasant death at that. The media and the tobacco control agenda[122] reinforce the association between smoking and lung cancer and hold individuals with the disease as accountable for their situation. This position was reflected upon in the interview interaction by one participant, as illustrated in the following excerpt.

I: and how, how do you think that your GP, were you, did you find it quite easy to go along to her did you find that, they were quite approachable and?
P: oh she's approachable yeah
I: and she listened to what you say?
P: I get the feeling at times, and not in the hospital but um, in the GPs particularly, if you're a smoker 'it's your own problem', self-inflicted
I: do you?
P: I get that feeling at times yes (101)

Though this situation was raised only once within this study it does highlight the way in which interpretations are subject to value judgements. Through emplotting a symptomatic experience into a particular narrative plot, an individual becomes the

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[121] It is important to note that the current campaign developed to influence individuals to stop smoking is centred on 'getting unhooked' and does not associate smoking with lung cancer.

[122] Whilst the current campaign (getting unhooked) does not draw attention to the association between smoking and lung cancer, one of the warnings which features periodically on tobacco products reinforces the link (see section 7.2).

protagonist in the story and thus has a specific identity. One ramification of this is that an individual could be seen as deserving of that particular diagnosis and this could lead them to avoid situations which are likely to enforce this negative value judgement. Though presentation for medical advice may be positioned as the next step in the sequence, the individual does not have to adopt this course of action and may indeed choose not to.

6.7 Responding to the second research question – revised understanding

The narratives of genesis, as narratives of how and why lung cancer develops, positioned the disease as developing in a particular way, as having a particular beginning. Implicitly, this introduced who will develop the disease and who, significantly, will not. Lung cancer, then, is positioned as a disease of current, heavy smokers of a certain age. Initially, my thoughts were that this understanding led many individuals away from interpreting their experience as related to lung cancer since they could not see their biography in their understanding of the disease's genesis. Conceptualising specific diseases in terms of a narrative structure, the concept of experiential emplotment and the exploration of the narrative of lung cancer beyond the issue of genesis led me to revise my initial understanding. Whilst lung cancer is understood as having a particular beginning, it is also understood as having a particular middle which extends beyond symptom labels. In this way, lung cancer is understood to begin in current, heavy smokers of a certain age who then develop multiple, continuous, debilitating respiratory symptoms, experience a high level of pain, and who feel and look ill. The narrative of lung cancer, positioning the disease in this way, was not then a narrative plot that many of the individuals who developed the disease could draw on to create sense out of their experience for they could not see themselves, their biography or their experience, in it. I have illustrated this revised understanding in Figure 8.

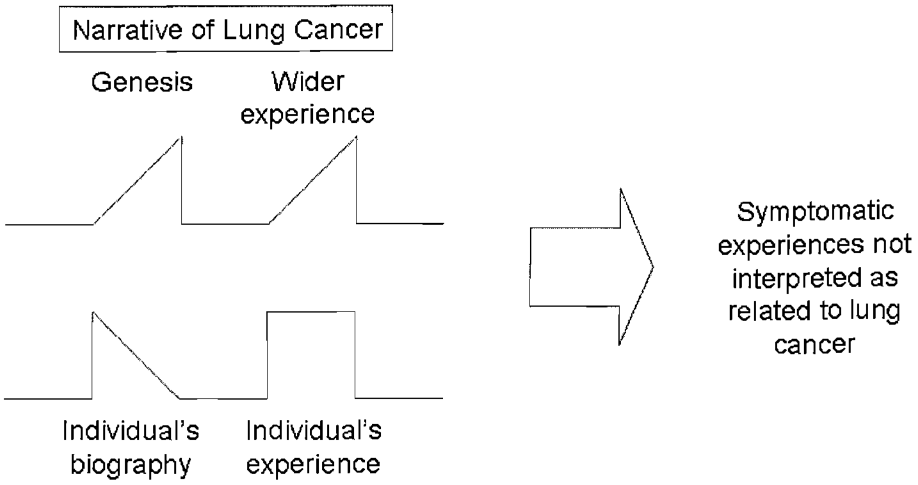

Figure 8: A schematic representation of my revised understanding of why individuals did not interpret their symptomatic experience as related to lung cancer.

Whilst the majority of the participants were not in a position to draw upon the narrative of lung cancer, two of the participants had considered that their experience was related to the disease prior to presenting for medical advice whilst others had suggested that they were anticipating or were not surprised by the diagnosis of lung cancer. For this interpretation to be available to the individual, they needed to see their biography in the beginning of the disease's narrative (genesis) and their experience in the middle of the disease's narrative (wider experience). I have illustrated this in Figure 9.

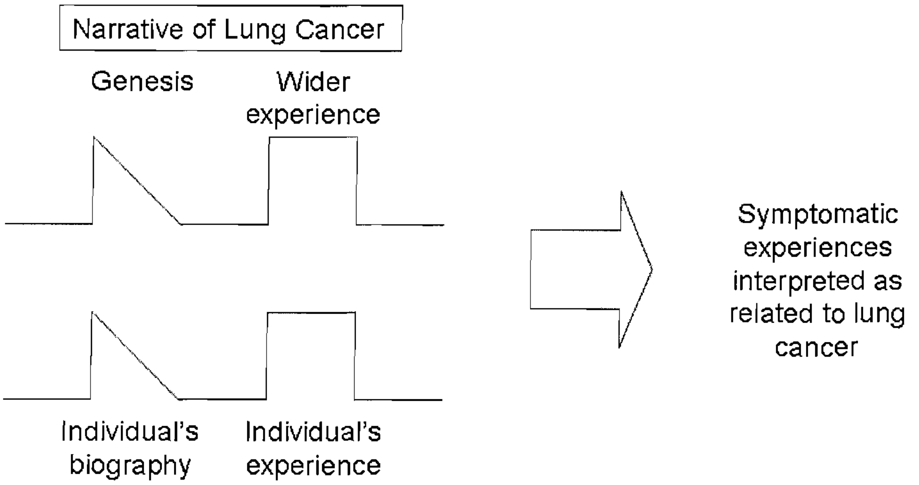

Figure 9: A schematic representation of my revised understanding of why individuals did interpret their symptomatic experience as related to lung cancer.

6.8 The narrative structure of specific diseases – revised understanding

My revised understanding of why many individuals seemed not to interpret their experience as related to lung cancer led me to reformulate my representation of the narrative structure of specific diseases. Where previously I considered the middle of the narrative structure of a specific disease to relate to the symptom labels associated with it, in my revised understanding it related to the wider experience beyond symptom labels[123]. I have presented my revised understanding of the narrative structure of specific diseases, such as lung cancer, in Figure 10.

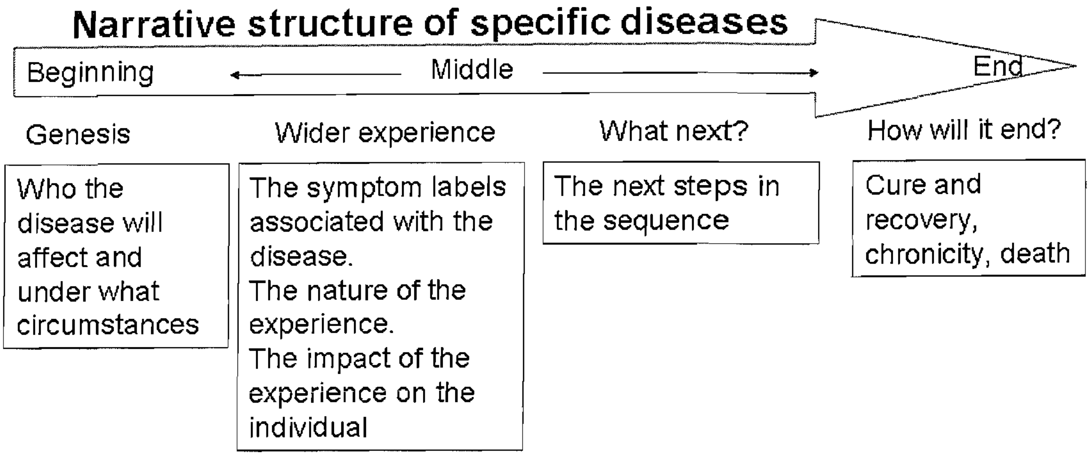

Figure 10: A schematic representation of my revised understanding of the narrative structure of specific diseases.

6.9 Chapter summary

In this chapter I have tried to present my journey through the data and my shifting understandings. I have explored the potential of narrative for understanding the experience of developing and being diagnosed with lung cancer. I began by offering my initial response to the second research question. It was this which led me to understand specific diseases in terms of a narrative structure and I presented my initial understanding of what such a structure encompassed. From this I suggested 'experiential emplotment' as a potentially useful way of conceptualising how individuals create sense out of their symptomatic experiences. Individuals draw on storied meaning within the storied social context and bring meaning to their experience through emplotting it into a narrative plot. The nature of this narrative plot is determined by those visible and acceptable within the storied social context and on the biography and experience of the individual (availability). In emplotting the symptomatic experience into a narrative, the story of another time or of another person becomes the story of the individual. Events and situations are positioned as next in the sequence and

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[123] The middle of the narrative structure, the main action, also relates to 'what next?' – the next steps in the sequence.

become available to the individual in light of the emplotment which provides a template for the future.

I attempted to ground the concept of experiential emplotment within the illness narrative data and presented excerpts from the illness narratives to illustrate the significance of narrative for interpreting and responding to the symptomatic experiences associated with the disease. On occasion the narrative plot which an individual drew upon to create sense out of their experience positioned presentation for medical advice as the next step in the sequence. Alternatively, presentation for medical advice was not positioned within the sequence of the initial narrative plot drawn on to bring meaning to the experience and only became available when a different plot was drawn on to create sense out of a changing situation. For two participants, the symptomatic experiences associated with lung cancer were emplotted into a narrative which never positioned presentation for medical advice as the next step in the sequence.

The grounding of experiential emplotment within the illness narrative data and the narrative case studies presented in chapter four drew attention to the many and varied narrative plots which can be drawn on to bring meaning to the symptomatic experiences associated with the development of lung cancer. Of the participants, two had drawn upon, and emplotted their experience into, the narrative of lung cancer prior to presenting for medical advice but one of the individuals was not able to sustain this interpretation. This led me to explore the narrative of lung cancer as generated within the illness narratives beyond the issue of genesis. I then offered my revised response to the second research question and an updated conceptualisation of the narrative structure of a specific disease. I suggested that the narrative of lung cancer, as espoused within the illness narratives of individuals who had been recently diagnosed with the disease, positioned it as having a particular beginning and a particular middle. Many of the individuals who developed the disease could not therefore draw upon it to create sense out of their own experience for they could not see themselves in it; could not see their biography in the beginning of the disease's narrative and their experience in the middle of the disease's narrative.

6.9.1 Key points to take away from this chapter

I have suggested that

- the sequential and temporal features of narrative position it as an important resource from which individuals can draw to create sense out of their symptomatic experiences

- individuals draw upon storied meaning within the storied social context and emplot their symptomatic experience into a narrative plot through a process of experiential emplotment

- the nature of a narrative plot drawn on to bring meaning to the experience is dependent upon those visible and acceptable within the storied social context and on the biography and the experience of the individual (availability)

- a specific disease is understood in terms of a narrative structure, in terms of a beginning, a middle and an end, and is just one such narrative plot which an individual can draw upon and emplot their experience into

- the narrative of a specific disease emphasises sequence and as well as giving meaning to the past and the present, provides a template for the future

- for an individual to draw upon the narrative plot of a specific disease, they must be able to see themselves in the story; see their biography in the beginning of the disease's narrative and their experience in the middle of the disease's narrative

7 Discussing the study: Implications, limitations and future directions

7.1 Introduction to the chapter

I have introduced data from the illness narratives to illustrate my understandings in the last three chapters and throughout these chapters I have tried to implicitly thread through the study's contribution. I have suggested that narrative, as storied meaning, is significant for the interpretation of symptomatic experiences and that all interpretations are made within a storied social context which influences, indeed limits, the possibilities of that interpretation. I have proposed that for individuals to draw upon a narrative plot and emplot their experience into it, it must be visible within the storied social context and available to them (such that they can see themselves in it). The acceptability of the narrative plot is also important. The narratives of specific diseases are just one type of narrative plot which an individual can draw upon and emplot their experience into. However I have suggested that many of the individuals who develop lung cancer cannot interpret their experience as related to the disease for they cannot see themselves, their biography and experience, in its narrative. Moreover, I have proposed that competing emplotments exist within the storied social context which are positioned as more visible, more acceptable and are more available.

How an individual interprets their symptomatic experience is of great importance for it influences how the individual will respond to that experience. Conceptualising interpretation in terms of experiential emplotment brings this situation to the fore since the narrative plot which an individual draws upon and emplots their experience into continues to move forward through time and positions events as next in the sequence. It is because the nature of the interpretation is viewed as central to the response that efforts developed to facilitate earlier diagnosis have sought to influence the way in which particular symptomatic experiences are interpreted, and specifically to influence individuals to correctly interpret particular experiences as related to a specific disease. Indeed, facilitating individuals to interpret particular symptomatic experiences as related to cancer is central to its timely diagnosis since this recognition endows the experience with significance and positions medical advice seeking as a step in the sequence. In this, consultation with a health professional may occur sooner than would have been the case if an alternative interpretation had been made. In seeking to understand the experience of developing and being diagnosed with lung cancer, and particularly through seeking to understand how individuals interpret the symptomatic experiences associated with the disease and why they often do not interpret them as related to it, this study has thus been able to fulfil its purpose of contributing to the earlier diagnosis of lung cancer.

The implications of the understanding generated through this study will be considered within this, the final chapter, as it is discussed in relation to the existing literature. I then consider some of the study's limitations and this leads me to identify the aspects of the research process which I wish that I had done differently, followed by lessons learnt for the future. From here I address the issue of moving forward and the possible future direction of research which fits within three broad areas.

7.2 Discussing the study and its implications

The experience of developing and being diagnosed with lung cancer is complex and variable. Individuals develop different symptomatic experiences which they interpret differently and thus respond to differently. If brought to the attention of medical professionals, the experiences can be interpreted differently further still and all of these factors serve to facilitate or impede the process of biomedical diagnosis.

That the experiences associated with the development of lung cancer are not inherently meaningful gives rise to the varying interpretations. As this study has reinforced, these interpretations often render the experience as related to normal life or normal illness. Interpretations which associate the experience with a serious or significant situation can be evoked but only a minority of individuals with lung cancer interpret their symptomatic experience as related to the disease prior to presenting for medical advice. Why is this the case? If a range of interpretations are possible, why is lung cancer often not one of them?

Within much of the existing literature, an individual who does not interpret their experience as related to the disease with which they are subsequently diagnosed is positioned as failing. For them not to have made the correct interpretation there must be a deficit which could have been avoided if the individual had been educated as to the symptom labels associated with the disease. If this had been the case, a process of passive detection could have occurred whereby the individual would have become 'aware of a cancer symptom without a conscious action' (de Nooijer *et al* 2002, p362). In this way, the individual would have been able to compare his symptomatic experience with the disease/illness prototypes within his mind and to arrive at the correct interpretation (Bishop and Converse 1986; Andersen *et al* 1995). Indeed, Andersen *et al* (1995) conceptualise the process of interpretation

> 'as one of psychophysiological comparison – a comparison of bodily symptoms with at least two types of circumstances: salient situational events and/or circumstances (e.g. nausea may be due to eating something 'bad', low back pain may be due to strenuous exercise) and/or those of known illness prototypes (e.g. acute abdominal pain may be appendicitis)' (p36).

Following from this, whether the individual was in a position to make the correct interpretation would have been entirely independent of the social context in which he was situated and solely dependent on the correctness and the completeness of his cognitive structures. This is the understanding of interpretation within much of the existing literature. But what happens if you think of interpretation not as a passive process, but as an active one? If you position storied meaning as highly significant for interpretation? And if you suggest that interpretation is not solely determined by the individual but by the social context within which they live? Where does that take you and what does it mean for promoting the earlier diagnosis of lung cancer?

