

**How people affected by laryngeal cancer source
and use different types of information over time:
a longitudinal qualitative study**

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Volume I

**Prefaces
and
Chapters 1 to 5**

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Abstract

Due to changes in UK and Scottish policy and NHS directives, there have been many changes and improvements in the way information is provided to patients affected by cancer and their families over the last decade. The information provided should be accurate, detailed and tailored to the individual's needs across the whole of their cancer trajectory. People affected by laryngeal cancer could be classed as a "Cinderella" group as there is a lack of research with this group of patients and their families, in comparison to other types of cancer, even though the impact of treatment can have a profound and debilitating effect on the individual and their family's quality of life. How this group of patients and their families use and source information to help them make sense of their experiences across their trajectory is unknown, therefore this study explored the role of information based on the experiences of people affected by laryngeal cancer across their cancer trajectory.

The study adopted an interpretive prospective longitudinal approach, using two in-depth qualitative interviews with twenty patients and eighteen carers from across the main treatment pathways associated with this type of cancer. The data were analysed using Framework Analysis and influenced by Dingwall's Illness Action Model. Four broad thematic headings were developed to explain the role of information: "Search for Normality", "Illusion of Certainty", "Reality of Uncertainty" and "Culture of Caring". Relationships were identified between these headings at four key stages across the cancer trajectory. The

broad theme “Search for Normality” overarched the whole of the cancer trajectory explaining how information was sourced and used to help this group understand their experience of symptoms.

The main findings from the study show that two broad categories of information are used: information from health professionals and experiential information from one’s own and others’ experiential knowledge of health and illness. Both categories of information are sourced and used in different ways at different stages over the course of the trajectory and become inextricably linked over time. The study shows that information is not an entity that can be studied on its own but needs to be studied and explained in the ways it is situated, used and experienced within the context of the complex needs and experiences of this group of patients and their families.

This study is the first longitudinal study to provide an explanation of the role of information with people affected by laryngeal cancer across their cancer trajectory. The findings show how the different types of information used from the various sources influence how people affected by laryngeal cancer perceive and understand their diagnosis, treatment and the outcome of treatment. The study findings suggest that health professionals need to situate information in the context of the individual’s understanding and prior knowledge of health and illness to ensure that it does not set unrealistic expectations, with a clear need for continuity and supportive care identified in the post-treatment and follow-up phases.

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To my parents, brothers and sisters I would like to say a big thank-you, as you have been at my back since starting this and always pushed me to achieve it through your continual love, support and encouragement. To my “girlies” what can I say, you were on the rollercoaster with me and were always there to help me move on to the next level with your words of encouragement and support, we have achieved.

Lastly, but by no means least, to my husband Norman and my sons, Scott, Mark and Stephen who have provided me with every kind of support and encouragement imaginable over these last four years. Thank you for your patience, tolerance and love; the “book” has now been written.

Declaration

I declare the work in this thesis to be my own, except where otherwise stated.

A handwritten signature in black ink, appearing to read "Anne Taylor". The signature is written in a cursive style with a long, sweeping tail on the final letter.

Anne Taylor

September 2011

Chapter One

Introduction

This chapter sets the scene for the research described in this thesis. I will provide an overview of my personal interest and drivers for doing this study and my role as “nurse” researcher and the influence this had on the development of the study. I will provide an overview of the recent changes in cancer services and the importance now placed on the provision of information from the policy context and its influence in clinical practice. I will discuss “information” and “knowledge,” defining the terms used in this thesis and why, which will lead to a description of the aims and structure of the thesis.

1.1 Background to the study

This study stems from my clinical experience of over a decade working in a district general hospital where I nursed many patients and their families affected by cancer of the larynx. During this time, I witnessed how a diagnosis of laryngeal cancer and the subsequent treatment they experienced had a major impact on both the patients’ and their families’ lives. At this time, there was an overall lack of written information and long-term support apparent in order for them to adjust and cope with this life-changing diagnosis.

During the late '80s and early 1990s, the main treatment for laryngeal cancer was surgical removal of the larynx with radical neck dissection depending on the level of nodal involvement in the neck. Radiotherapy was used with this group of patients mainly post-laryngectomy where patients would return from the treatment centre to the ward for recuperation and supportive nursing care. Treatment changes were evident at this time with some of the patients with earlier stage cancers attending for radiotherapy and returning to the ward as required for further nursing care and support. In many areas, the care pathways were disjointed, with many patients and their families being ill-prepared due to a lack of formal support to help them cope and manage the impact of the treatment and the long-term recovery that ensues.

During my clinical experience, there was no multi-disciplinary team approach, no clinical nurse specialists and no nurse-led clinics. The nurses on the ward were the link and support to this group of patients and their families where an "open door policy" was adopted from their diagnosis (and ultimately, for some) to their death. In 1995, a close friend of the family was diagnosed with laryngeal cancer and required laryngectomy. This experience provided me with an "insider" view of the impact that this type of cancer has on the individual and the family. Through this personal experience, in combination with my clinical experience, I realised the profound impact that this type of cancer had on the patient and their family and the need for nursing research with this group of patients and their families to help improve their overall experience.

Due to policy changes in cancer services (Calman & Hine 1995) in combination with research in this field (Edwards 1998), improvements have been adopted and integrated into health care with a more coherent approach to treatment, information provision and follow-up care. Many hospitals now adopt a multi-disciplinary approach to treatment and overall care, with clinical nurse specialists employed to provide one-to-one support for the patient and their families from diagnosis into follow-up. In addition, recent developments and improvements in treatment regimes, such as concurrent chemo-radiation regimes, now see the focus of treatment on organ preservation with more positive functional outcomes for patients predicted in the post-treatment phase (Cognetti et al 2008).

Due to a career change in 2001, I had the opportunity to take a “step back” from clinical practice and learn new skills and gained knowledge in nursing research through my involvement in various health-related projects that eventually led to the development of this study. Although I was not actively involved in the clinical environment, through my research I maintained my clinical links and developed new links with other clinical staff involved and interested in improving the experience of people affected by laryngeal cancer. The trigger for the study was my involvement in a study looking at the information needs of people affected by different types of cancer in Forth Valley (Hubbard, Taylor & Kearney 2005). During this study, I realised there were few studies that identified the information needs of this group of patients and their families in comparison to other cancers such as breast, colorectal and prostate cancer. Based on this finding and discussion with clinical colleagues there was

agreement that there was an overall lack of nursing research and insight into this group's particular information needs across the cancer trajectory, thus the inception of this study.

1.2 The importance of information – the policy context

The provision of information to individuals is widely regarded as essential in health care to help patients and their families understand what is happening and enable them to be involved in their treatment and care decisions. Policy over the last ten years has influenced major changes in the provision of cancer care and cancer services across all cancers types. The Calman-Hine report, "*A policy framework for commissioning cancer services*" (1995), was one of the first main policies that changed the way in which cancer services were structured in England and Wales. The commissioning of this report was influenced by several factors: the overall increase in cancer incidence, the variations in outcomes of treatment across the UK, and the overall financial cost of cancer to the patient, carer and the health service. The report advocated that cancer services needed to change and that better communication should occur between primary, secondary and tertiary centres to allow all cancer patients, carers and families access to uniformly high quality care and high quality service. Central to this report was the recommendation that communication across all sectors of the NHS had to improve to allow a better pathway for the care of patients, carers and families. Stemming from the Calman-Hine report (1995) was the change in policy direction where the

experiences of patients with cancer were at the centre of service delivery and service organisation across the UK.

Information plays an important role in helping people manage the impact of a cancer diagnosis and their treatment with many policies over the last decade identifying the importance of the provision of information and that the central providers of this information should be health professionals from across the various sectors in the NHS. For example, the *Cancer Information Strategy* (NHS Executive 2000) identified a greater need for a coherent approach to the provision of information across all sectors of the NHS. This document highlighted the central role that health professionals play in the provision of detailed information to patients and their families across the cancer trajectory. It also recognized the different types of information that can assist patients and their families, such as verbal and written information and information from those with direct experience of cancer, in order to ensure the information needs of people affected by cancer are being met.

Similarly, through the Scottish Executive Strategy, *Cancer in Scotland: Action for Change* (Scottish Executive 2001a), saw the establishment of Regional Cancer Advisory Groups and Managed Clinical Networks to ensure there was a better integration of the long-term needs of people affected by cancer and that their support and information needs were being met. The emphasis was not only placed on the provision of information but also on the importance of the communication of information between the acute and primary care teams, as more people affected by cancer will be cared for in their local

communities. This strategy also identified the limitations of the time health professionals had to provide the information to help patients to understand their cancer diagnoses, with an imbalance identified in the quantity and quality of the information provided to people affected by cancer.

Similarly, in *Cancer in Scotland: Action for change: A Guide to Securing Access to Information* (Scottish Executive 2001b), the way in which information is communicated to patients and the amount of information given in a consultation was addressed. This policy document states: "All staff concerned with patient care should be aware of the potential problems with communication and be aware that patients often find it difficult to take in information during consultations, especially after hearing a diagnosis of cancer or other 'bad news'"(Ibid.:10). This policy again emphasises the important role of health professionals caring for people affected by cancer providing and communicating information to ensure patients and their carers can understand and make sense of the information they receive. As the Department of Health (2005) policy states: "people should have access to accurate, high quality, comprehensive information delivered in the way they want; have their personal information needs considered and discussed at every contact with health professionals and receive as much support as they want to access and understand information" (DOH 2004).

Recently there has been a focus on the needs of carers through new policy initiatives addressing their need for information and knowledge in order to have the appropriate skills to assist them care for their spouses affected by

cancer. These new initiatives see the carer as central in promoting patient self-care, exploring their needs and ensuring they have the appropriate support and skills (Scottish Government 2005), by encouraging two-way communication with health professionals with carers viewed as central in all aspects of the patient's care (Scottish Government 2008).

Thus, the changes in UK and Scottish policy along with NHS directives over the last decade have seen changes and improvements in the way people affected by cancer experience their care and the delivery of their cancer services. These policies have evolved a new culture in the National Health Service where patients, carers and families have expectations of health professionals and of the services they provide. Their experiences are at the heart of these policies integrated into a "culture of caring" where they should be seen as a human being, not the patient number (Scottish Executive 2006:3). Thus, patients and their families should expect and experience a uniformly high quality service with the provision of quality detailed information, specific to their needs, along with a seamless pathway from diagnosis through treatment and into follow-up care.

1.3 Policy and Practice – The Study

As stated in section 1.1, the trigger for this study was my realization of the lack of research into the information needs of this group of patients in conjunction with my personal and clinical knowledge of knowing the impact this type of cancer and its treatment has on the individual and their families. Through informal discussions with clinical colleagues, issues had been raised

surrounding information provision and the challenges they were addressing in practice at this time. The “blue folders” were in development by the regional cancer networks, through focus group discussions with patients, carers and clinicians. This newly devised system aimed to provide patients and their family members with detailed written information on various aspects of their diagnosis, treatment and follow-up care tailored to their needs. Through this system, in combination with policies stating that information must be tailored to the individual’s needs, the initial aim of this study was to explore and define what information people affected by laryngeal cancer received across their cancer trajectory and whether that information was being tailored to their needs.

Fundamentally, as a nurse, face-to-face communication is central to determining the explicit needs of the patient and their family in the clinical setting based on their experiences of care, which influenced the approach I adopted to the study and the methods I used for data collection, discussed more in-depth in Chapter 4. It is obvious that my clinical role influenced the inception of the study, how I would collect the data and my interpretation of the data generated. Adopting a qualitative approach to the study allowed me to explore and gain an insight into the subjective experience of this group of patients and their families, with the importance of transparency and reflexivity crucial, to ensure that the reader views the data generated and analysed as being both rigorous and valid.

My influence as a “nurse” researcher and the challenges that can present themselves during the course of the research process are discussed in

the literature. I am aware as a “nurse” researcher I entered this study, not as a blank sheet, but with a personal history and clinical experience of different events that could affect how I understood and managed the data I was collecting and analysing. However, as Colbourne and Sque state; “If the nurse cannot be removed from the researcher why pretend? This fact should be used to the advantage of the research” (Colbourne & Sque 2004:303) and should not be viewed as a disadvantage. No one involved in qualitative research can truly “bracket off” their personal history, influences or interests in the topic under study, but the most important factor is recognising the existence of this dilemma and discussing it and its implications throughout the whole research process. The approach I used and the justification for the study were influenced by my clinical and research experience. By reviewing relevant literature (Newell et al 2004, Ziegler et al, 2004), which identified unmet information needs with this group of patients, and finding no studies identifying the specific information needs of carers, in combination with the policy rhetoric stating how information needs to be tailored to the individual needs, a lack of research in this particular field was identified.

Over the course of the study, my initial research questions seemed narrow and prescriptive, which did not fully justify the data that I generated. As the interviews progressed, it became apparent that the types and sources of information and this group’s need for information varied enormously. It became evident that information is not an entity that can be studied on its own per se, but needs to be studied and explained in the ways in which it is situated, used and experienced, within the context of the complex needs of this group of

patients and their families. Therefore, the overall aim of this study changed to explain the role of information with people affected by laryngeal cancer based on their experiences across their cancer trajectory. To allow me to achieve this aim, the following research questions were set:

1. What are the experiences of people affected by laryngeal cancer across their cancer trajectory?
2. In response to their experiences what information do they need and use?
3. Why do they need these types of information?
4. In what ways do they use these types of information?
5. Are there factors that influence or inhibit their need and use of information?
6. Is information being tailored to their individual needs based on their experiences?

1.4 Information and Knowledge

At this point in the thesis, I think it is important to define and discuss “information” since it is the central focus of this thesis. In simplistic terms, information is defined as ***“knowledge obtained from investigation, study or instruction or facts or data pertaining to a particular subject or regarded as significant”*** (Penguin English Dictionary 2002). This definition would suggest, therefore, that the information provided to people affected by cancer provides them with the knowledge and/or facts on the various aspects of their cancer, its treatment and future outcomes. Equally, the definition suggests that

this information has derived from knowledge gained through scientific investigation or study, or instruction. Thus, information for people affected by cancer could come from a range of sources including instruction from health professionals.

The majority of information that patients, carers and their families receive from health professionals over their cancer trajectory can be classed as “biomedical” information, derived from medical knowledge gained through decades of scientific studies and investigations influencing clinical care and, more recently, evidence-based practice. “Biomedical” information incorporates the aetiology or biology of the disease, with medicine providing the knowledge on the best treatment and management of the disease. This stems from the focus of medicine in the 19th and 20th centuries, where medicine focused on the normal, with disease viewed as deviating from statistical norms, independent of the individual’s experiences or circumstances, in many ways viewing disease as a shift from the “natural state” of the individual (Lawrence 1994). The idea of disease as individual pathology had become the dominant paradigm and was linked to the development of a “bounded” medical profession that forced complete power over illness and its treatment (Bury 2001; Lawrence 1994). The “bounded” medical profession held the knowledge and the expertise (Bury 2001), where the doctor was viewed as the possessor of expert knowledge.

The view that doctors possess the “expert knowledge” stems from theories of knowledge (epistemology) which makes assumptions on “how, what and can we know about the world” (Willig 2001:2) and the assumptions or

claims that can be drawn from the phenomenon being studied. Medicine is based in the paradigm where knowledge is deemed true and justifiable based on the evidence generated from objective scientific experiments, using large numbers of observable events, noting causal or plausible explanations, which can be replicated and verifiable over time; science assumes that there is one reality that is objective and can be measured. Based on this assumption, the information drawn from the knowledge gained from scientific studies and investigations can be viewed as “true and justifiable” due to the method of non-biased data collection and analysis. Equally, health professionals who have gained knowledge by meeting the requirements of specialised education and formal training in their professional discipline and who possess the appropriate credentials (Borkmann 1976) provide this information to patients, carers and their families. Thus, the biomedical information provided to patients, carers and their families is drawn from knowledge that is often constructed as true and verifiable from health professionals who possess expert knowledge gained through instruction in their particular subject or discipline, which is regarded as significant; thus justifying its power and dominance over other types of knowledge.

However, the epistemology of medicine based on the concept that disease is something that can be treated “objectively”, separate from the individual’s experience of illness and its impact on the reality of their everyday lives (Popay & Williams 1996), has been questioned and challenged. The “ideology of the biomedical model, tends to disregard the significance of the experience and impact of illness, and concentrates instead on symptoms as

indicators of disease and tolerance of treatment” (Wells 1998a:841). Few would “espouse a strict logical positivism in which knowledge is understood and demonstrated through its direct correspondence with observed events” (Madill et al 2000:1) and appreciate that there is even a level of interpretation in social scientific theories and findings. The traditional quantitative methodologies over the last couple of decades have been deemed inadequate to study or capture the experience of illness and health and its impact on the individual in the context of their lives. This has seen a plethora of studies exploring the various aspects and dimensions of illness and health on the individual in the context of their lives through qualitative methodologies (Prior 2003).

Qualitative methodologies explore the subjective experiences of individuals in the context of a specific phenomenon. They vary on how knowledge is generated based on the epistemological stance of the researcher but, fundamentally, share the belief that there is not one objective reality independent of our perception of it but that reality is fluid and changes over time. Qualitative methodologies suggest that knowledge is context-specific and influenced by the perspectives of the perceiver, through their subjective experience of the phenomenon being studied (Madill et al 2000). Thus, the knowledge generated is subjective and gained from the individual’s direct involvement or participation in the phenomena being studied which their socio-cultural and historical perspectives will influence. As Jaeger and Rosnow (1988) highlight, “human activity (*thus experience*) does not develop in a social vacuum but is vigorously situated in the socio-historical and cultural milieu of meanings and relationships” (1988:65) with Code (1993) suggesting that

knowledge comes from and is shaped by personal circumstances and the experiences of the knower.

However, this type of knowledge has been questioned, due to the unreliability or repeatability of its findings through the methods of biased data collection and analysis, in comparison to the traditional scientific methods of non-biased data collection and analysis. Borkmann (1976) disputes this argument and suggests that knowledge generated from direct participation can be claimed as “truth” as it is “learned from personal experience with a phenomenon, rather than truth acquired by discursive reasoning, observation or reflection on information provided by others”. She justifies this statement by saying: “The wisdom or knowledge gained is concrete, specific and commonsensical, based on the actual experience of the individual, which is unique and limited, but can represent the experience of others in similar circumstances” (1976:446). She defined this type of knowledge as “experiential knowledge”. Thus, information gained from experiential knowledge learned from the direct participation or experience of a phenomenon could be claimed to be as valid and true as information gained from biomedical knowledge.

Experiential knowledge is strongly linked with education and how, through the process of direct participation and experience, experiential learning can be achieved leading to the development of knowledge (Kolb 1984). Equally, I have memories of nurse education having similar approaches, through the statement of “see one, do one, teach one”, implying that through direct participation or involvement in a specific nursing procedure, experiential

learning occurs, thus leading to experiential knowledge that can be passed on to fellow student nurses or colleagues. Therefore, knowledge gained through direct participation or direct experience of phenomena is evident across all spheres of life and it is through those varied experiences, gained over time, that we develop our experiential knowledge.

The concept of “experiential knowledge” has evolved over time into terms such as “lay beliefs”, “lay understandings” and “lay knowledge”, specifically within the social science literature (Young 2004; Lawton 2003). The use of the word “lay” was to distinguish between those with professional or expert knowledge (i.e. medical) in comparison to those without. However, Popay & Williams (1996) argue that “through a more or less systematic process whereby experience is checked against life-events, circumstances and history, lay people acquire an “expert” body of knowledge, different from but equal to that of professionals” (1996:760). This concept, however, has been challenged by Prior, who argues that the concept, in her opinion, is an oxymoron (2003:53). Although it is generally agreed and accepted in health care today that patients, carers and their families possess information and knowledge on illness, their bodies and the impact of their illness in the context of their lives, that does not make them “experts” (Prior 2003). She justifies this by claiming that “experiential knowledge is invariably limited and idiosyncratic” (2003:53), in many ways based only on the particular experience of the individual and their perception and knowledge of their experience.

However, I would argue that some patients, especially those suffering from chronic and long-term illness could become “experts” about their “own” condition and not necessarily an expert about the medical condition per se. Equally, I would argue that patients, carers and their families have experiential knowledge developed through direct and indirect experiences, past and present, of illness. This experiential knowledge is further developed by participating in the actual experience of their cancer diagnosis, treatment and follow-up, which can provide facts and information based on the commonsensical, concrete knowledge developed through their actual experiences which, in turn, can provide information to others in similar circumstances and experiences.

For the purposes of this thesis I therefore define “information from professionals” as the biomedical types of information that patients, carers and their families receive over the cancer trajectory and “experiential information” to define information gleaned from their own or others’ experiential knowledge.

1.5 Overview of the thesis

Chapter 2 will provide an overview of the epidemiology of head and neck cancer with specific reference to incidence, prevalence and survival rates in Scotland and risk factors associated with laryngeal cancer. The chapter will present a description of the main treatment pathways for this group of patients and their side effects to demonstrate and inform the reader of the profound effect this type of cancer can have on the individuals’ and their family’s quality of life.

Chapter 3 will provide an overview of the subjective experiences of people affected by head and neck cancers leading to a discussion of the experiences of people affected by cancer across the cancer trajectory. This chapter will lead to a discussion of the different strategies that people adopt to manage and cope with their experiences of cancer, which then leads to a discussion of the role and importance of information. An overview of the “information needs” literature will be presented with a description of research on how people use information, linking evidence of the relationship between “information” and “knowledge” by drawing on wider literature.

Chapter 4 describes how I carried out the main study to meet the study aim. I will justify the methodological approach I adopted and describe the methods that I used for data collection, leading to a description of my sampling approach and study participants. I will discuss the recruitment process and the challenges I experienced during data collection, finishing the chapter by discussing my analytical approach, the themes generated from my data analysis, leading to a description and explanation of the study findings in Chapter 5.

Chapter 5 presents a description and thematic explanation of the needs of this group of participants, leading to an explanation of the role that information plays from diagnosis into follow-up in the context of their lives. Following a description of the structure of the interviews, I present the analysis at key clinical time points across the cancer trajectory where the need for

information, in combination with their experience, was significant as reported by participants.

Chapter 6 summarises the main findings in relation to the study aim by presenting first the needs of this group of participants and the answers to my research questions. I will discuss the findings in relation to sociological theories and relevant literature leading to a discussion of the strengths and limitations of the study. Finally, I will present my conclusions and the implications of the findings in relation to policy, practice and future research.

A note for the reader. Throughout the following thesis, the term “head and neck cancers” is used when there is a lack of detailed research specifically on laryngeal cancer.

Chapter Two

Introduction

This chapter will provide an overview of the epidemiology of head and neck cancer with specific reference to incidence, prevalence and survival rates in Scotland and risk factors associated with laryngeal cancer. The chapter will describe the main treatment pathways for this group of patients and their side effects to demonstrate and inform the reader of the profound effect this type of cancer can have on the individuals' and their families' quality of life.

2.1 Incidence and Prevalence

Head and neck cancers cover a range of lesions that represent squamous cell carcinomas of the upper respiratory and gastrointestinal tract. Globally, they represent the sixth most common cancer, with Hungary, France and Scotland identified as having the highest prevalence rates in Europe (Rapidis & Scully 2009; Cognetti et al 2008). The Scottish Executive has predicted that incidence rates of head and neck cancer will rise, with an overall increase of 31% by the year 2020 (Scottish Executive, 2001c).

There are two main broad categories of head and neck cancers: cancer of the oral cavity and cancer of the larynx. Cancer of the larynx comprises a small proportion of the total worldwide cancers (2.4%), with 159,000 new cases of laryngeal cancer diagnosed worldwide in 2002, however,

these represent 2.1% of total worldwide cancer deaths (90,000), highlighting the poor survival rates associated with this type of cancer, discussed in more detail later in this section (Parkin et al 2005). Cancer of the larynx is predominantly a cancer of older males with a median age of sixty years and a peak in incidence at the ages of 75 to 84 years (Cognetti et al 2008; CRUK 2006).

Globally, the highest incidence of cancer of the larynx is in males in France, Italy and Spain, with approximately 11 males per 100,000 diagnosed, in comparison to 6 males per 100,000 diagnosed in Scotland (Parkin et al 2005). However, the highest incidence rates globally in females diagnosed with cancer of the larynx is in Scotland, with 1.3 females per 100,000 diagnosed in comparison to 0.1 per 100,000 females diagnosed in Spain (Parkin et al 2005). Globally, cancer of the larynx is rare in women from developed countries, with a gender ratio estimated at 7:1 male to female (Parkin et al 2005) with recent figures showing the sex ratio dropping to 4:1 male to female in the UK, and 3:1 male to female estimated in Scotland (CRUK 2006; Robertson et al 2004).

In 2006, the number of people diagnosed with laryngeal cancer in the UK was 2,213 with Scotland showing the highest incidence rates across males and females (see Table 1). Table 1 demonstrates higher incidence rates of laryngeal cancer in males compared to females with the sex ratio in Scotland approximately 3:1 male to female, in comparison to 4:1 in England and Wales and 5:1 in Northern Ireland. These figures show that people are more at risk of

developing laryngeal cancer in Scotland in comparison to others across the UK, with females in Scotland having the highest risk overall.

Table 1: Number of new cases and rates of laryngeal cancer, UK, 2006

	England	Wales	Scotland	N Ireland	UK
Cases					
Males	1,405	89	240	68	1,802
Females	303	20	75	13	411
Persons	1,708	109	315	81	2,213
Crude rate per 100,000 population					
Males	5.6	6.2	9.7	8.0	6.1
Females	1.2	1.3	2.8	1.5	1.3
Persons	3.4	3.7	6.2	4.7	3.7

Cancer Research UK, 2006

The geographical variations in incidence and subsequent mortality are indicative of differences in the prevalence of risk factors between countries (Harris et al 1998). These differences have implications for Scotland as recent figures show that overall survival rates for people affected by laryngeal cancer remain poor, with females in Scotland showing the poorest survival rates overall at five years (ISD 2007).

2.2 Survival Rates and Risk Factors

Survival rates for head and neck cancers overall are poor in comparison to other types of cancers. Figures from ISD (2007; 2004) suggest that overall, one-year survival rates have improved for most cancers and that some show improved survival at five years. However, Table 2 shows that people diagnosed with laryngeal cancer do not follow this trend as one- and five-year survival rates have not improved for this particular group over the last couple of decades although treatment regimes have.

Table 2: Trends in survival by cancer, sex and period of diagnosis

Cancer	Year	Male at 1 year	Female at 1 year	Male at 5 year	Female at 5 year
Larynx	1977-1981	84.4%	71.7%	65.2%	53.9%
Larynx	1997-2001	87.3%	71.8%	67%	52.3%

Trends in Cancer Survival in Scotland, 1977-2001, ISD, 2004

Similarly, a Scottish audit by Robertson et al (2004), found that although laryngeal cancer had the highest survival rate in comparison to other head and neck cancers, females diagnosed with laryngeal cancer, aged 69 years and over, had the poorest survival rate, with overall survival rates considerably lower in patients aged 85 and over. Thus, survival rates, especially overall survival rates at five years for head and neck cancers, remain poor in comparison to other cancer types with males diagnosed specifically with laryngeal cancer tending to survive longer than females (ISD 2007).

Age is a factor related to survival for people affected with cancer, with laryngeal cancer showing overall poorer survival rates in people aged 69 years and over. This rate may reflect a general trend in the population as figures from ISD (2007) show younger patients in general are showing more favorable survival rates in comparison to older patients across all cancer types (ISD 2007). One explanation for this rate could be the greater influence of co-morbidities in the older population than in the younger population.

Robertson et al (2004) in their Scottish audit showed survival with people affected with laryngeal cancer had the expected association between poor survival rates and age but they also demonstrated that the stage at which the tumour was diagnosed and the level of deprivation were also strongly associated with survival rates. They found that people diagnosed with less advanced tumours, for example "Stage I", showed survival rates of 100% at eighteen months, in comparison to those diagnosed with more advanced tumours, i.e. "Stage IV", showing survival rates of 52% at eighteen months (Robertson et al 2004). Many of the patients included in the audit who presented with advanced disease were from the lower deprivation quintiles. Survival rates of 80% were noted in the least deprived areas in comparison to 68% in the most deprived areas at 18 months post-diagnosis (Robertson et al 2004). The audit figures showed that just under half of the total sample presenting with clinically staged advanced disease lived in the lower deprivation quintiles of IV and V.

These findings are in line with recent figures highlighting how head and neck cancers in general are a disease of the deprived, with males living in the most deprived areas being four times more at risk of developing the disease (SIGN 90 2006). The majority of Robertson et al's sample lived in the Greater Glasgow Health Board where the highest concentrations of multiple deprivations are found, with over 50% of the communities defined to be in the most deprived 15% of communities nationally (Scottish Executive 2005), providing one explanation for the higher incidence of laryngeal cancer in the West of Scotland.

The established risk factors for the development of laryngeal cancer are smoking and high alcohol consumption (Cognetti et al 2008; SIGN 90 2006). Feber (2000) suggests that people from socially deprived backgrounds tend to fall into vulnerable groups who are more likely to smoke and have high alcohol consumption thus increasing their risk of laryngeal cancer. Laryngeal cancer is generally described as a cancer of males who smoke and have high alcohol consumption, however, this description is changing due to an increase in the smoking and drinking habits of females over the last few decades being linked with the increase in the incidence of females diagnosed with laryngeal cancer (Siesling et al 2003). Of the sample in the Scottish audit, 93% were smokers or ex-smokers and 53%, predominantly males, having or having had previous problems with alcohol (Robertson et al 2004). The importance of reducing the prevalence of these established risk factors in the population is central to preventing the incidence of head and neck cancers (Döbrössy 2005) with NHS Scotland and ASH Scotland (2006) making recommendations for the

organisation and implementation to promote smoking cessation in Scotland along with clinical guidelines in assessment of alcohol consumption (SIGN 90 2006).

2.3 Presenting Symptoms and Treatment Pathways

The most common presenting symptoms of cancer of the larynx are persistent hoarseness and pain on swallowing with 82% of the sample in the Scottish Head and Neck Audit presenting with persistent hoarseness and 26% presenting with pain and discomfort in the throat. Only a small percentage, 16%, presented with difficulty in swallowing, most commonly associated with advanced disease (Robertson et al 2004). SIGN guidelines (2006) recommend that an urgent referral is required for patients who experience these symptoms on average for three weeks with no improvement after the use of antibiotics. Early diagnosis and the accurate staging of the tumour is crucial to the clinical management, prognosis and treatment pathway offered to the individual ensuring positive functional outcomes in the post-treatment phase.

Clinical staging in head and neck cancers follows the Tumour, Node, Metastases method (TNM) as illustrated in Table 3 (SIGN 90 2006; Robertson et al 2004). T is the size of the primary tumour, N is the degree to which regional lymph nodes are involved, and M is the absence or presence of distant metastases. Once the TNM is determined, a tumour stage of I, II, III, or IV is given, with Stage I cancers being typically small, localised and curable. Stage II and III cancers are typically locally advanced and/or have spread to local lymph nodes, and Stage IV cancers typically metastatic (have spread to distant

parts of the body) and generally considered inoperable with treatment tending to be palliative.

Table 3: TNM Method and Treatment pathways

Clinical Staging	Description	Treatment
T1–N0–M0 – Stage I	Small localised curable	Radiotherapy for 4 to 6 weeks
T1/T2 N1 M0 – Stage II	Locally advanced with spread to node	Radiotherapy/ chemotherapy For 6 to12 weeks Plus/minus surgery
T2/T3 N1 to 4 M0 – StageIII	Locally advanced with spread	Radiotherapy/ chemotherapy plus laryngectomy Radiotherapy usually post-surgery for 6 weeks
T4 – N1 to 4 with M1 Stage IV	Advanced tumour with wide spread metastases	Palliative radiotherapy

Scottish Audit of Head and Neck Cancer (2004)

The clinical management and treatment for people affected with head and neck cancers is complex due to the anatomical structures surrounding the larynx (see Figure 1); for this reason, a multi-disciplinary team (MDT) approach is now used to improve the overall treatment and outcomes for this group of patients (Cognetti et al 2008; SIGN 90 2006; NICE 2004).