The interpretation of a symptomatic experience is at all times, irrespective of the outcome, an active and creative process. Symptomatic experiences are not inherently meaningful and so it is not the case that they can be passively detected. A symptomatic experience is brought into being and into significance. Narrative and the creation of narrative are highly important for creating sense out of a symptomatic experience. Narrative, connecting as it does a sequence of events, serves to suggest, if not causality, the relatedness of distinct happenings. This relationship positions storied meaning as an invaluable resource from which an individual can draw to create sense out of an experience[124]: if this happens, then this happens, then this happens in a story, then might this story be what is happening to me? If an individual can see themselves in the story, they can then draw upon that narrative plot and emplot their own experience into that sequence in a process of experiential emplotment. In this way, the story of another person or of another time becomes their story of the present and the future as events are identified as next steps in the sequence.

Experiential emplotment is different to the understanding of narrative within much of the existing literature which positions the creation of narrative as a mechanism for bringing order to the chaos of events that have been lived (Murray 2003). From this perspective, it is important that the experience has ended so that only those events which contribute to the plot and to the ending can be narrated (Sandelowski 1999; Lawler 2002). A frequently encountered term within the sociological literature, for example, is narrative reconstruction which involves identifying events and situations from one's biography and, with the benefit of hindsight, constructing them into a narrative which portrays a connectedness of events (Williams 1984). As Williams (1984) writes,

> 'Narrative reconstruction is an attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society' (p197).

But just as we might strive to find connection in events and experiences that have been lived, so we also strive for connection in events and experiences in the time that they are lived and we draw upon and create narrative to this end. In experiential emplotment, as in the concept of therapeutic emplotment which has informed it (Mattingly 1994; 1998), the creation of narrative is a prospective endeavour undertaken to create meaning out of experience. In this understanding, narrative is a powerful medium for communicating experience because narrative is drawn upon to construct and inform experience. From this perspective, the ending does not need to be known (see also Wikan 2000), though it can be imagined since the narrative plot moves forward through time positioning other events and situations in the sequence. Whilst there is not a firm ending, there is always a beginning which opens up a range of possibilities for emplotment. Indeed, the storied

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[124] Indeed, Andersen *et al* (1995), though not recognising it as such, acknowledge the significance of storied meaning in their conceptualisation of the process of psychophysiological comparison: 'e.g. nausea may be due to eating something 'bad', low back pain may be due to strenuous exercise ...acute abdominal pain may be appendicitis' (p36). These examples are small snapshots of narrative, events meaningfully connected over time.

social context is replete with storied meaning and narrative plots which can be drawn upon to create sense out of any one experience. But different narrative plots are more visible, more available and more acceptable than others and, in the case of narrative plots relating to specific diseases, may not reflect epidemiological and physiological understandings. In this way, the social context impacts on the interpretations that an individual can make of their experience. Interpretation is not independent of the social context or entirely contingent upon an individual's cognitive structures, but a complex interplay between the individual and the storied world within which they live.

There are many narrative plots which an individual can draw upon to create sense out of the symptomatic experiences associated with the development of lung cancer. Often the narrative plots drawn on to bring meaning to the experience interpret it as related to normal life or normal illness. This is a situation which I highlighted, indeed drew attention to, when I developed the narrative case studies and when I sought to ground the concept of experiential emplotment within the illness narrative data. Within the existing literature, such normative interpretations are presented as at once a failure and a tendency of the individual. Andersen *et al* (1995), for example, outline eight principles which they suggest characterise psychophysiological comparison. The sixth principle concerns the significance of optimistic bias and stipulates that an individual will prefer to make a benign interpretation over and above a disease-related one. But from the position of experiential emplotment, it is not that the individual prefers to make normalising interpretations but that the storied social context prefers the individual to do so. The storied social context, through influencing the visibility, availability and acceptability of narrative plots, influences, indeed limits, the possibilities of interpretation.

The narrative of lung cancer, I propose, is neither a visible, available nor acceptable narrative plot for individuals to draw upon and emplot their symptomatic experience in to. The narrative of lung cancer is, in comparison to alternative emplotments, a little-encountered story within the storied social context. When the narrative of lung cancer is constructed and communicated, it positions the disease in a particular way; as having a particular beginning, middle and end. This sequence, and specifically the beginning and end, constructs the disease in such a way that the implications and repercussions for the individual ensures that it is not an acceptable emplotment and so, potentially, one that individuals would avoid creating.

The narrative of lung cancer, as it is constructed and communicated within the storied social context, positions it as a disease of smokers who develop severe, debilitating symptoms which make them look and feel ill. The 'what next?' aspect of the structure is implicit but could be considered to be palliation or waiting to die since the end of the narrative of lung cancer culminates in the death of the smoker. Through my extensive engagement during the study, absorbing as much as I could to help me to understand the experience of developing and being diagnosed with lung cancer, I encountered this narrative of lung cancer within many facets of the wider social world. It was in the interventions and measures which have been developed as part of the tobacco control agenda, for example the television advert featuring Steve that I described in section 2.4.11.3 and the warning on tobacco products that 'Smoking causes fatal lung cancer'[125]. It was in the literature produced by non-governmental organisations, for example when Cancer Research UK provided information about lung cancer in the leaflet concerning the impact of lifestyle on the development of cancer and not in a dedicated leaflet as they did for breast, bowel, cervical, skin, mouth, prostate and testicular cancer (see CRUK 2007b). It was in the general media and particularly the news media which reported the diagnosis, and subsequent death, of an individual with lung cancer[126]. It was in the literature produced by the government which conveyed information relating to the disease, for example that contained in the NHS Direct encyclopaedia which presents lung cancer as a fatal disease whilst pancreatic cancer, though it has a lower rate of survival, is presented in an altogether more positive and hopeful light[127]. And all the time this narrative of lung cancer is evident, it is exerting an influence. It is influencing how individuals understand the disease and it is limiting the possibilities of interpretation.

Certainly the participants of this study constructed and communicated a narrative of lung cancer which reflected the disease's narrative within the storied social context. Through my exploration of the narratives of genesis, lung cancer was understood to have a particular beginning which positioned the disease as one of current, heavy

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[125] See the 2001 European Union (EU) Directive relating to the manufacture, presentation and sale of tobacco products (EU 2001).

[126] The media coverage of the deaths of Cheryl Barrymore (2005), Fred Trueman (2006) and Allen Carr (2006) exemplify the portrayal of lung cancer within the news media.

[127] The following two excerpts appear at the end of the introduction to each of the disease types: 'The outlook for people with lung cancer is not good. Only 20% of people are alive one year after being diagnosed with the disease, and only 8% survive for five years' (NHS Direct 2007a) compared with 'Cancer of the pancreas affects about 7,000 people in the UK each year. It is very serious and it can be difficult to treat, especially if it is not diagnosed early' (NHS Direct 2007b).

smokers of a certain age. Stemming from my exploration of the illness narratives beyond the issue of genesis, the narrative of lung cancer was associated with a particular middle; a main action which outlined the wider experience as one of multiple, continuous, debilitating respiratory symptoms, a high level of pain and looking and feeling ill. The implication of this was that many of the individuals who developed lung cancer could not draw upon the narrative of lung cancer and emplot their experience into it for they did not see themselves in it: they could not see their biography in the beginning of the disease's narrative and their experience in its middle. I have illustrated this situation in Figure 11.

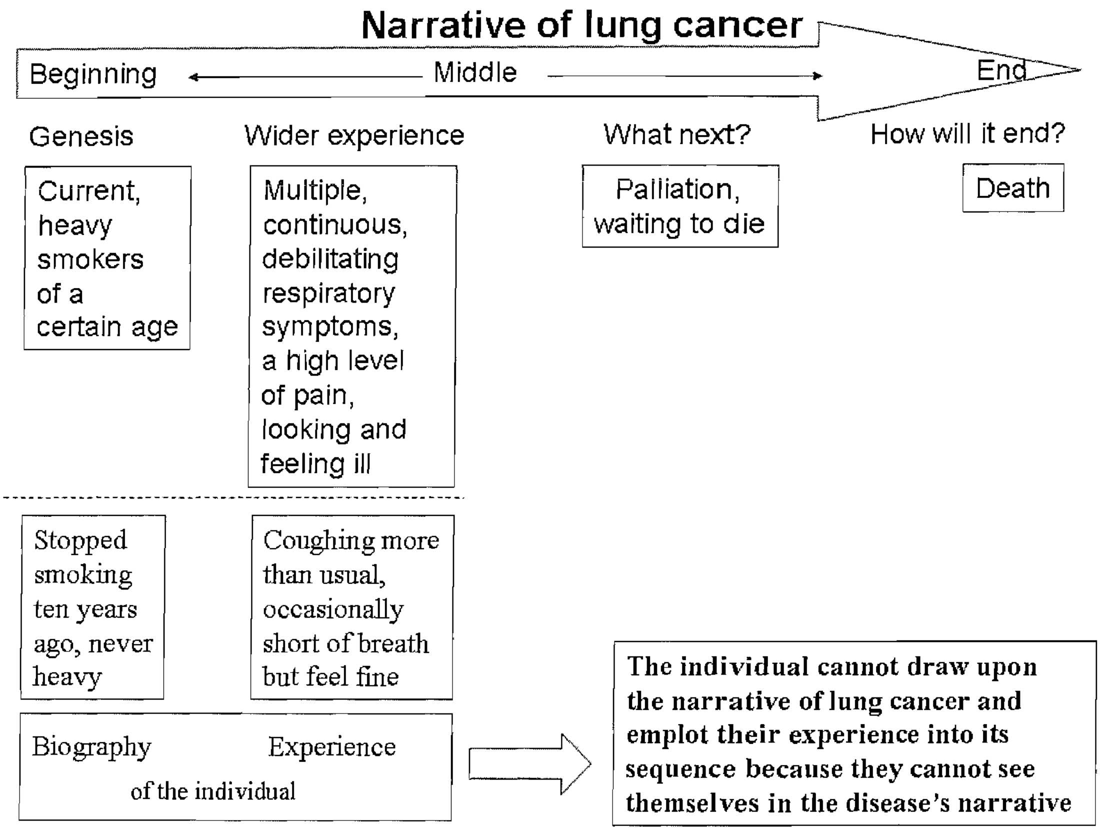

Figure 11: A schematic representation of the importance of seeing oneself in the narrative of the disease and the implication of not seeing oneself.

The narrative of lung cancer, as it is constructed in aspects of the wider social world, and as it was espoused by individuals who had been recently diagnosed with the disease, does not reflect how the disease is experienced and in whom. Lung cancer is not just a disease of current, heavy smokers of a certain age but positioning it in this way means that only current, heavy smokers of that age can see their biography in the disease's narrative and potentially draw upon it to create sense out of their symptomatic experience. Similarly, the experience of developing lung cancer is complex and varied with individuals experiencing a range of different symptomatic experiences which have different characteristics and implications for the individual. To be developing lung cancer, as the disease's narrative goes, one has to look and feel ill. But for the individuals who do not look or feel in this way, the potential for them to see themselves in lung cancer and to emplot their experience into its sequence is not there. For all of these factors the interpretation of lung cancer was, thus, unavailable to many of the individuals who developed the disease.

7.3 Responding to the third research question

Through this study I sought to develop an understanding of the experience of developing and being diagnosed with lung cancer. In responding to the first and second research questions, I demonstrated my particular interest in understanding how the symptomatic experiences associated with the development of lung cancer are interpreted. This understanding is important because the interpretation that an individual makes of their experience influences their response to it. The understanding which I developed through this study allows me to respond to the third research question:

3. How might the processes of interpretation and presentation be influenced so as to make a contribution to the earlier diagnosis of the disease?

Influencing the process of interpretation, influencing how the symptomatic experiences associated with the development of lung cancer are interpreted, is fundamental to diagnosis and thereby to its earlier diagnosis. However, facilitating the correct interpretation of the symptomatic experiences is not about helping 'people at risk, recognise their symptoms' as Baird (2003, p119) suggests. Rather it is about positioning the narrative of lung cancer, which is faithful to how the disease is experienced and in whom, as a visible and acceptable story for individuals to draw upon and emplot their experience in to. Once emplotted, the disease's narrative would identify the next appropriate step in the sequence, specifically presentation for medical advice, signalling the close relationship between interpretation and the potential for presentation[128].

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[128] I acknowledge that there are many factors which may influence whether presentation actually occurs (see Gulliford and Morgan 2003) but as with interpreting particular symptomatic experiences as related to lung cancer, it is that it is a possibility for individuals: individuals *could*, not that they *will*.

7.3.1 Existing interventions for influencing interpretation

Existing interventions which have sought to influence the way in which the symptomatic experiences associated with lung cancer are interpreted have been developed from the understanding of interpretation within the literature. In this, the individual is perceived as deficient and the emphasis is on completing or correcting an individual's cognitive prototype of the disease. The dissemination of categorical information, primarily relating to the symptom labels associated with the disease, is seen as an important mechanism for facilitating passive detection and securing prompt medical attention. In this it is assumed that symptom labels are the principal aspect of how a specific disease is understood. Moreover, it is assumed that individuals within the general population, or those at increased risk of developing the disease, do not have knowledge of the symptoms associated with lung cancer for if they did, individuals would more often interpret particular symptomatic experiences as related to lung cancer and present for medical advice accordingly. The following excerpts, for example, have been extracted from the leaflet produced by The Roy Castle Lung Cancer Foundation and Macmillan Cancer Support to coincide with lung cancer awareness month in November 2006.

Excerpt 1

WHAT TO LOOK FOR

There are lots of reasons why you might have some of the symptoms below. But it's worth getting yourself checked out because whatever it is, your GP will be able to help.

-Chest infections that won't go away, even with antibiotics.
-Having a cough for more than three weeks.
-Feeling more tired than usual.
-More spit or phlegm, especially with blood in it.
-Feeling very out of breath.
-Losing your voice but no sore throat.
-Chest pains.
-Swelling in your face or neck.
-Losing weight, but not sure why.

If you have any of these symptoms, make an appointment today to see your GP.

Excerpt 2

'I had aches and pains, breathlessness and was very tired. It was only when my family insisted I get myself seen to that I went to the GP. I am so glad that I didn't wait any longer'

'I VISITED MY GP BECAUSE I HAD BEEN SWEATING AT NIGHT, HE SENT ME FOR A CHEST X-RAY STRAIGHT AWAY AND THEN I WAS DIAGNOSED

WITH LUNG CANCER. I WISH I HAD GONE EARLIER BUT I DIDN'T WANT TO BOTHER HIM'

'I HAD A BAD COUGH FOR ABOUT SIX MONTHS AND DIDN'T REALISE IT COULD BE A SYMPTOM OF LUNG CANCER. IF I HAD I WOULD DEFINITELY HAVE DONE SOMETHING ABOUT IT SOONER'

The Roy Castle Lung Cancer Foundation and Macmillan Cancer Support (2006)

Communicating information relating to the symptom labels associated with lung cancer reflects the recommendations within the literature (see for example Christensen *et al* 1997; Koyi *et al* 2002; Bowen and Rayner 2002; Taggart *et al* 2005). However, there is little evidence to suggest that the approach is effective and indeed its limitations have been recognised for many years. Zola (1966), for example, suggests that many symptom-based health education initiatives fail because they make the assumption that 'a symptom or sign is fairly objective and recognizable and that it evokes similar levels of awareness and reaction' (p630). As well as attempting to educate individuals as to the symptom labels associated with lung cancer, the existing interventions have also attempted to address other aspects of how the disease is known, as illustrated by the modified question and answer section in the most recent leaflet.

Excerpt 3
MYTH 1: There's no such thing as just a smoker's cough.
FACT: A persistent cough is evidence that something is wrong and needs checking out.

MYTH 2: Lung cancer is just a smoker's disease.
FACT: Although the major risk factor of lung cancer is smoking, around one in six people with lung cancer have never smoked.

MYTH 3: Lung cancer is a working class male disease.
FACT: Lung cancer can affect anyone and there has been a big increase in the number of women who are affected.

MYTH 4: It's only old people who get lung cancer.
FACT: Whether you're in your twenties or nineties, anyone can get lung cancer.

MYTH 5: Lung cancer is a death sentence.
FACT: It does not have to be. New treatments are being developed all of the time. If caught early enough it may be curable.

The Roy Castle Lung Cancer Foundation and Macmillan Cancer Support (2006)

Relevant to my revised understanding of why many of the participants did not seem to interpret their symptomatic experience as related to lung cancer, the myth and fact section does address the issue of genesis as it is relevant to the disease. The leaflet emphasises, for example, that lung cancer is not just a disease of smokers, of working class men and of old people. But this is categorical meaning and the issue of genesis is considered entirely independent of the symptom labels associated with the disease and so there is no sequence or connection. Similarly, whilst the quotes (featured in excerpt 2) are written in the first person and are presented as real individuals speaking about a real experience related to developing and being diagnosed with lung cancer, they are not affiliated to a person. There is no prior sequence, no name, no age, no biography to allow the individual reading the leaflet to see themselves in the experience that they are reading about. Within this leaflet, as in the other products developed for the campaign, there is absolutely no story for individuals to see themselves in and thus be in a position to draw upon and emplot their experience into.

7.3.2 Health education and empowerment

Within the existing interventions, health education is viewed as a means through which to influence individuals to act in line with a pre-defined, correct response and behaviour through the provision of information. However, there are alternative ways in which health education can be viewed which are more congruent with my understanding of how individuals interpret the symptomatic experiences associated with disease. Tones and Tilford (2001), for example, see the potential for much gain in an empowerment model of health promotion and present it as being in contrast to the preventive model, which seeks to 'persuade and coerce', and the educational model, which 'merely aims to provide information' (p49). Key to their empowerment model are health education and healthy public policy, the interaction and integration of which fosters individual and community empowerment and equity. Indeed, the authors define self-empowerment as

> 'a state in which an individual possesses a relatively high degree of actual power – that is, a *genuine* potential for making choices' (Tones and Tilford 2001, p40, emphasis in original).

The empowerment model recognises the implications of an individual living within a particular social context and the impact that this can have on the choices that an individual can make in relation to their health. In much the same way, my understanding of interpretation recognises the significance of the storied social context for the interpretations that an individual can make of their symptomatic experiences.

Health education, when drawn upon within the empowerment model, seeks to facilitate understanding and to enhance 'individuals' control over their lives and their health' (Tones and Tilford 2001, p50). Health education interventions which are built upon the 'actionable insight' (NCC 2006) developed through this study would address the visibility, availability and acceptability of the disease's narrative and make the interpretation of lung cancer accessible to those who may need to draw upon it. In this way, there is the potential for genuine choice and therefore greater equity and enhanced control. Of course, it is entirely reasonable that some individuals would prefer not to have the option of interpreting their experience as related to lung cancer, would prefer not to be empowered, and this is why it is important to be conscious of the drivers of health education (see Thorogood 1992; 1996). In whose interests, for example, is it for individuals to be empowered, and equally, in whose interests is it for individuals to be disempowered?

7.3.3 Implications for a health education intervention

7.3.3.1 The provision of storied meaning

A health education intervention which is based on my understanding of interpretation would be very different to the existing interventions. If, as I have proposed, narrative is central to the interpretation of symptomatic experiences, then a health education intervention built upon this understanding would seek to construct and communicate storied meaning. The provision of storied meaning which draws attention to how lung cancer is experienced and in whom, would maximise the opportunity for individuals to see themselves, or be seen by others, in the disease. If individuals could see aspects of their biography and their experience in the narrative of lung cancer, the potential is there for them to draw upon it to create sense out of their own experience and emplot their experience into it: if this happens, then this happens, then this happens in (the story of) lung cancer, then might lung cancer be what is happening to me? First person narratives which construct the experience of developing and being diagnosed with lung cancer would thus be central to the intervention. The narratives would also extend forwards in time to identify the next steps in the sequence, sanctioning presentation for medical advice as the justified, and potentially beneficial, next step.

There would, in effect, not just be one narrative of lung cancer but many incorporated into a range of interventions so as to reflect the complex and varied nature of the experience. Figure 12 highlights the facets of the narrative of lung cancer which would need to be constructed and communicated for it to be faithful to how the disease is experienced and in whom.

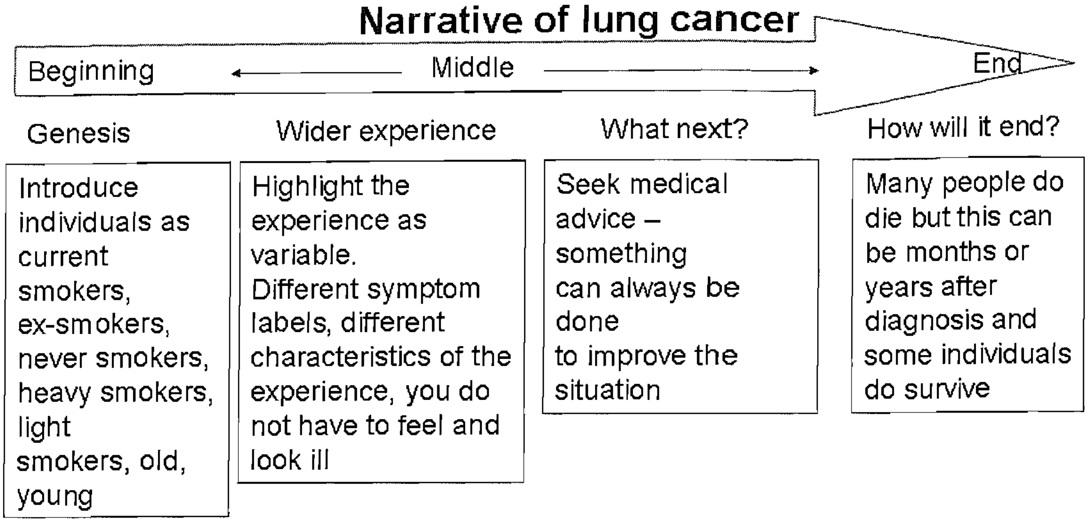

Figure 12: A schematic representation of the faithful narrative of lung cancer.

Whilst, for purposes of representation and understanding, I have made a distinction within the narrative of lung cancer between the beginning, middle and end and between genesis, wider experience, what next? and how will it end?, I want to emphasise that the whole is greater than the sum of the parts and that it is the sequence, and not solely the content, which is important. As I have previously mentioned, the existing interventions do attempt to address the issue of genesis as it relates to lung cancer, but it is not enough to produce health education materials which communicate that you do not have to be a current, heavily smoking older person to develop lung cancer or that you do not have to experience pain or feel ill to be developing the disease. There is no sequence in doing this, no story for individuals to see themselves in and to draw upon to create sense out of their symptomatic experience. The interventions built upon my understanding would seek to maintain the connectedness between the events and present the stories of lung cancer: 'this happened, then this happened, then this happened and I had lung cancer, *and* I am …'

Similarly, the publication of the symptom labels associated with lung cancer would not form the crux of the intervention shaped by experiential emplotment. Individuals do not live a life defined by symptoms. Moreover, as Corbin (2003) suggests, individuals do 'not talk a language of symptoms. They talk about a change in sensations or appearance'[129] (p258). Each symptomatic experience associated with the development of lung cancer can have a very real and tangible impact on the life of the individual. To illustrate, where the symptom label is a cough, the individual may experience it in terms of not being able to maintain a full conversation, or as for participant 110:

P: [it was] more of a nuisance than anything else and when you were out or you'd be eating or something like that, you know, when you're driving the car, you start coughing when you're driving the car ...so you either pull over or what have you (110)

Where breathlessness or feeling very out of breath is the label, the impact on the individual might be in terms of adjusting levels of activity; taking life at a slower pace and integrating additional rests where possible:

P: I go out to the kitchen and all like that but then after a while I gotta sit down cos I got no breath (133)

Or an individual may recognise a change in the tightness of clothes or belt notch as the tangible experience of actually having had lost weight:

P: I've got a straight skirt, I've only worn it 'bout twice. Put it on and it fell down on the floor (121)

An intervention informed by my understanding of interpretation would seek to present these tangible impacts within first person narratives in anticipation that it would enhance the opportunity for individuals to see themselves, or be seen by others, in lung cancer and so to consider drawing upon and emplotting the experience into the disease's narrative.

7.3.3.2 Narrative: transportation versus reflection

The use of narrative as a mechanism for communicating information and changing situations has been advocated in the literature. Green (2006), for example, writes that research

> 'has shown that individuals who are transported into a narrative world are likely to change their real-world beliefs in response to information, claims, or events in a story' (pS165).

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[129] Though some individuals, for example medical professionals, do talk a language of symptoms, at least in the course of their professional life. Indeed, symptoms are central to a biomedical frame of reference and this is why I deemed it appropriate to construct the narrative case studies around particular symptomatic experiences – ultimately, I thought this was of the most use.

As may be evident from this quote, Green is heavily drawn to transportation theory and considers narrative to be a vehicle through which individuals can become 'absorbed in a story or transported into a narrative world' (Green and Brock 2000, p701). This is entirely congruent with the existing narrative literature which suggests that narratives are absorbing because they allow the audience to enter into an experience (Greenhalgh and Hurwitz 1999) and indeed that through illness narratives, individuals are invited into the experience of illness (Frank 2000). But from my understanding of interpretation, the strength of narrative would lie in its ability to allow individuals to see themselves, or be seen by others, in an experience and in so doing offer a possibility, a narrative plot for an experience to be emplotted in to. In this way, the emphasis would be on facilitating reflection rather than facilitating transportation.

An intervention which is congruent with my understanding of interpretation would, then, strive to communicate and construct narratives of lung cancer which are faithful to how the disease is experienced in whom. There are a range of mediums through which such narratives could be made visible since narrative can take on written, visual and audio forms (Bleakley 2005). The choice of medium is likely to depend on who it is that one strives to make the interpretation of lung cancer available to.

7.3.4 Levels to be addressed by health education interventions

The existing interventions which have been developed to influence interpretation and presentation in lung cancer have a tendency to address the level of individuals. This may be because these interventions have been managed by non-governmental organisations and so are likely to be subject to resource constraints. However, it is widely acknowledged that, to increase success, health promotion efforts target a number of different levels and factors (Macdonald and Bunton 1993; Ewles and Simnett 2003) and so it follows that a health education intervention developed so as to influence interpretation and presentation in lung cancer must do the same. I have represented these levels in Figure 13.

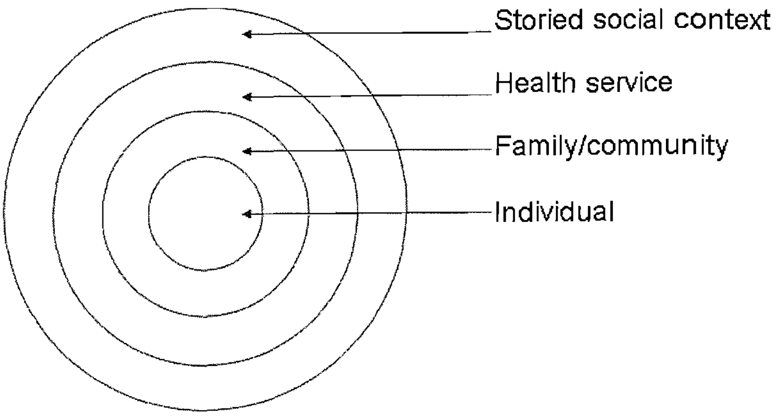

Figure 13: A schematic representation of the levels to be addressed by health education interventions.

It is now my intention to consider what it is that I mean by each of the levels.

7.3.4.1 The individual

At the level of the individual I am referring in particular to those who may develop lung cancer. As I mentioned earlier in this thesis, the development of lung cancer has been associated with a number of factors such as age of 55 years and over (Peto *et al* 2000); current smoking status (Doll *et al* 2004) and the cessation of smoking in the previous 12 months (Doll *et al* 2004). Whilst lung cancer can in effect develop in any individual, these factors are helpful for identifying sections of a whole population who are at increased risk of developing the disease.

Health education interventions which incorporate first person narrative experiences of lung cancer can be delivered to individuals deemed at risk of developing the disease through a range of media. Written material, particularly in the form of leaflets is one such vehicle though there are limitations of this type of approach. There are important issues to consider relating to how to disseminate the leaflets and inappropriate decisions in this regard may severely limit their impact. One route through which individuals at increased risk of developing lung cancer could receive this type of written information could be through accessing those who have attended NHS stop smoking services. Alternatively, many individuals who undertake smoking cessation attempts do not utilise organised services and instead choose to co-ordinate their own effort. Whilst some of these individuals adopt a 'cold turkey' approach, others buy their own nicotine replacement products (NRT). This raises the possibility that individuals at increased risk of developing lung cancer could receive intervention materials through these products or as a result of purchasing such products. In this way, an existing service could extend its role so that it becomes a mediator through which a health education intervention is provided. This would not restrict the form of such intervention to written material, and could allow for alternative, potentially more interactive, interventions.

Similarly, it is not just that a service can act as the deliverer of an intervention once an individual accesses the service, but that a service can go out to the individual. In light of the smoking legislation within the UK, smoking cessation has been heavily promoted and innovative ways of accessing individuals who may need advice about stopping smoking have been developed. Within the geographical locality of this study, members of the NHS stop smoking service have gone into workplaces and similar environments to support employees who, in light of the legislation, are no longer able to smoke as they have done. A similar approach of 'going forth' into particular arenas (Downie *et al* 1996) could be used to deliver health education interventions which seek to construct and communicate the narratives of lung cancer and the nature of this approach may allow for imaginative and interactive mechanisms of delivery.

7.3.4.2 The family/community

At the level of the family/community I am referring to a collective who, whilst not developing lung cancer themselves, are likely to have contact with an individual who develops the disease. It is understood within the existing literature that significant others can influence the way in which symptomatic experiences are interpreted and responded to and indeed this situation was encountered within this study. Members of family and friends and the non-specified 'they' influenced the interpretations of many of the participants since they emplotted the individual's experience into a particular narrative or reinforced the legitimacy of a particular emplotment. A health education intervention targeted at the level of the family/community would allow them to see individuals close or known to them in lung cancer when they might not have otherwise done so. The interventions could be based on written narratives but there may also be scope for more interactive or visual dissemination. An approach informed by the Macmillan Cancer Information Centre, which tours the country and situates itself in accessible places of a community, may be an appropriate one to employ. Going forth into communities in this way could be used to sensitise them to the inequity that surrounds lung cancer and to mobilise their opinion, something which Tones and Tilford (2001) suggest is the most important principle of health education with a model of empowerment. The public health observatories collect data relating to the incidence of diseases and it is recognised, for example, that even across small geographical distances, the incidence of lung cancer can vary significantly. But the communities in question may not know this information and if they did, they may be pressed to ask uncomfortable questions and to seek the creation of immediate and more distant policies which could impact on this situation.

7.3.4.3 The health service

At the level of the health service I am referring to the disease-based services which are likely to encounter individuals who have developed the symptomatic experiences associated with lung cancer, principally pharmacists, pharmacy employees and GPs and surgery employees.

Before presenting for medical advice, if indeed they did present, the management sequence undertaken by several of the participants in this study positioned the taking of medicinal preparations such as cough medicines, cough sweets and throat soothers as an appropriate and available next step. Whilst some of the participants already had access to such preparations, others had to buy them and this meant that the individual came into contact with a service. Often, contact with this facet of service provision served to reinforce the participant's benign, or at least unproblematic, interpretation of their experience and significantly, postponed the need to present to a GP for medical advice.

Similarly, surgery employees and GPs can significantly facilitate or impede the process of biomedical diagnosis. For many of the participants in this study, more than one GP consultation was necessary before further action was taken. Such a situation is not always unreasonable since the guidelines outline a policy of caution so as to assess the significance of particular symptomatic experiences. But within this study there were a small number of examples which led me to call into question the GPs response[130]. Of course, this judgement was based entirely on the illness narrative of the participant, but it is important to consider the practices of GPs as they are the gatekeepers to further investigation and specialised services. Given this and the previous discussion concerning pharmacists and pharmacy employees, a health education intervention which

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[130] One example which I remember clearly is the experience of one of the male participants. He had presented for medical advice in the January of one year for he was having difficultly breathing. He was sent for a spirometry test but shortly afterwards he had a heart attack which displaced the interest in his chest. He recovered from the heart attack and later in the year developed shoulder discomfort, for which the GP made a physiotherapy referral, and occasional haemoptysis for which no further action was taken. At the time of the interview, more than one year following the initial breathlessness, the participant still thought that his occasional haemoptysis was caused by the damaging effects of his nicotine gum.

draws attention to the narratives of lung cancer may allow individuals working within the health services to see the disease in individuals who they would otherwise not see it in.