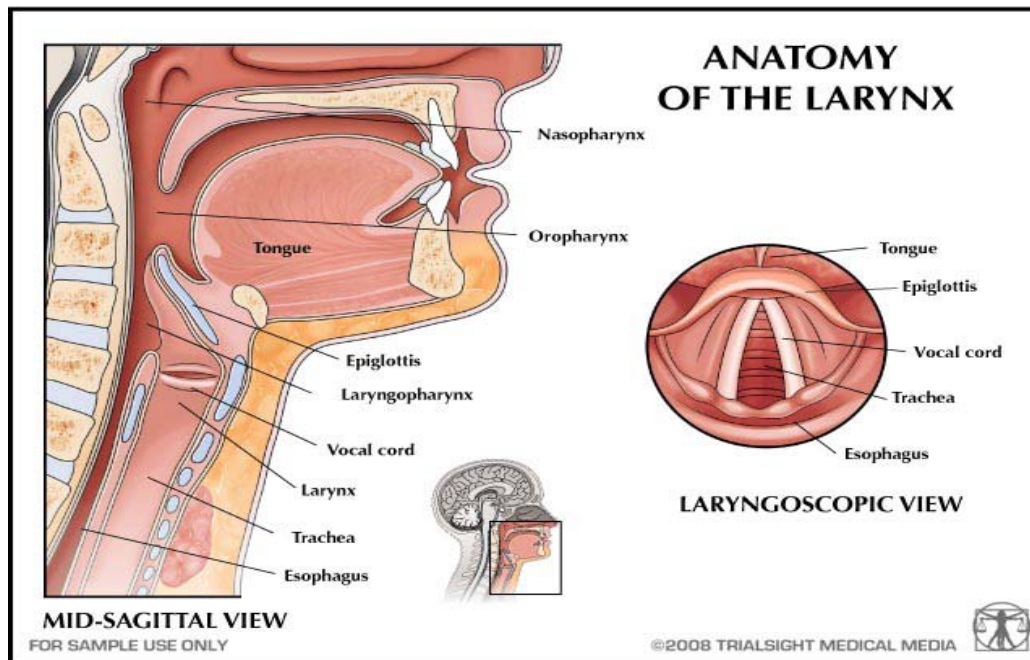


Figure 1: Anatomy of the Larynx

The larynx, or as it is better known, the “voice box”, is a 2-inch tube-shaped organ in the neck through which air passes on its way in and out of the lungs. When people talk, the vocal cords inside of the larynx tighten up and vibrate, producing sound. In the laryngeal area, there is the larynx (voice box), the supraglottic region (vocal cords) and sub-glottic regions. The larynx lies anatomically on the anterior surface of the neck, superficially protected on the front by the glottic cartilage (Adam’s apple) and the posterior wall of the larynx lies on the anterior surface of the oesophagus. Considering where the larynx lies anatomically, the physical impact of any treatment on the core physical functions of the patient is profound. Patients during and post-treatment have to encounter the reality of major changes in relation to their breathing, speech and swallowing as well as noticeable changes in their physical appearance.

The treatment regimes for cancer of the larynx vary depending on the clinical staging of the tumour and the level of nodal involvement in the neck region; the more advanced the tumour the more invasive and disabling the treatment. Less advanced tumours (Stage I) more commonly receive laser therapy or radiotherapy as the treatment of choice with more advanced tumours, such as Stage III undergoing surgery and radiotherapy or concurrent chemo-radiation as the treatment of choice. Prior to treatment, the physical assessment of the patient, in combination with their predicted functional impairment post-treatment, are used as guides for the clinicians and patient to decide the best treatment pathway (Cognetti et al 2008). Through recent developments and improvements in treatment regimes for head and neck cancer patients, such as concurrent chemo-radiation treatment, organ preservation rates have increased with curative rates and positive functional outcomes predicted in the post-treatment phase for patients (Cognetti, et al 2008).

During the course of treatment, patients may experience a combination of surgery, radiotherapy or chemo-radiation lasting several weeks. Although treatment regimes for cancer of the larynx are improving, the treatment toxicities patients experience can have a profound effect on every aspect of their lives (Wells et al 2007). A diagnosis of a head and neck cancer is described as more emotionally traumatic than any other type of cancer because of the disfiguring and functional impairment experienced by the individual (Ziegler et al 2004; Koster and Bergsma 1990). The impact of the

treatments for laryngeal cancer on the individuals' and their families' quality of life will be discussed in the following section.

2.4 Quality of Life Issues

The evolution of treatment regimes for head and neck cancer has seen the focus of treatment on preserving the larynx and anatomical structures of the head and neck area ultimately aiming for a disease-free patient (Nguyen et al 2002). However, the reality for many patients is that they may be disease-free with their larynx intact but suffer severe treatment toxicities and long-term functional and psychological issues arising from their cancer and the associated treatments (Penner 2009). The impact of treatment could explain the dramatic increase in health-related quality of life studies with people affected with head and neck cancers in the literature (Rogers et al 2007). In the review carried out by Rogers et al (2007) they note that the majority of studies were longitudinal in nature, using cohorts of patients affected with different types of head and neck cancers, which makes the presentation of the findings specifically on laryngeal cancer challenging.

A cancer diagnosis has a negative impact on an individual's psychological well-being with increased levels of depression noted in the first few months compared to the normal population (Zabora et al 2001). People diagnosed with head and neck cancers have been found to demonstrate significantly higher levels of distress in comparison to other cancer types, such as breast, colon and prostate (Zabora et al 2001). Due to treatment toxicities and the functional impairment experienced during and post-treatment, people

affected by head and neck cancers find it challenging to resume normal life (Wells 1998a) and have a residual fear of recurrence in the post-treatment phase (Hodges & Humphries 2009). Due to these factors, there is now a wealth of literature reporting this group's health-related quality of life during and post-treatment (Rogers et al 2007).

The construct of "quality of life" is complex, multi-dimensional and unique to the individual, suggesting that the correct assessment of the individual is crucial to effective clinical management and future care delivery (Maclean et al 2009). The World Health Organisation (1994) defines quality of life as "an individual's perceptions of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO 1994 cited in Maclean et al 2009:43). This definition suggests that there is a subjective level to an individual's quality of life, which requires clinicians to measure and assess quality of life through using person-centered subjectively-reported measures. However, the majority of studies exploring quality of life with patients affected by head and neck cancers have used quantitative methods using validated questionnaires, such as: The Health Related-Quality of Life Questionnaire (Terrell et al 1997); The University of Washington Quality of Life Questionnaire (Rogers et al 2002); The Functional Assessment of Cancer Therapy Questionnaire (FACT) (Cella et al 1993); and The Functional Assessment of Cancer Therapy Questionnaire Head & Neck (List et al 2002).

Broadly speaking, quality of life questionnaires explore specific issues reported by patients categorised across four domains: physical/functioning, psychological, social and occupational, that are affected by the disease or treatment (Nguyen et al 2002). The main areas identified from this body of work are in the physical/functional domains relating to speech, eating/swallowing and drinking. In the psychological domains, areas identified are in relation to distress, depression and fear of recurrence, and, in the social domains, smoking, alcohol and isolation (Nguyen et al 2002). In the following sections, I will provide an overview of quality of life research under the four main domains, however, it is evident how the domains and issues identified are interlinked and cannot be simply categorised into any one of the specific domains.

2.4.1 Physical Domain

Across all treatment modalities, the physical domain associated with functioning has been shown to be a strong predictor of an individual's overall quality of life with the impact of treatment on issues such as pain, speech and dysphagia consistently identified (Kelly et al 2007; Kohda et al 2005). Due to the toxicities of chemo-radiation and radiotherapy alone, the most common side effects reported by patients in long-term follow-up were xerostomia (dry mouth), dysphagia (difficulty in swallowing) and sticky saliva. These symptoms affected many patients' ability to eat and drink normally post-treatment thus affecting their quality of life significantly (Nguyen et al 2002) and were linked with the patients' inability to return to normal diet post-radiotherapy (List et al 2002).

Additionally, Rogers et al (2009), in their recent study of 65 patients affected with a range of head and neck cancers, found that those patients who had had a gastrostomy and had received radiotherapy reported lower functional scores than those without and were at the greatest risk of reporting a reduced quality of life six months post-diagnosis.

Similarly, for those patients requiring surgery, studies have reported a significant reduction in their quality of life scores in areas of speech and swallowing which is not surprising due to the major disruption of the anatomy and physiology in the head and neck area. This type of surgery affects the individual's speech, swallowing and breathing with Armstrong et al (2001) reporting a significant reduction in patients' quality of life in these areas six months post-laryngectomy. In a recent Australian study exploring the impact of dysphagia with 110 post-laryngectomy patients, Maclean et al (2009) found that all laryngectomy patients, irrelevant of whether they had dysphagia, demonstrated a significantly lower quality of life score across the physical, psychological and social domains of the WHOQoL-Bref in comparison to the normal population. However, the authors note that a negative change in physical function using the UW-QoL did not show similar quality of life scores suggesting that a change in an individual's function does not necessarily result in a change in their quality of life. Ramirez et al (2003) similarly found that having negative changes in functioning; i.e. a permanent stoma and loss of speech after surgery, were not the core factors in an individual reporting poor quality of life. From the results the authors suggest that the level of functioning affects an individual's psychological well-being, which, in turn, can affect the

individual's quality of life, but reported poor function is not necessarily the only predictor of an individual reporting poor quality of life (Maclean et al 2009).

The experience of pain was found to have a significant negative effect on a patient's quality of life across all treatment modalities, especially with those who experienced both surgery and radiotherapy (Kelly et al 2007; Kohda et al 2005; Nguyen et al 2002, Whale et al 2001). The pain reported by many who received surgery was due to their experience of arm/shoulder pain due to neck dissection (Nguyen et al 2002, Whale et al 2001) with many patients reporting persistent pain two years post-surgery (Chaplin & Morton 1999). However, the pain experienced by patients appears to be multifaceted, complex, and not only related to physical function but also linked with psychological morbidity (Moore et al 2004; Whale et al 2001).

2.4.2 Psychological Domain

People diagnosed with head and neck cancers have reported significantly higher levels of distress and depression, both in the pre- and post-treatment phases, which affect their quality of life (Karnell et al 2006; de Leeuw et al 2001; Zabora et al 2001). Some studies have reported over one-third of patients show scores indicative of depression at one year post-treatment (Hammerlid et al 1999) with others suggesting that the psychological distress, i.e. anxiety and depression, associated with the treatment for this group, is still evident in some patients three to eleven years post-treatment (Bjordal & Kaasa 1995).

Many studies report how psychological distress associated with this group of patients is high in the first six months due to treatment and the acute toxicities associated with treatment but also how the psychological distress for many patients reduces as their treatment side effects improve (Kelly et al 2007; Nguyen et al 2002, de Leeuw et al 2001; Funk et al 1997). However, many of the above authors highlight the inconsistency across study results to identify what the potential factors are that could assist clinicians to determine potential patients who may report residual psychological distress beyond the first six months. Maclean et al (2009), in their recent study of laryngectomy patients, found significantly higher levels of depression, anxiety and stress with participants suffering with dysphagia in comparison to those participants not suffering with dysphagia one year post-surgery. These findings are congruent with Campbell et al (2000) who found lower levels of quality of life scores with people who had undergone laryngectomy three years post-surgery in relation to areas of eating, speech and level of perceived disfigurement. The findings suggest that patients are experiencing long-term side effects of their surgery with significant changes and challenges to core physical functions that are having a negative impact on their quality of life.

The perceived level of disfigurement by people affected with head and neck cancers has shown that more distress is evident in female patients than men (Cassileth et al 1983) with Baker (1992) finding no correlation between level of disfigurement and psychological morbidity. However, Gamba et al (1992) found that those patients with extensive disfigurement reported greater issues with self-image, such as touching the site, looking in the mirror

and feeling less attractive. Not surprisingly, participants also reported issues relating to their relationships with their partners leading to issues of social isolation. Out of the 66 participants involved in their study, 18% reported that the disadvantages experienced from their treatment outweighed the advantages of having the treatment. The issue of disfigurement associated with people affected with head and neck cancers needs to be addressed to allow them to reintegrate with their body thus improving their quality of life (Dropkin 1999). However, Newell (2000) points out that this could be challenging due to the well-known psychological issues associated with being diagnosed with a life-threatening illness, therefore highlighting the complexities in addressing psychological morbidity within this group of patients.

de Leeuw et al (2001) identified eight pre-treatment variables that could address the complexities associated with psychological morbidity within this group of patients. Building on previous work, they found that these eight variables were significantly associated with determining psychological issues such as depression, at one year and three years post-treatment. The authors report that depressive symptoms assessed in the pre-treatment phase were the best predictor of depressive symptoms up to three years post-treatment from their prospective study. They suggest that these variables (see Table 4) can provide clinicians with an insight to those patients who may suffer lower levels of quality of life and require appropriate psychological interventions across the treatment pathway and subsequent care.

Table 4: Pre-Treatment Variables

Pre-Treatment Variables
1 – Tumour Stage
2 – Sex
3 – Depressive symptoms
4 – Openness to discuss cancer in the family
5 – Available appraisal support
6 –Received emotional support
7 Size of formal social network
8 – Tumour-related symptoms

(de Leeuw et al 2001)

From their studies, de Leeuw et al (2001) report that the more depressive and tumour-related symptoms present at pre-treatment were related to more depressive symptoms present in the patient post-treatment. The authors found that almost half of the sample who completed data collection (n=123) in their prospective study developed levels of depressive symptoms between six months and three years after the start of treatment. They suggest that the eight pre-treatment variables detailed in Table 4 could predict which patients became depressed during this period with women showing higher

levels of depressive symptoms during this period (de Leeuw et al 2001:887). The authors conclude that from these findings clinicians can assess patients who are most likely to develop depressive symptoms post-treatment in the pre-treatment phase and provide the appropriate support and interventions during consultations to improve their overall quality of life (de Leeuw et al 2001).

2.4.3 Social Domain

The variables identified in the de Leeuw et al (2001) study show the important role that both informal and formal social networks play in improving an individual's quality of life. They found that patients who reported discussing their cancer more within the family and had good social support reported lower depressive symptoms. Research into the role of social support with people affected with head and neck cancers is limited with emotional support linked with an improvement in health-related quality of life outcomes with people affected with other cancer types (Ross et al 2010; Karnell et al 2007).

Social support is a common strategy used by people affected with head and neck cancer to help them cope (List et al 2002) with higher levels of social support identified at diagnosis and less perceived at one year post-treatment (Derks et al 2005). Karnell et al (2007) discusses previous research highlighting a lack of social support with people affected with head and neck cancers linked with higher levels of depressive symptoms and psychological distress. The lack of social support in helping patients affected by head and neck cancer to change their smoking and alcohol behaviours was identified by Duffy et al (2006), who found males who were unmarried continued to smoke

and drink after diagnosis, thus impacting on their post-treatment symptoms and overall quality of life.

In a recent study by Karnell et al (2007), they found that the levels of support post-treatment reported by patients were significantly associated with health-related quality of life outcomes in areas of speech, aesthetics, social disruptions and general mental health linked with depressive symptoms. They identified that higher levels of perceived social support resulted in clinically important increases in health-related quality of life scores. Similarly, Vakharia et al (2007) found that patients who attended a support group for people affected with head and neck cancers reported increased levels of health-related quality of life scores in comparison to those who did not attend. The results of their study showed improvements in the domains of eating, emotion and pain with those attending the support group reporting being less bothered with their cancer and responding better to their overall treatment in comparison to those who did not attend (Vakharia et al 2007:408). The findings from these studies would suggest that perceived social support relates to improvements in health-related quality of life outcomes for patients affected with head and neck cancers.

The findings from this body of literature report the impact that this type of cancer and its treatment has on this group's quality of life and, additionally, highlights how each specific Health Related Quality of Life (HRQoL) domain is intertwined due to the complexities this group experience over their cancer trajectory. However, we know that cancer does not just affect

the patient but also the wider family. In the following section I will describe the impact of head and neck cancer on the spouse's overall quality of life from the few studies that have explored this area.

2.4.4 Quality of life of Carers

Cancer does not only affect the patient but also the wider family with many family members needing to provide a wide range of care. The care given ranges from the physical management of the disease and its treatment side effects to providing the emotional and psychological support needed to manage the challenges involved in the changing relationship and social roles between the couple and the family as a whole (Ross et al 2010; Kim & Given 2008). In the context of head and neck cancer there is little research available into the quality of life of carers post-diagnosis (Rogers et al 2007, Baghi et al 2007; Verdonck-de Leeuw et al 2007). From the small number of studies, the evidence suggests that carers report higher levels of anxiety than patients, especially during the acute treatment phase (Vickery et al 2003), with those caring for people with laryngectomy demonstrating higher levels of distress than the patient (Mathieson et al 1991).

A recent study with both patients and their spouses found that a clinical level of distress was apparent in 20% of spouses, which was associated with the presence of a feeding tube and a disrupted daily lifestyle (Verdonck-de Leeuw et al 2007). The authors suggested that systematic screening for distress in spouses should be part of routine clinical practice to ensure spouses have the skills and coping strategies to deal with the many complex issues this

group encounter during and post-treatment (Verdonck-de Leeuw et al 2007). Similarly, Baghi et al (2007) investigated the need for supportive care for spouses of those affected by head and neck cancers and found that 44% of the sample experienced the need for psychological support specifically for themselves. The participants also highlighted the need for precise information on the disease with nearly 90% of the sample wanting information on different treatments with approximately 45% reporting they did not receive any information on other treatment modalities. The need for social support was identified with 44% of the sample reporting the wish to have contact with self-help groups. The authors suggested that the findings from their study merit the need for clinicians to involve and assess the needs of carers as they experience high levels of psychological distress coping with the complex issues encountered by this group. The need for the provision of information on all treatment modalities informing both patients and carers of the advantages and disadvantages of treatment pathways was recommended.

The need for the provision of information is not only required at diagnosis around treatment options and their side effects but also required in the early post-treatment phase (Ross et al 2010). In their study exploring psychological adjustment with family caregivers, six to twenty-four months post-treatment, Ross et al (2010) found that only 39% of participants reported that their practical and informational needs were met. Their findings suggest a large proportion of participants were not provided with the information they required to help them manage at this time. The study found that family caregivers reported increased levels of psychological distress and lower levels of

psychological well-being compared to the normal population, with nearly 38% of the sample reporting moderate to high levels of distress, highlighting the psychological challenges experienced by some carers in the early post-treatment phase.

From the limited number of quality of life studies exploring the impact of head and neck cancers on family caregivers (carers), the evidence suggests that they experience increased psychological distress and anxiety, with a lack of information and support identified across the cancer trajectory, especially in the post-treatment phase. The complex issues associated with treatments for head and neck cancers and the impact these can have on an individual's quality of life is evident with families who are central in dealing with the changing physical, psychological and social outcomes of treatment. The evidence from these studies suggests that family caregivers/spouses have needs of their own that require support and information from clinicians across the cancer trajectory to prevent the burden of care affecting their own overall quality of life. One of the recommendations from the review carried out by Rogers et al (2007) was the need for more research exploring the distress to carers/spouses longitudinally and the impact that a diagnosis of head and neck cancer has on their lives and the relationships in their lives. They suggest that future studies should explore site-specific issues relating to quality of life rather than the mixed cohorts evident in the literature to date.

2.4.5 Summary

In this chapter, I have presented that globally, the incidence and prevalence of head and neck cancer is small in comparison to other cancer types. I have identified that Scotland has the highest incidence rates of laryngeal cancer, especially in females. Survival rates from head and neck cancers broadly remain poor in comparison to other cancer types, with females in Scotland diagnosed with laryngeal cancer showing the poorest survival rates overall. The main risk factors associated with laryngeal cancer are smoking and alcohol, with advanced disease strongly associated with living in deprived areas with Scotland having some of the most deprived communities in the UK.

From the health-related quality of life literature, it is evident that the treatment modalities for laryngeal cancer can have a profound effect on the physical, psychological and social well-being in both the shorter and long term, affecting the individual's overall quality of life. Although there is a paucity of research on the impact of laryngeal cancer on family members, the existing evidence suggests they experience an increase in their psychological distress associated with the burden of care and a lack of information and support reported across the cancer trajectory. Penner (2009) and Semple et al (2008) suggest the effects of treatment on this group's physical, psychological and social well-being cannot be compartmentalized into quality of life domains and are inextricably linked and multifaceted in how they affect an individual's overall quality of life. As the WHO (1994) definition implies, there is a subjective level

to an individual's quality of life that is influenced by their position, values and the culture systems in which they live.

The following chapter will describe literature pertaining to the patient's and carer's subjective experiences of head and neck, specifically laryngeal cancer, and the strategies they adopt to help them manage and cope with the impact of their diagnosis and the complexities associated with its treatment in the context of their lives.

Chapter 3

Introduction

Chapter 2 outlined the impact that head and neck cancers can have on the quality of life of both the individual and their family. This chapter will discuss the subjective experiences of people affected by head and neck cancers, and, where possible, laryngeal cancer in particular, reported in the literature. I will discuss the strategies adopted by patients and their families to help them manage or cope after a diagnosis of cancer, leading to a discussion of the role and importance of information. The specific types and sources of information reported in the literature will be described, linking evidence of the relationship between “information” and “knowledge”. This chapter will therefore draw on the wider cancer literature and literature from social sciences.

3.1 Patients' Experiences

Chapter 2 discussed how head and neck cancers have a profoundly negative effect on the patient's quality of life, although the impact on family members' quality of life is less well known (Rogers et al 2007). The findings from the health-related quality of life studies have produced a wealth of important data, but due to the specific method adopted for data collection, they do not allow for the patient and family members' subjective experiences to be captured about this specific type of cancer and its impact in the context of their lives. As Wells (1998a) states: “Fixed quality of life categories may not capture

the individuality of patients' experiences and interpretations of illness, and are therefore at risk of omitting important symptoms that patients might express in another way" (1998a:841). Patients have been found to under-report their experience of symptoms during the clinical consultation (Wells et al 2007; Moore et al 2004) with disparities evident between what the clinician can observe clinically and what the patient may actually experience (Elting et al 2008).

Qualitative studies exploring the experiences of the individual patients over the whole cancer trajectory are lacking (McQuestion et al 2011; Semple et al 2008; Semple 2001) with a dearth of studies exploring the experiences of their family members noted. This is surprising given that it has been suggested that this patient group's experiences can be more challenging than those affected by other cancer types (Ziegler et al 2004; Frampton 2001).

Edwards (1998; et al 1997) conducted a landmark qualitative study for the King's Fund exploring the service experiences of 33 people affected with a range of head and neck cancers (22 patients and 11 relatives) and 33 health professionals using focus group discussions. The findings were used to influence service delivery and resulted in the establishment of a more coherent multi-disciplinary team approach to the treatment and care for this group. Edwards (1998) identified that although patients and their family members were generally satisfied with their overall care there were discrepancies and disparities across the cancer trajectory. Disparities occurred between the levels of information available to patients to participate in treatment decisions; family

members reported inconsistencies and discrepancies with information provided post-operatively with the health professionals focusing more on information regarding disease and treatment, i.e. surgical procedures. Many participants reported a lack of information on the side effects of treatment with a disparity evident on the level of information received during the treatment phase in comparison to the post-treatment phase. A feeling of “abandonment” was reported by many in the post-treatment phase with a lack of knowledge and information on who to contact when they were experiencing problems managing and coping with the side effects of their treatment.

Wells (1998a) highlighted how earlier studies exploring the impact of the side effects of treatment with this group of patients had not considered the whole treatment experience. She noted how many studies had focused mainly on the time point of treatment with little known of the experiences of patients beyond that phase. She comments how these studies were based on “the ideology of the biomedical model, which tends to disregard the significance of the experience and impact of illness, and concentrates instead on symptoms as indicators of disease or tolerance of treatment” (1998a: 841).

As noted in Chapter 2 section 2.3, most patients will receive radiotherapy as part of their treatment, so it is hardly surprising that the focus of many studies has been on the side effects of this treatment modality during that time. The main side effects of radiotherapy reported in the literature are mucositis, xerostomia, dysphagia, pain, loss of taste, fatigue, and difficulties with speech and swallowing (Moore 2004; Larsson et al 2003; Rose-Ped et al

2002; Rose & Yates 2001; Larsson 1999; Wells 1998a; Whale et al 1998), with more recent studies identifying the increase in toxicities associated with new treatment regimes, such as chemotherapy (Logan 2009; Verdura et al 2005; Rose-Ped et al 2002).

In her retrospective study of 12 patients affected by a range of head and neck cancers, Wells (1998a) found that the impact of the side effects from radiotherapy one month after completion of treatment disrupted the patients' daily lives profoundly. This study moved beyond the treatment phase and explored the experiences of patients through interviews and personal diaries in an attempt to understand the whole experience of treatment in the context of the individual's life. Due to their experience of symptoms, many patients reported uncertainty and unpredictability in the context of their lives, which led to a loss of self-integrity and feelings of ambiguity about the future. Although many patients endured unpleasant symptoms, they were reluctant to ask for help and showed resilience in coping with the changing side effects of treatment on a daily basis. Based on her findings Wells (1998a) recommended better communication and provision of information by clinicians to address the needs of this group of patients during and beyond the treatment phase.

The needs of people with head and neck cancers can be complex as many may present at diagnosis in a compromised physical state due to their lifestyle or due to the impact the tumour may have on their physical ability to breathe, eat and swallow. Compromised nutritional status can lead to further complications and more complex challenges as treatment progresses. During

and beyond treatment, we know that patients experience distressing and debilitating clusters of symptoms which impact greatly on those very basic, taken for granted functions of breathing, eating and speaking. These symptoms, in conjunction with the effects of treatment, lead many to have psychological morbidity, as identified in Chapter 2.

One of the needs reported in Edwards' (1998) study was recognising the challenges patients experienced with eating after completion of their treatment with many having the view that health professionals did not understand this problem from their perspective and adopted a more psychological, rather than practical, approach to its management. Larsson et al's work (2007; 2005; 2003) acknowledges this and highlights the major challenges patients experience with eating across the cancer trajectory. Their work demonstrates that eating is not merely a physical function to sustain life, but a complex web of physical, psychological and social challenges that patients experience far beyond the treatment phase.

In their 2003 prospective phenomenological study with eight patients receiving radiotherapy, Larsson et al found that patients experienced taste changes from the start of their treatment that influenced their view of food and their willingness to eat throughout their treatment. Over the course of treatment, eating became more challenging due to the pain and trauma to the oral cavity, with the desire to eat and associated nausea leading to a loss of appetite, causing patients to swing between feelings of hope and despair. Patients commented on how they hoped the symptoms would ease as

treatment progressed and that their experience of suffering would be worth it with the eradication of their cancer. Feelings of despair were caused by symptoms worsening, leading patients to experience anxiety and a feeling of uncertainty for what the future may hold. Many patients in her study perceived a loss of self due to their inability to speak, loss of weight, and the embarrassment associated with a bad taste in their mouth and breath, which brought a personal sense of disgust. Their experience of symptoms led many to perceive a sense of isolation due to their inability to join in on the social togetherness that eating with family and friends brings. Due to the challenges many experienced, her participants discussed how they adopted different strategies of trial and error with food choices on a daily basis with the support and motivation they received from family and friends deemed crucial for them to survive. From this study, Larsson et al (2003) highlight how life itself was threatened not only by a diagnosis of cancer but also by the inability to eat and drink, which is viewed as essential for human survival.

Similarly, McQuestion et al (2011) found patients reporting a sense of loss associated with food and eating during the post-treatment phase across three domains: physical, emotional and social. In their retrospective interview study of 17 patients affected by a range of head and neck cancers three months post-radiotherapy, many reported a sense of physical loss associated with not being able to eat what they would like or the loss of taste from food they once enjoyed. The physical side effects from radiotherapy raised patients' awareness of what they "couldn't eat" with noticeable weight loss and physical changes that, for some, would be life-long, requiring long-term changes. This

physical loss was linked with an emotional loss due to the pleasure and enjoyment of food now having been removed. The aim of eating, for many, was for nutritional purposes only and to prevent further weight loss. As the authors state, “what people experienced was more than the physical and emotional disruption of side effects but a disempowering transformation of their body over a short period of weeks during treatment” (2011:148). This “transformation” and feeling of disempowerment was linked with the social loss of eating with friends and family and the social interaction that this brings. Many reported the challenges associated with the practical function of eating publicly, due to food preparation and the actual act of eating taking longer and being more troublesome, which affected the joy of the social gathering, leading to a feeling of social isolation.

Maclean et al (2009) also highlighted the challenges associated with eating in their retrospective mixed methods study with 110 post-laryngectomy patients. The authors found that nearly 30% of the sample had long-term challenges with their swallowing which they commented on in their questionnaires. The written comments were categorised into four main challenges: the consistency of food, regurgitation or reflux, time taken to swallow, and the social consequences of a swallowing impairment. The most common long-term challenge experienced was on the consistency of food and the difficulties patients experienced with common every-day foods like bread, cakes and meat. Some commented on the challenges of repeatedly needing to chew the bolus of food, regurgitating it several times before they could properly swallow, with some commenting that they could not bend over after eating, in

fear of regurgitating their food via their nose or mouth. The time that it took to eat was also commented on, as some patients had to cut their food into very small pieces and carefully chew the food to enable them to swallow which led to them feeling embarrassed and reluctant to eat out socially. As one participant said, “the whole cancer issue is not an issue, compared with my inability to eat” (2009:177).

It is evident that the side effects of treatment have a greatly profound impact on patients with the clustering of symptoms affecting their daily life. Treatment symptoms have been studied on their own, but it is evident how they are interlinked, affecting the individual in complex ways and therefore should not be viewed in isolation (Logan 2009). Due to pain and trauma to the oral cavity, patients experience severe challenges with food leading to weight loss and fatigue, which presents the individuals with psychosocial issues that can last beyond the treatment phase. The length of time and the ambiguity surrounding their experience of symptoms leads many to have a fear of the unknown, as they do not know whether their symptoms will be experienced over the short-term or whether they will be permanent.

Larsson et al (2005) found that patients still experienced eating problems and associated weight loss one year post-treatment, conditions which were not properly addressed during the treatment phase with consequences still evident in the follow-up phase. As Wells (1998a) identified, there are few studies exploring the experiences of patients beyond the treatment phase, with Larsson et al (2007) identifying that patients “were left” with their problems,

questions and worries in the post-treatment phase. In their study with 9 patients, 6-8 weeks after completing radiotherapy treatment, they found that patients reported a sense of security during the treatment phase, although there were issues raised with the provision of information from health professionals and a lack of adequate length of time reported by patients in which to have their questions answered. However, during the post-treatment phase many reported a feeling of being left alone to manage and cope with the problems they experienced and an overall lack of information provided at this time. These findings are in line with Edwards (1998), who found that patients had unanswered questions in the post-treatment phase and perceived the provision of information to be a “one-way process” with the health professional giving and the patient receiving. Larsson et al’s (2007) findings also resonate with Wells (1998a), who noted the profound disruption symptoms had on the individuals’ daily lives and how these symptoms are experienced well beyond the treatment phase.

Due to the debilitating and distressing symptoms experienced by patients affected by head and neck cancers, there is evidence of how the individuals’ view of themselves and their social world changes (Moore et al 2004). In their study with 18 patients diagnosed with a mix of early stage head and neck cancers, Moore et al (2004) identified the need for increased social support by clinicians to ensure patients are able to express their concerns and issues and feel supported to reduce the psychological distress associated with their treatments. This need is based on the quiet “suffering” that patients experienced over the course of their treatment trajectory during which they

evolved as a diminished individual with feelings of loss of certainty about their future health and life. The effects of treatment on the individual's sense of self was identified over a decade ago with the emphasis placed on clinical teams to support and communicate with patients in the initial post-treatment phase to "support the return to normal life, and to help restore self-confidence which is so vital to the renewal of social acceptance" (Wells 1998a:846).

The return to normality is central to enable this group adjust in the post-treatment phase; Semple et al (2008) identified the important role of social support at this time to ensure social acceptance is achieved. Participants in their qualitative study identified the important role that family and friends played in helping them cope and adjust to the changes and challenges that they experienced from their treatment. Some experienced changing dynamics within relationships and associated intimacy issues, which influenced how they coped and managed in the post-treatment phase. Many participants reported how the influence of family and friends helped them to re-enter and adjust to social encounters and activities. Similar to previous research, the main challenges identified in their study that impeded participation in social life were with eating and speaking, which led many to experience low self-esteem and a loss of identity (Semple et al 2008).

"Loss of identity" is a multifaceted and complex term, which encompasses both the physical changes that treatments for head and neck cancers can have on the individual, but also the psychological issues associated with receiving a cancer diagnosis and living with the consequences

of treatment. For many, the consequences of treatment for head and neck cancers are evident to the world and cannot be masked or covered, which will affect how the person ultimately views themselves in the context of their social world. As Thorne et al (2009) highlight, being diagnosed with cancer “is a moment in time when an individual’s identity, sense of meaning and future takes on a new meaning” (2010:746), and where the patient has to learn to negotiate their way through new treatment regimes, changing bodies and begin to manage a disrupted life (Mathieson & Stam 1995). For the individual diagnosed with a head and neck cancer and their family, learning to adjust and cope with a changing body and the physical disruption treatment can have on their body goes far beyond the treatment phase and can fundamentally change their identity and social world forever.

The anxiety and threat of a cancer diagnosis leads many to seek information as a strategy to help them cope and manage (Rutten et al 2005; Costelloe & Nelson 2004; Lazarus & Folkman 1984). Lazarus and Folkman’s (1984) theoretical framework suggests that information is used as a strategy to help people cope with the threat and harm they perceive as a result of their cancer diagnosis. Over two decades ago, Derdrian (1987) used Lazarus and Folkman’s (1984) theoretical framework in her two-phased study to develop a “needs assessment tool” in a study of 60 patients diagnosed with various cancer types. She found that all patients, irrelevant of age or gender, reported needing information as a resource to cope with the harms and threats triggered by their diagnosis of cancer. Her findings are not surprising as information is central to our everyday lives, as we need and use information to make sense of

our experiences, with information providing us with new knowledge that will help in our understanding of new experiences so we can communicate our experiences to others in the context of our lives.

In the following section I will discuss the use of information as a strategy and how it helps patients and their families cope with a diagnosis of cancer and the important role it plays across the cancer trajectory.

3.2 Information and its role

Chapter 1, section 1.2 highlighted the importance placed on the provision of information to people affected with cancer drawn in both policy and NHS directives. Health professionals working in multi-disciplinary teams are seen as having a central role in providing information to patients and their families. The provision of information to individuals in health care is widely regarded as essential to help them understand what is happening and to enable them to be involved in their treatment and care decisions. However, the way in which an individual responds to their cancer diagnosis and the perceived threat they associate with their diagnosis will influence the types, sources and amounts of information they seek over their trajectory (Lambert & Loiselle 2007; Llewellyn et al 2005; Leydon et al 2000).

Studies exploring how patients use information as a coping strategy in response to the threat associated with their diagnosis and subsequent cancer treatment have classed patients into two categories; either “monitors” or “blunters”. “Monitors” are people who actively seek out information to help them cope with the threats and harms associated with their diagnosis and

subsequent treatments (called *monitoring*), whereas “blunters” avoid information and prefer distraction from the threat associated with their diagnosis and subsequent treatment (called *bluntering*) (Lambert et al 2009; Lambert & Loiselle 2007; Lazarus & Folkman 1984). However, there is now evidence in the literature to suggest that patients may vary in their approach to seeking out information within the cancer context. Drawing on previous research, Lambert et al (2009) suggest that patients may move along a continuum between “monitoring” and “bluntering” across their illness trajectory and seek out information to varying levels and from various sources according to their perceived need at specific time points across their illness trajectory (Lambert et al 2009). From their grounded theory study with 30 patients affected with breast, colorectal and prostate cancer, the authors suggest that there are differential patterns of information-seeking behaviour adopted that can be contextualised under the broader categories of “monitoring and bluntering”. For example, some patients may be intense information-seekers initially, i.e. post-diagnosis surrounding treatment decisions, but over the course of their trajectory, they may adopt a more minimalist approach to information-seeking. These differential patterns highlight the complex ways in which some patients source and access different types of information depending on their level of perceived need and understanding of their situation at that time.

As cancer occurs within a complex web of interpersonal and relational contexts in which many aspects of the individuals' and their families' lives are affected, “myths, misconceptions and uncertainties surrounding cancer are fertile grounds for creating unnecessary anxieties and in producing

inappropriate responses” (McCaughan & McKenna 2007:2097). The need and provision of information at this time can play a central role in alleviating some of the anxiety, uncertainty and misconceptions that people may have surrounding cancer and its treatment.

Llewellyn et al (2005) conducted a study with 15 people affected with a range of head and neck cancers and found that the need for information varied depending on how they responded to their diagnosis. The authors found that some patients reported wanting detailed information in an attempt to minimize the threat and take control of what was ahead, whereas others did not wish to seek detailed information, especially in the early stages between diagnosis and treatment, thus avoiding the threat of gaining new information and subsequently knowing what lay ahead (Llewellyn et al 2005).

Being prepared for what lies ahead is an important aspect of feeling in control and alleviating the uncertainty surrounding a cancer diagnosis and subsequent treatment. Accessing and using information as a coping strategy after a cancer diagnosis is well documented in the literature; it reduces overall psychological distress, enabling patients to gain a feeling of control when the future is uncertain (Stiegelis et al 2004; Ziebland et al 2004; Ream & Richardson 1996) and reduce levels of anxiety (Davison & Degner 1997; Thomas et al 2000). Information has also aided patients to cope with their diagnosis and treatment (Rutten et al 2005) and has improved their knowledge and recall, experiences of symptom management, and satisfaction with services (Mesters et al 2001), with a reduction in anxiety for family members

noted (Feltwell & Rees 2004; Morris & Thomas 2002). The use of information as a coping strategy can vary between individual patients and may change over time but research has shown that family members proactively seek information to help them cope and manage with the uncertainty surrounding the diagnosis and future treatment.

Feltwell & Rees (2004) conducted a small pilot study of 6 patients recently diagnosed with prostate cancer and their spouses to investigate their information-seeking behaviour. They found that many of the spouses actively sought information to reduce the anxiety and uncertainty they themselves experienced around the patients' treatment options and living with the cancer. Similarly, Morris & Thomas (2002) found that carers viewed the provision of information more importantly than the patients at specific points in their mixed method study. The findings from their survey of 664 patients and carers, from a mix of cancer types, showed that the areas of information identified as important to them were on medication and the side effects of treatment (87% of carers vs 82% of patients), on treatment plans (90% of carers vs. 86% of patients) and how information let them know what to expect (90% of carers vs. 86% of patients). In their qualitative interviews (a sub-set of 70 respondents), carers highlighted that the provision of information allowed them to cope with the different types of information given during consultations and enabled them to feel involved in the cancer experience and be prepared for what lay ahead (Morris & Thomas 2002). Although research has shown that the information needs of carers run parallel with the information needs of patients across the

cancer trajectory (Harris 1998), they do have specific information needs of their own that need to be addressed (Adams et al 2009; Morris & Thomas 2002).

It is evident that one of the roles of information is to provide patients and carers with a sense of control at diagnosis and entering treatment with the need for more biomedical information required at this time. Stiegelis et al (2004) conducted a randomised controlled trial of the effect of an informational self-management intervention (booklet), with 209 patients affected by a mix of cancer types, prior to starting radiotherapy. They found that the provision of information at this time promoted perceptions of control and diminished illness uncertainty. The participants in their study had completed pre-study questionnaires and demonstrated mixed perceptions of control and illness uncertainty prior to starting their treatment. Participants who reported low control pre-study, who were randomised to receive the information intervention (n= 103), reported less tension, anger and depression post-study in comparison to those not receiving the intervention. Similarly, those participants who reported high illness uncertainty pre-study reported less feelings of tension, anger and depression post-study than those participants who did not receive the information intervention. The authors conclude that the provision of an informational intervention to patients prior to starting treatment can play an important role in reducing their overall psychological distress. Ream & Richardson (1996) support this view in their review of informational intervention studies with people undergoing chemotherapy and radiotherapy. Six intervention studies were reviewed and the authors suggest that the provision of information plays a crucial role in enhancing patients' control and self-

efficacy and in reducing their anxiety at this important stage in the cancer trajectory (Ream & Richardson 1996).

In an era where patients are being encouraged to play an active role in making decisions about their treatment and care, it is imperative that they have at their disposal appropriate and accessible information (Coulter et al 1999). There is a consensus that health professionals should provide patients with the relevant information to ensure that they can make an informed choice regarding their treatment, understand the risks associated with their choice, and have their own values considered during the exchange of information with health professionals involved in their care. There is a wealth of research focusing on the benefits and challenges of patients participating and being involved in their treatment and care decisions (Power et al 2011, Collins et al 2007, Bugge et al, 2006, Entwistle et al 2004, Thompson 2007) with the expressed need for information certainly associated with preferences in relation to involvement in decisions.

Younger patients have been found to express their need for more information in comparison to older patients (Rutten et al 2005), with Ankem (2006) suggesting that younger female patients (predominantly breast cancer patients) attribute more importance to certain types of information in comparison to older patients. In his review, Ankem (2006) found that individuals who play an active role in their decision-making attribute high importance to information on all aspects of their illness and disease, especially at the time point of diagnosis. However, Cox et al (2006) would argue that

although older patients (defined as being aged over 60 in their study) are more likely to take a passive role in decision-making and in making treatment choices, it does not imply that they do not want information. Their audit showed that patients still want information in all aspects of their care and treatment even if they do not play an active role in decision-making.

Power et al (2011) highlight the challenges associated with medical decision-making around treatment choices and the burden experienced by patients having to make choices at this emotionally difficult time. They highlight previous works that show how patients can adopt biases and shortcuts in their reasoning at this time, based on the information they receive, which can lead to “bad” decision-making. There is now an evident wealth of research on developing interventions or decision aids to assist patients in making “logical” treatment decisions based on unbiased information and where their values and needs are being taken into consideration. To demonstrate the wealth of research around involvement in treatment decision-making, there are 54 Cochrane systematic reviews available on the use of decision aids with people affected by different types of cancer. However, there is comparatively limited research with people affected specifically by head and neck cancers and their involvement in treatment decision-making.

Edwards (1998) found that many participants commented on their wish to be involved in decisions regarding their treatment, with younger patients wanting most involvement and many commenting that they were not as involved as they would have liked to have been. Clinicians gave mixed

responses in the study, with many supporting the view that patients should be involved in rehabilitative and palliative care decisions but the decision for primary treatment should remain with the clinician. This outcome supports a recent study by Davies et al (2010) who found that physicians did make the final decision with regards to treatment with patients across a range of head and neck cancers. This finding was based on the patients (n=39) having implicit trust and confidence in their physician and on the treatment decision they offered. Similarly, Newell et al (2004) reported how participants accepted the treatment offered by the doctor as “he was the expert” and “he would know best”, with many patients commenting on “being presented” with their treatment option in the study by Pollock et al (2008).

However, the amount and timing of information delivered to patients can influence their involvement in decision-making as previous research has shown that patients can forget between 40 and 80% of medical information provided during consultations with poorer levels of recall where large amounts of information are provided (Kessels 2003). In his review, Kessels (2003) discusses various factors that can influence the level of recall of information which are: the format of the delivery of information, the anxiety and distress provoked by the information, and how the information provided situates within the individual’s cognitive schemas (Kessels 2003).

The amount and timing of information is a common complaint found with people affected by head and neck cancers (Stafford et al 2001), with a lack of time to assimilate the amount of information given at diagnosis found by

Llewellyn et al (2005). In their study, Llewellyn et al found participants did not want too much detailed information in the pre-treatment phase as they reported an inability to absorb the information due to the lack of time between their diagnosis and their treatment starting. Similarly, Newell et al (2004) found that patients reported difficulty in absorbing information regarding their treatment as it was given at the same time as they were informed of their diagnosis. This finding resonates with the findings from Stafford et al (2001), who found that 84% of consultants reported delivering information to their patients on their diagnosis and planned treatment in the same fifteen-minute consultation, with Pollock et al (2008) reporting how the patients in their study wanted information on a “need to know” basis rather than a pre-emptive basis. They found that patients appeared to select information specific to their needs at different time points across their cancer trajectory. However, Davies et al (2010) found that patients (n=22) could give a clear account and recall of the information they received from their physician around treatment options, procedures and potential outcomes in their interviews which corresponded with the information provided from the taped consultation. This shows the challenges that health professionals face when providing patients with information and the various ways in which patients respond and use information across their cancer trajectory.

In this section, I have shown how seeking information is a common strategy used by patients and their family members to help them cope with the threat and uncertainty of a cancer diagnosis. It is evident that the threat patients and their family members associate with a diagnosis of cancer influences the

way in which they seek and use information, with younger patients found to be more active seekers of information than older patients are. Although there is evidence that suggests the expressed need for information is associated with preferences in relation to involvement in decision-making, there are challenges and variation in the way patients make decisions regarding their treatment and care and the types of information they use to assist them in this process. In the following section I will discuss the specific types of information people affected by cancer have identified that they need from the broad cancer literature, highlighting the unmet information needs of carers leading to a description of the specific information needs of people affected by head and neck cancers in section 3.4.

3.3 Information Needs

The term “information needs” is widely used in many of the research studies exploring the different types of information that patients and, more recently, carers, require over the cancer trajectory. However, the use of this term has been criticised; there is no clear definition of the term or clarity on how to distinguish it from other concepts (Adams et al 2009; Timmins 2006; and Endacott 1997). In their systematic review of the information needs of carers, Adams et al (2009) comment that greater clarity is required in future studies to ensure that the reader is clear that it is the information needs of the patient or the carer being addressed and not those of health professionals involved in their care. Timmins (2006), in her concept analysis, describes the information needs of patients and their family as “expressed needs” as they are subjective

and unique to the individual in comparison to the “normative needs” of health professionals, which are prescriptive and generic. Endacott (1997) discusses the important role that health professionals play in establishing the expressed needs of patients to ensure that the appropriate action is taken to satisfy them at specific time points over their illness trajectory. If health professionals are to match the provision of information to the expressed needs of patients, then they must ask patients at each consultation what those specific needs are, as their need for information will change over time (Butow et al 1997).

Studies exploring the “information needs” of patients and, more recently, carers, affected by different types of cancer have primarily reported their findings in two distinct ways. Some have reported the patient’s information needs as a broad list of “issues and/or areas” from across the cancer trajectory (see, for example, Ziebland et al 2004; Newell et al 2004; Birchall et al 2002; Atkinson et al 2002; Feber 2003; Hope et al 2000; Leydon et al 2000). Whereas others have reported patients’ and carers’ information needs as specific categories at specific time points across the cancer trajectory (see for example Adams et al 2009; Ankem 2006; Rutten et al 2005; Feber 2003; van der Molen 1999; Graydon et al 1997; and Degner et al 1997). Regardless of how studies have reported their findings, there is now a strong body of evidence to demonstrate the specific types of information that patients, and to a lesser degree carers, need at specific time points across the cancer trajectory. Using the results from three systematic reviews I will demonstrate the main categories of information and the need for specific types of information identified from the broader cancer literature.

Rutten et al (2005) carried out a systematic review to provide a comprehensive overview of the main types of information needs reported by people affected with cancer from 1980-2003. Out of the 112 studies included in the review, 51 were qualitative, 53 were quantitative and 8 did not discuss the methods adopted for the study. The articles covered a range of cancers such as gynaecological, colorectal and lung, with breast and prostate cancer having the highest numbers of studies. No articles exploring the information needs of people affected with head and neck cancers were included in the review. A year later, Ankem (2006) carried out a systematic review of eighteen quantitative studies to synthesize the most important ranked information types that cancer patients had attributed to specific types of information across the cancer trajectory. Not surprisingly, there is an overlap with the studies used in both these reviews, with the majority of studies reporting the information needs of women affected by breast cancer. More recently, Adams et al (2009) carried out a systematic review of the information needs of carers of people diagnosed with cancer. Thirty-two articles were used in the review with the majority of studies focusing on the information needs of carers of people diagnosed with breast and prostate cancer. No articles were included on the information needs of carers of people affected by head and neck cancers.

The results from the reviews identified that most studies exploring the information needs of cancer patients relate to the time around diagnosis and treatment. Therefore it is not surprising that the most frequently cited information need categories and the information needs ranked highest in the reviews were about treatment-related information and cancer-specific

information. Specifically, both patients and carers want information about diagnostic investigations, how their cancer will be treated and treatment options, the stage of their disease, and the side effects of treatment both short- and long-term. There was a lack of specific information noted on the side effects of radiotherapy and the overall physical impact of radiotherapy on the individual (McNamara 1999; Bakker et al 1999) with Cox et al (2006) identifying recently a lack of information on the short- and long-term side effects of chemotherapy treatment. In their audit of 394 patients affected by breast, colorectal and gynaecological cancer, Cox et al reported that despite all patients having received information about treatment, participants reported having received no information about the side effects relating to physical function and well-being during treatment (13% and 23% respectively) (Cox et al 2006). Adams et al (2009) highlighted the specific unmet information needs of carers on the side effects of treatment, the development or cause of the cancer, understanding the medical terminology and the spread/stage of disease.

The need for specific information on prognosis and, in particular, the chances of cure and survival rates was identified by Ankem (2006) and Rutten et al (2005), with patients reporting specific information needs on the spread of the disease and the possibility of recurrence, with a need for information on the overall plan for the future, both short- and long-term. Patients and carers wanted to know how best to inform and communicate their cancer to family members and friends, with Adams et al (2009) reporting significant unmet information needs for carers in this area with Ankem (2006) and Rutten et al

(2005) identifying a need for information on the risk of future disease to other family members, especially siblings.

As mentioned earlier, the majority of studies of information needs of patients and carers have focused on their specific needs at diagnosis and during treatment. Both Adams et al (2009) and Rutten et al (2005) comment on the relative paucity of research on information needs post-treatment, through follow-up and on survivorship. This has led Hesse et al (2008) to suggest that both patients and carers have information needs that need addressed in the post-treatment and follow-up phases because not enough longitudinal research is being conducted in this area.

The categories of information needs identified in the reviews in the post-treatment and follow-up phase focus more on the management of the long-term side effects of treatment and the practical aspects of living with cancer on a daily basis for both the patient and the carer. Patients reported the need for information to allow them to become self-caring again, or return to a level of “normality” during the post-treatment phase (van der Molen 2000 & 1999), with the need for information on the long-term consequences of cancer and follow-up required (Bungay & Copello 2009; Adams et al 2009; Cox et al 2006; Rutten et al 2005). The lack of information on the long-term side effects of treatment is still evident, as Bungay and Cappello (2009) found that elderly men (aged over 75) in their study reported a lack of information on the effect of impotency post-prostate treatment and the impact this had on their overall quality of life. Interestingly, the need for information on issues around sexuality

was ranked least important at diagnosis in the review by Ankem (2006) but ranked more highly in the post-treatment phase, suggesting there is a need for information with respect to sexuality and body appearance in the post-treatment phase. Recent research would suggest that there is still a lack of information provided on these issues in the post-treatment phase. Cox et al (2006) found that over a third of their sample were provided with no information on the issues of body image and sexuality post-treatment. Adams et al (2009) found significant unmet information needs with carers on issues of sexuality, relationship issues, intimacy and body image in the post-treatment phase.

In summary, the syntheses carried out by Ankem (2006), Rutten et al (2005) and Adams et al (2009) provide an overview of the reported information needs of people affected with different types of cancer. The categories illustrate that people need cancer-specific information, treatment-related information and rehabilitation information. These categories of information needs are consistent across many different types of cancers and across different groups of patients and carers, thus the research provides a substantial body of literature on which health professionals can base their work. However, gaps are evident on the information needs of patients and carers in the post-treatment and follow-up phases, with categories of unmet information needs on the impact of cancer on the family and living with the long-term side effects identified. The majority of studies in the reviews have focused on the information needs of patients and carers affected by breast and prostate cancer. Research with people affected by other cancer types is needed to gain

an in-depth understanding of their specific information needs across the cancer trajectory.

In many ways, people affected by head and neck cancers can be viewed as a “Cinderella” group in relation to the research attention paid to them, which is illustrated by the fact that none of the three systematic reviews included any studies with people affected by head and neck cancers and their information needs. In the following section, I review what little research has been conducted on this particular group of patients’ information needs across the cancer trajectory, identifying how their unmet needs has led to some having had poor experiences and highlight the dearth of studies exploring the information needs of carers affected by head and neck cancers.

3.4 Information needs of people affected with head and neck cancers

From the literature reviewed in section 3.1, it is evident that people affected by head and neck cancers experience very particular physical and psychological challenges that are different from those faced by people with other types of cancers (Ziegler et al 2004), with Semple (2001) arguing that this group of patients have very specific needs that must be addressed. Some researchers have suggested that the psychological distress experienced by people affected by head and neck cancers, as discussed in Chapter 2, could be partly explained by their information needs being unmet at certain points across the cancer trajectory (Baghi et al 2007; Verdonck-de Leeuw et al 2007; Stafford et al 2001; Mesters et al 2001; Edwards 1998).

Like people affected by other cancers, patients and carers affected by head and neck and laryngeal cancer want information about their cancer and how it will be treated (Feber 2003). As in the studies reviewed by Adams et al (2009), Ankem (2006) and Rutten et al, (2005), most studies on the information needs of people affected by head and neck cancers have focused on their information needs at the time points of diagnosis and treatment. Studies have either identified respondents' information needs at diagnosis and/or during treatment where they have been asked to report their current needs (Ziegler et al 2004; Newell et al 2004, Stafford et al 2001), or have identified respondents in the post-treatment phase and asked them to retrospectively discuss their information needs at diagnosis and during treatment (Pollock et al 2008; Feber 2003; Edwards 1998; Feber 1998). Therefore, the main types of information need categories identified in this literature are diagnostic, prognostic and treatment-related, and primarily focus on surgical intervention.

The most common type of information need reported by patients affected by head and neck cancers are on treatment-related information with specific information needed on the overall physical impact of treatment side effects (Stafford et al 2001; Newell et al 2004; Feber, 2003; Birchall 2002; Bakker et al 1999; McNamara 1999; Edwards 1998). Specifically, respondents in these studies reported wanting information on the overall treatment plan, focusing on issues with communication, eating and swallowing difficulties, and the effects of treatment fatigue (Larsson et al 2005 & 2003; Newell et al 2004; Ziegler et al 2004; Feber, 2003, Wells 1998a). However, the majority of studies

reported how the information needs of patients and carers across all treatment modalities and on the side effects of treatment were generally unmet (Newell et al 2004; Feber 2003; Feber 1998; Edwards 1998) with the need for more communication from health professionals identified by Larsson et al (2005; 2003) and Wells (1998a).

Feber (1998) conducted a service evaluation by interviewing fifty patients affected by laryngeal cancer and identified unmet information needs in both pre- and post-operative care. She found that 55% of participants reported that the information they had received at diagnosis had not prepared them for their loss of voice post-surgery. A later intervention study by Feber (2003) found that patients still reported an overall lack of consistent information in relation to information preparing them for treatment. She found that patients highlighted a lack of information that provided them with the support they required post-treatment, with patients undergoing surgery reporting an overall lack of supportive post-operative information. However, a recent study by Pollock et al (2008) suggests that the provision of treatment-related information is improving, as they found that the majority of their 27 participants in their qualitative study were satisfied with the overall information they had received at their diagnosis on specific investigative procedures and on their treatment pathway.

As discussed in section 3.2, the need for information on available treatment pathways is not necessarily viewed as important by people affected by head and neck cancers. Newell et al (2004) reported how participants in their study accepted the treatment offered by the doctor as “the expert” and he

would “know best”, with only two patients in their study refusing the treatment offered by their consultant and making their own decision regarding their treatment pathway. Pollock et al (2008) supports this finding, as they found that most patients discussed “being presented” with their treatment option and few reported having the desire for more information to discuss other treatments available or were unaware that this was a possibility. However, Davies et al (2010) suggest that the severity of the illness could explain why patients affected by head and neck cancers do not need information regarding their treatment decisions. They found that patients facing serious illness, defined in their study as a patient who has “considerable pain, discomfort or alteration to complete daily activities and fears imminent death” (2010:2444), relied on the information from the physician as the expert. This finding could be linked with a perception by those people affected with advanced head and neck cancers who are experiencing severe symptoms that they must take the treatment option offered by the consultant or they will die (Davies et al 2010; Pollock et al 2008; Newell et al 2004).

After receiving a diagnosis of head and neck cancer, the need for information by patients and carers on the outcome of treatment and on the chances of cure was reported by Pollock et al (2008) and Feber (2003). However, Stafford et al (2001) found that 40% of the 529 consultants who participated in their study reported that they did not inform their patients about curative and survival rates during their consultations. This finding resonates with the findings from Pollock et al (2008) who found that many participants reported information on prognosis as vague and ambiguous. From the findings,

they suggest that some participants were confident of cure from the information they had received at diagnosis but that the majority remained uncertain of the outcome of their treatment due to the lack of prognostic information given in the post-treatment phase. Participants discussed how they had learned to accept that no amount of information from health professionals could reduce the uncertainty of their illness and thus predict the outcome of their treatment. It is interesting to note that Wells (1998a) and Edwards (1998) identified this uncertainty and ambiguity beyond the treatment phase over a decade ago and yet patients are still experiencing a lack of information on the outcome of their treatment, which subsequently affects their quality of life.

Newell et al (2004) identified a lack of information on issues associated with communication in the post-treatment phase, especially with those patients who required laryngectomy. They found that 10 out of their 42 participants had unmet information needs about the potential difficulties of communication post-surgery, with 12 participants reporting the need for information on the impact of surgery on their relationships with family and friends. The difficulty in communicating with partners post-treatment was identified by Rapoport et al (1993) who found significant issues between patients and their partners in areas of social and interpersonal relationships and family relations due to the impact of treatment and the long-term consequences of treatment, with the negative effects becoming evident over time. The authors suggest that there is a need for interventions for both patients and their families to ensure that they receive the required support to enable communication which, in turn, will help them manage and cope with these issues over the

course of their trajectory. Mah & Johnston (1993) suggest the need for health professionals to carry out continuous assessment over the cancer trajectory to ensure that the specific needs and concerns of both patients and their families are being addressed.

The recovery from treatment for people affected by head and neck cancers is long, with many patients having to deal with major physical and bodily changes due to the impact of their treatment. This has seen a move towards a more psychosocial rather than biomedical approach to care for this group of patients and their family members across the cancer trajectory (Penner 2009) as it is evident the important role that family and friends provide to patients through their supportive network in the post-treatment phase (Semple et al 2008). Many patients have reported the need for specific information on knowing what to expect in the post-treatment phase as they have reported feeling vulnerable and lost, leading to an increase in their psychological distress (Llewellyn et al 2005; Newell et al 2004; Feber 2003). Llewellyn et al (2005) suggest that the information patients receive in the pre-treatment phase may lead to the development of unrealistic expectations in the post-treatment phase, as many patients in their study were shocked at the extent to which their life had changed in the post-treatment phase.

Using semi-structured interviews with a convenience sample of 15 patients diagnosed with a range of head and neck cancers (10 female, 5 male), the authors asked participants to give a retrospective account of the information they had received and their experiences since their diagnosis. From the

findings, the authors categorised the patients' expectations into two sub-themes: global expectations and specific expectations. Global expectations related to the unexpected enormity of treatment and the length of time for their recovery. Patients reported how the recovery process took longer than they had expected and how their expectations had been unrealistic entering the post-treatment phase. The recovery process was linked with specific expectations patients had in relation to the side effects of treatment, with many reporting mixed expectations based on the information they had received in the pre-treatment phase. Some participants reported that they had received too much information in the pre-treatment phase, which they could not absorb, with others reporting that they had received too little information too late to help them manage and cope with the consequences of treatment in the post-treatment phase (Llewellyn et al 2005).

Patients reporting how the side effects of treatment had been worse than they expected is a common finding across studies with people affected by head and neck cancers. Feber (2003) identified how patients needed specific information on living with eating problems, mucositis and dry mouth in the post-treatment phase. From her study, patients reported that living with the long-term side effects of radiotherapy affected the practical aspects of their lives, such as getting back to work, financial issues, and social activities, for example, going out for dinner. These findings are consistent with the findings discussed in section 3.1. Due to the long-term impact of symptoms, it is surprising that there is limited research on carers living with the impact of treatment. However, research has shown that they experience increased levels of distress and

anxiety due to the functional and social impairment of their spouses in the acute post-treatment phase (Ross et al 2010; Baghi et al 2007; Verdonck-de Leeuw et al 2007). This psychological distress is reported to be associated with the lack of specific information to carers on the impact and outcome of treatment, with these authors recommending future research on exploring the carer's specific needs and their specific information needs over the cancer trajectory.

During the post-treatment phase, patients have reported the need for information to use as “benchmarks” to allow them to gauge where they are and what to work towards and to monitor their own progress specifically with the physical aspects of swallowing and speech (Ziegler et al 2004; Feber 2003). However, Pollock et al (2008) identified that even though patients had received written information to use in the post-treatment phase, the impact of their post-treatment symptoms in the context of their daily lives was a cause for concern due to the ambiguity and lack of consistency in the written information they had been provided with. Having specific information on the long-term physical changes is crucial for patients to adjust and cope with the long-term changes and is an area that has been identified where there are significant unmet information needs (Ziegler et al 2004; Newell et al 2004) as the information they receive may not be addressing the specific needs of each individual patient.

The ambiguity and uncertainty that many patients report experiencing post-treatment leads many to experience a loss of self or a feeling of a diminished self, which is linked with a loss of identity (Semple et al 2008, Moore et al 2004, Wells 1998a). Although a lack of information can lead to

these “metaphoric feelings of loss”, for some patients there is real identity loss due to the disfigurement and mutilation associated with certain treatments for head and neck cancer, for example, laryngectomy. Many patients post-laryngectomy initially fear looking at themselves due to the fear and uncertainty of what they will look like (Llewellyn et al 2005), which is compounded by the loss of their natural voice. Newell (2000) suggests that only a minority of patients affected with disfigurement will have meaningful contact with a health professional and receive the information and support required at this time. A study exploring the challenges of disfigurement across a mix of patient populations, including people affected by head and neck cancers (Cartwright & Magee 2006), identified an overall lack of information available on the expectations about the extent of the disfigurement and the impact that this might have on their daily lives reported by patients and carers. The authors found through focus group discussions with health professionals that they were aware of the need to identify and address the psychological needs of patients with disfigurement and the important role that information plays at this time. However, although health professionals were aware of the need to provide patients with information at this time, patients and carers reported that they did not always receive the specific information they needed when they needed it, leaving them with questions and worries unanswered.

From the few studies exploring the information needs of people affected by head and neck cancer, it is evident that overall, the majority of patients have reported being ill-informed and unprepared, especially in the post-treatment phase. In addition, there is a lack of studies exploring the

specific information needs of carers, even though quality of life research has shown the psychological distress associated with the care-giving burden within this group of carers in the acute post-treatment phase. A lack of information on the consequences of treatment and how best to manage these consequences is evident with the need for a longitudinal study to explore their specific information needs and how these needs change over time required.

Although the need to provide people affected by head and neck cancers with information is vital, the way in which the information is communicated and the sources from which the information is accessed from can play a crucial role in how this group understand and make sense of that information in the context of their lives. In the following section I will discuss the main sources from which patients and carers affected by cancer receive information from across their cancer trajectory, drawing from the broader cancer literature and, where possible, the head and neck cancer literature.

3.5 Information Sources

The various information sources that patients and their families access after a diagnosis of cancer has been widely researched in the literature. Key sources identified are: health care professionals; written material; family and friends; and the media and internet (Rutten et al 2005; Ankem 2006; Balmer 2005; Ziebland et al 2004; Mills & Sullivan 2000; Hope et al 2000; McNamara 1999). The use of these sources enables patients and their families to access information to learn, decide, adjust and cope with their diagnoses and the ensuing treatment (Mills & Davidson 2002; Raupach & Hiller 2002).

Additionally, previous research has highlighted that the main preference for the provision of information by patients and their families is verbally, through an honest and open discussion with health professionals, complemented by written information (Pollock et al 2008; Timmins 2006; Rutten et al 2005; Ankem 2006; Feber 2003). This finding is not surprising as we have seen that the main information needs of cancer patients are on the nature and course of the disease and on treatment related-information, with information provided and sourced on these categories at diagnosis and during treatment, when contact with health professionals is at its highest. However, recent research has found that health professionals do not always address carers' specific information needs as their focus is on the patients' needs at this stage and carers have reported being dissatisfied with the information they have received (Adams et al 2009; Pollock et al 2008) and reported accessing information from other sources (Morris & Thomas 2002).

Health professionals are reported as the main source of information to patients who place their implicit trust in them (Leydon et al 2000; Mills & Sullivan 2000) with the importance on clear and honest communication viewed as important by patients (Atkinson et al 2002; Mills & Sullivan 2000). In a recent study with people affected by head and neck and lung cancer, Pollock et al (2008) found many participants reported their appreciation of the direct and blunt manner in which the clinician gave them their diagnoses. Patients commented on how they valued this honest and direct manner from the clinician at this early stage, and found that this gave them faith that honesty would be central in all future consultations, thus supporting the findings above.

In addition, the presence of clinical nurse specialists within the field of head and neck cancer provides the patient and carer with additional knowledge, support and expertise across the cancer trajectory. Research has shown the important role that clinical nurse specialists play in helping people affected with head and neck cancers adjust and cope with the diagnosis and consequences of their treatment by providing information, support and reassurance (Wells et al 2007; Larsson et al 2007; Semple 2001; Wells 1998b).