7.3.4.4 The storied social context

At the level of the storied social context I am referring to all of the levels previously discussed since any intervention would, as necessarily situated within the social context, influence it. But the interventions directed at these levels, because of the sheer size of the populations and the limited resources, would not reach all of those who may need to draw upon the narrative of lung cancer and there would be areas without attention both within and between the levels. Other interventions could, then, be developed so as to seek to address this situation and to position the narratives of lung cancer within the storied social context as a whole. Such interventions would make use of existing media channels and could involve the development of first person audio and visual narratives to be disseminated as radio and television adverts or through e-mail attachments. Whilst these are dedicated health education interventions, intensive and effective lobbying of significant individuals may lead them to incorporate the narratives of lung cancer into soap opera storylines, topics on chat and current affairs shows and articles within newspapers and magazines and in this way enhance the visibility of the disease.

The health education interventions developed on the basis of the ‘actionable insight’ (NCC 2006) developed through this study would seek to construct and communicate narratives of lung cancer which are faithful to how the disease is experienced and in whom. Overarching the provision of these narratives is a concern with equity and with positively advocating the disease. If such interventions are not developed, then many of the individuals who develop lung cancer will not be in a position to interpret their experience as related to the disease. The implication of this is likely to be that a greater period of time elapses between the initial symptomatic experience and presentation for medical advice. Certainly many of the participants in this study interpreted their experience as related to normal life or normal illness with the subsequent implication that presentation for medical advice was not a step in the management sequence. That these normative emplotments were made is not a sign of the deficiency of the individual, but of the storied social context which positions these interpretations as more visible, available and acceptable. Any intervention which seeks to position the faithful narratives of lung cancer within the storied social context has to be aware of this and needs to be able to compete with the alternative emplotments. With this in mind, the intervention would need to consider whose interests were served through restricting the interpretation of lung cancer and envisage ways in which any conflict of interest could be resolved. Indeed, any intervention would exist within a storied social context which consistently, at least at the current time, serves to construct and reinforce the exclusive and inequitable version of the disease's narrative. This is certainly in the interest of the tobacco control agenda and there may be others who are served by this. But if any health education intervention is to be successful and to reach its fullest potential, then there is a real need for a policy shift which obliges all individuals and agencies which refer to lung cancer to consider the implications of what they say and do for the individuals who are to develop the disease (and those who have been diagnosed with it). Only then may all of the individuals who need to draw upon the narrative of lung cancer be in a position to do so.

7.4 Limitations

Whilst I feel that this study is a valuable contribution it is important to acknowledge its limitations and to recognise aspects of the research process which, should I have the opportunity again, I would do differently.

Within the existing literature, a small sample size is often presented as a limitation of studies. Certainly when one is attempting to confer statistical generalisation there is usually a minimum requirement for the number of participants or units of analysis. However, my intention was never to offer statistical generalisation and instead I opted to adopt a case study approach to the research. The nature of case study research is that it attempts to understand and explore the unique and the particular (Stake 1995) and in this way it is usual to draw upon small sample sizes. Indeed, to do otherwise would be to limit the extent to which the researcher would be able to understand the nuances and complexity of the case. In developing an understanding of the case, the researcher offers their interpretation which, though tentative, can be insightful for understanding other cases, other situations. The exploration of the unique can then be drawn upon outside of the tight boundaries of the case through conceptual, as opposed to statistical, generalisation (Radley and Chamberlain 2001).

Another frequently encountered limitation within the existing literature is the retrospective nature of the generated data. Indeed, I attempted to understand the experience of developing and being diagnosed with lung cancer prinipally through engaging individuals recently diagnosed with the disease in the generation of their illness narrative. This meant that the participants retrospectively constructed and communicated their experience from the vantage position of being diagnosed with a serious disease. But this is not viewed as a limitation within much of the existing narrative literature (see for example Sandelowski 1999). Moreover, it is accepted that, whilst narratives may be constructed around 'remembered facts' (Lieblich *et al* 1998), they are ever-changeable phenomena, constructed to fit the particularities of the context. In positioning retrospectively generated data as inferior, prospectively generated data are held in high regard and viewed as the optimum approach. However, this accords somewhat greater value to a prospective approach than may be warranted. Even with a prospective approach, I would need to be there at all times, as if a fly on the wall, to know that the events, situations, experiences were happening in the way that they would be, subsequently, prospectively described and still I would be seeing through my eyes whilst the participant would be seeing through theirs.

The intention of this research was to make a contribution to the earlier diagnosis of lung cancer and with this the practical aspects of the research process took precedence over any ideal. It is for this reason that I, as the researcher, and you, as the reader, have to have trust. Trust in the participants but also trust in me. I believe that the following excerpt from the final interview of the study highlights this.

I – is there anything that you've said that you'd rather me not include in the study or are you happy for me to use everything that you've said today?
P – it ain't gonna do me no harm love is it?
I – no, well I won't let it do you any harm no it's, it's just, just to make sure that you're happy that I use what you've said
P – if it's any beneficial to you love use it **cos I ain't told you nothing that's not true** so okay (my emphasis)
I – alright, thank you (133)

I am quite sure that all of the participants, like participant 133, felt as though they were telling me the truth of their experience[131]. It then fell to me to incorporate these data into the study in an ethical and informative way. The issue of harm raised in this excerpt is an important one and I have tried, as difficult as it has been at times particularly on an emotional level, to keep the participants with me and to think of them as I have sought

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[131] Recall the excerpt from my research log in section 3.7.13 in which I wrote how one of the participants who declined to be recorded wanted to check my notes because she 'was concerned that I should only write down what was true'.

to generate understanding. In this, I have strived to view consent as an on-going process (Estroff 1995) and to consider the impact that my understandings might have on the individual participants and on the community of individuals with lung cancer as a whole, both now and in the future. Whilst I position my understandings as tentative, it is ethically important that they are defensible and justified but also that they are useful. I believe that this study is useful on a number of different levels and it is on this merit that I hope it will be judged.

7.4.1 Lessons learnt

Conducting this study was a huge learning experience for me and I have tried to convey this through writing of my journey both through the existing literature and the generated data. With this comes a number of regrets and wishes that I had done things differently. Because I view my understanding as tentative, I do not wish that I should have conducted the study in a different way so as to achieve more truthful findings, but I have learnt lessons which would allow me to be more comfortable in conducting future studies. At the time of engaging in the consent procedure, for example, I told the participants that from that point forwards they would be referred to as a number. At the time I did not think too much of this but as I came to write this thesis and to present excerpts from the illness narratives, the only way that I could link the excerpts to a participant was by associating them with the number. I felt uncomfortable with this since there is much negativity attached to numbers as if to be referred to by a number is to neglect everything that makes an individual unique.

In retrospect, I may have found the situation easier if I had allocated each of the participants a pseudonym, as I did when I referred to individual health professionals in an excerpt from my research log (section 3.7.4). But Grinyer (2002) raises three interesting points in relation to the use of pseudonyms. Firstly, the chosen pseudonym may not reflect the original name of the participant, for example the transcriber in Grinyer's study gave a participant the name Joan, when her real name was Gabrielle. Secondly, the name allocated to a participant may hold particularly negative connotations for that participant. Thirdly, individuals may not want to be anonymised and may prefer that their original identity be preserved in any publication of the study. Indeed, when asked how they would like to be referred to, approximately three-quarters of the participants in Grinyer's study specified that they would like to be referred to by their own name, with just seven choosing to be allocated a pseudonym. There can be, of course, both positive and negative implications for maintaining the identity of participants in publications and an interesting discussion article considers a number of these (Giordano *et al* 2007). The article highlights that it may never be possible to anticipate the impact of maintaining an identity and for this reason it may be safer to err on the side of caution and to protect anonymity. In light of this discussion, should I be in a similar position again, I shall ask the participant to choose a name by which they would like to be referred. In this way, a balance is struck between maintaining anonymity and allowing interview excerpts to be linked to a unique person.

Related to this issue, as I have discussed previously (section 3.7.10), I have learnt that it is important to engage all of those present in the formal consent procedure since it is not possible to anticipate an individual's involvement in an interview.

The participants who took part in the study gave me their time and their experience. Many of those who chose to participate said it was because they wanted to help people in similar circumstances. Others said that they wanted to help me and I often found this difficult since I felt as though I gave them nothing in return. There is a school of thought which suggests that participating in research can be beneficial to the individual, for example because it gives them an opportunity to tell their story to individuals who want to hear it, but I wish that I had recognised their input in a more explicit way. It is my regret that I did not write the participants thank you cards once the interview had been completed and I had returned to the office. Whilst I did express my thanks and gratitude to the individuals at the interview, and again when I sent them the newsletter (to the 32 participants who chose to receive it), I think that I would have felt less as though I had taken what I needed and run if I had taken the time to send them a small note of thanks shortly after we had conducted the interview.

7.5 Future directions

I developed this study in response to Corner *et al*'s (2006) statement that the processes through which individuals become diagnosed with lung cancer are poorly understood and warrant further detailed investigation. My approach to this task was to seek to understand the experience of developing and being diagnosed with lung cancer, guided by three questions:

1. What is the experience of developing and being diagnosed with lung cancer?

2. Why may, or may not, individuals realise the significance of their symptomatic experiences? Specifically, why do individuals not seem to interpret their experience as related to lung cancer?

3. How might the processes of interpretation and presentation in lung cancer be influenced so as to make a contribution to the earlier diagnosis of the disease?

Through exploring the illness narratives of individuals recently diagnosed with lung cancer and through drawing upon alternative sources of data, I responded to these questions. In so doing, I proposed a number of possibilities of thought. Though I never intended to position my understanding as right or correct, I do think that it has utility. But perhaps, as I have intimated previously (section 3.6.3), the potential of some of that utility will only be known at a time in the future. This paves the way for directions of future research which can be used to explore the possibilities of thought and enhance the potential utility of this and future studies.

The future direction of research fits within the three broad areas: the narrative of lung cancer; the significance of narrative for the interpretation of symptomatic experiences; and developing health education interventions.

7.5.1 The narrative of lung cancer

The narrative of lung cancer constructed by individuals who had been recently diagnosed with the disease positioned it in such a way that it could not be drawn upon by many of the individuals who developed the disease. Whilst my extensive engagement in the study led me to see the congruency between this narrative and the narrative of lung cancer within the storied social context, further exploration is warranted to explore how individuals, particularly those at risk of developing lung cancer, understand the disease. Related to this, investigation of the social distribution of the narrative of lung cancer is necessary to establish if particular individuals, by virtue of their social position, are more or less likely to have access to the interpretation of lung cancer.

Beyond exploring the understanding of lung cancer constructed by individuals at risk of developing the disease, further research is required to explore the understanding of the disease held by individuals within the health service. GPs are an obvious example but less obvious are those who work within pharmacy or similar environments.

Looking beyond the narrative of lung cancer, it may be useful to explore whether other specific diseases are understood in terms of a narrative structure, as I have suggested. This may be insightful for understanding interpretation and management sequences as they relates to other types of disease, for example breast cancer and myocardial infarction.

7.5.2 The significance of narrative for interpretation

Within the existing literature, interpretation is largely understood as a process of comparison between cognitive structures and actual experience. In this way, one can influence interpretation through the provision of categorical meaning which complete or correct an individual's understanding of a specific disease. In my understanding, interpretation is driven by narrative and by the creation of narrative and so is an active, creative process operating between the individual and the storied social context within which they live. Additional research is required to further explore the significance of narrative for the interpretation of symptomatic experiences and so strengthen or weaken the understanding of interpretation that I developed through this study.

7.5.3 Developing health education interventions

Any future studies which support the significance of narrative for interpretation will strengthen the challenge to the existing interventions which rely on the provision of categorical meaning, primarily relating to the symptom labels associated with lung cancer. Attention can thus be focussed on developing health education interventions which incorporate storied meaning and construct and communicate faithful narratives of lung cancer. In order to increase the likely impact of such interventions, care must be taken to involve in the process those who are to be addressed by the intervention.

Related to this, future studies could explore the potential of social marketing as a guiding framework for the development of health education interventions. Social marketing, as an approach under the broad umbrella of health promotion, is usually associated with behaviour change. However, the emphasis on behaviour does not position social marketing as inappropriate, to my understanding, since the marketing knowledge of branding may be useful in an intervention which seeks to position lung cancer as a visible, available and acceptable interpretation.

7.6 Concluding remarks

The symptomatic experiences associated with a developing disease are not inherently meaningful and can be interpreted in a range of different ways. The sequential and temporal features of narrative position it as an important resource for creating sense out of symptomatic experiences. Indeed, the process of interpretation is highly influenced by narrative and by the creation of narrative. If a narrative plot is visible and acceptable within the storied social context and the individual can see themselves in it, they can draw upon that narrative plot and emplot their experience into its sequence in a process of experiential emplotment. In this way, the story of another time or of another person becomes the individual's story of the present and the future.

The narratives of specific diseases are just one narrative plot that an individual can draw upon and emplot their experience into. In this way specific diseases, such as lung cancer, are not understood in terms of a collection of categories, but in terms of a narrative structure, a beginning, middle and end. For this reason, and for the concept of experiential emplotment, the existing interventions which seek to influence the interpretation of the symptomatic experiences associated with lung cancer are inappropriate. These interventions attempt to rectify a perceived deficiency of the individual and seek to communicate categorical information, primarily relating to the symptom labels associated with the disease. In this way, they neglect the significance of storied meaning and ignore the importance of the wider social context. If individuals are to interpret particular symptomatic experiences as related to lung cancer, the narratives of the disease should be highly visible within the storied social context, faithful to how the disease is experienced and in whom, and positioned as an acceptable alternative to the competing narratives of normal life and normal illness. Only then will the interpretation of lung cancer be accessible to those who may need to draw upon it and, potentially, will the earlier diagnosis of the disease become a distinct possibility.

List of appendices

Appendix 1: Autobiographical statement

I was born in the south of England in 1980, the first child of a project manager, Paul, and secretary, Christine. My sister Stefanie followed not long after and when I was four my brother Michael was born. I really enjoyed attending school and was an extremely conscientious pupil. My interest in school continued at secondary level and I started to consider what I would do when I left. I always expected to attend university, initially to do medicine and then pharmacy. I took the three sciences at A-level and it soon became apparent that I was not going to achieve the grades necessary for medicine or pharmacy and so I looked around for another career path. This is how I came to study therapeutic radiography.

My training was pretty uneventful. I met Andrew who is now my husband and I took great pride in my studies. I attended a military college, though I myself was civilian, and there were many more male than female students. Because of this, for my dissertation I developed an information leaflet about testicular cancer and distributed it to the first and second year male undergraduates. I did pre- and post-intervention questionnaires, and interviews with the third year students to establish their awareness and knowledge of the disease. This was where my interest in health education began.

In 2001 I graduated with my degree. Three weeks after graduation I began work in the radiotherapy department close to where I'd grown up. Though I enjoyed my work, I felt unfulfilled. It was Andrew who searched the internet and found the details of a Masters degree in health education with health promotion. I lobbied my boss for permission to attend the course, one full day each week over two years.

As I began to near the end of the Masters course, I started to consider what might lie ahead. I answered an advertisement for a PhD studentship; in fact I answered two, just to be on the safe side. I was offered the studentship on condition that I achieve the Masters degree and fortunately I graduated with distinction. In October 2004 I began my PhD studies and I have enjoyed nearly every minute of it since.

Given that the study at the centre of this thesis focuses on lung cancer, I feel it important that I tell you what I think about lung cancer and about smoking. In my life, I have smoked one cigarette. It was not something that I enjoyed, plus I felt guilty. I'm not sure why I felt so bad since at that time my mum was smoking, and though she has not smoked for several years, my sister and brother have both been smokers. I worry about this, since I do think that smoking increases your chance of developing a number of diseases, not least lung cancer. But I could never hold anyone who develops the disease as responsible for their situation. People smoke for lots of different reasons and they give up smoking too. All diseases deserve the attention of researchers, of government and of society regardless of how they begin and how they end.

Appendix 2: Literature search strategy

As I mentioned, a great deal of literature was already available to me, retrieved through the search strategy outlined in the first appendix of Corner *et al* (2003). My task was then to build upon this literature. I sourced the most recent, related literature and also expanded into other areas, particularly symptom interpretation and narrative, which had not been explored previously. Whilst the search terms and the databases were helpful, I discovered some of the most useful literature by reading through reference lists and talking to others, particularly in relation to narrative and narrative research.