The way in which health professionals deliver information can have a profound effect on how patients experience the rest of their cancer journey (Fallowfield & Jenkins 2004; Feber 2003; Leydon et al 2000). Insensitive communication and poor or inaccurate information can reduce the faith and trust that patients have in their health professionals (Balmer 2005; Fallowfield & Jenkins 2004; Newell et al 2004; Leydon et al 2000; Mills & Sullivan, 2000). The way in which health professionals communicate or deliver information to patients and the challenges health professionals experience is a vast topic, too large to discuss in this thesis. However, Fallowfield and her colleagues (2004; 2002; 2001 & 1998) have developed a programme of work in the UK showing the importance of good communication skills in oncology and the benefits this can bring to consultations. This programme of work demonstrates how detailed training by expert facilitators can improve oncologists' communication behaviours leading to improvements in their communication of detailed and often challenging information with patients and their families. Communicating "bad, sad and difficult news" is part of the role of most health professionals and having the ability and skills to impart information in a manner that is conducive

to the patients' understanding and acceptance is vital. The way in which information is communicated and the language used during key consultations can improve the patients' and their family members' understanding of the care pathway and result in satisfaction with their overall care (Fallowfield & Jenkins 2004).

Although much information is sourced through verbal communication, it is not the only source of information that people affected by cancer use, with the benefits of providing patients with written information well documented (Ankem 2006; Stieglis et al 2004; Hope et al 2000; Reynolds et al 1981; Hinds et al 1995). Written information has shown to support and confirm the verbal information that patients and their families receive from health professionals (Hubbard et al 2005; Birchall et al 2002; Leydon et al 2000, Hope et al 2000; Mills & Sullivan 2000). People affected by head and neck cancers also report the need for more written information to be available (Pollock et al 2008; Balmer 2005) with the use of personal care diaries used throughout treatment found to be beneficial with patients and family members in aiding better communication and overall care with clinicians (Sharp et al 2004). However Pollock et al (2008) found that patients did not use the written information provided as often in the post-treatment phase due to their experience of profound symptoms. They suggest that this is due to the written information in the post-treatment phase not meeting with their expectations drawn from the information they received in the pre-treatment phase, which resonates with the findings from Llewellyn et al (2005). The way in which the written information is laid out is also important (Audit Commission 1993); the

appropriate reading level is crucial to ensure patients understand the information being provided (Wong 1992) and the language used needs to be viewed as “user friendly” (Mumford 1997).

Although written information is widely given to patients affected by different types of cancer, there have been deficits identified with the content being too general and not specific enough for some patients’ particular information needs (Pollock et al 2008; Balmer 2005) and the positive way in which the written information is presented as being unrealistic (Mills & Sullivan 2000).

Television and radio have also been seen to have had positive responses with some patients as sources of information in order to enable them to learn about the availability of new treatments (Balmer 2005), with high profile figures diagnosed with specific types of cancer raising the profile and information around these specific cancers (for example, Kylie Minogue and Michael Douglas). Although some patients do perceive this source of information as an unwelcome threat, delivering false hope (Leydon et al 2000), the use of the internet is becoming an increasingly popular source of information for patients, especially younger patients, and their families (Ziebland et al 2004). Through the support of other cancer patients, the internet provides certain groups of patients with an information source that allows privacy, is available 24 hours a day and can help patients to understand their diagnosis and ensure they are receiving the best treatment, which can empower some in future consultations (Ziebland et al 2004; Mills & Davidson

2002). However, there are risks associated with the information available via the internet which patients are aware of, as they have reported how some information is not relevant and appears biased, with the content of information on some web sites too in-depth or frightening for some to use (Balmer 2005; Hubbard et al 2005; Ziebland et al 2004).

We know the important role that family members and friends play with patients across the cancer trajectory and how they can be a trusted source of information to patients. Previous research has shown how family members can retain information at consultations when the “patient” is unable to absorb information due to the shock of their diagnosis or due to illness. Also revealed is how they can relay information back to the patient at appropriate stages across the trajectory by drawing on the verbal and written information provided by health professionals, thus enabling them to feel more involved and engaged in the illness experience (Ankem 2006, Hubbard et al 2005; Morris 2001).

However, another source of information that is becoming more evident is that of the role of other patients. Atkinson et al (2002) found that patients were found to help other patients “learn the ropes” regarding aspects of their treatment, with Leydon et al (2000) reporting how women in their study valued the information and knowledge from other patients more than the medical knowledge provided by health professionals. Feber (1998) found in her early work how newly diagnosed patients with laryngeal cancer benefited from the peer support and information provided by post-laryngectomy patients. She found that the information and experience ex-patients provided to the newly

diagnosed patients aided in their understanding and future adjustment. More recently, Pollock et al (2008) described participants in their study as “active interpreters” as they were found to use “experiential” information gained from the interpretations and observations of the behaviours and experiences of other patients and people directly known to them, to gain new knowledge and insight into aspects of their illness and treatment. Further research is needed to explore this source of information as this group of patients and their carers may be a group that use different sources of information in comparison to other cancer types, based on their experience of debilitating and distressing symptoms

From this section it is evident that patients and carers do not use only one source of information but instead draw on several sources of information depending on their specific needs at specific points over their cancer trajectory. Health professionals are the most common source of information, which emphasises the crucial roles they play in meeting the information needs of patients and carers. During diagnosis and the treatment phase, both patients and carers rely heavily on both verbal and written communication from health professionals about their illness and the future trajectory, but there is a lack of both sources evident in the post-treatment and follow-up phases. Research has shown how the layout of written information is crucial to patients to ensure it provides the right level of information and in a language that is understandable to them.

Once patients and carers leave “active treatment” then health professionals may not be the main source of information they use. Previous research has shown that patients’ information needs change across the cancer trajectory (Lambert & Loiselle 2007), but with little research highlighting whether the sources of information that patients and carers use also change as they progress across their cancer trajectory (Ankem 2006). Rutten et al (2005) suggest that if there are inadequacies in the provision of information from health professionals this may lead certain groups of people affected by cancer to seek alternative information sources as found with carers (Morris & Thomas 2002), and also head and neck cancer patients who were found to rely heavily on “experiential” knowledge as a source of information across their cancer trajectory (Pollock et al 2008).

Experiential information is a recent concept defined in the nursing literature (Pollock et al 2008) as information learned through direct experience of an event or from others’ experience of an event. The term “experiential information” derives from a body of literature based in sociology that discusses experiential knowledge, which encompasses both embodied knowledge, or that which people already have and have experience of themselves, and empathetic knowledge, or that which people learn from others’ experiences, both of which aid in people’s understanding of illness and disease.

In the following section, I will outline literature explaining the relationship between information and knowledge and how they are used to help people make sense of and understand illness and disease.

3.6 Knowledge and Information

Borkmann (1976) developed the concept of “experiential knowledge” to differentiate analytically between experiential and professional knowledge in the context of self-help groups and professionally-led groups. The distinction she makes is that experiential knowledge is “truth learned from personal experience with a phenomenon, rather than truth acquired by discursive reasoning, observation or reflection on information provided by others” (Borkmann 1976:446). She highlights how there are two distinct elements to experiential knowledge: the information on which the knowledge is gained, and the individual’s attitude towards the information. The type of information gained from the experience is wisdom and “know-how” which can only be gained through the direct participation in a particular phenomenon. The wisdom or knowledge gained is concrete, specific and commonsensical, based on the actual experience of the individual, which is unique and limited, but can represent the experience of others in similar circumstances. The belief that the information gained through direct experience is knowledge and that this knowledge is truth can be validated by the individual as they are the authority on it, due to their direct participation in the phenomenon.

Abel and Browner (1998) further categorised “experiential knowledge” into the two broad categories of embodied knowledge and empathetic knowledge. For them, embodied knowledge refers to the subjective knowledge derived from an actual bodily experience (pregnancy, in their study), suggesting that an individual gains knowledge through the direct experience of

a particular phenomenon. Empathetic knowledge refers to knowledge that is derived from close associations with others experiencing a particular event (female carers of parents affected with dementia, in their study), suggesting that knowledge is gained by being indirectly involved in a particular phenomena. Abel and Browner (1998) suggest that the knowledge gained from these two categories enables individuals to make sense of their own symptoms and/or manage the impact of their condition or a family member's condition in relation to their own lives, based on past and present experiences.

In the above definitions by Borkmann (1976) and Abel and Browner (1998), information is central to people gaining wisdom or knowledge from a particular experience that then becomes "experiential knowledge". However, information and the knowledge we gain from it, is achieved through both verbal and written language, but how that language is interpreted and understood will vary from individual to individual. The knowledge we have of ourselves and of our social world is obtained through the learning and the sharing of language, which comes from our past and present experiences. The use of language from our social worlds is fundamental to how we discuss, describe and make sense of our experiences. As Burr (1995) comments, "we can only represent our experiences to ourselves and to others by using the concepts embedded in our language" (Burr 1995:39). So much of what we know is based in our experiences and from the language used to communicate those experiences in the context of our lives. Code (1993) suggests that knowledge comes from and is shaped by personal circumstances and experiences of the knower, with other terms used for describing this type of knowledge as "lay understanding"

(Lawton 2003) or a “common sense knowledge”, which is developed through the interactions and experiences gained of self and from others (Dingwall 2001).

The use of people’s experience and knowledge to explain and understand health and illness has been widely researched in sociology for many years (Young 2004; Lawton 2003), a trend which has seen the development of many theories and explanatory stances to show how people make sense of their illness and manage the consequences of their illness in the context of their lives. Sociologists suggest illness is a socially interpreted event that manifests within complex social structures that influence how the illness experience is interpreted and understood by the individual (Young 2004; Locker 1981, Dingwall 1976). The experiences and the knowledge gained from illness experiences of self and from others provide us with knowledge that enables us to interpret what is normal and abnormal in our social worlds and how we use this knowledge will influence how we react or respond to illness experiences. The meaning we attach to illness stems from the “common sense knowledge” on which Dingwall (2001, 1976) based his illness action framework. Embedded in this illness action framework (Dingwall 2001; 1976) is the assumption that we all have a “stock of knowledge” regarding health and illness, which Dingwall calls “common sense knowledge”, or, as Borkmann (1976) calls it, “commonsensical knowledge”, that has developed through the interactions and experiences we have gained of ourselves and by interacting with others. Through the knowledge gained, we do not consciously think about how we breathe or how we walk as that is part of our routine physical functions that are

in balance with, or in “equilibrium” with, our normal bodily functions. It is only when there is an imbalance in our normal bodily function due to a biological disturbance or problematic experience that we use our stock of knowledge of health and illness to interpret what the problematic experience could mean (Dingwall 1976: 93).

Similarly, Locker (1981), drawing on Dingwall (1976), defines problematic experiences as “events, situations, or states of affairs which disturbs our taken for granted attitude towards the world and calls for interpretive and explanatory activity” to take place (Locker 1981:49). Through the interpretative and evaluative work carried out by the individual, based on their experiences and stock of knowledge of health and illness, the individual decides what response or action is appropriate to make sense of the problematic experiences in the context of their life. This explanatory stance suggests that how an individual decides to act regarding their symptoms of illness is not only a cognitive process but is also influenced by social processes central to the individual’s social world. As Kleinman et al (1978) suggest, our perception of illness is culturally bound and how we explain and understand sickness is linked with the social positions we employ and the meaning we attach to them (Kleinman et al 1978). However, the emphasis placed on lay knowledge of the individual to explain their symptoms and illness in the context of their lives diminished with the development of the biomedical model of illness (Lawrence 1994).

Historically, the information shared between a doctor and their patient was core to the doctor being able to diagnose disease or illness by obtaining information on the patient's lifestyle, his or her moral stance and the wider environment in which the patient lived (Bury 2001). During 18th century medical practice, medics viewed disease as deviant from the individual's "natural state." Whereas, in the 19th and 20th centuries, medicine focused on the normal, with disease viewed as deviating from statistical norms, independent of the individual's experiences or circumstances; a shift from the "natural state" of the individual (Lawrence 1994). This move away from the emphasis on the individual or lay experience of illness by the medical profession encouraged a gap between the lay world and the professional world. The idea of disease as individual pathology had become the dominant paradigm and was linked to the development of a "bounded" medical profession that forced complete power over illness and its treatment (Bury 2001; Lawrence 1994). The "bounded" medical profession held the knowledge and the expertise, and lay knowledge was viewed with scepticism (Bury 2001; Lars-Christer 1997), which ultimately led to the development of the passive patient and the paternalistic doctor, where the doctor was viewed as the possessor of expert knowledge.

However, due to societal changes, there is now a greater access to medical knowledge through the media and the internet, allowing individuals to gain knowledge about many aspects of their health and illness. As Bury (2001) states, "where once the biomedical paradigm held sway (and where doctors jealously guarded its secrets), now lay people have access to an increasing

range of information and ideas about the origins, course and outcomes of illness and its treatment” (Bury 2001). The ability for lay people to access such a wealth of information and knowledge about various aspects of illness and health has raised the question, “*How lay are lay beliefs?*” (Shaw 2002).

In his paper, Shaw (2002) argues that, due to the wealth of information available in today’s society, there is no “indigenous cultural development which is not informed by an expert (if not a biomedical) conceptual framework” (2002:294). The world-wide media has caused the evolution of a society where lay beliefs on health and illness are dominated by the biomedical model in which lay people now situate their lay beliefs and internalise them as their own. He uses the term “proto-professionalization” which was used by de Swaan (1990) who stated, “The internal process of professionalization creates external effects among ever widening circles of laymen, who adopt basic stances and fundamental concepts of the profession as a means of orientation in their everyday life: it is a process of proto-professionalization” (cited in Shaw 2002:289). Lay people’s accounts of illness are now influenced by medical rationality and the propaganda available now on every aspect of health, illness and disease. Today’s society is viewed as an “information society” and the experiential knowledge people now have of illness and health will influence their use and understanding of professional or biomedical information (Berg 2002). Generally, people now have semi-expertise in medicine or “proto-professionalization” explanatory frameworks, which they draw upon to explain and make sense of their illness. Therefore, the experiential knowledge that people draw on is a collection of information gleaned from their socio-cultural

experiences, societal messages and understandings of health, illness and disease, each of which are contextualised by that individual's social world.

Experiential knowledge and the information gleaned from it is the first type of information that people draw upon to make sense of and understand their experiences of symptoms or to explain what is normal or abnormal. The literature suggests that individuals use experiential knowledge in combination with information from professionals to assist them in making sense of the situation that they are currently experiencing. As Abel and Browner (1998) highlighted in their study, "women seek biomedical information partly to explain their own experiences" (1998:316) with Pollock et al (2008) identifying that both the verbal and non-verbal cues received from health professionals allowed their respondents to "shed light on their own situation" (2008:970). However, D'Agincourt-Canning (2005) highlights the importance of recognising that both socio-cultural and medical knowledge shape people's experiential knowledge of cancer through the social discourses used in society. France et al (2011) also suggest that experiential and biomedical knowledge are intertwined, as neither took privilege in the accounts of their female participants regarding decisions on diagnostic testing for foetal abnormality. This would suggest that experiential knowledge and the information gleaned from it should not be viewed in isolation from the biomedical information gleaned from health professionals as both are used in a "complex and synergistic" way (Markens et al 2010) by individuals through their own interpretive and evaluative framework of health, illness and disease.

3.7 Summary

From this chapter it is evident that people affected by head and neck cancer experience very distressing and debilitating symptoms throughout their cancer trajectory, with little known of their overall information needs, specifically in the post-treatment and follow-up phase. Many of the studies discussed have used mixed samples of different types of head and neck cancer patients, where they have focused retrospectively on specific symptoms of treatment or issues at diagnosis or during the treatment phase, with few longitudinal studies evident. A diagnosis of cancer, as we know, affects not only the individual but family members too, with a dearth of studies exploring the specific needs of carers of patients affected by head and neck cancer and what their specific information needs are from diagnosis onwards.

Research has shown that patients and carers want and need different types of information to help them manage and cope with their diagnoses and ensuing treatments with evidence showing the various sources of information they use. It is well documented how the information needs of patients and carers change over the cancer trajectory, with little known about whether the sources from which they access information change as well. Recent research has shown that patients use information drawn from experiential knowledge in combination with information from health professionals to help them make sense of their current illness experiences. How patients understand and interpret that information is influenced by their direct and indirect experiences of health and illness, both past and present,

situated in the context of their social world. This would suggest that the need for information for people affected by head and neck cancers will be influenced by their explanatory stance of how they make sense of their illness and manage the consequences of their illness in the context of their lives.

In the following Chapter, I will discuss my approach to the study, the methods I adopted and the justification for adopting those methods for data collection and analysis.

Chapter Four

Methods Chapter

4.1 Introduction

In this chapter, I will present how I carried out the main study to meet my study aim. In the following sections I will justify the methodological approach I adopted for the study and outline the methods that I used for data collection, leading to a description of my sampling approach and study participants. I will discuss the recruitment process and the challenges I experienced during data collection, finishing the chapter by discussing my analytical approach and framework, leading to a description and explanation of the study findings in Chapter 5.

Chapter 1 identified the importance of providing verbal and written information emphasised in health care policy and NHS directives to people affected by cancer across their cancer trajectory by health professionals, with Chapter 2 showing the negative impact that a diagnosis of a head and neck cancer has on the individual's quality of life. From the evidence we know that people affected by head and neck cancers have many distressing and debilitating symptoms due to the impact and outcome of their treatment over the cancer trajectory. However, few studies have focused specifically on the needs of people affected by laryngeal cancer with an overall dearth of studies identifying the specific needs of family members. Chapter 3 identified the

important role that information plays in helping patients and their family members cope and manage after a diagnosis of cancer, with a wealth of evidence from the broader cancer literature on the specific types of information people affected by cancer need, and how their need for information can change across the cancer trajectory. However, it was evident from that body of literature that there is a lack of research carried out with people affected by laryngeal cancer to establish what their overall needs are and what information they specifically need, based on their experience of treatment and its outcome over the cancer trajectory. Therefore, the overall aim of this study is:

To explain the role of information with people affected by laryngeal cancer based on their experiences across the cancer trajectory. To enable me to answer the study aim, the following research questions were developed:

1. What are the experiences of people affected by laryngeal cancer across their cancer trajectory?
2. In response to their experiences, what information do they need and use?
3. Why do they need these types of information?
4. In what ways are they using these types of information?
5. Are there factors that influence or inhibit their need and use of information?
6. Is information being tailored to their individual needs based on their experiences?

4.2 Approach to Study

Because the focus of my research was to explore the role of information with people affected by laryngeal cancer and how they use it across their cancer trajectory, I had to find the appropriate method that would allow me to answer the research questions thus fulfilling the study aim. The most appropriate method for data collection to use in this particular study was from the paradigm of qualitative research, as one of the fundamental aims of qualitative research is to investigate and explore people's subjective experience and understanding of their experiences in the context of their lives and social world.

I identified a lack of research with people affected by laryngeal cancer and therefore wanted to explore, from their perspective, what their experiences were, what information they needed, from whom and in what ways they integrated that information into the context of their lives to make sense of their experiences across the cancer trajectory. Qualitative research has been described as a way to capture the perspectives of the individual's social world by "seeing [their world] through the eyes of the people you are studying" (Bryman 1988:61) or "to emphasise the dynamic, holistic and individual aspects in their entirety, within the context of those who are experiencing them" (Polit & Beck 2004:16). In other words, by exploring the interactions of people within their social worlds, the researcher can provide explanations of the understandings or meanings they attach to their experiences by identifying and describing the social structures and processes that shape these understandings

and meanings (Popay et al 1998). Adopting a qualitative approach to the study allowed me to place an emphasis and value on the human interpretive aspects of participants' knowledge of and about their social world. The interrelatedness of different aspects of the participants' lives, such as their psychological, social, historical and cultural factors, play important parts in shaping how that individual understands their world (Ritchie & Lewis, 2006).

As highlighted in Chapter 3, section 3.4, there is a lack of knowledge and understanding of the types of information this group of patients and carers need across the cancer trajectory and how they use information at different points in time. Therefore, using qualitative methods allowed me to explore in depth their accounts of the information they needed and to discuss the ways in which they used and integrated the information to make sense of their cancer experiences in the context of their lives.

Qualitative research stems from the philosophy of "relativism" which assumes that "reality and our knowledge of it are socially constructed in that they are a product of particular social, political and historical circumstances" (Greene & Browne 2005:19). In taking a relativist stance, I agree that the perspectives of others on reality are equally legitimate to my own. I may not agree with the individual's perspective but still view it as a legitimate perspective as each individual's historical, cultural and social/political view of reality evolves from their individual experience of the world. Relativists believe that reality is constantly changing and therefore cannot be objectively measured (Greene & Browne 2005). Stemming from this philosophy is "Interpretivism".

Interpretivism focuses on the meaning of reality rather than reality itself (Ritchie & Lewis 2006; Greene & Browne 2005). Many qualitative researchers starting from an interpretive approach assume that if one can come to understand how respondents see the world then they will understand the logic and rationale behind their individual behaviours thus enabling them to interpret how people conceptualise their world (Greene & Browne 2005). Many of the methodological approaches used in qualitative research stem from Interpretivism with the assumptions that “realities are multiple, fluid and co-constructed, and knowledge is taken to be negotiated between the observer and participants” (Cohen & Crabtree 2008:333).

Researchers who adopt an interpretivist stance believe reality to be understood “intrasubjectively and intersubjectively through the meanings and understandings gathered from our social worlds” (Angen 2000:385). Human understanding of the world develops both socially and experientially and links who we are and how we understand the world (Cohen & Crabtree 2008). Interpretivism focuses on how humans experience reality in their everyday lives through the “embedded” language and socio-historical experiences that intrasubjectively influence how they view and make sense of their reality in the context of their worlds. As Angen (2000) states “we live as if the world exists apart from us but we only know it and understand it through our attempts to meaningfully interpret it” (Angen 2000:385). A deeper understanding of how humans experience their worlds is through the interpretation of language, context and time and the intersubjective actions of the people involved in their worlds (Cohen & Crabtree 2008; Moss 1994).

An interpretive approach was appropriate for this study, as I wanted to understand the experiences of people affected by laryngeal cancer across specific time points, why they needed specific types of information and in what ways they used the different types of information in the context of their lives. As discussed in Chapter 2, section 2.4, the impact of this type of cancer and its treatment has a profound and negative effect on many aspects of the individual's and their family's lives. An interpretivist approach allowed me to gain an insight and an understanding of how this group of patients and carers used different types and sources of information to make sense of their experiences across the cancer trajectory in the context of their social worlds.

However, an interpretivist approach does not have clear distinct methodological procedures like the four main methodologies commonly discussed in qualitative textbooks (Ethnography, Phenomenology, Grounded Theory and Case Study). The lack of methodological procedures is justified by Angen (2000) who suggests, "It is through an academic world that is still tied to positivism" that leads the interpretive researcher to search for "a recipe or map" to show the correct research process has been followed. She implies that by following strict methodological procedures the knowledge generated is viewed as valid and true in comparison to "subjective opinion or philosophical ruminating" (Angen 2000:379-380).

The need to find "a recipe or map" to justify the research process was a huge challenge at the beginning of my PhD as my study aim did not seem to "fit" within the methodological procedures of the four main methodologies discussed

in the qualitative literature. I was not aiming to answer what was the meaning or essence of information to the participants (Smith et al 2009), nor was I aiming to develop a theory of how participants used information across their cancer trajectory (Glaser & Strauss 1967). I did not aim to triangulate the need for information between patients and carers with the provision of information by health professionals (Yin 1994) or to observe the actual information given in a consultation between patient, carer and health professionals (Hammersley 1992). Through time and further reading, I realised the processes used by the interpretivist researcher are fundamental to qualitative research, irrespective of methodology, and were embedded in the overall approach I took to the study starting from my research questions right the way through to my analysis and the writing up of my findings, thus allowing me to carry out a study that would be deemed “trustworthy” by the reader.

One of the main challenges faced by qualitative researchers is proving the “scientific” rigour of their study and the production of its findings. This challenge has been the focus of much debate and discussion over the last few decades (Holloway & Wheeler 2002; Mays & Pope 2000; Koch & Harrington 1998; Sandelowski 1995) in an attempt to quash criticisms that the findings from qualitative research are anecdotal, impressionistic and strongly subject to researcher bias (Koch & Harrington 1998). The need to develop criteria to evaluate the “quality” of qualitative research was required (Mays & Pope 2000) but there was debate about applying the same concepts available to evaluate quantitative research such as objectivity, validity, reliability and generalisability. This led Guba and Lincoln (1985) to develop parallel concepts

that were specific and applicable to qualitative research under the over-arching concept of “trustworthiness” that Sandelowski (1995) embedded strongly into nursing research. The concepts developed were credibility, transferability, dependability and conformability which allowed qualitative researchers to illustrate and explain the “pathway” through their study, thus allowing the reader to evaluate the rigour, and, in turn, the quality of the study. As May & Pope (2000) highlight, the most important aspects of carrying out a qualitative study to ensure its quality is through a systematic, self-conscious research design, data collection, interpretation and communication (2000). In the following sections I will communicate through detailed description and explanation how I adopted these concepts over the course of the study to ensure that this study was carried out in a rigorous and trustworthy way.

4.2.1 Method and Study Design

Research methods have been defined as sets of strategies for asking useful questions, designing a study and collecting and analysing data from the study (Green & Browne 2005); as Willig suggests, “research methods are the means to an end” (2001:20).

Willig (2001) implies here that the research question informs the research methods and not the other way around. She goes on to elaborate this point by suggesting that once the researcher has formulated the research question they need to choose the appropriate method for data collection. The appropriate method will allow for the collection of the appropriate data that will answer the research question as different research methods yield different

types of data. I alluded to this link between methods and research questions above in the discussion of which research methodology would be best to answer my research questions.

Silverman (1993) defines a research method as a “specific research technique” which helps the researcher clarify how the data are collected and how the data are analysed. This distinction shows the researcher that there are different techniques for data collection and for data analysis. The chosen research method then needs to link the research questions, the design of the study, data collection and data analysis as each part is dependant on the other in achieving the overall research aims or the “goal” (Ritchie & Lewis 2006; Morse 2005; Green & Thorogood 2004; Willig 2001; Kvale 1996).

As my research questions were to explore the experiences of people affected by laryngeal cancer over their cancer trajectory and explain the ways in which they used and integrated information into their lives, a longitudinal design was appropriate along with qualitative interviews as my method of data collection. By adopting a longitudinal design, I was able to gain an understanding of their experiences and the different types and sources of information participants reported needing and the different ways in which they used the information at different time points across their cancer trajectory. From an interpretivist perspective, “reality” is fluid and changes occur over time, therefore one would expect that the need for information and the ways in which people affected by laryngeal cancer used information would also change over

time, based on their interpretation and understanding of their experiences over the cancer trajectory.

The decision to use qualitative interviews stems from the premise that to get to know people in our every day lives, we use conversation. Conversations enable us to learn about others' experience and how they understand those experiences in the context of their world (Kvale 1996). As Berger and Luckmann state: "Language is fundamental to human understanding, to how we make sense of and shape the world around us; it is the most important sign system of human society" (1967:51).

In qualitative interviews, knowledge is constructed through an interchange of language between two people about a particular phenomenon (Kvale 1996). This interchange allows the individual participating in the interview to express their own thoughts, feelings and beliefs in their own words and in their own time. Their thoughts and feelings will be "inextricably and unavoidably historically, politically and contextually bound" in the participant's frame of reference (Denzin & Lincoln, 2005:695). The language used through the interviews is a medium for the individual to give an account of their views and experiences of the social world as "everything we know about the world is mediated through language" (Holloway & Jefferson, 2000:14).

By adopting qualitative interviews as my method for data collection, participants could describe their needs and the types and sources of information they used to understand their experiences over their cancer trajectory. In addition, it allowed both the patient and the carer to give me their

accounts, either singly or jointly, using their own frames of reference. This method allowed me to access their intrasubjective and intersubjective understandings of the information they needed and used in the context of their world.

There are two main types of interviews discussed in qualitative research; the semi-structured interview and the unstructured interview. Each yields different data, therefore the type chosen by the researcher depends on the research questions. The most common interview used in qualitative research is the semi-structured interview. This can be described as an interview whereby the researcher uses a guide in which a set of questions are specified but the researcher is allowed to probe, clarify and elaborate on the respondents' answers (Greene & Browne 2005). The use of this approach is appropriate when the researcher has specific questions that they want answered and they gently direct the course of the interview to gather the data required. However, throughout this type of interview the researcher allows the interviewee to elaborate and expand on the answers allowing the researcher to explore and probe deeper.

The unstructured or in-depth interview is where the researcher uses a topic guide with broad areas for discussion but the respondents' answers predominantly guide the final questions that the researcher asks (Greene & Browne 2005). The use of the unstructured interview is when there is not a lot known about the area under study, where the researcher asks open questions, possibly just one, and allows the interviewee to lead and direct the interview.

This type of interview is central to specific methodologies in qualitative research where the researcher aims to explore the meaning or essence of the phenomenon to the individual thus allowing the interviewee to take control and direction of the interview (Smith et al 2009). Although the description of this type of interview in the literature is an in-depth interview (Cancer Care Research Centre 2007; Ritchie & Lewis 2006; Greene & Browne 2005), I would argue that both types of interviews could be described as in-depth, depending on the level of probing and clarification required by the researcher to answer the research questions. All research studies have questions that need answered and all researchers require topic guides to guide the interview process. I would suggest that it is in the flexibility and skill of the researcher to respond to the answers given by the respondent and to probe in-depth to reach an understanding of the phenomena under study.

The literature discusses both types of interviews as separate and how the researcher needs to choose one depending on their specific research questions, however, May (2001) suggests that researchers can use both approaches to a study. She highlights that the time point of the interview can dictate how unstructured or structured the researcher's questioning needs to be. May (2001) suggests that the researcher may adopt an unstructured approach at the beginning of the data collection process but as time moves on and early analysis has started then a more structured approach to questioning can occur.

In my study, I used an in-depth unstructured approach in the first interview, which gave me the flexibility to ask participants open questions. This approach allowed participants to describe and discuss their needs and the types of information they needed and used in the time leading up to their diagnosis, at their diagnosis and through their treatment phase, based on their experiences at these time points (Appendix 1). I then adopted a more structured approach in the second interview, which allowed me to explore specific issues around information provision and its use, discussed in the first interview. I was also able to explore the different types of information participants needed and used at the end of their treatment and into follow-up, based on their experiences at this time. Using a structured approach in the second interview allowed me to ask participants their views of the different types, sources and use of information they needed from across their cancer trajectory as a whole (Appendix 2).

By adopting this mixed approach, I received the patients' and carers' verbal accounts leading up to their diagnosis through into their follow-up which remained close to the actual events experienced. This approach allowed me to probe and enquire deeper into both the generic and specific types of information they needed and used at different points in time. The accounts provided an in-depth view of the information this particular group needed and how they used it to make sense of their experiences in the context of their lives. As people's accounts of reality change over time, influenced by their experiences and needs, by adopting a longitudinal design to the study it allowed me to capture changes in their specific need for different types, sources

and uses of information as participants progressed through their cancer trajectory.

4.2.2 Longitudinal Design

The term “longitudinal” in research is defined as data that is collected at two or more time points on the same cases or variables. The chosen cases or variables are the same or comparable from one time point to the next. During the analysis, there is some comparison of the cases or variables between or among the specific time points (Ruspini 1999; Menard 1991) or where change occurs over specific time points (Murray & Sheikh 2006).

Longitudinal studies have been used in other disciplines for several decades, such as anthropology, ethnography and psychology (Holland et al 2006) but there is a lack of studies using this approach in the nursing literature (Rutten et al 2005). Longitudinal designs used in social research tend to be cross-sectional studies, prospective studies, or retrospective studies, such as oral, life or work histories. It is a popular design because it allows changes in social behaviours, attitudes and/or beliefs to be measured (Ruspini 1999).

However, in health research the dominant approach has been to use a cross-sectional design, exploring specific issues at one specific time point over the illness trajectory. Whereas, a prospective qualitative longitudinal design in health research would allow the researcher to understand the “dynamic illness experience and how patients’ physical, psychological, social and spiritual needs and their use of services varies over time” (Murray & Sheikh 2006:901). The authors imply that by adopting a longitudinal design the

researcher can capture the process that evolves over time or the impact, consequences and/or outcomes that can occur over time (Murray & Sheikh 2006). Time is fluid and, “in the theory of relativity there is no unique absolute time, but instead each individual has his own personal measure of time that depends on where he is and how he is moving” (Hawking 1988:33 cited in Saldaña 2003:5), thus time is individually and subjectively interpreted in the context of the individual’s social world (Saldaña 2003). In the realm of cancer nursing, adopting a longitudinal approach allows the whole illness experience to be explored and the changes to an individual’s quality of life over time are captured (Cancer Care Research Centre 2007).

Ultimately, the use of a longitudinal design will depend on the “goal” of the study and the research questions. Ruspini (1999) in her discussion paper highlights the need for the researcher to be clear on which longitudinal approach to use, as each approach has limitations with regard to the changes that can be measured or explored over time.

The advantages of a longitudinal design are that the researcher can measure or explore changes with a specific group of participants over specific time points of varying lengths. This allows the researcher to capture the evolving process or capture the impact, consequences and outcomes of the phenomena being studied which do not necessarily emerge in the first interview (Murray & Sheikh 2006). By capturing the evolving process of change, it implies a more temporal-based perspective that details the complexities of the journey rather than measuring the change at two specific time-points (Saldaña

2003). Additionally, a longitudinal approach allows the researcher to build rapport with participants, which permits trust, empathy and a deeper understanding to emerge, allowing the collection of rich data around sensitive issues such as death and dying to be captured (Murray & Sheikh 2006).

Holloway and Jefferson (2000) used a longitudinal design and found that it allowed them to build rapport with the interviewee that aided future discussion. Additionally, it allowed them to read and analyse the first interview prior to the second, so that clarification of specific points and issues raised were probed deeper which aided further understanding during analysis. The authors also discussed how the respondents appeared to be more open about their experiences and more comfortable discussing their experiences during the second interview. However, by applying a longitudinal design to a study, the researcher needs to be aware of the challenges that can arise.

Attrition and retention of participants are two of the main challenges the researcher faces with this design and is usually caused by participants refusing to take part in long-term research, the deaths of participants, and/or changes in their personal circumstances (Murray & Sheikh 2006). Ethical issues around maintaining consent and preserving confidentiality of participants are a concern, as well as the emotional effects of the research itself on the participants and the researcher over a long period of time (Murray & Sheikh 2006; Saldaña 2003; Ruspini 1999). Additionally, longitudinal research is time consuming and costly, both in the data collection and data analysis phases, due to the amount of data generated. The question of the quality of data generated

being poorer from a longitudinal study has been raised due to participant recall, distortion and post-event rationalisation. Some authors suggest that data generated from retrospective accounts of specific events and the timing of those events may not be suitable to a longitudinal design if the change that occurs is complex (Ritchie & Lewis 2006; Ruspini 1999).

A prospective longitudinal approach was appropriate for this study as I wanted to explore what information people affected by laryngeal cancer needed and how they used and integrated this information over the cancer trajectory based on their experiences, i.e. at the time points of leading up to diagnosis, diagnosis, during treatment and follow-up. As we have seen in Chapter 3, patients' information needs do change over the course of the cancer trajectory from the medically driven information at diagnosis, to more supportive information towards the end of their treatment (van der Molen 1999). Yet Rutten et al (2005) in their review highlighted that there is a deficit of prospective longitudinal studies exploring the specific information needs of patients affected by cancer at specific stages over the trajectory, particularly in the follow-up phase. By adopting a longitudinal design to this study, I was able to gather data on the participants' descriptions and use of information from diagnosis into follow-up, and explore whether their need and use for information changed based on their actual experiences in the context of their lives.

As highlighted in Chapter 2, this type of cancer is predominantly a cancer of males, associated with certain lifestyle risk factors, such as smoking and alcohol, with people predominantly from lower socio-economic classes

presenting with advanced disease. In addition, the impact of treatment can have a profound effect on various aspects of the individual's life, such as communication, eating and swallowing, each in combination with visual facial disfigurement. Adopting a longitudinal design allowed me to build a relationship with study participants in which trust and confidence developed. This approach seemed to encourage open discussions about the information they needed and in what ways they used it to make sense of their cancer experiences over the trajectory. A longitudinal approach also allowed me to explore issues raised in the first interview in more depth in the second interview, where the participants were more comfortable and confident discussing their personal experiences of the consequences of their treatment and their overall views on the information they had needed and used since their diagnosis. Many couples insisted on being interviewed jointly during the first interview but were more relaxed at being interviewed separately in the second interview, thus showing the development of rapport and trust between myself and this group of participants. This approach also allowed me to explore the complexities that had developed over time based on the information they received and the reality of their actual experiences.

The first interview was in the last two weeks of the participants' treatment, which was a retrospective account of the types and sources of information they had needed and used leading up to their diagnosis and during their diagnosis. This interview also explored the different types and sources of information needed and being used concurrently during their treatment. The second interview was approximately six months post-treatment where

participants gave retrospective accounts of the different types and sources of information they had needed and used during the treatment phase and concurrent accounts of the need for different types of information to use in this early follow-up phase.

The use of concurrent and retrospective accounts in qualitative interviews again depends on the design of the study and the phenomena under study. Due to the method of probing and clarifying through questions in qualitative research, the researcher can obtain detailed accounts of current and retrospective events that can provide rich data at a specific time point, i.e. at diagnosis or at treatment. However, a concurrent approach only allows a snapshot of the particular event at that particular time point and is inadequate to explore fully the issues raised in the phenomena (Murray & Sheikh 2006; Ritchie & Lewis, 2006).

Discussion and debate in the research literature is scarce around the benefits and weaknesses of concurrent and retrospective accounts and one could say that most interviews are retrospective accounts irrelevant of the specific time point of the interview. One of the main criticisms of a retrospective account is participants' recall and post-rationalisation of the event; however, the accounts given by my study participants about their need and use of information leading up to and at diagnosis were within three months of their formal diagnosis. Similarly, the accounts given by my study participants about their need and use of information at the end of treatment were within six months of finishing treatment. Therefore, I would argue that the accounts given by my

study participants and their recall of their need for the different types of information and how they used it across their trajectory remained close to the actual events, therefore limiting recall problems (Murray & Sheikh 2006; Ruspini 1999). The similarities of the accounts given by my study participants across different cases and within cases, i.e. accounts given by couples, provided a coherent picture of the generic types, sources and use of information they needed across the cancer trajectory. As Thorne et al (2009) state, “the diagnosis experience becomes the reference point for all that follows in the cancer journey. It is recalled and retold, even decades later, with the vivid colour, texture and sound of an immediate experience” (2009:747). Ultimately, the accounts given by participants were based on their interpretations and understanding of their cancer experiences located in the context of their life at particular time points across their cancer trajectory.

4.2.3 Sampling and Recruitment

Qualitative research has been criticised by some authors in terms of the lack of information provided about the approach to sampling and the characteristics of the sample that are available to the reader (Coyne 1997; Morse 1991). This lack of information means that the reader has difficulty in interpreting the findings and/or replicating the study (Kitson et al 1982). The sampling approach is influenced by the methodological approach and Coyne (1997) suggests that in many qualitative studies it is unclear which approach has been used and why, making the validity and quality of the study findings questionable (Coyne 1997; Sandelowski 1995; Becker 1993).

Non-probability sampling is primarily the approach used in qualitative research and the sample selected reflects particular features of, or specific groups within, the population under study. The sample selected is not intended, nor required to be, statistically representative, and the chances of selection are unknown. The basis of selection is on the key characteristics of the specific population being studied (Ritchie & Lewis 2006) as the quote below illustrates:

“Sampling is like taking out a few grains of rice from the cooking vessel to know if the dish is done or not.”

(Commonwealth Educational Media Centre for Asia 2007, Chapter 13, Sampling)

As the aim of my study was to explain the role of information with people affected by laryngeal cancer across the cancer trajectory, the target population were patients and their main carers affected by a diagnosis of laryngeal cancer. To achieve the aim, I needed to gather information-rich accounts (Patton 2002) from both patients and carers on their need and use of information across the cancer trajectory based on their experiences. I therefore selected a range of people affected with this type of cancer using a purposive sampling approach.

By adopting purposive sampling, I was able to “home in on” people for whom there were good grounds for believing that their participation would be critical to the research (Denscombe 2003). The sample had key characteristics for detailed exploration, which would enable me to meet the aim of my study (Ritchie & Lewis 2006). However, all sampling approaches could be classed as

purposeful as each researcher purposefully selects the sample that will best answer the research question/s. Patton (2002) suggests that there are several different strategies that the researcher can use for purposefully selecting information-rich cases depending on the phenomena being studied and the methods used in the study (2002:230). The two key sampling strategies considered which would allow me to meet the overall aim of the study and fit with my data collection method were maximum variation sampling and criterion sampling.

Maximum variation sampling is an approach widely used and advocated in qualitative research (Ritchie et al 2006; Ziebland & McPherson 2006). In this approach, the study sample captures and describes the core variants that cut across the target population as a whole. Through the development of a sample matrix, the variation and diversity of the study sample are highlighted based on the core variants of the target population. When looking at the sample variations of the target population, i.e. people affected by laryngeal cancer, the possible variants that could have been included in the sample matrix were many which would have led to a fragmented sample of one or two participants from across and within each core variant, as shown in Table 5 below.

Table 5: Sample Matrix

	Male	Female	Total
Age			
45-54	1-3	1-3	4
55-64	2-4	2-4	6
65-74	2-4	2-4	6
75-84	1-3	1-3	4
Stage of Tumour			
Stage I	1-3	1-3	4
Stage II	2-4	2-4	6
Stage III	2-4-	2-4	6
Stage IV	1-3	1-3	4
Area			
Area 1 Argyll	1-3	1-3	4
Area 2 G/Glasgow	2-4	2-4	6
Area 3 Lothian	2-4	2-4	6
Area 4 Lanarkshire	1-3	1-3	4

The other option was to increase the sample size, as this approach is commonly used with a team of researchers, but for one researcher to conduct

two interviews with a large sample across many health boards in Scotland would have been impossible in the period allocated for the purpose of this study. However, this approach influenced my decision to use criterion sampling.

Criterion sampling is similar to maximum variation sampling as it selects specific criteria relevant to the target population aiming to capture the diversity of the target population. However, in contrast to maximum variation sampling, not all of the core variants of the target population need to be included in the selected sample. In criterion sampling, the researcher develops a pre-determined set of criteria based on key characteristics or key features of the target population. Applying this sampling approach to my study, the main criterion I identified was the stage of tumour, a decision made based on my clinical experience, the literature and discussion with key health professionals involved in the care of this group of patients. The staging of the tumour dictates the subsequent treatment and prognosis for the patient; the more advanced the tumour the more invasive and disabling the treatment. This would suggest that the need for different types of information and the way in which patients and their carer used information would differ across each tumour stage due to their treatment and overall cancer experience.

The identification of the stage of tumour is through the Tumour Node Metastases (TNM) method of categorisation as discussed in Chapter 2 with the type and duration of the treatment varying according to the stage of the tumour. This would suggest that the types of information that people needed and how

they used and integrated the information would differ according to the stage of tumour and the impact of their treatment mode.

As laryngeal cancer is predominantly a cancer of males with 80% of the total population diagnosed being male (CRUK 2006), I expected to recruit more males than females throughout data collection. However, gender became an important criterion for sampling as data collection progressed, as the women who agreed to participate in the study were those with advanced disease. Few women with early stage disease seemed to be “diagnosed” during my initial recruitment phase (T1/T2) and of the two women who agreed to speak with me regarding the study (both diagnosed with T2 disease) both refused to participate due to the impact of their treatment on their lives at that time. In an attempt to balance out the sample between male and female, I decided to extend data collection for a few months in an attempt to access more women with early stage disease to the study.

As the study aimed to include carers of patients as well, by using criterion sampling it allowed me to access the experiences of carers from across the different treatment pathways associated with this type of cancer. This strategy allowed me to explore with the main carer their need for information and how they used the different types of information over the cancer trajectory.

4.2.4 Recruitment

Because the West of Scotland has the highest incidence of laryngeal cancer, covers both rural and urban areas, and encompasses a wide spectrum

of socio-demographic areas, study participants were recruited from four clinical sites in this area. Additionally, the West of Scotland was close to my place of work, meaning that respondents were within a reasonable distance for data collection and that I had a ready-established network of health professionals to assist me in the recruitment process.

In order to capture the range of experiences of both patients and carers over the cancer trajectory whilst keeping data collection and analysis manageable I decided on a sample size of twenty patients and their carers. As the study was exploratory, this sample size was deemed large enough to capture the types and sources of information needed and used across the cancer trajectory. The sample were from a range of experiences across the four tumour stages with the associated treatment pathways yet small enough to allow me to conduct two interviews with both the patient and the carer in the data collection period (potentially eighty interviews).

Table 6 below highlights the characteristics of the patient and the carer sample from the study (where applicable) and shows there were more males recruited than females, which one would expect with this type of cancer. By extending the recruitment period, I managed to recruit only one female with early stage disease. No participants were recruited with Stage IV disease due to few being diagnosed during my recruitment phase and the one couple who were approached declined. From the table it is evident that the majority of carers were female and were either the wife or the daughter of the patient. The initials J or S mean joint or single interviews.

Table 6: Sample of Participants

Patient	Carer	Stage of Tumour	Treatment	
PO1 Male	C01 Brother	T3 (L) palsy	Chemo & Radio	S
PO2 Male	CO2 Wife	T1	Chemo & Radio	J
P03 Female	C03 Husband	T3 - recurrence	Laryngectomy	S
P04 Male	N/A	T3	Chemo & Radio	S
P05 Male	C05 Wife/daughter	T1a	Radiotherapy	S
P06 Male	C06 Wife	T2	Radiotherapy	J
P07 Male	N/A	T1a	Radiotherapy	S
P08 Male	C08 Wife	T1	Radiotherapy	S
P09 Male	C09 Wife	T2 N3	Radiotherapy	J
P10 Male	C10 Wife	T3 died in F/up	Radiotherapy	J
P11 Male	C11 Wife	T2	Radiotherapy	J
P12Female	C12Daughter	T3 - recurrence	Laryngectomy	J
P13 Male	C13 Wife	T3	Laryngectomy	J
P14Female	N/A	T3 died in F/up	Laryngectomy	S
P15 Male	C15 Wife	T3	Laryngectomy	J
P16 Male	C16 Wife	T2	Radiotherapy	J
P17 Male	C17 Daughter	T3 recurrence	Laryngectomy	J
P18Female	C18 Husband	T3	Laryngectomy	J
P19 Male	C19 Wife	T1	Laser	J
P20Female	C20Daughter	T2	Chemo & Radio	J

A multi-centre ethics committee approved the study and NHS approval was granted from each health board prior to data collection starting (see Appendices 3 and 4). The consultants and the clinical nurse specialist from each of the clinical sites were informed of the study, commented on the study, supported it and were willing to identify potential participants on my behalf (see Appendix 5). The identification of potential participants formally diagnosed with laryngeal cancer was by the clinical nurse specialists from the key hospitals throughout the West of Scotland.

The clinical nurse specialists provided potential participants, both patients and their carers, with a written information sheet about the study (Appendices 6 and 7) and asked permission for their telephone number to be passed on to me. If they agreed, consent was obtained and their contact number passed on to me (see Appendix 8). I then called the individual patient and/or carer at least 48-72 hours later, allowing the individuals time to read the study information sheets and discuss the possibility of participating in the study with family, friends or clinical staff.

After contacting the potential participants via the telephone, I organised a face-to-face meeting to discuss the study in more depth before obtaining written consent. These meetings were either at the patients' homes or at the treatment centre where I discussed the study and answered any questions they may have had regarding participating in the study. I explained what was involved with participating in the study and ensured that both individuals fully understood, emphasising that they were able to withdraw at any

time from the study without giving reasons and it would not affect their subsequent care. If they agreed to participate, we arranged a suitable date and time for the first interview at the participant's home. I obtained written consent from both patient and carer (see Appendices 9 and 10) at the first interview and subsequent verbal consent at the beginning of the second interview to ensure individuals were still willing to continue to participate in the study. All interviews were audio taped and later transcribed.

4.2.5 Joint and single interviews

My initial plan was to carry out individual interviews with both the patient and the carer as this would allow each individual to give their own account of their need for information, the sources they accessed and in what ways they integrated and used the information in the context of their lives based on their experiences. I had considered that their need for information might be similar or overlapping or might be different from each other's, therefore, by carrying out the interviews separately, participants could discuss their individual perspectives of information based on their implicit needs and experiences over the cancer trajectory in the context of their lives.

I developed separate information sheets for the patient and their carer and stated that the interviews would be separate to gain their own perceptions of information and its use in the context of their cancer experience. I discussed the plan of the interview when organising the interview/s with the appropriate couple, however, the predominant request was a joint interview with both the patient and the carer.

In many of the qualitative research textbooks and journals there is a wealth of discussion and guidance about carrying out qualitative interviewing. The discussion centres on the researcher carrying out an interview with one participant, commonly known and discussed as “the individual in-depth interview” (Ritchie & Lewis 2006). However, there is little discussion or guidance for the researcher carrying out an interview with two people, commonly known as “the joint interview” (Song 1998), which is surprising as joint interviewing has been used since the 1970s and possibly used more often than is reported in the research literature (Arksey 1996).

The majority of studies that have used joint interviewing are from the social sciences, exploring issues such as finance (Eardley & Corden 1996; Jordan et al 1994; Jordan et al 1992; Huby & Dix 1992; Pahl & Pahl 1971) and unemployment (Ritchie 1990). In health care, the focus of many studies has been illness and disability, with the care recipient and the main carer (Baldock & Ungerson 1994; Shakespeare et al 1993; Parker 1993; Gerhardt 1991) and, more recently, a study exploring the psychosocial needs of cancer patients and their main carers (Morris 2001).

The key issues of the joint interview addressed in these studies are around power and dominance, conflicts of interest amongst couples, issues around data analysis, and the practicalities of data collection. The issue of power and dominance was evident in several of the social science papers referring to the female being inhibited to talk in front of her male partner (Jordan et al 1992; Pahl 1989; McKee & O’Brien 1983). The authors found that women

were more inhibited in joint interviews than in single interviews. According to Pahl (1989), the joint interview can offer insights into power relations between couples through their non-verbal interaction. Others found that males tend to be the “scene stealers” more than women (Shakespeare et al 1993) and men are more likely to be overbearing, to interrupt, or to speak on the other person’s behalf (Arksey 1996; Jordan et al 1992). However, joint interviews can also offer a “voice” to those who might be silent through illness or disability as the carer could act as a prompt or a translator on the patient’s behalf (Shakespeare et al 1993). Additionally, joint interviews can help establish rapport and put the participants at ease (Arksey 1996) aiding the discussion and “completeness of the data generated” (Seymour et al 1995).

Considering these findings with my own study, I can relate to the issues raised by Shakespeare et al (1993) and Seymour et al (1995) respectively. I found that the carer would give “voice” when the patient’s voice would weaken due to the impact of their treatment over the course of the interview, allowing the patient to take a socially acceptable rest. Similarly, where the patient had no voice due to laryngectomy, the carer would act as their “voice” when possible to help them make their views known. In contrast with the other authors, I did not experience any issues around dominance and power in the relationship apparent in the interview; there did not appear to be conflicts of interests raised and no one individual dominated the interview at the expense of the other.

Indeed, many couples shared the interview equally and allowed each other time and space to give their accounts of their cancer experiences and their views on information. On reflection, I may not have encountered these issues as the study focused on cancer and the couples seemed to be “united” in their accounts, presenting a very different stance in the context of cancer in comparison to the context of social issues such as unemployment and finance. Morris (2001), who explored the psychosocial needs of patients and their carers affected by cancer, raised similar issues.

Morris’ (2001) paper focuses on the methodological, ethical and analytical issues that her study encountered during data collection. She agrees that there is very little discussion and guidance in the literature around joint interviewing and discusses four main issues that were raised when many of the patients and the carers in her study requested to be interviewed jointly (dyad). The issues raised were: secrets; intrusion and choice; public accounts; and joint frameworks. All of these issues required flexibility, adaptability and a common sense approach which I could relate to when reflecting on my own experiences during data collection.

Morris (2001) discussed how the potential dyad felt uncomfortable with the idea of separate interviews highlighting that they had “no secrets” from each other (2001:555), provoking anxiety between the dyad due to disclosure during the separate interviews. She highlights that in recent events in cancer care where non-disclosure of diagnosis and prognosis are still evident “there are cultural memories that may be more acute than with other topics”

(2001:555). She comments on how the logistics of interviewing separately meant that one of the couple had to be out of the house or keep out of the way during the interview, which could be physically difficult, rude or intrusive. She makes the point that for many of these couples exclusion from the interview echoes feelings of exclusion that they have experienced through medical consultations and, for some, the cancer experience as a whole.

I experienced similar issues with the couples who requested a joint interview, as they highlighted they had no secrets from one another and had discussed the diagnosis and subsequent treatment pathway together so they would know what “lay ahead”. Fundamentally I was a guest invited into their home and could not expect one to leave to allow the one-to-one interview to take place because my study approach dictated. Many of the couples who requested joint interviews had been married for many years and talked about their cancer experiences from a “we” perspective viewed as a “consensual and supportive approach” through their public account (Morris 2001:556).

Although methodological approaches in qualitative research do not consider the data generated from a joint interview, I agree with Morris (2001) when she states, “data produced are context responsive; a separate account does not therefore provide deeper data but different data” (2001:556). Through the joint interview I experienced couples working together to provide me with a full account, their story, of the information they needed and used through their cancer experiences through the process of a joint framework. The joint framework allowed couples to clarify areas, fill in each other’s gaps and expand

on issues discussing their shared experiences over the cancer trajectory. As highlighted in section 4.2, understanding how humans experience their worlds is through the interpretation of language, context and time, and the intersubjective actions of the people involved in their worlds. This concept implies that the carer is an integral part of the patient's world and therefore cannot, and should not, be separated from it.

In considering the intersubjective actions of people, I also had to be reflexive of my own actions during the course of the study, as I entered it from both a nursing and researcher perspective. Some authors suggest that there can be a conflict due to the inability of the nurse to separate the "researcher" during the research process (Holloway & Wheeler 2002). I appreciate and understand what Holloway and Wheeler (2002) are suggesting, but would argue that being a "nurse" researcher did not hinder the research process but rather, enhanced it. I believe that my nursing background and clinical experience of working with this group of patients enhanced the relationship I developed with the participants, during the interviews and over the course of my study and the data that I ultimately collected.

Due to my clinical background, I could negotiate and navigate the clinical environment and clinical teams to assist in the recruitment of patients to the study. I understood the challenges that clinicians experience in their clinical environment and adopted recruitment strategies accordingly. During data collection, I approached the participants and subsequent interviews honestly and openly. I did not withhold information of my nursing background, and,

when asked my clinical opinion, I provided participants with an answer to the best of my clinical knowledge, however, I always stressed in my answer that I had been out of clinical practice since 2001 and that treatment regimes have changed during this time and, instead of giving advice as a nurse, provided them with avenues that they should pursue as soon as possible, i.e. with their clinical nurse specialist or clinical team. Through my clinical knowledge, I appreciated the complex lives some of these patients have through their lifestyle choices and could understand and appreciate the difficulties of others experiencing challenges with their speech and the side effects of their treatment, allowing them the time to articulate themselves to discuss the issues they wished to raise.

Similarly, Colbourne & Sque (2004) discussed similar issues through the dilemma of leaving a clinical role to take on the “nurse” researcher role. I can relate to the issues they raise but feel that I have “moved on” and did not have the same angst of giving up my clinical role that they discuss and experienced at this time. However, there is a synergy in our view that the role of the nurse researcher should be viewed positively with the skills gained from our nursing careers used to enhance and benefit the whole research process.

4.3 Analytical Approach

In this section, I will discuss my approach to the analysis of my data and describe the systematic process that I adopted to produce the findings. I begin by discussing qualitative analysis broadly, highlighting the concerns discussed by other authors, leading to a justification of my own analytical

approach. Through the discussion, I will introduce my analytical framework leading to a detailed description and explanation of the data in the following chapter.

The analysis of data from a qualitative study is the “most complex and mysterious phase” (Morse 2005), whereby the researcher needs to work actively and engage with the raw data to produce new knowledge about the phenomena under study; this is by no means an easy task. Morse (2005) highlights in her paper that data analysis is the most difficult phase of a research study yet there is little discussion in the literature to assist novice researchers in moving from raw data to the generation of new knowledge.

The most common method of data collection used in qualitative research is the interview but as Kvale (1996) highlights, the “varieties of qualitative interviews span across the spectrum of human conversation”, therefore the forms of interview analysis “can differ as widely as there are ways of reading a text” (1996:13). Thus the researcher needs to consider a range of approaches focusing ultimately on the research objectives but considering the tradition and “theoretical lens” of how the researcher views how knowledge is produced in the social world (Morse 2005; Paley 1996)

Qualitative analysis, unlike quantitative analysis, has no set procedures or agreed rules, thus leading to criticisms in the past due to the difficulty readers have had in deciphering what the researcher has done with the voluminous amounts of data generated. At times qualitative data analysis has been viewed as an “almost esoteric process shrouded in intellectual

mystery [...] or it appeared largely haphazard with discovery falling from the evidence as if somehow by chance” (Spencer et al 2006:199). To address these criticisms, advances over the last decade have allowed for much more visibility about how qualitative data is managed through the assistance of analytical tools (Ritchie et al 2006).

Analytical tools provide the researcher with a robust and transparent approach to data analysis that allows for the production of refined, synthesised and interpreted data irrespective of the theoretical perspective of the researcher. Through using analytical tools, the researcher can manage and work with the data to show the reader the production of new knowledge in a clear and non-mysterious manner.

Analytical tools are not central to one type of data analysis and are useable with all analytical approaches to varying levels as they assist the researcher manage, organise and begin to synthesise the data to allow for in-depth analysis. It is at the abstract level of interpretation or explanation that the function of the tool changes and where the goals of the research, the tradition and the theoretical lens of the researcher influences how the new knowledge is produced. Each study has an interpretive element where data analysis is not the end-product of a linear process but an ongoing process throughout the study as new data is generated and the thoughts and inferences made by the researcher influences future data collection. This iterative process ensures that the researcher gains an in-depth understanding of the experiences and/or

meanings that people attach to their lives about the phenomena under study (Denzin & Lincoln 2005; Morse 1991; Willig 2001; Kvale 1996).

To enable me to manage the voluminous amount of data generated from the interviews and provide me with a transparent and robust analysis to produce findings that are scientifically worthy, I adopted Framework Analysis as my analytical approach. This analytical approach is used across many methodologies and fits within the interpretive paradigm as discussed in section 4.2.

The National Centre for Social Research developed Framework Analysis during the 1980s (Spencer et al 2006). It is a matrix-based method that adopts the key features of an analytical tool. Framework analysis allows for transparent and rigorous data management using a thematic framework and provides a step-by-step guide to assist the researcher to manage and synthesise the raw data. Framework analysis assists the researcher to conceptualise the data through the development of an “analytical hierarchy” utilising the conceptual and analytical skills of the researcher throughout the whole process. The analytical hierarchy is described as “conceptual scaffolding” as it consists of platforms that allow the researcher to move upwards and forwards to a different level of analysis through three distinct phases and gain an overview to make sense of the data at each phase (Ritchie et al 2006:220). There are three main phases in the analytical hierarchy: the first is the Data Management phase; the second the Descriptive Account phase; and the third, the Explanatory Account phase.

4.3.1 Data Management Phase

The first step in this phase is to manage and organise the raw data to a workable level. The researcher achieves this by familiarising themselves with the data and begins to organise the data into initial themes, concepts and emergent categories. This first step is paramount to ensure that the researcher is very familiar with the data set as a whole to allow for the development of well-founded themes and concepts. As Spencer et al (2006) state, “if that foundation is ill-conceived or incomplete, then at best it could jeopardise the integrity of the construction, or at worst bring the whole structure crashing to the ground” (2006:221)

Through the “familiarisation process” the researcher is looking for recurrent themes, ideas or concepts that are evident through the data, which are then placed under a list of main broad thematic headings that are additionally guided by the interview questions and the study objectives. The emphasis at this stage is to look across all the themes noted and see where there are links and similarities, which could then be categorised under the broader thematic headings. This is how the conceptual framework or “index” is developed. Through the process, the “index” consists of a list of broad thematic headings with a list of sub-themes underneath, each sub-theme having a number assigned for identification. These indexed numbered themes are applied to the data as a whole, leading to the data being sorted into thematic sections and leading to the development of the thematic matrix/chart.

Applying the data management phase to my own data set I read and re-read the transcripts from the first set of interviews several times manually, allowing me to become familiar with data. My supervisors read a sample of transcripts (five each) to familiarise themselves with the data to ensure that there was agreement on the broad thematic headings and sub-themes being generated. Through the process I began to write down broad headings informed by my study aim and the research questions, and developed eight broad themes with several sub-themes and displayed them in an index chart as the authors suggest (see Table 7 below). This allowed me to begin managing the raw data to a workable level.

Table 7: Indexing Chart from first set of interviews

1. Getting a diagnosis	2. Information	3. Impact of Cancer	4. Impact of Treatment
1.1 Symptoms	2.1 Written	3.1 On Patient	4.1 On patient
1.2 Trigger	2.2 Verbal	3.2 On Carer	4.2 On carer
1.3 Delay	2.3 About what		
1.4 Referral	2.4 Lack of info		
1.5 Route to formal diagnosis	2.4.1 to patient 2.4.2 to carer		
5. Role of CNS	6. Self Care Strategies	7. Role of Info	8. The “System”
	6.1 By patient	7.1 On patient	8.1 Environment
	6.2 By carer	7.2 On carer	8.2 Attitude of ward staff
			8.3 Hospital transport
			8.4 Appointment times

The application of the initial index chart to the transcripts by my supervisors and I highlighted that we agreed that the broad themes were right but the sub-themes were fragmenting the data too much and subsequent revisions to the chart were made. I then applied the broad themes only to the data but at the end of this process I still did not feel that I was familiar with my data and at points felt overwhelmed with the amount of data evident in this set of transcripts.

As the aim of this study is to explain the role of information with people affected by laryngeal cancer across the cancer trajectory, I needed to embed information in all themes identified across the data and not as a separate theme. After discussion with my supervisors, we agreed that I would re-read the transcripts again, merge some of the initial thematic headings and carry out a detailed account of each individual case (i.e. each patient and carer dyad). Doing this would enable me to become “familiar” with the data at this crucial stage and be confident that the thematic headings were justified across the data set as a whole.

The headings developed for the detailed accounts were as follows: 1) Route to diagnosis; 2) Process through treatment; 3) The role of health professionals; 4) The role of Family; 5) The “System”; and 6) Other. These broad headings described the information that participants reported, for example, route to diagnosis described the information that participants were given and used from various sources leading up to their formal diagnosis. By writing the detailed accounts in this way, I became familiar and confident with

my data and was assured that the broad headings identified were evident across all of the data set thus ensuring the first platform in this process was established.

To move the data on and at the same time further reduce the data to a workable level, I entered the transcripts onto NVivo 7 which assisted me manage and refine the data in a clear and transparent manner. I began coding the data using the “tree node” only facility, using the six broad headings used in my detailed accounts.

I started with the first thematic heading, “Route to Diagnosis”, and developed three child-nodes: 1) Symptoms; 2) Biopsy; and 3) Formal Diagnosis, and coded each transcript from each case to the appropriate child node. I then printed out each child-node to review and to explore that section of data further. By doing this and through discussions with my supervisors it became apparent that both the patient and their carer received, sourced and were using various types of information leading up to and during their formal diagnosis

The types of information that became evident at this particular time point can be placed under two broad categories: information based on experiences (hereafter called experiential information) and information from professionals (hereafter called professional information), although it has to be recognised that professionals may have been drawing on their own experiences, thus experiential information, in providing the information they did.

Experiential information is a recent concept defined in the nursing literature as discussed in section 1.4 and derives from a body of literature based in sociology discussing experiential knowledge using both embodied knowledge and empathetic knowledge. As discussed in Chapter 3, section 3.6, Abel and Browner (1998) categorised experiential knowledge into two broad categories of embodied knowledge and empathetic knowledge. The authors suggest that from the knowledge gained through these two categories, individuals make sense of their own symptoms and/or manage the impact of their condition or a family member's condition in relation to their own lives, based on past, present and current experiences.

In this study, experiential information is defined as the types of information that patients reported using about their own bodies, influenced by previous illness experiences of themselves or from others and the information they received from others, such as a family member or other patients. The experiential information used by participants is shaped from their own personal identities, circumstances, experiences and interests (Code 1993) and ultimately makes us who we are.

The definition of professional information in the literature is knowledge or information given by those who have met the requirements of specialised education and formal training in a discipline and who possess appropriate credentials (Borkmann 1976), as discussed in section 1.4. In relation to my study, the definition of professional information is the verbal, non-

verbal and written biomedical information that participants reported receiving from health professionals across the multi-disciplinary team.

As discussed in Chapter 3, section 3.6 the use of both experiential information and professional information assists individuals to make sense of the situation that they are currently experiencing. As Abel and Browner (1998) highlight, “women seek biomedical information partly to explain their own experiences” (1998:316), and Pollock et al (2008) identified how the cues, both verbal and non-verbal, from health professionals allowed their respondents to “shed light on their own situation” (2008:970).

Through reading the literature and discussion with my supervisors it was agreed that I would look at the first heading again (route to diagnosis) and apply this section of the data to a thematic chart using the broad headings of experiential and professional information. Through the development of the thematic charts, I reduced and synthesised the data further by combining the roles of health professionals, the family and the “system” under these two broad information categories.