Database	**Search years**
CINAHL	1982-2006
BNI	1994-2006
Ovid Medline	1996-2006
PsycInfo	2000-2006
Web of Knowledge Social Science Citation Index	1970-present

Search terms	AND	AND
Patient delay		
Lung cancer	Delay	
Lung cancer	Patient delay	
Lung neoplasm	Delay	
Lung neoplasm	Patient delay	
Symptom experience		
Symptom experience	Cancer	
Symptom interpretation		
Appraisal delay		
Illness behavior	Cancer	
Illness behaviour	Cancer	
Illness behaviour	Symptom interpretation	
Help seeking	Cancer	
Help seeking	Neoplasm	
Lung cancer	Experience	
Cancer	Narrative	
Illness	Narrative	
Illness	Experience	Narrative

Appendix 3: My personal experience of illness story

It was May 2005 and I was sitting at my computer in the postgraduate research room. I can't remember exactly what I was doing but whatever it was I was looking at the screen. And then all of a sudden I couldn't see the cross in the top right corner of the window which you click on to close it. I knew where it should be, I'd seen it hundreds probably thousands of times before, but it wasn't there. In a short space of time I knew that I had to leave; I had to go and lie down somewhere. I collected my things together and went over to Andrew's office to tell him what was going on and that I was going to head home. He said that I should get the bus home but I just wanted to make tracks and decided to walk the 20 minutes back to our flat. The walk was like a daze. I knew I was walking but there was a separation between me and the world around me. At one point I needed to cross the road and I could see that a car was coming but I couldn't judge how far away it was or how fast it was going. Rather stupidly I decided to cross and the car was much nearer than I anticipated. When finally I arrived home, I put on my pyjamas and got straight into bed. I stayed there for 36 hours. I had such a headache. I quite often get headaches but this was something completely different. I couldn't face food – just the smell of food wafting in from the kitchen made me feel nauseous and on a couple of occasions I was sick. I just did not know what was happening to me. I thought that perhaps the headache would go overnight but when it was still there in the morning I was upset and confused. I wanted it to be over so badly. I began to think that maybe I'd developed a brain tumour. I began to imagine my collapse, my admission to hospital, my diagnosis and my demise. I was so worried about this that I decided to look up the symptoms of brain tumours in my radiotherapy handbook. I compared the location of the pain in my head with the symptoms that I would expect if I were to have a tumour in that area. I couldn't link the two but I was still worried. I tried to think of another explanation. I thought about what I had been doing at the time that I first thought something was wrong. I'd been sat at my computer which was a relatively new thing for me since I was more used to running around a clinical department. I thought that maybe I had a migraine and that maybe the migraine was brought on by focusing hard at the screen. I thought maybe my eyes weren’t up to this sort of strain. I felt sure I never wanted to experience anything like those 36 hours ever again and so within a week I made an appointment to see an optician. The optician did various tests and told me that I could reduce the strain in my eyes by wearing glasses. Great, a cause had been found. I felt safe. All I needed to do was wear the glasses and never again would I feel as bad as I had done. But that was not the end. The experience that I dreaded happening again happened again. It wasn't as bad as before, I wasn’t sick, but I felt more awful than words can describe. And I was confused. I thought we’d found out why it was happening and clearly we hadn’t. I’d been wearing my glasses as I’d been advised and still it had happened. I didn’t know what to do next. I phoned my mum and she said that I should go and see my GP. In fact she’d told me the same thing when I first felt so bad. I thought she was right. I thought that they would probably say that I had been suffering from migraines and would offer me some tablets to stop it happening again which I would accept with open arms. I saw the GP and yes he did confirm that I had been suffering with migraine, but he didn’t give me any tablets. Quite the contrary he advised me to stop taking a particular contraceptive pill for it can bring on migraines. Indeed, it can bring on stroke. So I stopped the tablets and not since have I re-visited that awful experience. Thank goodness.

Appendix 4: Study paperwork

PATIENT LETTER (Ver 4: 21.4.05, 05/Q1702/46)

Title of project: A STUDY TO EXPLORE THE EXPERIENCE OF DEVELOPING CHEST PROBLEMS
Sponsor: UNIVERSITY OF SOUTHAMPTON

Date

Dear

I am a research worker with experience of caring for people with chest problems. I would like to invite you to take part in a research study that is being conducted by researchers from the School of Nursing and Midwifery, University of Southampton, working in collaboration with others [identifiable information].

Before you decide, it is important that you understand why the study is being carried out and what it will involve. This letter and the details on the accompanying Information Sheet give you information about the study that you might like to discuss with your family, friends and hospital staff. Take time to decide whether or not you wish to take part. Please ask if anything is not clear or if you would like to know more. You can contact me directly or you can ask a member of staff to contact me. My telephone number, postal address and e-mail address are given at the top of this page.

The purpose of the study.
The purpose of the study is to find out more about what you experienced before your diagnosis. This information will allow us to identify ways to improve success in the early diagnosis of chest disease in the future.
The study will take place at [identifiable information] over a period of approximately one year.

Thank you for taking the time to read this information.

Yours sincerely

(handwritten signature)

Jodie Moffat
Research worker

INFORMATION SHEET (Ver 4: 21.4.05, 05/Q1702/46)

Title of project: A STUDY TO EXPLORE THE EXPERIENCE OF DEVELOPING CHEST PROBLEMS
Sponsor: UNIVERSITY OF SOUTHAMPTON

What will the study involve?

I am planning to interview 40 people with chest problems over approximately one year. I will be doing this to gain a better understanding of what people experience before they are given a diagnosis. This information will allow us to identify ways to improve success in the early diagnosis of chest disease in the future.

Do I have to take part?

It is up to you whether you take part in the study. If you do decide to take part, you can withdraw at any time and without giving a reason. Any decision you make in regards to this study will not affect your care or treatment in any way.

What will happen to me if I take part?

If you decide to take part we will meet up to talk for 30-60 minutes about your experience of having chest problems. When and where we talk is up to you. The purpose of the interview is to find out about things that happened before your diagnosis. I will ask you to tell me how you came to be attending the hospital clinic, and I shall also ask you some questions about what you experienced before your appointment. With your permission, the interview will be tape-recorded but it is fine if you would prefer the interview not to be tape-recorded. The information gathered will be stored and processed using a computer.

What implications are there for me becoming involved in the study?

If you agree to take part, I will inform your hospital doctors of your involvement and will ask their permission to look at your medical records.

What if something goes wrong?

You are unlikely to be harmed by taking part in this study, but if you are, there are no special compensation arrangements. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints procedures are available to you.

Will my taking part be kept confidential?

All information that is collected about you during the course of the study will be kept strictly confidential. In addition, any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it.
I may present some of your direct quotes in any publication of the findings to illustrate your experience, however, it will not be possible to identify you in any publication of the study findings.

Who can I contact for further information?

Please contact me, Jodie Moffat, if you require any further information. My contact number is *****.
I have experience of working in the NHS but I am currently studying for a higher degree in the School of Nursing and Midwifery. This study is being conducted as part of my studies.

Who has reviewed this study?
This study has been reviewed by [identifiable information] Research Ethics Committee.

You can keep this information leaflet. You can also keep a signed copy of the consent form if you decide to take part in the study.

Thank you again for your time.

Appendix 5: Consent form

CONSENT FORM FOR PATIENTS (Ver 4: 21.4.05, 05/Q1702/46)

Title of project: A STUDY TO EXPLORE THE EXPERIENCE OF DEVELOPING CHEST PROBLEMS
Sponsor: UNIVERSITY OF SOUTHAMPTON

Please read the following statements, and if you are in agreement with them initial the box at the end of each statement. I am happy to explain anything if that will help you.

- I confirm that I have read and understood the Information Sheet. ☐
- I confirm that I have had the opportunity to ask questions and find out more about the study. ☐
- I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving reason, and without my treatment, care or legal rights being affected. ☐
- I understand that sections of my medical notes will be looked at by the research worker. ☐
- I give permission for the interview to be tape recorded. I understand that the tape will be kept according to University Regulations. ☐
- I understand that the information gathered will be anonymised, so that individuals cannot be recognised, then stored and processed using a computer. ☐
- I understand that the information I give will be kept strictly confidential. ☐
- I agree to take part in this study. ☐

Appendix 6: Example of a newsletter

NEWSLETTER – April 2006

Title of project: A STUDY TO EXPLORE THE EXPERIENCE OF DEVELOPING
CHEST PROBLEMS (05/Q1702/46)
Sponsor: UNIVERSITY OF SOUTHAMPTON

Thank you for taking part in the interview study, this is the newsletter that you said that you would like to receive and it tells you a bit about how the study is going.

Update
I thought you might like to know that so far I have interviewed 22 other people who are in a situation similar to yourself. This means that recruitment is going to schedule and that the study has been received well by those approached.

Analysis
I have been transcribing the interviews as I go along and then analysing the transcripts on their own and by comparing them with the other transcripts in an attempt to establish the key points in your experience. It is a bit too early to be drawing any definitive conclusions but it has been interesting to note the similarities and differences between experiences. The differences in experiences mainly stem from particular symptoms and this is why it has been so important to speak to a range of people.

What now?
The initial analysis has demonstrated how important it is to gain an appreciation of peoples' experiences of developing chest problems and so the plan is to continue to recruit participants until we reach 40. The task then becomes one of analysing a huge set of data and working out the best way to present it and publish it so that it can be of the greatest impact and benefit. This is likely to be challenging but it is important that the valuable information that you have given is used to its fullest potential.

I hope that you have enjoyed reading about how the study is going.

Best wishes

(handwritten signature)

Appendix 7: Example of an interview note

This is the note that I wrote after the interview with the first participant. I wrote a similar note after each of the subsequent interviews.

Interview conducted at participant's home on (date) July 2005. Lasted 50 minutes. The home was part of a modern terrace in a quiet part of [identifiable information]. The house was small but perfectly formed. The garden was neatly tendered and the front door was open throughout to let the breeze through. We sat in the lounge, the gentleman sat in the single chair under the window and I sat on the three-seater, positioning myself so that I was near to him.

I was initially very nervous and I think that was probably apparent to the participant as my face normally goes bright red when I am nervous. After a few minutes I really got in to what he was saying and forgot about my nerves. I feel that the participant was okay about the interview, there were some empty moments but I felt happy to leave them, and quite often he would add something else. He looked at me most of the time that he was talking, and there were lots of smiles.

Towards the end of the interview the wife came back into the room and sat on the other single seater opposite the window. She was very friendly and joined into our conversation, which had by this time moved on from health changes to more general things. This weekend the couple and a bunch of their family and friends are going for a camping trip, and they seem to be really looking forward to it. Once the break is out of the way, the gentleman will start chemotherapy.

Appendix 8: Example of a completed pro forma

Participant	101
First question	I was wondering if you could tell me about how you came to be in Dr (name) clinic on Monday?
Response to first question Clarification? Where does the illness narrative begin?	Okay, I'd been a couple of weeks before to Dr (chest physician)
Narratives of personal experience	
Dominating symptomatic experience	Cough
Narrative excerpts relating to symptomatic experience, interpretation and response	I started going there (GP) in January because I was coughing a lot. (p1, 1st telling) So I started taking them (inhalers) …and then I still continued with the coughing so went back to doctor again. (p1, 1st telling) Because I was fed up with it (p4) And occasionally I was coughing up a bit of blood (p4) (Didn't mention in first telling, page 1) (Hoarseness) That started when I started the inhalers (p6) (Didn't mention in 1st telling, p1) I didn't have any other problems and I seen the doctor on a regular basis on follow up for the bladder problems and so I was seeing him. We had a company doctor and she sounded me chest and said yeah everything sounds alright (p9)
Narratives of genesis	
Narrative excerpts relating to how and why lung cancer develops	As I said I smoked for many years and anybody who denies they know the risks is a, fooling themselves …Anybody with any intelligence has known that if they smoked for years they are putting themselves at risk. I realise that. But it's the old thing, well you think it can't happen to me. (p5) My grandfather smoked and he died when he was 87 or something (p5) Wife – But every doctor that we've talked to has said to him have you been working

	around asbestos? Yeah (p12) I was in the navy 23 years, every ship is full of asbestos (p12)
Participant age Participant sex Histology Stage of disease Treatment option	(mid sixties) Male Squamous cell carcinoma (NSCLC) T4N2M1 Chemotherapy
Interview before or after initiation of treatment?	Before
Storying? Emplotment?	My job was in a container terminal, cranes so I was spending times up and down cranes, that gets more difficult when you get older. So you don't know whether to put it down to pure ageing or deterioration or some other thing. But I noticed as well last year I used to go through (city) quite a lot which is high …so low oxygen and I found it more difficult to carry suitcases through (city) airport …and I put this down, why is this altitude? (p2, 1st telling) The last couple of months I was in (country) I was working a lot of hours, a lot of responsibilities so I did tend to neglect myself then and my weight did actually drop 3 or 4 kilos but within a month of coming home I'd put it back on (p3, 1st telling) (events, location, time - return home) People said to me 'oh you give up smoking you start coughing' (p3) (short narrative – has sequence and is temporal) Well she asked me what I thought, what did I think I might have. Well I said I might have um tuberculosis, I might have asbestosis, I might have, oh I had another one, I can't remember, I said I might have lung cancer. She said yes, that's what you have. Thank you. (p5, 1st telling) I was given three different inhalers, one was a steroid one and, the wife particularly reads all the notes that come in the medicines, I sometimes don't, but one of the side-effects of this was hoarseness and not long after I started this steroid inhaler I started losing my voice (p6) Yes I stopped taking them and the voice is actually getting a little better (p6)
Narrative of lung cancer?	It's pretty terminal, it is controllable with um radiotherapy and chemotherapy but I think like the rest of the population I knew very little (p5).

	As I said I smoked for many years and anybody who denies they know the risks is a, fooling themselves …Anybody with any intelligence has known that if they smoked for years they are putting themselves at risk. I realise that. But it's the old thing, well you think it can't happen to me. (p5)

List of references

Adlard, J.W., Hume, M.J. (2003) Cancer knowledge of the general public in the United Kingdom: Survey in a primary care setting and review of the literature. *Clinical Oncology* **15** pp.174-180

Allgar, V.L., Neal, R.D. (2005) Delays in the diagnosis of six cancers: analysis of data from the National Survey of NHS Patients: Cancer. *British Journal of Cancer* **92** pp.1959-1970

Anagnostopoulos, F., Spanea, E. (2005) Assessing illness representations of breast cancer. A comparison of patients with health and benign controls. *Journal of Psychosomatic Research* **58** pp.327-334

Andersen, B.L., Cacioppo, J.T., Roberts, D.C. (1995) Delay in seeking a cancer diagnosis: delay stages and psychophysiological comparison processes. *British Journal of Social Psychology* **34** (1) pp.33-52

Armstrong, D. (2003) *Outline of Sociology as Applied to Medicine* (5th Edition). London: Arnold

Atkinson, P. (1981) Inspecting Classroom Talk, In C. Adelman (Editor) *Uttering, Muttering. Collecting, Using and Reporting Talk for Social and Educational Research.* London: Grant McIntyre Limited, pp.98-113

Atkinson, P. (1995) Some perils of paradigms. *Qualitative Health Research* **5** (1) pp.117-124

Atkinson, P., Delamont, S. (2006) Editors' Introduction: Narratives, Lives, Performances, In P. Atkinson, S. Delamont (Editors) *Narrative Methods* (Volume 1). London: Sage Publications, pp.XIX-LIII

Aveyard, H. (2002) Implied consent prior to nursing care procedures. *Journal of Advanced Nursing* **39** (2) pp.201-207

Ayres, L., Poirier, S. (2003) Rational solutions and unreliable narrators: content, structure and voice in narrative research, In J. Latimer (Editor) *Advanced Qualitative Research for Nursing*. Oxford: Blackwell Science Limited, pp.97-114

Bailey, P.H. (2001) Death stories: Acute exacerbations of chronic obstructive pulmonary disease. *Qualitative Health Research* **11** (3) pp.322-338

Bailey, P.H., Tilley, S. (2002) Storytelling and the interpretation of meaning in qualitative research. *Journal of Advanced Nursing* **38** (6) pp.574-583

Baird, J. (2003) Raising the public profile of lung cancer – report of a national lung cancer awareness campaign. *Lung Cancer* **42** pp.119-123

Bal, M. (1985) *Narratology. Introduction to the Theory of Narrative*. Toronto: University of Toronto Press. Translated by C. van Boheemen