4.3.2 Descriptive Phase

Using thematic charts enabled me to move the data onto the second phase of this analytical approach, where I was able to illustrate the types and sources of experiential information and the types and sources of professional information the participants reported receiving and using. Through the process, it became evident how the combination of these types of information assisted the participants to make sense of their route to diagnosis.

The thematic chart (matrix) comprised of four columns and I used direct quotes from the patient and family member data (see Appendix 11) to ensure linkage with the raw data and ensure transparency. The first column in the chart was my typed summary of what happened to the participant at that specific time point. The second column illustrated the types and sources of experiential information that the patient or family member reported receiving. The third column illustrated the types and sources of professional information that the patient or family member reported receiving, and the fourth column illustrated how the patient or family member used the types and sources of information to make sense of the situation at that specific time point.

I completed a matrix for each individual patient and carer and after further discussion with my supervisors we agreed that I would continue to use this approach across the rest of my data.

I then coded the theme “Process through treatment” and developed three child-nodes: 1) The Mask; 2) Physical Symptoms; and 3) Psychological symptoms. Each transcript was coded and each child-node printed off to review and explore the data under the broad headings of experiential and professional information. I then entered the relevant sections of the data into the thematic chart. I continued this process through the second set of interviews under the codes of 1) Physical impact of treatment; and 2) Psychological impact of treatment. Upon completion I had a thematic chart for each individual patient and family member describing the types, sources and use of experiential and professional information across their cancer trajectory.

At this stage in this analytical approach, I had achieved the first phase whereby I had reduced the data to a manageable and workable level developed in the indexing table representing the data as a whole. Through the emergent categories of experiential and professional information, I described the types, sources and use of information using the thematic charts. Thematic charting is recommended for the second phase of this analytical approach to reduce and refine the data further through description. The researcher uses the thematic charts to look at patterns and comparisons within and across the data set as a whole. Through describing the types of experiential and professional information sourced by this group, broad thematic headings were developed from the data to explain how information was used in the context of their experiences across four key stages.

The four key stages were: route to diagnosis; diagnosis; treatment; and follow-up, which identified how people affected by laryngeal cancer sourced and used different types of information as they progressed across their trajectory. These key stages were significant as participants received and used different types of information from various health professionals in combination with experiential information from others and used them in different ways in an attempt to make sense of their actual experiences. These key stages are also deemed to be significant time points in a patient's trajectory in the literature and emerged from the data as many participants could recall the specific types of information they sourced and used as they entered and left the world of health care. By using these key stages it also allowed me to maximize on the longitudinal design of the study showing the role of the different types of

information to explain how information gained over the trajectory influenced how people affected by laryngeal cancer responded to their actual experiences.

Route to diagnosis had three child nodes initially, which were: 1) symptoms; 2) biopsy; and 3) formal diagnosis. However, it was decided that formal diagnosis should be a heading on its own as participants received, sourced and used a lot of information from health professionals at this key stage in their trajectory and therefore it required description and explanation in the context of their experiences at this time.

Looking at the data as a whole using the thematic charts there were four main patterns that emerged from the data: firstly, how participants focused on their experience of symptoms and how this influenced the types of information they sourced to help them explain and understand them across the whole of the trajectory, in other words how participants attempted to “normalize” their experience of symptoms. Secondly, based on the accounts from participants, the way in which health professionals provided the biomedical information to them with such certainty, especially at diagnosis, was perceived to be hugely influential in how they responded and managed their treatment and the outcome of their treatment. Thirdly, and linked with the second pattern, was the importance of a caring attitude and the attentiveness of health professionals involved in their care which varied for some participants over the course of their trajectory and again influenced how some participants viewed the information they had received, their treatment and its outcome. Finally, it became evident how the biomedical information received at diagnosis

influenced participants' expectations of the consequences of their treatment and how this impacted on their overall opinion of care and information received.

By analysing and reporting the findings under these four key stages it became apparent how these four main patterns interlinked and influenced how people affected by laryngeal cancer sourced and used the different types of information over the course of their trajectory, thus maximizing on the longitudinal design of the study. The advantages of a longitudinal design are that the researcher can measure or explore changes over specific time points, thus allowing the researcher to capture the evolving process or impact, consequences and outcomes of the phenomena being studied, which do not necessarily emerge in the first interview (Murray & Sheikh 2006). Across the participants' trajectories, it became evident how each key stage and the information sourced at each stage played an influential role on how participants used the information to make sense of their actual experiences. The use of both experiential and professional information was interlinked and interweaved and demonstrated how participants explained and made sense of their experiences.

To explain these four patterns, I developed four broad themes that linked the four key stages along with sub-themes specific to each key stage. By adopting these broad themes and sub-themes, this allowed me to describe and explain the role of information based on the actual experiences of the participants at key stages across their trajectory. The themes and sub-themes are described in Table 8.

Table 8 Themes and sub-themes at key stages in trajectory

Key Stages	Main themes	Sub-themes
<u>Route to Diagnosis</u>	<i>Search For Normality</i>	<i>Nothing's wrong Something's wrong</i>
	<i>Culture of Caring</i>	<i>Limbo</i>
<u>Diagnosis</u>	<i>Illusion of Certainty</i>	<i>Cancer Cured Live or Die They know best Hope for the future Certainly Not Lost in Translation</i>
	<i>Search for Normality</i>	<i>Cultural Understandings Family History Lifestyle Time out</i>
	<i>Culture of Caring</i>	<i>Role of the clinical nurse specialist</i>
<u>Treatment</u>	<i>Culture of Caring</i>	<i>The mask Impact of Treatment Myths and Misconceptions Limbo</i>
<u>Follow-up</u>	<i>Search for Normality</i>	<i>Worse before it gets better Time</i>
	<i>Reality of Uncertainty</i>	<i>Cure vs Clear Lost in Translation Experience v information</i>
	<i>Culture of Caring</i>	<i>Limbo Carer Needs</i>

To enable me to further describe and explain the types and use of experiential and professional information sourced by the study participants, the “illness action” framework developed by Dingwall (1976) was used to situate the data. As participants’ experiences of symptoms under the broad theme of “search for normality” influenced how they sourced and used different types of information across each stage of their trajectory (illustrated in Table 8), adopting this framework allowed me to show how they used and integrated the different types of information in response to their illness experience and symptoms across the cancer trajectory.

4.4 Analytical Framework

The use of people’s experience and knowledge to explain and understand illness and illness symptoms has been widely researched in sociology for many years, (Young 2004; Lawton 2003). This trend has seen the development of many theories and explanatory stances to show how people make sense of their illness and manage the consequences of their illness in the context of their lives. Sociologists suggest illness is a socially interpreted event that manifests within complex social structures, which influence how the illness experience is interpreted and understood by the individual (Wyke et al 2011a, pending publication; Young 2004; Locker 1981, Dingwall 1976). The experiences and the knowledge gained from illness experiences of self and of others provide us with knowledge that enables us to interpret what is normal and abnormal in the context of our lives; how we use this knowledge will influence how we react or respond to illness experiences.

The meaning we attach to illness stems from the “common sense knowledge” on which Dingwall (2001; 1976) based his illness action framework. Embedded in this illness action framework (Dingwall 2001; 1976) is the assumption that we all have a “stock of knowledge” regarding health and illness, which Dingwall calls “common sense knowledge”, which has developed through the interactions and experiences we have gained of ourselves and by interacting with others. Through the knowledge gained, we do not consciously think about how we breathe or how we walk as that is part of our routine physical functions that are in balance with or in “equilibrium” with our normal bodily functions. It is only when there is an imbalance in our normal bodily function due to a biological disturbance or problematic experience that we use our stock of knowledge of health and illness to interpret what the problematic experience could mean (Dingwall 1976: 93).

Similarly, Locker (1981), drawing on Dingwall (1976), defines problematic experiences as “events, situations, or states of affairs which disturbs our taken for granted attitude towards the world and calls for interpretive and explanatory activity” to take place (1981:49). Through the interpretative and evaluative work carried out by the individual based on their experiences and knowledge of health and illness, the individual decides what response or action is appropriate to make sense of the problematic experiences in the context of their life. This suggests that how an individual decides to act regarding the symptoms of illness is not only a cognitive process but is influenced by social processes central to the individual’s social world.

Dingwall (1976) suggests that illness action is a three-stage process. Firstly, the individual evaluates the problematic experience based on the knowledge available to identify what is going on. Based on this evaluation the individual can identify what possible courses of action he can take. Dingwall (1976) notes that through interpretation and identification that just because something *is* going on does not mean that the individual “knows” what is going on. The action decided by the individual can be to ignore the problematic experiences or seek information from someone who has proficient knowledge to know what is going on. This level of action maybe the only action the individual may decide to take at this first stage.

The second stage of the process is deciding to take some form of action, which consists of: wait and see if the problematic experience alleviates; self-medicate based on prior knowledge of the problematic experience (common ailments); or to seek professional advice when there is a lack of stock of knowledge to enable alleviation of the problematic experience.

The third stage of the process is where the individual evaluates the action, either through self-medicating or prescribed treatment to assess whether he has returned to his normal level of functioning. Dingwall notes that this may not be the same point at which the individual started prior to treatment and he may need to evaluate and amend his view of his normal functioning in light of this new knowledge for future. If the individual evaluates that treatment did not work, then the interpretive, recursive process begins again to decide what other course of action is appropriate for him at this particular time. As

Dingwall (2001) admits, the three-stage process is not linear and his description simplifies a complex process, but the core tenets of how people act in light of problematic experiences evolves from this process. Figure 2 summarises the illness action framework.

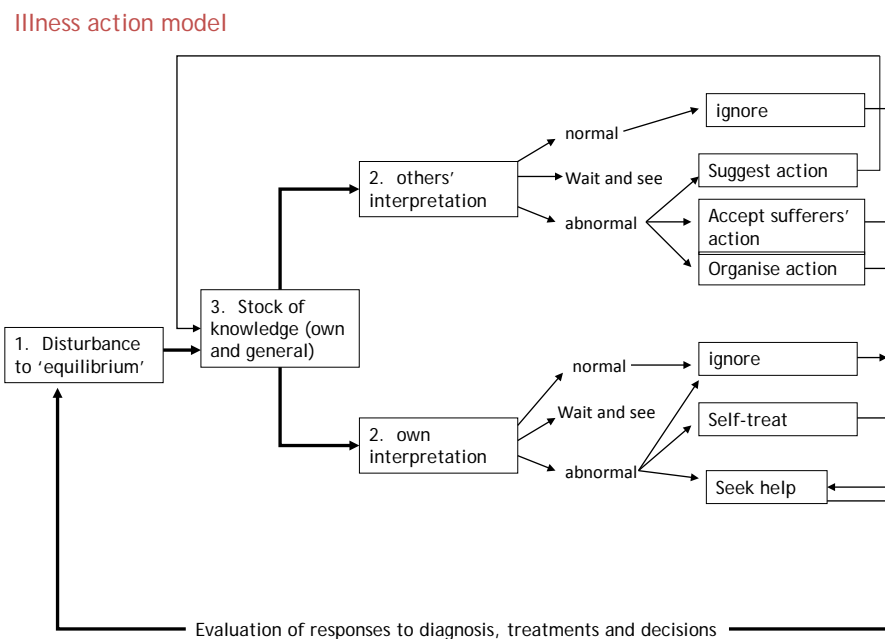


Figure 2: Dingwall's illness action model, 1976

Dingwall's model (1976) is one of the first process models to explain illness behaviour and stems from the sociology of deviance where illness can be viewed as “a failure in everyday life” as people need to be seen as “ordinary” (Wyke et al 2011a, pending publication). Although not widely cited until recently (Biddle et al 2007; Calnan et al 2007), the main tenets of this model are core to many sociological and psychological models that aid our

understanding of how people manage and explain illness and their symptoms in the context of their lives.

Calnan et al (2007) used Dingwall's framework to consider how people manage upper limb pain. He described how people experience a disturbance that affects the body and, depending on the priority accorded to the disturbance, the normal expectation of a stable and predictable relationship between the person and the body may not be sustainable if the person is to present themselves as a normal person (*ordinary*) in the context of their world. To present themselves as normal, then the individual needs to take remedial action through the process of interpretation of what the problematic signs and symptoms could be through a framework of knowledge gained from all sources. The decision-making process evident in this study was interpersonal, involving both formal and informal contacts for individual options to act. Action was described as how participants ignored the disturbances (pain), waited to see if the disturbance (pain) alleviated, or decided to seek help (Calnan et al 2007). This shows the interpretive and evaluative processes that occur when people are trying to make sense of their illness and the influence of others in that process. As Biddle et al (2007) highlight, "illness behaviour is not a simple decision about professional help-seeking but a multi-faceted, protracted career composed of a plurality of strategies and people consulted during the process of coping with symptoms" (2007:984). Thus, the model illustrates the processes and strategies people use, along with the outcome of their decisions to manage and explain their illness experience.

One criticism of Dingwall's illness action model is that he does not explicitly state how people respond emotionally to their experience of symptoms. This is in comparison to other more commonly cited psychological models, i.e. Leventhal's Common Sense Model of Illness (Leventhal et al 1997), and how the emotional response to symptoms has a major influence on how people respond to their experience of symptoms. However, it could be argued that within a person's "stock of knowledge" of illness, they will attribute an emotional response to the significance they attach to their physical experience of symptoms based on that knowledge, which will trigger their response, or lack of response, for action. Thus, by adopting this framework, I describe how people affected with laryngeal cancer used the different types and sources of experiential and professional information to explain their experiences across their trajectory, drawing from and adding to their stock of knowledge of illness. In many ways I will "*open up the stock of knowledge box*" to explain the role of information, drawn from the various sources, to demonstrate the processes and strategies used by people affected by laryngeal cancer in response to their experience of illness.

4.5 Summary

In this chapter, I have described and justified my interpretivist approach to this study using qualitative interviews for my data collection to ensure that the research questions would be answered, thus achieving the aim of the study. I have described my approach to the analysis of my data, introducing the four broad themes across the four key stages that were

identified, and described my theoretical framework. This framework will be used to describe and explain how this group of participants sourced and used information in response to their experience of illness and symptoms across their trajectory.

To demonstrate the role of both categories of information during and across the key stages in the participant's trajectory, I have presented the findings over two chapters. In Chapter 5 I will provide a rich description and explanation of the different types and sources of information that this group of participants reported using en route to diagnosis and around their diagnosis. In Chapter 6 I will provide a rich description and explanation of the different types and sources of information that this group of participants reported using during their treatment and into follow-up. I will use the four broad themes and sub-themes pertinent to both chapters as described in section 4.2.3.

Chapter 5

Results

En Route to Diagnosis

5.1 Introduction

In Chapter 4, I discussed my analytical approach and how, through the process of indexing and thematic charting, I identified two over-arching categories of information that participants reported using (“experiential” and “professional” information). From the data, it was evident how people affected by laryngeal cancer seemed to draw on both categories with differential patterns of use depending on their perceived level of need based on their experiences and understanding at key stages across their trajectory.

Experiential and professional information could be described as on a continuum of information, where patients and carers moved between and combined each category of information as they progressed through their trajectory. En route to diagnosis, it was evident how people affected with laryngeal cancer relied heavily on their experiential knowledge of illness and the information this provides to explain their initial experience of symptoms. Whereas, at diagnosis and in the early treatment phase, the information they relied on was more orientated to the biomedical information from health professionals, in combination with experiential information from family members

and ex-patients. Moving through the trajectory, patients and carers appeared to use both categories of information from various sources to tailor information in response to their specific need for information, based on their actual illness experiences.

As discussed in section 4.3.2, the data will be presented across four key stages to reflect patients' and carers' changing use, and sourcing of, different types of information, based on their experiences at these times. The following chapters (5 & 6) will present the findings using the four broad themes and sub-themes identified in section 4.3.2 to describe and explain the role of information in response to the experiences of this group of patients and carers.

This chapter presents how participants discussed their experience of symptoms leading up to their diagnosis and during their diagnosis and how the role of information, sourced from both categories, influenced how they responded to the experience of their symptoms. I will present the findings through thematic description and explanation, integrating the findings with a discussion of relevant literature and Dingwall's Illness action model (1976) with a summary of key findings at the end of each section.

5.2 Route to Diagnosis

In the first interview I asked participants to tell me about the lead-up to their diagnosis by asking them questions such as, "if you would like to tell me your story from the beginning?" or "at the beginning, what was it that made you go to your GP?" Participants responded by talking about their physical experience of symptoms, how they interpreted and managed them over a

period of time, and what led them to finally acknowledge that they required their GP's advice. Based on the advice and treatment prescribed by their GP, this ultimately led to a referral to ENT, leading to a biopsy and finally, a formal diagnosis of laryngeal cancer. I describe accounts of participants' routes to diagnosis under two broad thematic headings: Search for Normality and Culture of Caring.

5.2.1 Search for Normality

This broad theme describes the strategies that participants adopted to explain and understand their physical experience of symptoms in the context of their "stock of knowledge" of illness or "common sense knowledge" of illness (Dingwall 1976). It was evident that participants searched to normalise their symptoms, using "normalising" strategies (Smith et al 2005) by using everyday common ailments initially to explain their experience of symptoms. Under this theme, two sub-themes describe how participants used the different categories of information leading up to their diagnosis and how their understanding of their symptoms shifted as they began the process of thinking that "nothing's wrong" to "there's something wrong".

5.2.1.1 Nothing's wrong

From the accounts given by participants, it was clear that many could explain their initial experience of symptoms based on their own knowledge and understanding of common everyday ailments. Few participants recognised their symptoms as serious or urgent enough to lead them to seek information from their GP. Rather, their interpretation seemed to be a cyclical process, where

they responded to their physical experience of symptoms by initially perceiving them to be normal based on their own and others' interpretations of common everyday illness explanations, drawing on their experiential knowledge of illness or their "stock of knowledge" of illness (Dingwall 1976). Participants drew heavily on their experiential knowledge, or what Abel & Browner (1998) called "embodied knowledge", to provide them with everyday explanations in the context of their understanding of illness. This experiential knowledge, gained through the patients' direct experience of similar symptoms, or through cultural understandings of illness, in combination with information from family and friends, provided them with simple explanations of what their symptoms could be. It was only when they could not explain their experience of symptoms as normal did they respond by actively seeking information from their GP.

The majority of patients discussed having distinct physical symptoms (as illustrated in Table 9), such as recurring episodes of sore throats, linked with episodes of hoarseness, breathing difficulties or changes to their normal voice. Others experienced symptoms such as a choking sensation, pain in the neck area whilst eating and drinking, a general feeling of unwell/dizziness or chest/breathing problems.

Table 9: Symptoms experienced

Participant	Symptoms experienced
P01	Choking sensation/inability to breath
P02	Recurring sore throat/hoarseness

P03	Recurring sore throat and hoarseness
P04	Hoarseness and sensation of lump
P05	Hoarseness
P06	Sore throat and sensation when speaking
P07	Recurring sore throat and hoarseness
P08	Recurring sore throat and hoarseness
P09	Swelling in neck
P10	Sore throat and hoarseness
P11	Sore throat
P12	Recurring sore throat and hoarseness
P13	Hoarseness and sensation of lump
P14	Chest infection and sore throat
P15	Recurring sore throat and hoarseness
P16	Recurring sore throat
P17	Recurring sore throat and hoarseness
P18	Breathlessness and inability to swallow
P19	Changes in voice/laryngitis
P20	Recurring sore throat and swelling

However, many explained their initial experience of symptoms based on simple explanations of common everyday illnesses leading to an understanding that “nothing was seriously wrong”. For example, P09 discussed how he thought the pain in his neck was due to a draught (a common explanation for such a pain):

It first started with eh, a pain in the side of the neck which I put down to a draught but then it came up as a swelling. (P09 male T2 N3)

Others explained their symptoms based on their experience of similar symptoms assuming that nothing was very different from before, therefore nothing was seriously wrong:

I've normally got a gravelly voice; I have had all my life. (P08 male T1)

Ten years ago I had similar symptoms; they removed a small polyp around the larynx I, obviously I had no idea before any diagnosis was made that it was going to be anything different from the last time. Aye, they assumed that it might be just another benign thing. (P11 male T1)

Family members also seemed to draw on their experiential knowledge of illness and used common illness explanations by adopting simple self-management strategies with over-the-counter medicines:

He [husband] said, "I've got a sore throat" so I got him some lozenges to begin wi', no they werenae working. (C02, wife, T2)

Similarly, one participant highlighted how this practice had been going on for many years and how he assumed nothing was wrong by drawing on his own experiential knowledge of his wife's past symptoms:

She [wife] has suffered chest and throat problems for years [...] so we didnae think anything about it, we yist to get her stuff for her chist and her throat. (C17, husband, T3)

In many ways, participants did not appear to associate their symptoms with anything being wrong as they could understand and explain their symptoms in the context of common everyday illness explanations. Inherent in these explanations was their understanding that the absence of pain meant that nothing was seriously wrong. As P19 highlighted, even though he sensed a change in his voice, he did not associate anything was wrong because his throat was not sore:

I noticed sort of changes in my voice feeling a wee bit deeper and a wee bit huskier, never really sore at any time but it wisnae a drastic change. (P19 male T1)

Similarly, P01 and P12 discussed how they lost their voices but thought that there was nothing seriously wrong, as they were not suffering from any pain or feeling unwell:

Well, the first time I had, eh, my throat wisnae sore, I'm losing my voice ... but I never done anything about it for 6 month but I've never been in pain wi' it, it's no been sore. (P01 male T3)

My voice just kept going away, no pain and not feeling ill. (P12, female T3)

Thus, the accounts suggest that there is an understanding with this group of participants that the absence of pain equates to nothing being seriously wrong and that their symptoms are normal as they can be explained in the context of everyday illness explanations. However, as time progressed and their symptoms persisted, many had to reinterpret their experience of symptoms and their impact in the context of their life, as they could not provide simple illness explanations to explain them at this point.

Based on their re-interpretation, many responded by actively seeking information from their GP. The most common information given by the GP at this time was a diagnosis of a throat or fungal infection and the most common course of action was a course of antibiotics, as described by P08 and C02:

Reckoned it was laryngitis so he [GP] gave us a course of antibiotics. (P08, male T1)

He'd said it looked like thrush so eh, prescribed Nystatin so he [husband] tried that maybe about a week but no it didnae shift it ... so again GP thought well, it's maybe a throat infection so he gave him a course of antibiotics. (C02, wife T2)

Others spoke about how their GP or practice nurse discussed how their symptoms could be explained by other common conditions which provided them with simple explanations such as “*the carotid artery*” (P09, male T2N3) and “*sleeping with his mouth open*” (C10, wife, T3). One GP could find nothing wrong on examination and the participant described a discussion with his practice nurse whilst having his ears syringed who told him, “*Och, it’s a wee nodule probably on your voice box*” (P06, male T1). Thus, accounts suggest that the initial information from the GP confirmed that there was nothing seriously wrong with their symptoms by providing patients with further plausible explanations that they understood in the context of their own common sense knowledge of illness explanations.

However, the assumption that “nothing was wrong” changed as participants’ symptoms became more problematic, affecting their daily lives and in response (or lack of response) to either self-treatment or prescribed treatment. Many described how they could no longer explain their symptoms using their own experiential knowledge of illness and the information they had received from the GP, therefore prompting them to re-evaluate and seek further information (Dingwall 1976). For example, P16 described how he had completed the course of antibiotics prescribed by his GP with no improvement in his symptoms:

I had a sore throat and it wisnae going away, finished the whole course of antibiotics and nothing happened. (P16 Male, T2)

Whilst others described how their symptoms were beginning to impact on their daily and working life:

I developed a sore throat, dry and raspy, starting to get a bit annoying. (P02 male T2)

I do presentations all the time at my work and it was getting a bit embarrassing, even my boss was saying "What's wrong wi' your voice?" (P08, male, T1)

This re-interpretation was also evident with some family members with some encouraging their spouse to seek professional advice to provide further explanation of their symptoms. For example, C18 was beginning to get suspicious as his wife's symptoms were beginning to impact on her physical functioning, which was different from her previous episodes:

She started that she couldnae eat, she couldnae swallow, awe she was eating was mashed banana, ice cream and jelly. (C18, husband, T4)

Whereas, C08 discussed how she felt her husband was not giving the prescribed medication time to work, as she knows how he can be impatient:

He [husband] kept saying "This isn't right there's something sort of worse going on," I said, "Well, I don't think, you're not giving the antibiotics enough time to work," because he is very impatient and wants things cured immediately. (C08, wife of T1)

These quotes show the discursive action between couples when they are attempting to explain symptoms drawing on their own experiential knowledge of their spouse and what seems normal or abnormal to them.

However, it became evident that as the physical experience of symptoms persisted, became worse or impacted on the individual's daily life, many participants could not explain them in the context of their own or others' experiential knowledge of illness. They could not "normalise" them in the context of their understanding and therefore, many went onto describe subsequent visits to the GP, which resulted in a referral being organised for an ENT consultation. These findings resonate with previous research, with Zola (1973) suggesting that when an individual's symptoms begin to impact on their functioning they are interpreted as serious, thus prompting the individual to seek a consultation. Smith et al (2005) suggests that this is due to the "normalising" strategies that people use breaking down when symptoms become severe, painful or frightening, thus prompting them to seek professional advice.

Some reported how they tried to explain the referral due to the standard course of treatment not working, or the length of time they had experienced their symptoms. For example:

He [GP] said, "You have been coming here for about four months now, think we maybe will send you to ENT just to get it checked."

(P12 female, T3)

Others, like P05, described it as the combination of the suddenness in which he lost his voice and the prescribed treatment not working, that made the GP decide to refer:

*I mean, a couldnae believe it when I went that night and lost ma voice and went to see him [GP] and he says, "Try some pills, come down and see me a week the day"... so he [GP] says, "Hospital."
(P05 male T1 radiotherapy)*

For some, however, the referral to ENT, together with the lack of response to prescribed treatment, indicated that something was wrong. Using their own experiential knowledge of illness and understanding that if it was a simple sore throat, for example, that the antibiotics would have worked and that they would be back to normal. As this was not the case, there was a shift with some participants at this point; by combining their own understanding of illness explanations and requiring to see a specialist. As P08 suggests he "knew his own body" and interpreted the significance of his symptoms in combination with being referred to "know" that something was wrong:

*I said "fair enough" **[about being referred]***

I know my body and I know there was something not right." (P08, male T1)

Similarly, partners and spouses gave similar accounts of recognising something was wrong as described by C03:

*I was beginning to smell there was something wrong by that time **[getting referred]** and I was quite worried about her, well, my own*

doctor had been speaking to her on the telephone and he actually said to me, "I think you better get Gemma to a doctor, I don't like the sound o' her throat." (C03, husband T3)

5.2.1.2 Something's wrong

The level of detail in which participants discussed the referral and the first ENT consultation seemed to depend on their perception that there was "something wrong" either leading up to or during the consultation. From the accounts, participants discussed how they began to realise that "something was wrong" as they were requested to attend for further investigations, i.e. biopsy. For example, P06 had assumed that there was nothing wrong; this meant being told by the consultant that there was "something there" and being told to attend for biopsy caused him and his wife to worry:

He [surgeon] saw me and he scopes the throat and camera down you know, he said, "One side of your voice box has got a, a sort of fungus on it," and they said they would have to do a biopsy. I think by that time I was starting to get worried, we both were uptight, to be honest, because originally it wasn't a bother, you know what I mean, to suddenly become aware, that, it was a bit frightening, you know?" (P06, male T1)

Similarly, P08's wife said how she was surprised and shocked, as she had not previously interpreted her husband's symptoms to indicate anything was wrong, although *he* had sensed that "something was wrong" leading up to the first consultation, which caused her then to feel guilty:

I felt that size, I must admit, I really felt as though, you know I'm always right but this time I wasn't, I thought, oh here, well, this, there must be more to this that I've actually given credence for all along, so, em, then I felt guilty. (C08, wife of T1)

Knowing "something was wrong" or "something was there" was not always confirmed through verbal information. For example, P20 reported how she knew by the consultant's body language the outcome of his initial investigations and asked him to confirm her own suspicion that something was wrong:

*You could tell he [surgeon] knew right away, you know, that it was cancer. I said, "It's cancer isn't it?" and he went "M-mmm, 90% sure."
(P20, female, T2)*

P07 reported how being asked to attend for biopsy raised his suspicions and prepared him for a potentially serious diagnosis. Although he does not say directly, based on his existing knowledge about the significance of a biopsy as a procedure to diagnose cancer, the link between smoking and cancer and his own and others' experiential knowledge of cancer, he suspected that a diagnosis of cancer was likely:

I got an appointment, I went up, they put this thing down my nose but they couldnae see anything cause it was too far doon, so they said "Right, we're gonnae need tae dae a biopsy". Well, I thought if they're doing a biopsy there's a chance it's going to be that. I've smoked for flaming 30-odd year, you know, I've known a few people that have had cancer in my time." (P07, male T1)

Similarly, for those participants who had recurrent disease, they described using their experiential knowledge of similar symptoms and understanding of procedures to interpret that something was wrong again. As described by P12:

My voice had got bad again, going away, and the surgeon said "Think I'm gonnae take you in and have a wee look down because it's taken an awful long time to heal and you say your voice is going away, better being safe than sorry,"... I thought, aye there's something suspicious." (P12, female, T3)

As we have seen, there was a shift at this point, for most participants, in response to the information they received. The referral or being told "something was there" during the first consultation, made many realise that their assumption that "nothing was wrong" was no longer an appropriate interpretation of their symptoms, shifting them to suspect or know that "something was wrong". At this stage in the pathway, participants began to combine their own understanding of illness with the professional information that "something was there", leading many to feel anxious and concerned about what the potential outcome could be. They could not explain or minimize their experience of symptoms and their experience of symptoms was not normal in the context of their own understanding of common everyday illness explanations anymore (Dingwall 1976).

However, one participant did receive information in the first consultation that he had a tumour. This couple gave a detailed description of

this consultation in their joint interview even though his wife was not present at the consultation:

He [consultant] turned back to his desk and he was writing away, he turned round, he said "Well, we'll need to do something about this," he says, "eh, you've got a tumour." I didnae know what to say. I said, "What do you mean, cancer?" "Oh yeah, I will make an appointment for you to see a colleague of mine," and that was virtually it. I said, "Is it curable?" and he said, "Of course it's curable." So that kinda cheered me up a bit. I know he was only cheering me up because there's no way he can say it's curable, you know? (P02, male T2)

His wife continued:

*He [husband] says, "Och I'll come back and get changed and then I'll go to work." So when he came back in, I said, "How did you get on?" Although at the back of your mind you know because he was a smoker, **was** a smoker. He just said to me, "It's cancer." 'Cause my fear was, would it be cancer because o' the smoking and ..." (C02, wife of T2)*

Ach, the fact that I liked a drink, tell her. (P02, male, T2)

The accounts of attending the clinic on his own and planning to return to work afterwards suggest that this man was not prepared to receive a diagnosis at this consultation. His wife's contribution suggests that her existing knowledge of the risks associated with smoking and alcohol highlighted her suspicions that

“something was wrong”. It is interesting how P02 gave his wife permission to tell me that he not only smoked but also enjoyed a drink; perhaps demonstrating to me how they explained his cancer diagnosis.

The continuation of the interview with P02 and C02 nicely illustrates the way in which participants used their own and others’ experiential knowledge to make sense of information they gleaned from the consultation. P02 describes a conversation he had with a friend prior to attending for biopsy and how his friend tried to dismiss a definite diagnosis of cancer based on his experiential knowledge and understanding of biopsy and cancer:

“Funnily enough, a friend had said, “How does he [consultant] know it’s cancer? What’s cancer? Tumours, but you can get cancer and cancer and until you get a biopsy you don’t know,” but, as I said to him, “I had every faith in Mr X, he’s no a consultant for nothing.”
(P02, male T2)

His wife adds how she was experiencing a similar dilemma, drawing on her own experiential knowledge of cancer, hoping that the information given by the consultant was wrong and that the outcome from the biopsy would prove that it was not cancer:

I kept thinking, well, he said he was to see Mr X [other consultant] to get a biopsy ‘cause I said, “Wait a minute, cancer? Do they no have to wait to get a biopsy before they can tell it’s cancer?” Then I started, oh, well maybe it’s non-malignant, you know, that was my perception of cancer was until you’ve had a biopsy to say whether it

is malignant or non-malignant how can they say it's cancer? I thought, no, a consultant like that would know what he was talking about, he's obviously seen something he knows is cancer.” (C02, wife of T2)

Their accounts illustrate the interplay between their own and others' experiential knowledge of cancer in an attempt to make sense of the information from the consultant. It is evident how this couple tried to “normalise” or make sense of the presence of the tumour, in a way, to try to minimize the potential seriousness of the outcome of the information given by the consultant. They responded by drawing on their own and others' experiential knowledge of cancer, through cultural understandings, drawing on lay understandings of a biopsy as a procedure to diagnose cancer, associated with their own and society's understanding of certain lifestyle behaviours linked with cancer. Using these different strategies, they attempted to make sense of the information from the consultant in the context of their own understanding of procedures to diagnose cancer.

5.2.2 Culture of Caring

This broad theme describes how patients and carers experienced the clinical environment whilst attending for their biopsy. This theme encompasses the attitude of health professionals in the clinical environment, the manner in which they conveyed information or not to participants and the “limbo” that some participants experienced due to a lack of information from health professionals at this time.

Most participants gave only a short description about going in for the biopsy (e.g. “cutting a bit out for analysis”), and then immediately talked of getting their diagnosis. The participants who did discuss the biopsy in more detail had received information from the first consultation that had either led to a strong suspicion that something was “wrong” or confirmed the presence of a tumour. Due to this information, these participants were exceptionally anxious; they wanted and needed to know exactly what the outcome of the biopsy would mean and therefore needed information from health professionals to help them understand the seriousness of the situation. Through some participants’ accounts, it was evident that there was a lack of information about the process of biopsy and its potential outcomes, which led some participants to have a poor experience, and a sense of being in “limbo”, which they discussed at length.

5.2.2.1 Limbo

P06 and his wife had been told “something was there” at the first consultation and perceived the request for biopsy to be “urgent”, a perception reinforced by the hospital’s request that they take a cancellation. Based on this information and the request for a cancellation they had cancelled their holiday, and as they say, “put their life on hold”:

The only thing is they took an awful long time to get the to the biopsy, that was the bad bit to me that was the agony period ... we were going to go on holiday, but that got cancelled, everything got cancelled for this urgent appointment.” (P06 male T1)

February to May is pretty soul-destroying, you know, it probably thinks you would get a different impression of the situation, you know.....doctors marking it urgent, is serious, you know. At one point somebody said "Would you take a cancellation?" and I said "Yes, yeah," you're waiting, when you are out and see if there's been a phone call while you were out, a message left, you know, that's what it's been, it's all focused on that, even if they gave you some guide.

(C06 wife of T1)

Thus, being informed that there was something "there" combined with the information about "urgency" of referral had a profound impact on this couple. If the information from professionals had provided practical guidance on the potential length of time to this appointment, this couple may have been able to "live" whilst waiting on the biopsy date instead of living in limbo. Due to the seriousness they attached to the information provided by professionals, this couple put their life on hold. The need for information on attending for biopsy became the centre of their world. Being in limbo appears to encapsulate this couple's position at this period in time; information from a professional was vital if they were to move from a state of unknowing to knowing the diagnosis.

Similarly, a lack of information from ward staff meant that P02 and C02 had a poor experience in the clinical environment due to the absence of information at such a critical time whilst attending for biopsy. P02 knew he had a tumour from the first consultation and attending for biopsy, this couple was extremely anxious and needed information from the health professionals to help

them know how serious the situation was. His wife describes the impact the lack of information had on her at this time, and how she thought she would have the results from the biopsy on the same day. She describes how she had herself prepared and “psyched up” for that piece of information:

I know now that wasnae practical, but I actually thought we would have got told there and then well this is what it is. I thought they had the biopsy results right away, now I understand they don't do that but actually that day I was really, so my daughter, the two of us were really uptight thinking [sighs] you know, that's how I wanted her wi' me 'cause I didnae want to get any kind o' bad news just me and him and the daughter wanted to be with us anyway. So I didnae realise that I still wouldnae know, I had myself all psyched up to get told well this is what it is and this is whether we can do anything or whether we can't do anything. (CO2, wife of T1)

The need for information from health professionals that this couple and their wider family required at this point is evident from this quote. Being psychologically prepared for the result of the biopsy and the information they would receive meant that its absence compounded their fears and concerns at a time when they needed information to clarify and make sense of the seriousness of situation thus leaving them in “limbo”.

Similarly, the absence of information initially post-biopsy was discussed by C19 from the opposite perspective. C19 had not interpreted her partner's symptoms to signify anything serious therefore attending for biopsy

she expected a simple explanation of nodules from the consultant initially post-biopsy. However, through the lack of information by the consultant initially after the biopsy, she knew that something was wrong, using her experiential knowledge of biopsy and lay understandings of potential outcomes:

When nothing had been mentioned when he had the biopsy about anything, both of us I think had an idea that it might be more sinister than we thought but neither of us mentioned it to each other ... he'd had the operation and he [consultant] never, nothing was mentioned about seeing nodules or ... anything, and I know sometimes they can tell by looking at them. (C19, partner of T1)

Thus, the lack of information from the consultant initially after the biopsy, in many ways, provided this couple with information drawn from their own experiential knowledge. Based on the lack of “official” information, this couple realised that the situation had progressed from not serious to serious and that it was more “sinister” than what they had first expected.

Linked with the lack of information on procedures and processes was the perception by C02 and her daughter of feeling like a number:

We went up the stairs to get admitted so we kinda stood at the reception desk, as I say my daughter was with me and you're all uptight going into hospitals aren't you, because you don't know what at that point in time, really hadnae been given a lot of information at all. It was like, oh well, just go into that room in there, and we went in and you know, my daughter is quite perceptive 'cause she says, “I

don't know if I like her," I says, "No, I don't think I like her, either" [meaning nursing staff]. First impressions, you know and you're fragile at this stage when you get told things like this and you just want someone to be nice to you. I had to go and ask the same nurse, I says, "When do we come back or what's going to happen?" You know? "Oh, em, just phone back at 6 o'clock." So, I felt there wisnae much information or anything." (CO2, wife of T2)

From the accounts it was evident how these participants needed to be "cared for" through the use of words and phrases "*fragile*" and "*you just want someone to be nice to you*", illustrating how vulnerable and frightened they were feeling at this time. Her husband had been diagnosed with a tumour and they needed nursing staff to be sensitive to their needs and put their needs at the centre of care; from the above quote they were treated as a number, going against the ethos of a culture of care.

In the absence of previous experience, information from ward staff about ward procedures and what to expect initially post-biopsy could have alleviated some of the anxiety experienced and how some participants experienced living in "limbo". Previous research has shown that there is a need for clear information and communication on procedures and outcomes from nursing staff in the pre-diagnosis phase as it can affect the overall satisfaction with care in subsequent phases (Leydon et al 2000).

In contrast to the above quotes, P20 describes how she had a positive experience due to the information given by the consultant initially post-

biopsy. She discussed how the manner and attitude in which the consultant provided her with the information gave her a sense of “being cared for”. This woman knew that there was a 90% chance that her symptoms were indicative of cancer from the first consultation and therefore needed that information to clarify her diagnosis:

He came and sat down and spoke tae yae, I think he was the only one, he came right into the ward sat doon and explained everything in detail. He just told me about how many nodules there wis, he needs to treat the throat cancer before it, they're aw in the thyroid as well ... so they've goat tae try and get rid of the throat cancer and then cut the thyroid oot.” (P20, female T2)

Thus, the quote illustrates how the provision of information from health professionals after biopsy given in a caring manner can have a positive effect on the experience of the individual patient and how they can perceive that they are being cared for.

One couple responded to the lack of information from health professionals initially post-biopsy by sourcing information from the internet on the possible outcomes and future treatment options available to them. Now sensing that something was wrong and knowing that his symptoms were indicative of something more sinister, they needed information:

Through the media, i.e. the internet, we sort of got a rough idea of the things that ... obviously as soon as something, you're going to start reading up oan it, so we know one o' the options was laser

surgery or the radiotherapy and eh, the radiotherapy didnae really appeal tae me. (P19, male T1)

This couple was the youngest in the sample, and it may be that being younger, they were more familiar and confident with information-seeking using the internet. Previous research has shown that younger people more commonly use the internet to access information around cancer and future treatments (Rutten et al 2005; Ankem 2006, Ziebland et al 2004). However, this was not a common response by the majority of participants in the study and many had to wait and see what the outcome of their biopsy would be at the results clinic ten days later.

In summary, en route to diagnosis, the broad theme “Search for Normality” described the strategies that participants adopted to explain and understand their physical experience of symptoms in the context of their “stock of knowledge” of illness or common sense knowledge of illness (Dingwall 1976). It was evident how participants explained their experience of symptoms by using common everyday ailment explanations. However, as symptoms persisted and affected physical functioning and daily life, participants could no longer dismiss them or class them as normal and responded by actively seeking advice from their GP. The information from their GP initially provided many with simple illness explanations that confirmed their “normalising” approach to their symptoms, whilst others were prescribed treatment, such as antibiotics.

However, as symptoms persisted, became worse, or failed to respond to self or prescribed treatment, many returned to their GP for further professional advice and explanation. The outcome of this help-seeking behaviour was a referral to ENT. It was evident how some participants used the information from the GP and the ENT consultant, in combination with their own experiential knowledge of illness and their symptoms, to sense that “something was wrong”. Their symptoms were no longer explainable through everyday common illness explanations, causing participants to realise that there was something more serious going on. Knowing this, in combination with the referral to a specialist or from the information given by the specialist, led some to become worried and anxious leading up to the biopsy.

Leading up to and during the biopsy it was evident how a lack of information from health professionals caused some participants to have a poor experience leading to a perceived state of limbo within a poor culture of caring. The information from the GP and ENT consultant had raised their awareness that something was wrong and these participants needed information from health professionals within the health care setting to understand and explain what their symptoms were indicative of as they had a lack of experiential knowledge to draw upon. However, due to a lack of information from health professionals pre- and post-biopsy, some perceived that they were not cared for and lived in a state of limbo. For this small number of participants their need for information did not seem to be addressed and shows the emotional response that information from professionals can cause at this key stage in their cancer trajectory.

Formal Diagnosis

5.3 Introduction

This section describes accounts of participants' experiences of their formal diagnosis of cancer, their reactions to the diagnosis, the treatment pathway they were offered and how they prepared for their treatment. At this point in the pathway, many knew that there was something seriously wrong and needed the information from health professionals to clarify what was going on. When I carried out the first interview, most patients had started their treatment and could discuss the different types of information they had received from health professionals and sourced from family and fellow patients during their diagnosis. I describe the accounts under three broad thematic headings: the illusion of certainty, the search for normality and culture of caring. These three broad themes describe and explain the different types of experiential and professional information sourced by participants in response to their experiences at this time.

In discussing professional information, I distinguish between information from the medical team and information from the clinical nurse specialist to illustrate the different types of information they provided. The main types of information provided by the medical team were: **diagnostic** (diagnosis of cancer); **prognostic** (prognosis/outcome of treatment); and **treatment pathway** (chemotherapy, radiotherapy or surgery) which can be combined under the broad term of biomedical information. The main types of information provided by the clinical nurse specialist were: **impact of treatment** (side

effects of treatment); **supportive information** (clarifying information from the medical team); and **practical information** (information around issues such as transport and finance).

The types and sources of experiential information participants reported were from family, friends and others, such as ex-patients. Through discussions, family and friends provided information of their own direct and indirect experience of cancer and many participants used that information to make sense of their own diagnosis or discussed how it influenced their treatment decision. Experiential information from ex-patients seems to have provided clarity “from the horse’s mouth” of what lay ahead and for some, confirmed and clarified the professional information they had received. The internet was a source of information for a small number of participants when the professional information they received was not sufficient for their specific needs at this time. Through participants’ accounts, it was evident how patients and their families combined both types of information to help them make sense of their diagnosis and ensuing treatment.

Although many participants had said they had a suspicion that “something was wrong” leading up to or during the biopsy and needed to know what their symptoms indicated, the reality of receiving a formal diagnosis of cancer was met with shock and disbelief; participants described their response to this information in emotional terms. For example:

You know, when she [consultant] told me it was cancerous I was gob smacked, oh dear, in the back of your head is it going to be a cyst or

is it going to be a wart? Is it going to be something, is it going to be benign, but, naw. (P08, male, T1 radiotherapy)

Some spouses described their response in a physical sense:

When he [consultant] told her [wife] she had cancer of the throat it was like getting hit on the head with a hammer. (C18, husband of wife, T4 with laryngectomy)

For those participants diagnosed with recurrent disease their response was anger, disbelief and fear due to their disappointment that their first line treatment had failed. All three participants said they thought the cancer was gone based on the information they had received at the follow-up clinic that they were “clear” after completing their first line treatment; therefore, being told it was back was met initially with anger and disbelief. The extract from P12 and C12 (mother and daughter) highlights this point:

P12 writes: *He [consultant] took biopsy and tumour was back. Options were voice box removal, take parts away or third option was to decide if I wanted to live or die. The options were rubbish in my mind. I was terrified because of the radiotherapy, my skin inside was badly damaged and can't cope with anymore surgery. (P12, female T2, radiotherapy (first) recurrence, laryngectomy, written account)*

This written account makes clear the fear engendered by the information that the cancer was back, drawing on her experiential knowledge of the side effects of her previous treatment and the potential outcomes of future treatments. Her

daughter goes on to explain the family's response to the information given during the consultation in more depth:

He [consultant] said, "I've got bad news, it's back," we [family] got a shock, em, he gave us options that day, voice box removal, my mum went, "No, nope, it just isnae happening," remove your voice box, we'll take it all away, my mum says "No." The other option was, he says, "I can go in and take bits away but it's gonnae keep growing and growing and growing," and my mum said, "Look, don't do anything," and he [consultant] said, "The tumour will grow so big that you'll suffocate and die," kinda thing.

She continued:

I'm saying I cannae believe this has happened again because she [mum] had started to pick up and she'd think, oh, it's great and you're going back every month and every two months there's nothing there, it's just fine. Mum had said to him [consultant], "You said, you said you got it," and he says, "I did get it, but it's come back somewhere else and I have no way of knowing that." My brother was rude to the consultant that day and he did apologise after it, kinda thing, and the consultant said, "People take news like this all different and it's partly my job," kinda thing, you know, "but I havenae lied to yous, I have been very honest." (C12, daughter of T2, radiotherapy, laryngectomy for recurrence)

The extract illustrates the emotional rollercoaster experienced by these patients and their families with the fear and disbelief associated with the information that the cancer was back and the anger that the first line treatment did not work. These patients perceived a disparity between the information from consultants in the follow-up clinics and their understanding and interpretation of that information. The outcome information based on their first treatment from the consultant at the follow-up clinic was interpreted to mean the cancer had gone through the repetitive use of the word “clear”, as highlighted by P17:

I thought I was cleared. I kept goin' and they kept putting that tube down, the camera and saying, "It was nice and clean, clear, clear," you know what I mean? "Clear, it's clear." (P17, T2, male, radiotherapy, partial laryngectomy, total laryngectomy)

The use of the word “clear” to mean that the cancer had gone is linked to specific information that participants reported receiving at the Multi-Disciplinary Team (MDT) clinic.

The MDT is a group of professionals from across the multi-disciplinary team (consultant surgeon, oncologist, radiologist, pathologist, CNS and allied health professionals) who meet weekly to discuss and decide what treatment pathway is in the best interest for individuals based on their stage of tumour. After discussion and general agreement, the consultant surgeon, radiologist, oncologist and CNS attend a consulting clinic where they meet together with the individual and their families to provide them with their prognosis and treatment pathway.

When discussing the MDT clinic during the first interview, some participants had received their diagnosis of laryngeal cancer at a results clinic and attended the MDT clinic needing to know what the outcome of their diagnosis would be. The majority of participants talked about “being told” information about their prognosis and their treatment pathway. Many used the word “told” recurrently through their interviews, suggesting that there was little discussion around treatment options and their potential outcomes. I describe the information that patients and their family members recall receiving in this clinic and explain how they used it under the broad theme of the “Illusion of Certainty” in conjunction with the sub-themes of “cancer cured”, “live or die”, “they know best”, “hope”, “certainly not” and “lost in translation”.

5.4 Illusion of Certainty

This broad theme describes how the prognostic and treatment information given by the consultant in the MDT clinic and the manner in which it was communicated allowed patients and their spouses to interpret that their cancer was curable if they followed the specific treatment pathway offered. This was linked with the heuristic adopted by many that the MDT were a group of experts and they would know best, leading many to have hope for the future. Although many relied heavily on the biomedical information provided by the MDT there was evidence at this key stage of the role of experiential information and how that influenced how some participants viewed their treatment decision.

5.4.1 Cancer Cured

This sub-theme describes how participants interpreted the prognostic and treatment information from the MDT to mean that their cancer would be cured if they followed the treatment pathway offered. For example, P05 reported:

They told me I had cancer. He says, "There are cancers and cancers," and he says, "and I promise you", he says, "twenty treatments and I'll cure yae." (P05 male T1 radiotherapy)

Similarly, P08 reported;

They've told me there's three types of cancers, there's terminal cancer, there's cancer that they can keep at bay and there's cancer they can cure, so they've told me they can cure me. (P08, male T1, radiotherapy)

P08's wife discussed how the information from the MDT helped her manage her husband's diagnosis knowing the outcome of his treatment would be curative based on the information they received:

*I thought well, they've told him they'll cure him, so let's just go and get this show on the road type of thing. I thought what ever it takes. They've told him it's not going to be in remission, it's not terminal, **they will cure him** [wife emphasis on tape] and I thought, well, as long as they've said that, I mean they're not going to say that willy-nilly type of thing. I thought that is what we have to focus on, that's always what we have to focus on. (C08, wife of T1 radiotherapy)*

Others described receiving information on the success rates of treatments, which they interpreted to mean that by following that specific treatment pathway, their cancer would be cured. As P07 highlighted:

He [consultant] says, "Right, you've got a wee touch of cancer, 80% chance you're going to be awright, everything's going to be back to normal, nothing tae worry about." (P07 male, T1 radiotherapy)

Similarly, P03 reported how she had interpreted the success rate of her first line treatment to mean the cancer would be cured:

They said they could cure it if I went for radiotherapy and chemotherapy. Well, they said, "There was a 90% chance they could get it cured." (P03, female, T2 1st line treatment radiotherapy, laryngectomy for recurrence)

Only one participant, diagnosed with very early disease, reported having a discussion with the consultant on treatment options and their associated success rates. He said:

Mr X who deals wi' this kind of thing, says, "Well, you've got two ways we can go about treating this, radiotherapy or laser surgery." I said to him, "Aye, I'll, I'm quite happy to go with that [laser surgery]," and he talked me through a wee bit o' the procedure and he explained to me, he says, "Look, it's like 95% success rate on both procedures." (P19, T1, male laser surgery)

In contrast to the above quotes, participants who received a diagnosis of advanced or recurrent disease did not describe discussions about how their

cancer would be cured, treatment options or success rates as there was only one treatment pathway offered: laryngectomy. Their accounts describe the urgency with which they had to decide whether to have laryngectomy based on the certainty of the information from the consultant that they would die if they did not take that treatment option.

5.4.2 Live or Die

As the following quotes from P18 and C18 highlight, she perceived she had no option but to have laryngectomy as the cancer was affecting her breathing and her prognosis was poor:

Mr. X [consultant] told me, they told me, "The operation would be the best," if I had come earlier the treatment [chemo/radio] would not work. (P18, T3, female, laryngectomy, written account)

Her husband continued;

He [surgeon] says that the chemo and radio widnae dae it, he had to git her voice oot, and they wanted to keep her in there and then because she couldn't breathe. They said that if we didnae take the voice box we probably would ... well, we might no see Christmas. What he says, it was aggressive and it was well advanced because obviously it was affecting her breathing and her eating, and he said "You're wasting your time going tae the treatment centre until you get the operation," plus he was saying it wisnae in any of your organs, if it had been he wouldnae have operated. (C18, husband of P18, T3 laryngectomy)

This couple's accounts imply that they had no treatment decision to make, as the options were whether they wanted to live or ultimately, die, as P15 highlighted:

He [consultant] gave me six months without treatment. There's no choice between life and death, who wants death? (P15, T3, male oesophagectomy and laryngectomy, written account)

Other accounts of participants in the same situation were similar. For example, P13's wife described the short time-frame (two weeks) in which her husband had to decide whether he would have surgery or ultimately die:

They said it was just straight cancer. He [surgeon] said he [husband] could have radiotherapy and chemo but we could do aw that and it wouldnae make any difference. You know, to take the whole lot oot and then start treatment after that would gie him a better chance. He [surgeon] says, "Think about it, you certainly don't have much time." (C13, wife of T3, Laryngectomy)

Similarly, P03 who initially challenged the diagnosis of recurrent disease based on the certainty of information she received at the end of her first line treatment realised she had no option but to agree to the treatment offered:

I went to his [consultant] clinic on the Friday and he told me the cancer was back. He says, "It's very small but I think I'll need to operate." He sent me for a scan and showed me it and showed me where the tumour was, he says, "I have to operate," but I says, "The Beatson said they were 99% sure that they got rid of it all." I was

crying, I was upset but I felt if I wanted to live I had to go through with it. (P03, female, T3 recurrence and laryngectomy)

These extracts strongly illustrate how participants perceive the biomedical information from the MDT to mean that their cancer is curable by following the specific treatment pathway offered. There was no discussion evident from the majority of participants around treatment options and their accounts portray an unquestioning acceptance of the treatment offered. For those participants with advanced or recurrent disease they perceived their only option was to choose between life and death and accept the treatment of laryngectomy. The time in which this group of participants had to absorb the biomedical information given at this clinic was short, which influenced how some coped with the outcome of their treatment, which will be discussed in more detail later on in this chapter.

These findings resonate with previous research as Newell et al (2004) who found that patients diagnosed with advanced laryngeal cancer requiring laryngectomy perceived their treatment decision was between life and death. More recently, Pollock et al (2008) and Davies et al (2010) found that there was no discussion around treatment options with people affected by a range of head and neck cancers. Their findings suggest that patients seem to be satisfied with the physician making the treatment decision and have no issues on agreeing with the treatment option offered (Davies et al 2010).

Only one participant in this study commented on his dissatisfaction with the approach taken by the MDT. He perceived the information and the manner in which the MDT conveyed the information as being dominant and

paternalistic. He described how he was not involved in any discussion around treatment options, he “was told” what was going to happen and what he had to do, without anyone asking what his preferences were:

They [MDT] just tell you had cancer and this is your treatment, this is what's happening. They just come in and say “This is what's happening, that's what's happening,” half the time you don't even get their name. I don't know any doctors' names, they just come in, “This is what's, that's what's happening, that's what happening, is that ok? Right, come on we're daing it.” (P07, male T1 radiotherapy)

The extract implies how he felt disempowered by the information he received in the MDT clinic and how the MDT had made his treatment decision for him. There appeared to be no input from him regarding his treatment decision and his potential preferences for treatment, which affected how he viewed and managed his future treatment. Although this participant discussed wanting to be more involved in discussion about possible treatment options, the majority discussed how they accepted the treatment offered linked with the certainty of cure it offered.

5.4.3 They know best

The acceptance of treatment was not only based on its curative intent but appeared to be based on the heuristic adopted by many of the participants that the MDT were a group of experts and they would know best. As explained by P02:

Absolutely nothing I can do about it. I've got it, it's in the hands of the experts and I'll just sit back here and let them do what they want. They know what they are doing, I hope, and see what comes. Simple as that. (P02, male T1 radio-chemotherapy)

Similarly, P16 described how he “had been told” he had the top man (expert) in the world planning his radiotherapy;

He [consultant] seems to think that they have caught it in time and he can get it cleared up and it should be okay. He [consultant] says, too, that he's [radiologist] the top man in the world for it, he says, “It's him that's daen the plans up for you.” (P16, male T2 radiotherapy)

The view of the MDT as the “experts” was also linked to their characteristics of being honest and trustworthy by the manner in which they communicated the information. Participants talked about how they received information about their prognosis and treatment in a “straight” and “direct manner”, which they needed and respected. As P06 highlights:

I think that's what really matters, really ... em, I think he was, you know, he was probably right on track with talking to people. He'd tell you it straight, he's one of these people that would tell you straight and that you felt that way about him and that's what you want you know. You don't want somebody working round the edges. (P06, male T2 radiotherapy)

Similarly, P03 talked about how she trusted her consultant as he was “straight” with her:

I trusted him; he was very good to me. Nae punches, nae nothing, he just told you, told me straight. (C03, T2 female, radiotherapy, laryngectomy for recurrence)

Again, P19 highlighted the importance he associated with his consultant being “straight” with him, in addition of being shown where the problem was:

Mr X who deals wi’ this kind of thing, took me in sat me down, straight, I mean straight down the line, this is exactly what’s the matter here, a drawing showed me exactly what had happened, which is a lot easier to understand, eh. (P19, T1, Laser surgery)

By the MDT communicating the information in a straight and honest manner, it seemed to instil a trust and confidence in participants. This trust and confidence was also apparent from spouses due to the information their husbands had received. As highlighted by C02:

This is the road they’re going down wi’ this, they must think this treatment is going to do the trick rather than operate. The way I look at it is, if it was so bad they would have operated right away, thinking, well, no much point going down the road at a’ because it’s needed to come out. I says, “We’ll settle for this if you’re fairly confident that this will do it.” (C02, wife of T2 chemo-radiotherapy)

Thus, the way in which the MDT communicated the prognostic and treatment information played a major role in how participants viewed and accepted their treatment and the perceived curative outcome of that treatment. Many participants adopted the heuristic that the MDT were the experts drawn from a

cultural understanding that “the doctor knows best”, implicitly placing their trust and confidence in them due to the honest and direct manner in which they conveyed the information. It was evident how the combination of these factors gave many patients and their family members the “illusion of certainty” that the outcome of treatment would mean their cancer would be cured

5.4.4 Hope for the future

Unsurprisingly, the “illusion of certainty” that the information provided by the MDT gave to participants gave them hope and optimism for the future. As P06 describes:

Well, I actually thought it wouldn't be repairable at the very beginning ... we both did. The trouble with that is we don't talk about it at that time point, you know, and then they tell you, "It's not as bad," you both find out that you thought it was going to be worse. He [consultant] said, "Even if it is the worst thing, we can do something about it," so to be fair I was easing off a wee bit at a time, you know, when he said that. (P06, male T2 radiotherapy)

Similarly, the relief that something could be done gave many hope for the future, as highlighted by C09 and C15:

I thought there was nothing they could have done for him, you know, then they mentioned the chemo and the radium, it gives you a wee bit of hope. (C09, wife of T2, N3 chemo and radiotherapy)

Just, you know, glad that something could be done about it, because we weren't told there was no hope and nothing could be done so it was good that there was something that could be done. (C15, wife of T4 oesophagectomy and laryngectomy)

Whereas P05 described how the information from the MDT gave him a chance:

You've to grab that chance, really when he [consultant] telt me, twenty times, I mean that's nae bother, I mean he telt me, as long as they were gien me a chance I was all for it, I jist need tae do it. (P05, T1, male radiotherapy)

Thus, the uncertainty that participants experienced leading up to their diagnosis about what their symptoms were indicative of and what lay ahead had been addressed by the biomedical information provided by the MDT. Participants needed to know that something could be done and that their cancer would be cured or they would live, which the biomedical information given by the MDT provided. This information gave participants hope for the future as they had confidence in the MDT and believed the information to be honest and trustworthy. Many participants appeared to rely heavily on the information from professionals, possibly due to a lack of their own common sense knowledge or "stock of knowledge" of cancer and its treatments (Dingwall 1976), with many accepting the treatment offered without question.

However, it became apparent that although many relied heavily on the biomedical information and the "illusion of certainty" this provided, it was not the only source of information participants were using. There was an

underlying “certainty” in some participants’ accounts where they had drawn on their own experiential knowledge of knowing others with laryngeal cancer and the information this provided, which influenced their response to the information from the MDT and the treatment offered. I describe the use of experiential knowledge at this point under the sub-theme of “certainly not”.

5.4.5 Certainly not

Only a small number of participants discussed how knowing others who had experienced treatment for laryngeal cancer had influenced their acceptance of the treatment offered. Although many participants discussed being “told” their treatment pathway with little discussion evident in the MDT clinic around different treatment options, there were participants who had decided on which course of treatment they would “certainly not” be accepting prior to attending the MDT clinic.

P19 was the only participant who reported having a discussion with his consultant regarding his treatment options of laser surgery or radiotherapy. He decided to opt for laser surgery and when I asked him why he had chosen this option, he explains:

Travelling aw the way to the hospital everyday for the next month or so ... I mean, don't get me wrong, ma work has been great with me, they've gave me time off and sort o' pulled a couple of strokes and I never lost any money, but running up there [hospital] five days a week ... (P19, T1 laser surgery)

His partner continues:

And it does take a wee bit more out of you and takes longer recovery. We've had a friend that's had radiotherapy and it really took it out of her. (C19 partner of T1 laser surgery)

P19 adds:

Funnily enough the, the job that I'm doing the now was actually vacated wi' a guy who had a cancer and he went through that and I ... I saw what he had to go through and I just thought, no, I don't fancy that. (P19, T1 laser surgery)

Thus, knowing others who had experienced radiotherapy and knowing the impact this type of treatment had on them influenced his decision to opt for laser surgery. Knowing the side effects of treatment and how “*it takes it out of you*”, along with the practical aspects of travelling each day for treatment requiring a length of time off work, demonstrates the influence of experiential knowledge on how this participant made his treatment decision. He highlights how he had really made his decision prior to attending the clinic before he had received any information from the consultant:

By the time I'd actually been in and spoke to them I'd pretty much made up my mind, 99% made up mind I would go for the laser surgery. (P19, T1, laser surgery)

Knowing the impact that certain treatments had on others was hugely influential on how some participants viewed and used the information from the MDT. For example, C12 highlights how her mum perceived people

with laryngectomy to be dying drawn from her experiences of seeing them at clinics after her first treatment. Knowing the impact had a major effect on her deciding to accept this treatment:

My mum was really determined that she didn't want the voice box removed, "That's no for me," she says, no, no," ... because erm, at ENT and things you see everybody and my Mum always says "That's no for me, people with this look as if they are dying ... they always look frail and old," and I said, "You don't know they people before they've had that," but that was my mum's perception. (C12, daughter of P12 laryngectomy)

Similarly, C18 highlights how his wife's experience of knowing others with laryngectomy influenced her negative view of the surgery which prolonged her decision to accept this surgery:

The problem with you [wife] is, she worked in a care home and there was this man, he had a laryngectomy, but he had no tube, just a hole eh, but that was thirty years ago and erm, when she went in she used to see a lot of glut down the back and this is what she thought she would end up like. (C18, husband of T4 laryngectomy)

P05 highlighted in his extract (P05 male T1 radiotherapy) how the information provided by the MDT gave him a "chance that he would grab," however, he discussed how he would have refused laryngectomy based on his experiential knowledge of knowing others' experiences and the impact this had on him:

I told them [MDT] I knew quite a few of the guys in the club that got cancer in their throat and they got the voice box out. I told him [consultant], I said, "Just forget all about it," I said, "cause you're no." I said, "I would rather die," because see when tae talk to anybody, they have tae put their fingers up and there is a croak, you know, it's a croak. So I said, "I don't want to be like that," I says, "if I cannae talk am as well no here." (P05, male T1 radiotherapy)

Similarly, P06 highlighted in his earlier quote "well, I actually thought it wouldn't be repairable at the very beginning" (P06, male T2), which was based on his experiential knowledge of knowing others who had laryngeal cancer and had undergone laryngectomy. The prospect of this type of surgery terrified him as the following quote highlights:

"I thought it would mean them putting the voice box in, you know ... that's, was the worst bit. I said I would prefer radiotherapy if it is, was at all possible, obviously you know if I'd have to ... the trouble was I had a customer when I was working that had it and he frightened the life out of me when he came in, you know? (P06, male T2 radiotherapy)

Thus, the quotes highlight how some participants had strong views on the treatment option they would "certainly not" want, based on their experiential knowledge of knowing others' experiences and how this influenced their acceptance of the treatment offered. In many ways, P05 and P06 were relieved and accepted the treatment pathway offered by the MDT without question, as it

was a better option than what they initially feared; therefore they had to “*grab that chance.*”

In contrast, P04 required laryngectomy and had been informed by the MDT that this would be the best treatment option for him. He described how he had considered both the verbal and written information provided to him through conversations with the clinical nurse specialist but responded by refusing a laryngectomy using his experiential knowledge of knowing others' experiences:

Aye, they wanted to take the voice box oot but I says, “That’s no happenin’.” I read the leaflets she [CNS] geed me and she came tae the hoose but I wisnae fir letting them taking it. Maybe younger, Anne, aye, but no, I’m too auld, I’m not gonnae go through aw that, I just don’t like it. I’m no feart aw surgery. I’ve spoken wi’ people who have had it done but I’m no speaking like a Dalek, then you’ve got to take it [tube] oot, clean it and if I’d tane maybe a drink it maybe come oot, no. (P04, male T3 radiotherapy)

These participants report how their experiences of knowing others who had had a laryngectomy had a major influence on how they viewed and responded to the information from the MDT and the treatment decisions made. C12 and C18 highlight how this prior knowledge delayed their mother and wife, respectively, agreeing to laryngectomy. Whereas, P05 and P06 were relieved and optimistic knowing that their treatment option was radiotherapy in comparison to laryngectomy, which would have been their biggest fear. In contrast, P04, who

alludes to not being frightened by the prospect of surgery, discussed how he would “certainly not” have laryngectomy due to the impact on him as an individual and the impact this type of surgery would have on his life. Even though P04 was told he had “six months” to live without laryngectomy, he still refused to have surgery and opted for radiotherapy.