Balshem, M. (1991) Cancer, control, and causality: Talking about cancer in a working-class community. *American Ethnologist* **18** (1) pp.152-172

Bankhead, C., Collins, C., Stokes-Lampard, H., Kehoe, S., Clements, A., Mant, D., Wilson, S., Rose, P., Austoker, J. (2006) *Identifying potentially significant diagnostic factors for ovarian cancer in primary care: a qualitative and quantitative study*. Report to the Department of Health

Barthes, R. (1977) *Image Music Text*. London: Fontana Press. Translated by S. Heath

Beckles, M.A., Spiro, S.G., Colice, G.L., Rudd, R.M. (2003) Initial evaluation of the patient with lung cancer. *Chest* **123** pp.97S-104S

Benwell, B., Stokoe, E. (2006) *Discourse and Identity*. Edinburgh: Edinburgh University Press

Birring, S.S., Peake, M.D. (2005) Editorial: Symptoms and the early diagnosis of lung cancer. *Thorax* **60** pp.268-269

Bish, A., Ramirez, A., Burgess, C., Hunter, M. (2005) Understanding why women delay in seeking help for breast cancer symptoms. *Journal of Psychosomatic Research* **58** pp.321-326

Bishop, G.D. (1991) Understanding the Understanding of Illness: Lay Disease Representations, In J.A. Skelton, R.T. Croyle (Editors) *Mental Representation in Health and Illness*. New York: Springer-Verlag, pp.32-59

Bishop, G.D., Converse, S.A. (1986) Illness representations: a prototype approach. *Health Psychology* **5** (2) pp.95-114

Blaxter, M. (1990) *Health and Lifestyles*. London: Routledge

Bleakley, A. (2005) Stories as data, data as stories: making sense of narrative inquiry in clinical education. *Medical Education* **39** pp.534-540

Bloor, M. (2001) The Ethnography of Health and Medicine, In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, L. Lofland (Editors) *Handbook of Ethnography*. London: Sage Publications, pp.177-187

Blumenfeld-Jones, D. (1995) Fidelity as a criterion for practicing and evaluating narrative inquiry, In J.A. Hatch, R. Wisniewski (Editors) *Life History and Narrative*. London: The Falmer Press, pp.25-35

Bowen, E.F., Rayner, C.F.J., (2002) Letter to Editor: Patient and GP led delays in the recognition of symptoms suggestive of lung cancer. *Lung Cancer* **37** pp.227-228

British Thoracic Society (2001) Guidelines on the selection of patients with lung cancer for surgery. *Thorax* **56** pp.89-108

Brown, P. (1995) Naming and framing: The social construction of diagnosis and illness. *Journal of Health and Social Behavior* **35** (Extra Issue) pp.34-52

Brunswick, N., Wardle, J., Jarvis, M.J. (2001) Public awareness of warning signs for cancer in Great Britain. *Cancer Causes and Control* **12** pp.33-37

Bryman, A. (2001) *Social Research Methods*. Oxford: Oxford University Press

Buccheri, G., Ferrigno, D. (2004) Lung cancer: clinical presentation and specialist referral time. *European Respiratory Journal* **24** pp.898-904

Burgess, C.C., Ramirez, A.J., Richards, M.A., Love, S.B. (1998) Who and what influences delayed presentation in breast cancer? *British Journal of Cancer* **77** (8) pp.1343-1348

Burgess, C.C., Ramirez, A.J., Smith, P., Richards, M.A. (2000) Do adverse life events and mood disorders influence delayed presentation of breast cancer? *Journal of Psychosomatic Research* **48** pp.171-175

Burgess, C.C., Hunter, M.S., Ramirez, A.J. (2001) A qualitative study of delay among women reporting symptoms of breast cancer. *British Journal of General Practice* Dec pp.967-971

Bury, M. (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness* **4** (2) pp.167-182

Bury, M. (2001) Illness narratives: fact or fiction? *Sociology of Health and Illness* **23** (3) pp.263-285

Calnan, M. (1987) *Health and Illness. The Lay Perspective*. London: Tavistock Publications

Chapple, A., Ziebland, S., McPherson, A. (2004) Stigma, shame, and blame experienced by patients with lung cancer: qualitative study. *British Medical Journal* **328** pp.1470-1474

Chase, S.E. (1995) Taking Narrative Seriously: Consequences for Method and Theory in Interview Studies, In R. Josselson, A. Lieblich (Editors) *Interpreting Experience. The Narrative Study of Lives*, Volume 3. Thousand Oaks: Sage Publications, pp.1-26

Christensen, E.D., Harvald, T., Jendreson, M., Aggestrup, S. (1997) The impact of delayed diagnosis of lung cancer on the stage at the time of operation. *European Journal of Cardio-thoracic Surgery* **12** pp.880-884

Cioffi, D. (1991) Beyond attentional strategies: A cognitive-perceptual model of somatic interpretation. *Psychological Bulletin* **109** (1) pp.25-41

Clandinin, D.J., Connelly, F.M. (2000) *Narrative Inquiry.* San Francisco: Jossey-Bass

Clark, A.M. (2001) Treatment decision-making during the early stages of heart attack: a case for the role of body and self in influencing delays. *Sociology of Health and Illness* **23** (4) pp.425-446

Coffey, A., Atkinson, P. (1996) *Making Sense of Qualitative Data.* Thousand Oaks: Sage Publications

Colbourne, L., Sque, M. (2004) Split personalities: Role conflict between the nurse and the nurse researcher. *NT Research/Journal of Research in Nursing* **9** (4) pp.297-304

Cooley, M. (2000) Symptoms in adults with lung cancer: A systematic research review. *Journal of Pain and Symptom Management* **19** (2) pp.137-153

Cooper, G.M. (1993) *The Cancer Book.* Boston: Jones and Bartlett Publishers

Copp, G. (1999) *Facing Impending Death.* London: NT Books

Corbin, J.M. (2003) The body in health and illness. *Qualitative Health Research* **13** (2) pp.256-267

Corner, J. (1993) Health Promotion and Cancer Care, In A. Dines, A. Cribb (Editors) *Health Promotion. Concepts and practice.* Oxford: Blackwell Scientific Publishers, pp.174-194

Corner, J., Hopkinson, J., Fitzsimmons, D., Muers, M., Barclay, S., Wells, F. (2003) *A pilot investigation of the symptoms associated with early and late stage lung cancer, and the factors associated with delay in presentation and diagnosis of lung cancer.* Report to the Department of Health

Corner, J., Hopkinson, J., Fitzsimmons, D., Barclay, S., Muers, M. (2005) Is late diagnosis of lung cancer inevitable? Interview study of patients' recollections of symptoms before diagnosis. *Thorax* **60** pp.314-319

Corner, J., Hopkinson, J., Roffe, L. (2006) Experience of health changes and reasons for delay in seeking care: A UK study of the months prior to the diagnosis of lung cancer. *Social Science and Medicine* **62** pp.1381-1391

Cornford, C.S. (1998) Why patients consult when they cough: a comparison of consulting and non-consulting patients. *British Journal of General Practice* **48** pp.1751-1754

Cornwell, J. (1984) *Hard-earned Lives: Accounts of Health and Illness from East London.* London: Tavistock Publications

Cortazzi, M. (2001) Narrative Analysis in Ethnography, In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, L. Lofland (Editors) *Handbook of Ethnography*. London: Sage Publications, pp.384-394

Crawford, R. (1984) A cultural account of "health": control, release, and the social body, In J.B. McKinlay (Editor) *Issues in the political economy of health care*. New York: Tavistock Publications, pp.60-103

Cribb, A., Dines, A. (1993) What is Health Promotion?, In A. Dines, A. Cribb (Editors) *Health promotion. Concepts and practice*. Oxford: Blackwell Scientific Publications, pp.20-33

Crotty, M. (1998) *The Foundations of Social Research. Meaning and Perspective in the Research Process*. London: Sage Publications

CRUK (2006) 'Kylie effect' can confuse women over breast cancer risk'. http://info.cancerresearchuk.org/news/pressreleases/2006/october/235144 Accessed 21.12.06

CRUK (2007a) Cancer Statistics http://cancerresearchuk.org/cancerstats. Accessed 6.6.07

CRUK (2007b) Cancer Awareness Leaflets http://info.cancerresearchUK.org/ourpublications/cancerawareness/cancerawarenessleaflets/ Accessed 2.4.07

Cutcliffe, J.R., McKenna, H.P. (1999) Establishing the credibility of qualitative research findings: the plot thickens. *Journal of Advanced Nursing* **30** (2) pp.374-380

Cutcliffe, J.R., McKenna, H.P. (2004) Expert qualitative researchers and the use of audit trails. *Journal of Advanced Nursing* **45** (2) pp.126-133

Davison, C., Davey Smith, G., Frankel, S. (1991) Lay epidemiology and the prevention paradox: the implications of coronary candidacy for health education. *Sociology of Health and Illness* **13** (1) pp.1-19

Degner, L.F., Sloan, J.A. (1995) Symptom distress in newly diagnosed ambulatory cancer patients and as a predictor of survival in lung cancer. *Journal of Pain and Symptom Management* **10** (6) pp.423-431

Denscombe, M., (1998) *The Good Research Guide*. Buckingham: Open University Press

Denzin, N.K. (1997) *Interpretive Ethnography. Ethnographic Practices for the 21st Century*. Thousand Oaks: Sage Publications

Denzin, N.K., Lincoln, Y.S. (2003) Introduction: The Discipline and Practice of Qualitative Research, In N.K. Denzin, Y.S. Lincoln (Editors) *The Landscape of Qualitative Research: Theories and Issues*. Thousand Oaks: Sage Publications, pp.1-45

De Nooijer, J., Lechner, L., de Vries, H. (2001) A qualitative study on detecting cancer symptoms and seeking medical help; an application of Andersen's model of total patient delay. *Patient Education and Counseling* **42** pp.145-157

De Nooijer, J., Lechner, L., de Vries, H. (2002) Early detection of cancer: knowledge and behavior among Dutch adults. *Cancer Detection and Prevention* **26** pp.362-369

Department of Health (2000a) *The NHS Plan. A plan for investment, a plan for reform.* London: HMSO

Department of Health (2000b) *The NHS Cancer Plan. A plan for investment, a plan for reform.* London: HMSO

Department of Health (2007) 12 key points on consent: the law in England. www.dh.gov.uk/en/polocyand guidance/healthandsocialcaretopics/consent/FAQ/DH_072934 Accessed 14.6.07

Deslauriers, J. (2002) Current surgical treatment of nonsmall cell lung cancer 2001. *European Respiratory Journal* **19** (35) pp.S61-S70

DiGiacomo, S.M. (1992) Metaphors as illness: Postmodern dilemmas in the representation of the body, mind and disorder. *Medical Anthropology* **14** pp.109-137

Dingwall, R. (1976) *Aspects of Illness*. London: Martin Robertson and Company Limited.

Dische, S., Gibson, D., Parmar, M., Saunders, M.I. (1996) Time course from first symptom to treatment in patients with non-small cell lung cancer referred for radiotherapy: a report by the CHART Steering Committee. *Thorax* **51** pp.1262-1265

Doll, R., Peto, R., Boreham, J., Sutherland, I. (2004) Mortality in relation to smoking: 50 years' observations on male British doctors. *British Medical Journal* **328** pp.1519-1528

Downie, R.S., Tannahill, C., Tannahill, A. (1996) *Health Promotion Models and Values*. Oxford: Oxford University Press

Edvardsson, D., Rasmussen, B.H., Riessman, C.K. (2003) Ward atmospheres of horror and healing: a comparative analysis of narrative. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* **7** (4) pp.377-396

Elliott, J. (2005) *Using Narrative in Social Research. Qualitative and Quantitative Approaches*. London: Sage Publications

Emden, C. (1998) Conducting a narrative analysis. *Collegian* **5** (3) pp.34-39

Emden, C., Sandelowski, M. (1998) The good, the bad and the relative, part one: Conceptions of goodness in qualitative research. *International Journal of Nursing Practice* **4** pp.206-212

Emden, C., Sandelowski, M. (1999) The good, the bad and the relative, part two: Goodness and the criterion problem in qualitative research. *International Journal of Nursing Practice* **5** pp.2-7

Ermarth, M. (1978) *Wilhelm Dilthey: The Critique of Historical Reason*. Chicago: The University of Chicago Press

Estabrooks, C.A. (1999) The conceptual structure of research utilization. *Research in Nursing and Health* **22** pp.203-216

Estabrooks, C.A. (2001) Research Utilization and Qualitative Research, In J.M. Morse, J.M. Swanson, A.J. Kuzel (Editors) *The Nature of Qualitative Evidence*. Thousand Oaks: Sage Publications, pp.275-298

Estroff, S.E. (1995) Whose story is it anyway?, In S.K. Toombs, D. Barnard, R.A. Carson (Editors) *Chronic Illness. From Experience to Policy*. Bloomington: Indiana University Press, pp.77-102

EU (2001) Directive 2001/37/EC concerning the manufacture, presentation and sale of tobacco products. Official Journal of the European Community 18.7.2001. http://eur-lex.europa.eu/LexUriServ/site/en/oj/2001/l_194/l_19420010718en00260034.pdf. Accessed 17.5.07

Evans, J., Ziebland, S., McPherson, A. (2007) Minimizing delays in ovarian cancer diagnosis: an expansion of Andersen's model of 'total patient delay'. *Family Practice* **24** pp.48-55

Ewles, L., Simnett, I. (2003) *Promoting Health. A Practical Guide.* Edinburgh: Bailliere Tindall

Facione, N., Giancarlo, C.A. (1998) Narratives of breast symptom discovery and cancer diagnosis: Psychologic risk for advanced cancer at diagnosis. *Cancer Nursing* **21** (6) pp.430-440

Finnegan, R. (1998) *Tales of the City. A Study of Narrative and Urban Life.* Cambridge: Cambridge University Press

Fleming, J.G. (1998) *The Law of Torts* (9th Edition). North Ryde: LBC Information Services

Flick, U. (1998) *An Introduction to Qualitative Research.* London: Sage Publications

Flyvbjerg, B. (2006) Five misunderstandings about case-study research. *Qualitative Inquiry* **12** (2) pp.219-245

Frank, A. (1995) *The Wounded Storyteller.* Chicago: The University of Chicago Press

Frank, A.W. (2000) The standpoint of storyteller. *Qualitative Health Research* **10** (3) pp.354-365

Freund, P.E.S., McGuire, M.B. (1999) *Health, Illness and the Social Body. A Critical Sociology* (3rd Edition). Upper Saddle River: Prentice Hall

Garro, L.C., Mattingly, C. (2000) Narrative as Construct and Construction, In C. Mattingly, L.C. Garro (Editors) *Narrative and the Cultural Construction of Illness and Healing.* Berkeley: University of California Press, pp.1-49

Gascoigne, P., Mason, M.D., Roberts, E. (1999) Factors affecting presentation and delay in patients with testicular cancer: Results of a qualitative study. *Psycho-Oncology* **8** pp.144-154

Gascoigne, P., Whitear, B. (1999) Making sense of testicular cancer symptoms: a qualitative study of the way in which men sought help from health-care services. *European Journal of Oncology Nursing* **3** (2) pp.62-69

Gergen, M. (1988) Narrative structures in social explanation, In C. Antaki (Editor) *Analysing Everyday Explanation.* London: Sage Publications, pp.94-112

Gijsbers van Wijk, C.M.T., Kolk, A.M. (1997) Sex differences in physical symptoms: the contribution of symptom perception theory. *Social Science and Medicine* **45** (2) pp.231-246

Giordano, J., O'Reilly, M., Taylor, H., Dogra, N. (2007) Confidentiality and autonomy: The challenge(s) of offering research participants a choice of disclosing their identity. *Qualitative Health Research* **17** (2) pp.264-275

Gillham, B. (2000) *Case Study Research Methods.* London: Continuum

Goff, B.A., Mandel, L., Muntz, H.G., Melancon, C.H. (2000) Ovarian carcinoma diagnosis. Results of a national ovarian cancer survey. *Cancer* **89** pp.2068-2075

Good, B. J. (1994) *Medicine, rationality and experience. An anthropological perspective.* Cambridge: Cambridge University Press

Good, M., Munakata, T., Kobayashi, Y., Mattingly, C., Good, B.J. (1994) Oncology and narrative time. *Social Science and Medicine* **38** (6) pp.855-862

Graham, H. (1993) *When Life's a Drag.* London: HMSO

Gray, R.E., Fergus, K.D., Fitch, M.I. (2005) Two black men with prostate cancer: A narrative approach. *British Journal of Health Psychology* **10** pp.71-84

Green, M.C. (2006) Narratives and cancer communication. *Journal of Communication* **56** pp.S163-S183

Green, M.C., Brock, T.C. (2000) The role of transportation in the persuasiveness of public narratives. *Journal of Personality and Social Psychology* **79** (5) pp.701-721

Green, J., Thorogood, N. (2004) *Qualitative Methods for Health Research.* London: Sage Publications

Greenhalgh, T., Hurwitz, B. (1999) Why study narrative? *British Medical Journal* **318** pp.48-50

Grinyer, A. (2002) The anonymity of research participants: Assumptions, ethics and practicalities. *Social Research Update*, Issue 36. Available from http://sru.soc.surrey.ac.uk

Grunfeld, E.A., Ramirez, A.J., Hunter, M.S., Richards, M.A. (2002) Women's knowledge and beliefs regarding breast cancer. *British Journal of Cancer* **86** p.1373-1378

Guba, E.C. (1990) The Alternative Paradigm Dialog, In E.C. Guba (Editor) *The Paradigm Dialog.* Newbury Park: Sage Publications, pp.17-27

Gulliford, M., Morgan, M. (2003) (Editors) *Access to Health Care.* London: Routledge

Hamilton, W., Sharp, D. (2004) Diagnosis of lung cancer in primary care: a structured review. *Family Practice* **21** (6) pp.605-611

Hamilton, W., Peters, T.J., Round, A., Sharp, D. (2005) What are the clinical features of lung cancer before the diagnosis is made? A population based case-control study. *Thorax* **60** pp.1059-1065

Hammersley, M. (1992) *What's wrong with ethnography?* London: Routledge

Hanahan, D., Weinberg, R.A. (2000) The hallmarks of cancer. *Cell* **100** pp.57-70

Hardey, M. (1998) *The Social Context of Health.* Buckingham: Open University Press

Hatton, M., Stephens, R. (2005) CHART in non-small-cell lung cancer: INCHing forward. *Clinical Oncology* **17** pp.207-209

Havard, C.W.H. (1987) (Editor) *Black's Medical Dictionary* (35th Edition). London: A & C Black Limited

Hoffman-Goetz, L. (1999) Cancer experiences of African-American women as portrayed in popular mass magazines. *Psycho-Oncology* **8** pp.36-45

Holloway, I. (2005) Qualitative writing, In I. Holloway (Editor) *Qualitative Research in Health Care*. Maidenhead: Open University Press, pp.270-286

Holloway, I., Wheeler, S. (1995) Ethical issues in qualitative nursing research. *Nursing Ethics* **2** (3) pp.223-232

Holstein, J.A., Gubrium, J.F. (2002) Active Interviewing, In D. Weinberg (Editor) *Qualitative Research Methods*. Malden MA: Blackwell Publishers, pp.112-126

Horne, R., James, D., Petrie, K., Weinmann, J., Vincent, R. (2000) Patients' interpretation of symptoms as a cause of delay in reaching hospital during acute myocardial infarction. *Heart* **83** pp.388-393

House of Commons Committee of Public Accounts (2006) *The NHS Cancer Plan: a progress report*. London: The Stationery Office

Hyden, L-C. (1997) Illness and narrative. *Sociology of Health and Illness* **19** (1) pp.48-69

Imperatori, A., Harrison, R.N., Leitch, D.N., Rovera, F., Lepore, G., Dionigi, G., Sutton, P., Dominioni, L. (2006) Lung cancer in Teesside (UK) and Varese (Italy): a comparison of management and survival. *Thorax* **61** pp.232-239

Jefferson, G. (2004) Glossary of transcript symbols with an introduction, In G.H. Lerner (Editor) *Conversation Analysis. Studies from the first generation*. Amsterdam: John Benjamins Publishing Company, pp.13-31

Jones, S. (1985) The Analysis of Depth Interviews, In R. Walker (Editor) *Applied Qualitative Research*. Aldershot: Gower Publishing Company Limited, pp.56-70

Jones, L., Douglas, J. (2000) The rise of health promotion, In J. Katz, A. Peberdy, J. Douglas (Editors) *Promoting Health: Knowledge and Practice* (2nd Edition). Basingstoke: Macmillan Press Limited, pp.58-79

Kavanaugh, K., Ayres, L. (1998) "Not as bad as it could have been": Assessing and mitigating harm during research interviews on sensitive topics. *Research in Nursing and Health* **21** pp.91-97

Kearney, M.H. (2001) Levels and applications of qualitative research evidence. *Research in Nursing and Health* **24** pp.145-153

Kendall, M., Murray, S.A. (2005) Tales of the unexpected: Patients' poetic accounts of the journey to a diagnosis of lung cancer: A prospective serial qualitative interview study. *Qualitative Inquiry* **11** (5) pp.733-751

King, R.J.B., Robins, M.W. (2006) *Cancer Biology* (3rd Edition). Harlow: Pearson Educational Limited

Klawiter, M. (2004) Breast cancer in two regimes: the impact of social movements on illness experience. *Sociology of Health and Illness* **26** (6) pp.845-874

Kleinman, A. (1980) *Patients and Healers in the Context of Culture*. Berkeley: University of California Press

Kleinman, A. (1986) Illness Meanings and Illness Behaviour, In S. McHugh, T.M. Vallis (Editors) *Illness Behavior. A Multidisciplinary Model*. New York: Plenum Press, pp.149-160

Koch, T. (1994) Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing* **19** pp.976-986

Koch, T., Harrington, A. (1998) Reconceptualizing rigor: the case for reflexivity. *Journal of Advanced Nursing* **28** (4) pp.882-890

Kocher, H.M., Saunders, M.P. (1999) Complacency or ignorance about rectal bleeding? *Colorectal Disease* **1** pp.332-333

Koyi, H., Hillerdal, G., Branden, E. (2002) Patient's and doctor's delays in the diagnosis of chest tumors. *Lung Cancer* **35** pp.53-57

Kvale, S. (1996) *InterViews*. Thousand Oaks: Sage Publications

Labov, W., Waletzky, J. (1967) Narrative Analysis: Oral Versions of Personal Experience, In J. Helms (Editor) *Essays on the Verbal and Visual Arts*. Washington: University of Washington Press, pp.4-44

Langellier, K.M. (1989) Personal narratives: Perspectives on theory and research. *Text and Performance Quarterly* **9** pp.243-276

Laroche, C., Wells, F., Coulden, R., Stewart, S., Goddard, M., Lowry, E., Price, A., Gilligan, D. (1998) Improving surgical resection rate in lung cancer. *Thorax* **53** pp.445-449

Lau, R.R., Hartman, K.A. (1983) Common sense representations of common illnesses. *Health Psychology* **2** pp.167-185

Lawler, S. (2002) Narrative in Social Research, In T. May (Editor) *Qualitative Research in Action*. London: Sage Publications, pp.242-258

Lawton, J. (2002) Colonising the future: temporal perceptions and health-relevant behaviours across the adult lifecourse. *Sociology of Health and Illness* **24** (6) pp.714-733

Levealahti, H., Tishelman, C., Ohlen, J. (2007) Framing the onset of lung cancer biographically: Narratives of continuity and disruption. *Psycho-Oncology* **16** pp.466-473

Leventhal, H., Meyer, D., Nerenz, D. (1980) The common sense representation of illness danger, In S. Rachman (Editor) *Contributions to Medical Psychology*, Volume 2. London: Pergamon Press, pp.7-30

Leventhal, H., Nerenz, D.R. (1985) The Assessment of Illness Cognition, In P. Karoly (Editor) *Measurement Strategies in Health Psychology*. New York: John Wiley and Sons, pp.517-554

Lieblich, A., Tuval-Mashiach, R., Zilber, T. (1998) *Narrative Research*. Thousand Oaks: Sage Publications

Lincoln, Y.S. (1990) The Making of a Constructivist, In E.C. Guba (Editor) *The Paradigm Dialog*. Newbury Park: Sage Publications, pp.67-87

Locker, D. (1981) *Symptoms and Illness. The Cognitive Organization of Disorder*. London: Tavistock Publications

Lockyer, L., Bury, M. (2002) The construction of a modern epidemic: the implications for women of the gendering of coronary heart disease. *Journal of Advanced Nursing* **39** (5) pp.432-440

Lupton, D. (1994) *Medicine as Culture. Illness, Disease and the Body in Western Societies*. London: Sage Publications

Lyons, A.C. (2000) Examining media representations: Benefits for health psychology. *Journal of Health Psychology* **5** (3) pp.349-358

Macdonald, G., Bunton, R. (1992) Health promotion: discipline or disciplines?, In R. Bunton, G. Macdonald (Editors) *Health Promotion: Disciplines and Diversity*. London: Routledge, pp.6-19

Macdonald, S., Macleod, U., Mitchell, E., Weller, D., Campbell, N., Mant, D. (2004) *Factors influencing patient and primary care delay in the diagnosis of cancer: a database of existing research and its implications for future practice*. Report to the Department of Health

Mansson, J., Marklund, B., Bengtsson, C., Fridlund, B. (1999) Evaluation of an educational programme for the early detection of cancer. *Patient Education and Counseling* **37** pp.231-242

Marshall, C., Rossman, G.B. (1999) *Designing Qualitative Research*. Thousand Oaks: Sage Publications

Martin, R., Lemos, K., Rothrock, N., Bellman, S.B., Russell, D., Tripp-Reimer, T., Lounsbury, P., Gordon, E. (2004) Gender disparities in common sense models of illness among myocardial infarction victims. *Health Psychology* **23** (4) pp.345-353

Mason, J. (2002) *Qualitative Researching* (2nd Edition). London: Sage Publications

Mathews, H.F., Lannin, D.R., Mitchell, J.P. (1994) Coming to terms with advanced breast cancer: Black women's narratives from eastern North Carolina. *Social Science and Medicine* **38** (6) pp.789-800

Mattingly, C. (1994) The concept of therapeutic 'emplotment'. *Social Science and Medicine* **38** (6) pp.811-822

Mattingly, C. (1998) *Healing dramas and clinical plots. The narrative structure of experience*. Cambridge: Cambridge University Press

May, T. (2001) *Social Research. Issues, method and process* (3rd Edition). Buckingham: Open University Press

McCance, T.V., McKenna, H.P., Boore, J.R.P. (2001) Exploring caring using narrative methodology: an analysis of the approach. *Journal of Advanced Nursing* **33** (3) pp.350-356

McKinlay, J.B. (1973) Social networks, lay consultation and help-seeking behavior. *Social Forces* **51** (3) pp.275-292

McLaughlin, J.R., Boyd, N.F. (1998) Epidemiology of cancer, In I.F. Tannock, R.P. Hill (Editors) *The Basic Science of Oncology*. New York: McGraw-Hill, pp.6-25

McLeod, J. (1997) *Narrative and Psychotherapy*. London: Sage Publications

McManus, K. (2001) Thoracic tumours, In R.A.J. Spence, P.G. Johnston (Editors) *Oncology: An Oxford Core Text*. Oxford: Oxford University Press, pp.283-317

Mechanic, D., Volkart, E.H. (1961) Stress, illness behavior, and the sick role. *American Sociological Review* **61** (1) pp.51-58

Mechanic, D. (1968) *Medical Sociology: A Selective Review*. New York: The Free Press

Mechanic, D. (1979) *Future Issues in Health Care. Social Policy and the Rationing of Medical Services*. New York: The Free Press

Meechan, G., Collins, J., Petrie, K.J. (2003) The relationship of symptoms and psychological factors to delay seeking medical care for breast symptoms. *Preventive Medicine* **36** pp.374-378

Miles, A., Waller, J., Hiom, S., Swanston, D. (2005) SunSmart? Skin cancer knowledge and preventive behaviour in a British population representative sample. *Health Education Research* **20** (5) pp.579-585

Minister, K. (1991) A Feminist Frame for the Oral History Interview, In S. Berger Gluck, D. Patai (Editors) *Women's Words. The Feminist Practice of Oral History*. New York: Routledge, pp. 7-41

Mishler, E.G. (1986) *Research Interviewing. Context and Narrative*. Cambridge, MA: Harvard University Press

Mishler, E.G. (1995) Models of narrative analysis: A typology. *Journal of Narrative and Life History* **5** (2) pp.87-123

Mishler, E.G. (2005) Patient stories, narratives of resistance and the ethics of humane care: a la recherché du temps perdu. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* **9** (4) pp.431-451

Mogensen, H.O. (1997) The narrative of AIDS among the Tonga of Zambia. *Social Science and Medicine* **44** (4) pp.431-439

Moghissi, K., Connolly, C.K. (1996) Editorial: Resection rates in lung cancer. *European Respiratory Journal* **9** pp.5-6

Morgan, M., Calnan, M., Manning, N. (1985) *Sociological Approaches to Health and Medicine*. London: Routledge

Morse, J.M. (2001) Interviewing the ill, In J.F. Gubrium, J.A. Holstein (Editors) *Handbook of Interview Research.* Thousand Oaks: Sage Publications, pp.317-328

Morse, J.M., Barrett, M., Mayan, M., Olson, K., Spiers, J. (2002) Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods* **1** (2) pp.1-19

Mountain, C.F. (1997) Revisions in the International system for staging lung cancer. *Chest* **111** pp.1710-1717

Mulshine, J.L., Smith, R.A. (2002) Lung cancer 2: Screening and early diagnosis of lung cancer. *Thorax* **57** pp.1071-1078

Munhall, P.L. (1988) Ethical considerations in qualitative research. *Western Journal of Nursing Research* **10** (2) pp.150-162

Murray, M. (1999) The Storied Nature of Health and Illness, In M. Murray, K. Chamberlain (Editors) *Qualitative Health Psychology.* London: Sage Publications, pp.47-63

Murray, M. (2000) Levels of narrative analysis in health psychology. *Journal of Health Psychology* **5** (3) pp.337-347

Murray, M. (2003) Narrative Psychology and Narrative Analysis, In P.M. Camic, J.E. Rhodes, L. Yardley (Editors) *Qualitative Research in Psychology. Expanding Perspectives in Methodology and Design.* Washington: American Psychological Association, pp.95-112

Myatt, R., Treasure, T. (2002) Lung cancer: the harsh reality. *Cancer Nursing Practice* **1** (9) pp.10-11

Naidoo, J., Wills, J. (2000) *Health Promotion: Foundations for Practice* (2nd Edition). Edinburgh: Bailliere Tindall

National Audit Office (2005) *The NHS Cancer Plan: A Progress Report.* London: The Stationery Office

NCC (2006) *It's our health! Realising the potential of effective social marketing.* London: National Consumer Council. www.ncc.org.uk. Accessed 5.7.06

Neal, R.D., Allgar, V.L. (2005) Sociodemographic factors and delays in the diagnosis of six cancers: analysis of data from the National Survey of NHS Patients: Cancer. *British Journal of Cancer* **92** pp.1971-1975

Newman, T.B. (2004) The power of stories over statistics: lessons from neonatal jaundice and infant airplane safety, In B. Hurwitz, T. Greenhalgh, V. Skultans (Editors) *Narrative Research in Health and Illness.* Oxford: Blackwell Publishing, BMJ Books, pp.257-272

NHS Direct (2007a) Health encyclopaedia Cancer of the Lung. www.nhsdirect.nhs.uk/articles/article.aspx?articleId=79&sectionId=33641&PrintPage=1. Accessed 11.5.07

NHS Direct (2007b) Health encyclopaedia Cancer of the Pancreas. www.nhsdirect.nhs.uk/articles/article.aspx?articleId=476&PrintPage=1. Accessed 11.5.07

NICE (2005) Lung Cancer. The Diagnosis and Treatment of Lung Cancer (Clinical Guideline 24) Quick reference guide. www.nice.org.uk Accessed 23.2.05

Nosarti, C., Crayford, T., Roberts, J.V., Elias, E., McKenzie, K., David, A.S. (2000) Delay in the presentation of symptomatic referrals: patient and system factors. *British Journal of Cancer* **82** (3) pp.742-748

Ochs, E. (1997) Narrative, In T.A. van Dijk (Editor) *Discourse as Structure and Process*. London: Sage Publications, pp.185-203

O'Donnell, S., Condell, S., Begley, C., Fitzgerald, T. (2006) Prehospital care pathway delays: gender and myocardial infarction. *Journal of Advanced Nursing* **53** (3) pp.268-276

OED (2001) *Paperback Oxford English Dictionary*. Oxford: Oxford University Press

Oliver, K.L. (1998) A journey into narrative analysis: A methodology for discovering meanings. *Journal of Teaching in Physical Education* **17** pp.244-259

Overcash, J.A. (2003) Narrative research: a review of methodology and relevance to clinical practice. *Critical Reviews in Oncology/Haematology* **48** pp.179-184

Oxford (1998) *Concise Colour Medical Dictionary* (2nd Edition). Oxford: Oxford University Press

Pack, G.T., Gallo, J.S. (1938) The culpability for delay in the treatment of cancer. *American Journal of Cancer* **33** pp.443-462

Patton, M.Q. (2002) *Qualitative Research and Evaluation Methods*. Thousand Oaks: Sage Publications

Payne, S. (2001) 'Smoke like a man, die like a man'?: A review of the relationship between gender, sex and lung cancer. *Social Science and Medicine* **53** pp.1067-1080

Peto, R., Darby, S., Deo, H., Silcocks, P., Whitley, E., Doll, R. (2000) Smoking, smoking cessation, and lung cancer in the UK since 1950: combination of national statistics with two case-control studies. *British Medical Journal* **321** pp.323-329

Petrie, K.J., Weinman, J. (2003) Editorial: More focus needed on symptom appraisal. *Journal of Psychosomatic Research* **54** pp.401-403

Pill, R., Stott, N.C.H. (1982) Concepts of illness causation and responsibility: some preliminary data from a sample of working class mothers. *Social Science and Medicine* **16** pp.43-52

Pill, R., Stott, N.C.H. (1985) Choice or chance: Further evidence on ideas of illness and responsibility for health. *Social Science and Medicine* **20** (10) pp.981-991

Pitiphat, W., Diehl, S.R., Laskaris, G., Cartos, V., Douglass, C.W., Zavras, A.I. (2002) Factors associated with delay in the diagnosis of oral cancer. *Journal of Dental Research* **81** (3) pp.192-197

Poirier, S., Ayres, L. (1997) Endings, secrets, and silences: Overreading in narrative inquiry. *Research in Nursing and Health* **20** pp.551-557

Polkinghorne, D.E. (1988) *Narrative Knowing and the Human Sciences.* New York: State University of New York Press

Polkinghorne, D.E. (1995) Narrative configuration in qualitative analysis, In J.A. Hatch, R. Wisniewski (Editors) *Life History and Narrative.* London: The Falmer Press, pp.5-23

Pollock, K. (1993) Attitude as a means of resisting illness, In A. Radley (Editor) *Worlds of Illness. Biographical and Cultural Perspectives on Health and Disease.* London: Routledge, pp.49-70

Pound, P., Gompertz, P., Ebrahim, S. (1998) Illness in the context of older age: the case of stroke. *Sociology of Health and Illness* **20** (4) pp.489-506

Price, L. (1987) Ecuadorian Illness Stories, In D. Holland, N. Quinn (Editors) *Cultural Models in Language and Thought.* Cambridge: Cambridge University Press, pp.313-342

Putnam, J.B., Fossella, F.V., Komaki, R. (2003) Implementation of Multidisciplinary Care in the Treatment of Patients with Lung Cancer, In F.V. Fosella, R. Komaki, J.B. Putnam (Editors) *Lung Cancer.* New York: Springer-Verlag, pp.1-24

Quekel, L.G.B.A., Kessels, A.G.H., Goei, R., van Engelshoven, J.M.A. (1999) Miss rate of lung cancer on the chest radiograph in clinical practice. *Chest* **115** pp.720-724

Radley, A (1999) Social Realms and the Qualities of Illness Experience, In M. Murray, K. Chamberlain (Editors) *Qualitative Health Psychology*. London: Sage Publications, pp.16-30

Radley, A., Chamberlain, K. (2001) Health psychology and the study of the case: from method to analytic concern. *Social Science and Medicine* **53** pp.321-332

Ragin, C.C. (1992) "Casing" and the process of social inquiry, In C.C. Ragin, H.S. Becker (Editors) *What is a case?* Cambridge: Cambridge University Press, pp.217-226

Ramirez, A.J., Westcombe, A.M., Burgess, C.C., Sutton, S., Littlejohns, P., Richards, M.A. (1999) Factors predicting delayed presentation of symptomatic breast cancer: a systematic review. *The Lancet* **353** pp.1127-1131

Rapley, T.J. (2001) The art(fullness) of open-ended interviewing: some considerations on analysing interviews. *Qualitative Research* **1** (3) pp.303-323

Reinharz, S. (1997) Who Am I? The Need for a Variety of Selves in the Field, In R. Hertz (Editor) *Reflexivity and Voice*. Thousand Oaks: Sage Publications, pp.3-20

Richards, H., Emslie, C. (2000) The 'doctor' or the 'girl from the University?' Considering the influence of professional roles on qualitative interviewing. *Family Practice* **17** (1) pp.71-75

Ricoeur, P. (1981) Narrative Time, In W.J.T. Mitchell (Editor) *On Narrative*. Chicago: The University of Chicago Press, pp.165-186

Riessman, C.K. (1993) *Narrative Analysis*. Newbury Park: Sage Publications

Riessman, C.K. (2003) Performing identities in illness narrative: masculinity and multiple sclerosis. *Qualitative Research* **3** (1) pp.5-33

Ristvedt, S.L., Trinkaus, K.M. (2005) Psychological factors related to delay in consultation for cancer symptoms. *Psycho-Oncology* **14** (5) pp.339-350

Robson, C. (2002) *Real World Research* (2^{nd} Edition). Oxford: Blackwell Publishers Limited

Rolfe, G. (2006) Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing* **53** (3) pp.304-310

Rozniatowski, O., Reich, M., Mallet, Y., Penel, N., Fournier, C., Lefebvre, J-L. (2005) Psychosocial factors involved in delayed consultation by patients with head and neck cancer. *Head and Neck* **27** pp.274-280

Rubin, H.J., Rubin, I.S. (1995) *Qualitative Interviewing: The Art of Hearing Data.* Thousand Oaks: Sage Publications

Ruston, A., Clayton, J., Calnan, M. (1998) Patients' action during their cardiac event: qualitative study exploring differences and modifiable factors. *British Medical Journal* **316** pp.1060-1065

Ryen, A. (2004) Ethical issues, In C. Seale, G. Gobo, J.F. Gubrium, D. Silverman (Editors) *Qualitative Research Practice.* London: Sage Publications, pp.230-247

Safer, M.A., Tharps, Q.J., Jackson, T.C., Leventhal, H. (1979) Determinants of three stages of delay in seeking care at a medical clinic. *Medical Care* **17** (1) pp.11-29

Salander, P. (2007) Attributions of lung cancer: My own illness is hardly caused by smoking. *Psycho-Oncology* **16** pp.587-592

Salomaa, E-R., Sallinen, S., Hiekkanen, H., Liippo, K. (2005) Delays in the diagnosis and treatment of lung cancer. *Chest* **128** pp.2282-2288

Sandelowski, M. (1999) Time and qualitative research. *Research in Nursing and Health* **22** pp.79-87

Sandelowski, M. (2004) Using qualitative research. *Qualitative Health Research* **14** (10) pp.1366-1386

Saunders, M., Dische, S., Barrett, A., Harvey, A., Gibson, D., Parmar, M. (1997) Continuous hyperfractionated accelerated radiotherapy (CHART) versus conventional radiotherapy in non-small-cell lung cancer: a randomised multicentre trial. *The Lancet* **350** pp.161-165

Savage, S.A., Clarke, V.A. (1998) Older women's illness representations of cancer: a qualitative study. *Health Education Research* **13** (4) pp.529-544

Scambler, G., Scambler, A. (1984) The illness iceberg and aspects of consulting behaviour, In R. Fitzpatrick, J. Hinton, S. Newman, G. Scambler, J. Thompson (Editors) *The Experience of Illness*. London: Tavistock Publishers, pp.32-53

Scheper-Hughes, N., Lock, M.M. (1986) Speaking "truth" to illness: Metaphors, reification, and a pedagogy for patients. *Medical Anthropology Quarterly* **17** (5) pp.137-140

Scott, S.E., Grunfeld, E.A., Main, J., McGurk, M. (2006) Patient delay in oral cancer: A qualitative study of patients' experiences. *Psycho-Oncology* **15** pp.474-485

Seale, C. (1998) Qualitative interviewing, In C. Seale (Editor) *Researching Society and Culture*. London: Sage Publications, pp.202-216

Seale, C. (2002) *Media and Health*. London: Sage Publications

Seale, C. (2003) Health and media: an overview. *Sociology of Health and Illness* **25** (6) pp.513-531

Seymour, J.E., Ingleton, C. (1999) Ethical issues in qualitative research at the end of life. *International Journal of Palliative Nursing* **5** (2) pp.65-73

Seymour, J., Payne, S., Reid, D., Sargeant, A., Skilbeck, J., Smith, P. (2005) Ethical and methodological issues in palliative care studies. *Journal of Research in Nursing* **10** (2) pp.169-188

Sheikh, I., Ogden, J. (1998) The role of knowledge and beliefs in help seeking behaviour for cancer: a quantitative and qualitative approach. *Patient Education and Counseling* **35** pp.35-42

Silverman, D. (2000) *Doing Qualitative Research. A Practical Handbook*. London: Sage Publications

Skott, C. (2002) Expressive metaphors in cancer narratives. *Cancer Nursing* **2** (3) pp.230-235

Sontag, S. (1983) *Illness as Metaphor*. Harmondsworth, Middlesex: Penguin Books

Souhami, R., Tobias, J. (2003) *Cancer and its management*. Malden: Blackwell Science Limited

Stake, R.E. (1994) Case Studies, In N.K. Denzin, Y.S. Lincoln (Editors) *Handbook of Qualitative Research*. Thousand Oaks: Sage Publications, pp.236-247

Stake, R.E. (1995) *The Art of Case Study Research*. Thousand Oaks: Sage Publications

Stake, R.E. (2005) Qualitative Case Studies, In N.K. Denzin, Y.S. Lincoln (Editors) *The Sage Handbook of Qualitative Research* (3rd Edition). Thousand Oaks: Sage Publications, pp.443-466

Strang, P. (2000) Qualitative research methods in palliative medicine and palliative oncology. *Acta Oncologica* **39** (8) pp.911-917

Strauss, A., Corbin, J. (1998) *Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory* (2nd Edition). Thousand Oaks: Sage Publications

Summerton, N. (1999) *Diagnosing cancer in primary care*. Abingdon: Radcliffe Medical Press Limited

Svedlund, M., Danielson, E., Norberg, A. (2001) Women's narratives during the acute phase of their myocardial infarction. *Journal of Advanced Nursing* **35** (2) pp.197-205

Taggart, S.C.O., Baxendale, M., Peplow, K., Murray, J. (2005) No symptom awareness in Salford lung cancer patients: The need for a public health awareness campaign. *Thorax* **60** (suppl. 2) p.ii53

The, A-M. (2002) *Palliative care and communication: experiences in the clinic*. Buckingham: Open University Press

The Lancet (2000) Editorial: Does lung cancer need a lapel ribbon? *The Lancet* **356** (9237) p.1205

The National Collaborating Centre for Primary Care (2005) Referral guidelines for suspected cancer in adults and children. Part one. http://guidance.nice.org.uk/CG27/guidance/pdf/English/download.aspx Accessed 13.6.07

The Roy Castle Lung Cancer Foundation and Macmillan Cancer Support (2006) Lung Cancer Awareness Month 2006 leaflet.

www.macmillan.org.uk/Documents/Support_Material/Get-involved/Campaigns/LCAM_leaflet.pdf Accessed 31.10.06

Thorne, S. (1998) Ethical and representational issues in qualitative secondary analysis. *Qualitative Health Research* **8** (4) pp.547-555

Thorogood, N. (1992) What is the relevance of sociology for health promotion?, In R. Bunton, G. Macdonald (Editors) *Health Promotion. Disciplines and Diversity.* London: Routledge, pp.42-65

Thorogood, N. (1996) What is the sociology of knowledge? The example of health education and promotion. In, A. Perry (Editors) *Sociology: Insights in Health Care.* London: Arnold, pp.235-249

Tishelman, C., Degner, L.F., Rudman, A., Bertilsson, K., Bond, R., Broberger, E., Doukkali, E., Levealahti, H. (2005) Symptoms in patients with lung carcinoma. Distinguishing distress from intensity. *Cancer* **104** pp.2013-2021

Tones, K., Tilford, S. (2001) *Health Promotion: effectiveness, efficiency and equity* (3rd Edition). Cheltenham: Nelson Thornes Limited

Tromp, D.M., Brouha, X.D.R., Hordijk, G.J., Winnubst, J.A.M., Gebhardt, W.A., van der Doef, M.P., de Leeuw, J.R.J. (2005) Medical care-seeking and health-risk behavior in patients with head and neck cancer. *Health Education Research* **20** (6) pp.665-675

Turkington, P.M., Kennan, N., Greenstone, M.A. (2002) Misinterpretation of the chest x ray as a factor in the delayed diagnosis of lung cancer. *Postgraduate Medical Journal* **78** pp.158-160

Twigg, L., Moon, G., Walker, S. (2004) *The smoking epidemic in England.* London: Health Development Agency

Tyczynski, J.E., Bray, F., Parkin, D.M. (2003) Lung cancer in Europe in 2000: epidemiology, prevention, and early detection. *The Lancet Oncology* **4** pp.45-55

Vendler, Z. (1984) Understanding People, In R. Shweder, R. Levine (Editors) *Culture Theory.* Cambridge: Cambridge University Press, pp.200-213

Wadsworth, M.E.J., Butterfield, W.J.H., Blaney, R. (1971) *Health and Sickness, The Choice of Treatment*. London: Tavistock Publications

Waller, W. (1934) Insight and scientific method. *The American Journal of Sociology* **XL** (3) pp.285-297

Waller, J., McCaffery, K., Wardle, J. (2004) Measuring cancer knowledge: Comparing prompted and unprompted recall. *British Journal of Psychology* **95** pp.219-234

Walton, J. (1992) Making the theoretical case, In C.C. Ragin, H.S. Becker. (Editors) *What is a case?* Cambridge: Cambridge University Press, pp.121-137

Watson, C. (2006) Unreliable narrators? 'Inconsistency' (and some inconstancy) in interviews. *Qualitative Research* **6** (3) pp.367-384

Weaver, K., Olson, J.K. (2006) Understanding paradigms used for nursing research *Journal of Advanced Nursing* **53** (4) pp.459-469

Wheeler, D.W., Wakefield, S.E., Mortensen, N.J., Kettlewell, M.G.W. (1999) Delays experienced by patients with symptomatic colorectal cancer. *Colorectal Disease* **1** pp.174-176

WHO (1986) Ottawa Charter for Health Promotion, First International Conference on Health Promotion. http://www.who.int/healthpromotion/conferences/previous/ottawa/en/. Accessed 18.4.07

Wikan, U. (2000) With Life in One's Lap: The Story of an Eye/I (or Two), In C. Mattingly, L.C. Garro (Editors) *Narrative and the Cultural Construction of Illness and Healing*. Berkeley: University of California Press, pp.212-236

Williams, G. (1984) The genesis of chronic illness: narrative re-construction. *Sociology of Health and Illness* **6** (2) pp.175-200

Wiltshire, J. (1995) Telling a story, writing a narrative: terminology in health care. *Nursing Inquiry* **2** pp.75-82

Wittekind, C., Greene, F.L., Hutter, R.V.P., Klimpfinger, M., Sobin, L.H. (2005) *TNM Atlas* (5th Edition). Berlin: Springer-Verlag

Yin, R.K. (2003) *Case Study Research* (3^{rd} Edition). Thousand Oaks: Sage Publications

Zola, I.K. (1966) Culture and symptoms – An analysis of patient's presenting complaints. *American Sociological Review* **31** (5) pp.615-630

Zola, I.K. (1973) Pathways to the doctor – from person to patient. *Social Science and Medicine* 7 pp.677-689