These quotes show how some participants used both categories of information to inform their decision regarding their treatment. It is evident how experiential knowledge and the information this provides enabled these participants to know and understand the outcome of their potential treatment and the impact it would have on their lives. Although there was no apparent discussion around treatment options during the MDT clinic, this data would suggest that some participants may make their treatment decision prior to attending this clinic drawing on their own experiential knowledge of knowing others’ experiences. Information from health professionals is seen as the dominant source around diagnosis and treatment options; they are the “experts and they know best”, therefore the information they provide can be taken as “truth”. However, experiential knowledge may be more influential in how some patients make treatment decisions and may dominate, in some cases, in comparison to the biomedical information provided by health professionals.

When discussing the information they received during the MDT clinic, some participants highlighted how they were overwhelmed with the amount of information from the “experts” and their recall of certain types of information was vague. This is where it became apparent the important role

that carers play in filling in the gaps or reiterating the information to their spouse given at this time. I describe participants' accounts under the sub-theme "lost in translation".

5.4.6 Lost in Translation

This sub-theme describes how some participants felt overwhelmed with the amount of information or how they didn't seem to "hear" the same information as their spouses during the MDT clinic. This led to a disparity in accounts between some couples, as some information seemed to have been "lost in translation", as highlighted in the following quotes:

C02: That's when he [consultant] very basically told him [husband] then, "Well, it's cancer," and he was very nice the way he put it and again, I think it shook you [husband] again, getting told. You're taking it more in then, well, this is what it is, what the biopsy, that's what it did say, that it was definitely cancer of the, he told you then it was larynx, I think. He [consultant] said it [tumour] would need to be removed. So we know an operation, that's what would entail, aye, you were quite taken aback at that if I mind right.

P02: Ach, I don't remember much, I honestly don't. My memory's poor at the best of time.

C02: I think I am taking more in than you, Eddie.

P02: Oh, probably, aye.

C02: I'm taking more in, I think, than he is at the moment. (C02, wife, T1 chemo/radiotherapy)

Similarly, P09 highlights:

The only thing that I found, there were too many round about you, too many experts if you like, consultants, doctors and they were all I mean, when I came out everything just went over my head, nothing went in, everything just went piff!!!! Over my head. (P09, T2 N3 male chemo-radiotherapy)

With P08 commenting on how he understood he had cancer from the information given but trying to take it all in, was the challenge:

After I had seen the MDT she [CNS] called me into a separate room and she says, "Take as long as you like, did you understand this? Did you understand?" and I says, "Well, I understand it but it was taking it in, it went over my head." (P08, T1 male, radiotherapy)

Some discussed how the clinical nurse specialist acknowledged the challenges associated with taking on board the amount of information they had received at this time, as C12 highlights in the following quote:

Mum was told to come home and have a think about it and the CNS said, "Go home, I know it's an awful lot for you to take in and I'll come out tomorrow and any questions you have to ask me I'll speak to you and tell you the answers." (C12, daughter of P12 laryngectomy)

Thus, the quotes show how the amount of information given in this consultation can be too much for some patients to absorb which may lead to some information being “lost”, leading to disparities on recall. Previous research has reported that the amount of biomedical information given to patients in this consultation is too much (Stafford et al 2001) which could explain the disparities evident between couples when they discussed specific aspects of the information given by the MDT. For example, P02 started telling me about the MDT and the information he received about his prognosis when his wife interrupted with what information she remembered from the MDT about his prognosis:

P02: We have a high;

C02: No guarantee, but it's fairly good.

P02: ... high success rate, something like that.

C02: “Fairly good success rate,” he [consultant] says, “What we are going for is curative intent.” (C02 wife of T1, chemo-radiotherapy)

Similarly, C06 corrected her husband when he said:

P06: Nothing's written in stone, but I think he went as far as near to guarantee to get rid of the tumour.

C06: Well, he said he hoped to get rid of it. (C06, wife of T2, radiotherapy)

Thus, information given by the MDT seems to be “lost in translation” as there appears to be a disparity on what the patient recalls hearing and what their

partner or spouse recalls hearing. Kessells (2003) suggests that stressful information such as a diagnosis of cancer can become the primary focus in a consultation, meaning that the individual diagnosed hears no further information during that particular consultation. The further information discussed in the consultation (such as information about prognosis or treatment) is defined as peripheral information. He suggests that if the individual does not hear that information it is not absorbed, processed or stored and therefore cannot be recalled. This may explain why family members' recall of the biomedical information is more detailed than the patients'.

After receiving the information from the MDT, many discussed meeting the clinical nurse specialist (CNS) who helped them begin to make sense of that information and prepare for what was ahead. The CNS was involved with both the person diagnosed with cancer and their spouse/family member and provided them with verbal and written information on treatment side effects, supportive and practical information. She provided them with the support that they needed at this time to help them understand and make sense of their cancer. I describe the role of the CNS at this time under the broad theme of "culture of caring".

5.5 Culture of Caring

This theme describes the influential role that the Clinical Nurse Specialist (CNS) played at this key stage in the participant's trajectory. The role was multi-faceted and led many to perceive that they were being cared for and

their needs addressed at this time, thus allowing them to feel as if they were in a culture of caring.

5.5.1 The Role of the Clinical Nurse Specialist

The following quote from C02 highlights the personable qualities of the CNS which were commonly described by participants as, for example, “approachable”, “concerned”, and how these qualities, along with the information she gave, made them feel supported and informed at this vulnerable time:

She was very, very concerned, very approachable and you felt as though she was just talking to us. We weren't like a case sheet or anything, no like a number, or, which means a lot doesn't it when you get told news like that? You don't want to be a number or a case sheet, you know? (C02, Wife of P02, T1, chemo-radiation)

Many participants talked about how the CNS provided them with the support they needed by knowing that she would be there for them to answer any questions, as described by P08:

After I had seen the MDT she called me into a separate room and she says, “Take as long as you like, did you understand this? Did you understand?” and I says, “Well, I understand, but it was taking it in, it went over my head,” and she couldn't have done enough for me. She said, “I'm your contact now until after you get into the Beatson, if you need anything, if you want any information just phone

me,” and she gave me her phone number. (P08, T1 male, radiotherapy)

Similarly, P06 reported how he contacted the CNS to know when his treatment would start. His quote shows the reassurance and the confidence this gave him and how he needed to know that she was looking out for him at this time:

About the time I was told about the cancer and the period between then and going for the treatment that was the point we were in touch with the CNS. I phoned her, like, “When is going to be starting?” She said, “There’s nothing on the thing yet, but I’ll have a word with appointments and see.” Eventually she came back and she says, “I think we’ve got it now, you’re going to be starting next Monday,” or something, you know, and she says, “You’ll get it officially but I can tell you now.” That was important. I kept saying, “That’s important,” you know, but that makes you feel that somebody’s looking after you, your affairs, you know, she did all that. (P06, male T1 radiotherapy)

Others discussed receiving written information from the CNS that supported and clarified the verbal information received at the MDT, as described by P06 and C11:

We got a book that explained it all pretty thoroughly and she also sent us a load of stuff. (P06, male T2 radiotherapy)

They [MDT] said that you would get painkillers and you might struggle to eat and you might need a feeding tube, and we were

given information sheets. The CNS handed out the information sheets and said, "Just phone any time." (C11, wife of T1 radiotherapy)

Based on the information they received, C06 highlights the importance of being able to contact the CNS to help her clarify the "silly things" that concerned her at this time:

We'd say, "We'll ask her [CNS]," you know, you could phone her and ask her, that was good and I think more important, actually, even than the booklet, you know, the book was good and it did tell you what to expect, but I think, the odd thing was the quirky things that would cross your mind I think, just having someone. (wife of P06, T1 radiotherapy)

Others talked about how they contacted the CNS about lifestyle issues. For example, P08 wanted to know how much alcohol he could have during his treatment:

She said, "Aye, you go have a drink, but don't go nuts. Don't go nuts, and drink water, have a glass of wine, a glass o' water because as the treatment goes on it will irritate your throat." (P08, male, T1, radiotherapy)

Others discussed conversations with the CNS about their smoking:

Aye, aye, she did tell me tae stop it but it's hard tae stop. I've been daing it for 40 year, so I cannae just stop like that [clicks fingers]. (P01, male, T3, chemo-radiotherapy)

It is interesting to note that P01 talks about being told to stop smoking but doesn't discuss being given any information or advice on helping him stop smoking. None of the participants discussed receiving any information or assistance from the CNS on smoking cessation highlighting a potential lack of information from someone in a prime position to assist participants at this time.

Family members also commented on the important role that the CNS played at this time and discussed how she signposted them to information about specific treatments and provided supportive information that helped minimise the threat associated with a cancer diagnosis, as described by C01:

The web address that she [CNS] gave me it was eh, very informative it was everything I wanted to know and understand. It told me mainly how they were going to approach it with his treatment and what they were going to do. I spoke with her quite regular and she phoned me at the house and different things keeping me up to date sort of thing. It made me understand that it [cancer] wasn't necessary a death sentence, how things have changed over the last ten years, the treatments getting better, so I was quite happy that way once I knew.
(C01 brother of T3 chemo-radiotherapy)

Supportive information from the CNS was very evident with those patients who required laryngectomy and their spouses through the provision of different types of information that helped them prepare for their surgery and what life would be like post-operatively, as highlighted by C15:

C15: They said what the operation entailed because that was all explained in great detail, plenty to read about it and also, em, a video to watch as well which was very good, too.

Interviewer: Did you find the video helpful?

C15: Yes, yes because you saw people speaking and people that had come through it and how people coped with it afterwards. (C15, wife of T4 oesophagectomy and laryngectomy)

Similarly, P18 and C18 discussed how meeting a laryngectomy patient, organised by the CNS, helped them to know what the stoma would be like and that she would have a voice post-operatively:

She [ex-patient] scared me at first, but that helped me know what it [stoma] would look like. (P18, female T3 laryngectomy)

Her husband continued

The CNS said, "I will send somebody up that will maybe help you to understand that you can get voice after an operation. She [ex-patient] was a great talker and she says, "You have to git through it." She said that she had been abroad and she is back at her work. That is what helped her tae make up her mind because she [wife] realised how good a speaker she was. (C18, husband of laryngectomy)

Thus, the quotes highlight the important role that the CNS played with both the patient and their spouse in helping them prepare for what lay ahead. However,

it was evident how some spouses would have benefited from a one-to-one discussion, to help them prepare for their husbands' treatment. C11's extract illustrates how spouses have specific information needs of their own that are not always addressed:

I could have done with, now you close your ears to this [says this to husband], I could have done with speaking to the CNS because I felt our reaction was not to talk about things at all, and if I hadn't wonderful friends to talk to, I would have been struggling, coping with him [husband] not talking about it. Being female and not male I wanted to talk, but I had super friends who were prepared to listen to me and I just wanted to talk and they were able to just sit there, just what we were going to have to face. (C11 wife of T1 radiotherapy)

One participant discussed the impact that having no contact with the CNS had on her as there was no specific person to contact to help them make sense of the situation and help them prepare for the treatment ahead:

The day he got diagnosed they [MDT] says they would have him in and his treatment started within two weeks, that was the 7th of June. He started his chemotherapy on the 20th of July and that was brought forward. I phoned secretaries, they said they would get back in touch with me, they weren't. I was chasing them for a solid week. Never got anything at all, no letter, no phone calls, we didn't speak to anybody, nobody gave us an update on when it was gonna happen. So, for all they weeks we were like, you know, "What's

gonna happen? What's ...” – didn't know anything. We were told there would be a nurse appointed to him but we've never heard from her. I couldn't even tell you her name, she's never phoned, either.”
(C09, daughter of T2 N3 chemo-radiotherapy)

Thus, the support and the various types of information that the CNS provided helped many participants begin to make sense of the information given by the MDT. Many discussed how the CNS clarified the verbal information from the MDT about their prospective treatment and side effects and provided written information to help them begin to understand what was ahead. There is a huge emphasis placed on the role of the clinical nurse specialists to provide support and information both verbal and written to patients and their families, as it has shown to have a positive impact on their understanding of their diagnosis and future treatment pathway (Semple & McGowan 2002), which was evident with this group of participants.

However, some participants did discuss how the written information provided by the CNS frightened them or how they were frightened to read the written information about their future treatment. For example, the written information shocked P08 about his prospective treatment:

I mean, it was, when I started reading it, all about radiation and about you know cancer of the larynx, I'm saying, “Oh God, do I need to go through all this?” you know? (P08, male T1 radiotherapy)

Whereas, P05 and his daughter explained how they were satisfied with the verbal information and “feared” knowing too much from the written information:

They gave me a book but I've never read that, I didn't think I needed, reading that, see when they telt me I had cancer I actually didnae think that could help me cause they were gonna tell me what was wrong wi' me. I need tae talk tae them. A says, "Well, why read it?" There's maybe something in there that if I had have read it, maybe I wouldnae have done it, I am no one for asking, I believe what they tell me. (P05, T1 male radiotherapy)

His daughter explained:

You know, if you don't know, you don't need to know. Sometimes you read a book and when it's there in black and white and you think, oh no, I don't want to read that, just go wi' what the guys have told us because the information that we goat, you know, wis sufficient enough, like we were always, we were never kept in the dark. We knew what to expect, we know what to expect and we know that 99% o' the time people are cured because they've caught it in time. (CO5, daughter to T1 radiotherapy)

Even those having laryngectomy commented on not needing to read the written information because they knew what was ahead from the verbal information they received from the CNS, as described by P13:

I didn't need to look at the book. I knew whit would be in it, whit I wis going fir. I didn't want tae read aboot it 'cause I knew whit it wis coming. The CNS telt me basically what could happen, how tae dae

these things but I knew within mesel whit I wis gonnae go through.

(P13, T3, male, laryngectomy)

These extracts would suggest that not all patients want and need written information and for some it caused fear and anxiety. This shows the differential patterns of information-seeking behaviour this group had (Lambert et al 2009) and how some adopt a minimalist approach to the level of information they needed. The extracts demonstrate the faith and trust this group of participants had in the verbal information provided and it could be suggested that they did not want to shatter the “illusion of certainty” it gave, by reading detailed information on the various aspects of their future treatment. The presence of the CNS and the support she provided allowed many to feel they were treated as “a person and not a number” where their needs and concerns were addressed at a time when many felt fragile and vulnerable, thus providing a culture of caring. However, it was evident how the CNS did not assess some individuals’ need for information at this time as the information was not tailored to participants’ specific needs and a generic approach to the provision of information was evident. Based on this generic and prescriptive approach by the CNS, some participants responded by actively sourcing information specific to their needs in order to increase their knowledge and understanding of what was ahead as some wanted to know what the worst case scenario would be.

Only one of the spouses described accessing information from the internet at this point, as she needed to know “the worst scenario” which had not been ascertained by the information she had received from the MDT and not

having had a one-to-one session with the CNS, as discussed earlier in this section:

After the MDT I went straight home and went onto the internet, but that's me, I like to know. I want to know what the worst possible scenario is and then anything else is a bonus. Obviously I didn't know very much about it at all, so I read up all that it had on offer, I felt I knew what was ahead of us, the worst scenario. (C11, wife of T1, radiotherapy)

Others talked about sourcing information from ex-patients and the value they placed on hearing it from "the horse's mouth", as highlighted by P08:

He [ex-patient] told me exactly what it's all about and you're saying "What?" and he didn't tell me any lies. He says, "You will sometimes feel low, very low," and he had six weeks, he was that low he didn't want to go in on the last week. He told me I was going to be down, I'm going to have a sore throat, he's told me all the unpleasant things. He says, "The worst thing is you will get very tired," he says, "but radiotherapy makes you like that." It's alright nurses and doctors and oncologists saying, "Now you're getting that and this is what's going to happen," I think it's better coming from the horse's mouth if you like, people that have gone through it, I think it would be great benefit, a great help, at least you know. I wanted the crap times and he told me, "You'll not even know that you're going through radiotherapy for the first couple of weeks," and he says,

“then it, it can hit you like a hammer, you’ll feel unwell, you’ll feel this,” but at least I knew that, I says, “Right, that’s me.” (P08, male T1 radiotherapy)

Similarly, P10 and his wife discussed how the experiential information sourced from an ex-patient helped them to know what to expect during treatment and how, based on this type of information, they did not need any further information from health professionals:

Well, there’s a chap in the village and he went through it and he explained everything tae me, helped me wi’ that. Aye, well they tell me about the mask, you know and eh, then I’d go every day Monday to Friday and that would last about seven weeks, you know, that it [tumour] will be reduced to nothing. (P10, male T3 radiotherapy)

His wife added:

He [man from the village] came up at the beginning, he told him no to worry about anything, you’ll get back to normal. Then we have a friend that went in at the very same time. We met him and we spoke to him, a wee bit rough, you don’t get the voice back that you did have at one time, but em, he’s fine, too. I mean there’s nothing that we need to ask because we know it; we know what’s in store. (C10, wife of T3, radiotherapy)

These accounts show how some participants sourced information from other sources in response to their specific needs at this time. In response to the information from the MDT, some required no further information as they were

satisfied with the level of information and the certainty this provided. Others found the written information helpful, whereas some actively sought information from the internet or from individuals who had direct experience of the event and, in some cases, deemed this more informative than the information from the health professionals. Many discussed how they used both professional and experiential information to help them begin to make sense of their diagnosis and to know what was ahead; this appeared to be an important step in them preparing for their prospective treatment. Many participants described taking “time out or away” to absorb and process the different types of information they had received and sourced in an attempt to regain a sense of normality so that they could begin to understand their diagnosis and ensuing treatment in the context of their lives.

5.6 Search for normality at diagnosis

Participants discussed how having “time out” allowed them to begin to make sense of the different types of information they had received. They made sense of their diagnosis by adopting different strategies that could help them explain and understand their diagnosis and their ensuing treatment. The most common strategy adopted was by “normalising” their diagnosis in the context of their own experiential knowledge of cancer, which was influenced by their “cultural understanding”, “family history” and “lifestyle”.

5.6.1 Cultural Understandings

For example, P04 viewed cancer as part of life and accepted his diagnosis as part of growing old. In his opinion, not many people got to his age without knowing someone who had cancer or having cancer themselves:

I've led ma life, Anne, and I'm no gonnae go aboot greetin aboot it, you know, as the good Lord says, once you have lived three score and ten then something's gonnae kill you. Let it be cancer, there are no many people that get through life without getting cancer. (P04, male T3 chemo-radiotherapy)

Female spouses commented on using their experiential knowledge and understanding of the link between smoking and cancer from other sources, such as magazines and the media, to make sense of their husbands' cancer, as demonstrated by C02:

It was mostly because of his smoking and the fact that he had a sore throat and his voice got hoarse. I think women are more clued up wi' things like that than men. We read magazines, you're watching television, you tend to know the symptoms of bowel cancer or whatever, you know the warning signs, where men maybe don't. (C02, wife of T1, chemo-radiotherapy)

Conversely, others made sense of their diagnosis through knowledge of their families' or others' history of cancer.

5.6.2 Family History

P01 told me in his first interview how his parents were “riddled” with cancer before they died. He perceived that because his cancer was “only in the throat” and treatable, he would be fine. It was evident how he used his experiential knowledge of cancer in combination with the biomedical information to interpret that he would be fine:

I know people that had cancer o’ the throat and they’re fine and so far I’ve only got it in the throat and I know something can be done about that. (P01, male T3 chemo-radiotherapy)

This expectation of having cancer due to family history was also evident in P19’s extract:

I mean, a lot a, helluva lot o’ my family to cancer, my mum, I think my mum, she must have had cancer, my dad, my grandfather, God knows how many uncles. The chances were on my side it was going to get me somewhere doon the line and I was a wee bit speechless but I wisnae 100% surprised, you know, and that I always had it at the back o’ my mind it would rear its ugly head up and sure enough. (T1, male, laser surgery)

Other participants did not discuss family history as a reason for their cancer but talked about how their lifestyle could have played a part.

5.6.3 Lifestyle

The majority of participants in the study were smokers or ex-smokers (only two did not smoke) and male participants talked about their alcohol intake, the main risk factors identified in Chapter 1. Some participants were very open about the likelihood that smoking and drinking alcohol had played a major factor in their diagnosis. For example, although P08 was shocked at his diagnosis, he spoke openly about being a heavy smoker and drinker for many years, which he suggested could explain his diagnosis:

I've got to admit, Anne, I was a heavy smoker for forty years, forty cigarettes a day for forty years and eh, I mean, I did drink a lot, I must admit, in my social life, in my work side. I mean, I was going over the top a wee bit, eh, I like lager and I like a few drams, believe me a few drams at the weekend. (P08, male, T1 radiotherapy)

His wife added how the written information helped her to make sense of his diagnosis:

When I read the booklets that they had given him and it said one of the causes em, it was em, I cannae talk, I'm a smoker, excessive smoking and drinking, I immediately said, "There's your answer." (C08, wife of T1 radiotherapy)

Similarly, P04, who smoked throughout our interview, spoke openly of his alcohol intake prior to his diagnosis:

Oh, aye, Anne, I was drinking about, aye, at least a litre of vodka a day. (P04, male, T3, radiotherapy)

Whereas others framed their lifestyle as a possible explanation for their diagnosis and linked it with fate, as highlighted by P02:

As I stated earlier in the interview I've got no control over this. Maybe I caused it, maybe it was my fault wi' the smoking, maybe it wisnae. (P02, male, T1 chemo-radiotherapy)

As discussed earlier in this section, those diagnosed with recurrent disease were angry and shocked at their second diagnosis as many had stopped smoking, and had suffered and achieved their first treatment. However, on reflection, there was a general acceptance amongst these participants that their smoking explained their diagnosis, as described by P03:

I was crying and upset. I think it was because the cancer was back and because o' the operation I had to get. 'Cause I worked fae I wis fourteen and I've worked hard. Mind you, I smoked and I smoked hard. Five year ago I had hoarseness in my voice and he [consultant] said if I don't stop smoking, "You'll end up wi' cancer." Of course, you don't listen, the man was right enough, that's when I should have stopped smoking. Too late. (P03, T3 chemo and radiotherapy first, then laryngectomy for recurrence)

Thus, these accounts show how participants used the information from professionals in combination with information drawn from their own experiential knowledge of cancer to explain and make sense of their diagnosis through reflection and situating it in the context of their lives. Having time to reflect was important and many talked about taking a holiday or a weekend away, to take

time out to process all the different types of information and how this helped them prepare for the start of their treatment.

5.6.4 Time out

This sub-theme describes how participants reported how having time out helped them to make sense of their diagnosis and feel “normal” for a short period of time prior to their treatment starting. It was also evident that some participants needed time out to consider their future treatment options. As highlighted in the following quote, having time out helped P02 and his wife forget about the diagnosis and future treatment for a short time:

Aye, it was great; I always come back fae there relaxed. (P02, male, T1 chemo-radiotherapy)

His wife added:

I think you said one o’ the nights we were sitting out for a meal and he says, “Do you know, I feel,” ... you felt as though it was like you’d forgotten all about this. As though I’ve came here and I’ve just forgot. So it did us both the world of good. (C02, wife of T1, chemo-radiotherapy)

By having “time out”, many talked about how they could take on board all the information received and begin to prepare for their prospective treatment as highlighted in P08’s account:

I was glad they let me go on holiday, it gave me time. I thoroughly enjoyed it, ate like a pig, had a few drinks, good company at night

and eh, but I says the last couple of days, I says, "Right, down to reality, I know what I've got to come back to, lets get on and get it over with." (P08, male, T1 radiotherapy)

Whereas others asked for "timeout" to decide and consider their options, like P13 who needed the time to prepare himself for this life-changing surgery:

That's when I got told I had cancer; I went back to the hospital and got told then. So I says, "Can have a couple of weeks?" I knew within maself I could handle it or I wouldnae be here the now. I got drunk every bloody day, my daughter gave me a litre bottle o' whiskey, it [cancer] would have killed me, there wasn't much choice. (P13, male, T3 laryngectomy)

Others needed "time out" to allow them to think everything through and prepare for the worst-case scenario. For example, P09 talked how he planned his funeral. I initially thought the worst-case scenario for him was the possibility of laryngectomy but he clarified that the worst-case scenario to him at this time was dying:

Before I started the treatment we went tae the caravan, well it did us good because we could sit there and without interference, got everything sorted out in case it didn't work out ... em, planning the funeral. We didn't want tae have the hassle wi' the family if anything did happen, funeral wise. Aye, if I lost the voice box I lost the voice box, but I was thinking more serious. (P09, male, T2N3 surgery and chemo-radiotherapy)

Thus the need to have time out to take on board all the information and situate it in the context of their own understanding is important and a common strategy that this group of participants used. It is evident how participants needed this time to regain a sense of normality or make sense of their diagnosis in the context of their own understanding and to prepare for their treatment ahead.

In summary, participants talked at length about the information they received at the MDT clinic as many had been anxious of what they would learn. They received information on their diagnosis, prognosis and treatment pathway from the “experts” in a direct and straightforward manner, which meant it was to be trusted, as they would know best. This provided many with an “illusion of certainty” that their cancer was curable which gave them hope for the future. It was evident how some participants relied heavily on the biomedical information and the “illusion of certainty” this provided, however, the use of experiential knowledge and the information this provided was used in a subtle way and influenced how some participants viewed the treatment offered. Some admitted feeling overwhelmed with the amount of information given and some information was “lost in translation” with family members and the CNS playing vital roles in providing clarity to the information they had been given.

The presence of the CNS and the information, care and support she provided allowed many to feel they were treated as “a person and not a number” where their needs and concerns were addressed at a time when many felt fragile and vulnerable. This led many to feel that they were in a “culture of caring” that was important for many to make sense of their diagnosis and the

information they had received. Making sense of their diagnosis by having “time out” between their diagnosis and starting treatment seemed to be crucial; it gave participants time to absorb the biomedical information they had received from health professionals in combination with experiential information from others, which enabled them to regain a sense of normality and make sense of their diagnosis situated in their own common sense knowledge of cancer. Having time out allowed some participants to report that they were prepared for their treatment, which was important and influenced how many viewed the outcome and consequences of their treatment.

In the following chapter, I will describe and explain how participants talked about going through their treatment and how they used both information from professionals and information from family, friends and fellow patients during this phase. This leads to a description and explanation of participants’ accounts of the follow-up phase, which includes their accounts of finishing treatment and the role information played over the whole of their cancer trajectory.

**How people affected by laryngeal cancer source
and use different types of information over time:
a longitudinal qualitative study**

Volume II

**Chapters 6 and 7
and
References and Appendices**

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Chapter 6

Results

Treatment

6.1 Introduction

During the first interview, participants were currently going through their treatment, therefore the accounts they gave were influenced by their experience of symptoms at that point. Many discussed receiving information on various aspects of their treatment from health professionals based at the treatment centre and talked of sourcing and using experiential information from fellow patients whilst attending for their treatment. Both sources of information were used to help participants learn what to expect through their treatment, understand their treatment and its side effects and how best to manage or cope with them. As discussed at the end of Chapter 5, many perceived that they were aware of and prepared for their treatment based on the information they had received, however, it became apparent that the information they received did not marry up with the reality of their experiences. I describe participants' accounts of their experience of treatment and the role of information under one broad thematic heading, "culture of caring", in conjunction with four sub-themes, which are: "The mask", "Impact of treatment", "Myths and Misconceptions" and "Limbo".

6.2 Culture of Caring

This broad theme describes participants' accounts of attending for their treatment and the various health professionals that were involved in their care at this time. Participants discussed how they received various types of information to help them understand and manage the side effects of their treatment. It was evident how many experienced a "culture of caring" due to the caring attitude, skills and attention from various health professionals which they needed and welcomed. However, over the course of their treatment there were inconsistencies and gaps identified in the information from health professionals requiring this group of participants to source information from others in response to their specific needs and experiences at this time. Four sub-themes describe and explain the role of both categories of information at this stage in the pathway, as they were influential on how participants coped and managed their treatment. As described above, the sub-themes are: "The mask", "Impact of treatment", "Myths and Misconceptions" and "Limbo".

6.2.1 The Mask

All but one participant received radiotherapy. To begin the process of radiotherapy treatment and to allow for the correct targeting of the radiation beams, a "mould" is developed and fitted for each person. Those with early stage disease for whom radiotherapy was their first line treatment attended the "mould room" to have a mask fitted leading up to the start of their treatment. Those participants who had laryngectomy attended the mould room four to six weeks post-operatively.

The mask is a warm plastic sheet, placed over the individual's head and neck so that a mould is made to the contours of the person's face and neck. The mask allows the consultant radiologist to target the radium beams at the tumour site, thus preventing or limiting radium damage to other tissues and organs in the head and neck region. All participants discussed "the mask", however, the level of detail seemed to vary depending on their experience, and on the amount of information they had received about this procedure prior to attending. In many ways, many participants seemed to "fall at the first hurdle" as this was the first part in the process of their treatment and many discussed how they were not prepared for the reality of this experience.

Participants' general experience of "the mask" is depicted in the written account given by P15:

Awful, but it has to be done to get better, small price. The mask is claustrophobic, your head is strapped to a bench very tightly but you resign yourself and think nice thoughts. (P15, male T3, oesophagectomy and laryngectomy)

It became apparent through the accounts that there was either a lack of information provided on the procedure or a disparity between the information participants had received, linked with their understanding, leading some to have poor experiences. For example, the quote from P09 would suggest that he had received no information prior to attending for this procedure and needed the member of staff to explain and clarify the procedure in more detail:

I went for the fitting, I was a bit apprehensive, they [radiographer] just brought it out, it was all warm and they started to mould it round

your head and face and I said, "What's going on here?" He says, "This is just to ..." and he took another mask out and brought it in and showed me exactly what it was for, it was to keep your head in position while this machine wi' the laser zones thing and they are able to concentrate on and it's all marked in red pencil, so they can apply the machine to where they should. So once they had explained aw that tae me it was awright. I realise that a lot of folk are very reluctant on wearing it; I've heard some of them saying they're definitely no effing wearing it. (P09, T2 N3, male, chemo-radio)

The end of his quote highlights the emotional reaction of some patients attending for this procedure, which is evident in the following quote. P07 discusses how he did receive information about the procedure but found the reality of the experience quite different and very hard to manage:

The nurse and me, we started talking about getting a mask made and that it was, och, a mask and that's nothing. It wisnae until I goat up tae the hospital and the lassies explained exactly what they were going tae be dain. We'll lie you doon, we're going tae put plastic over you face and we'll be running it right back. I couldnae get the mask on, I'd been up three days in a row and the doctor says, "Look, you'll need to get the mask oan or else we might need tae cut your voice box oot." I just says tae him "It's no happening, I'll die o' cancer, but you're no cutting oot ma larynx, it's no happening. (P07, T1, male, radiotherapy)

The quote highlights the challenges faced with this patient on wearing the mask and the fear engendered by the prospect of laryngectomy. This participant was

eventually prescribed Valium to help him cope with wearing the mask, which was a common strategy that a few of the participants had to adopt, as highlighted by P12 in her written account:

*Hardest part was the mask I had to wear, was the worst thing I ever had to do, couldn't breathe, I took Valium tablet but still very scared.
(P12, T2 radiotherapy then laryngectomy)*

Her daughter continues:

My mum was in a state every day going for it, she, she was getting the mask, my mum's a bit claustrophobic and she was terrible because she was bolted to a bed, basically, and she couldnae cope wi' that and she's no one for takin' sedation. (C12 daughter of P12 T2 radiotherapy then laryngectomy)

These patients explained how they suffered from claustrophobia and how this procedure exacerbated this condition, something that appeared not to have been addressed or discussed initially by staff at the treatment centre. By having simple conversations about their concerns attached to this procedure could have alleviated some of the fear and anxiety associated with this procedure, as illustrated by P08:

I says, "You know, I'm a bit, not app – apprehensive is the word, not knowing, cause I don't breathe through my nose too well." She says, "Well, don't worry 'cause there's a place for your mouth, your nose and your mouth." I was so relieved. Now I realise it's so that they can get the laser perfect and not be, you know, eh, burning, if you like, anywhere else. But once I found out that, you know, that I could

breathe through my nose and my mouth, and they eventually cut out the eyes, the holes so that I could see what I was doing, I mean it was a weight off my shoulders. I was so relaxed, so relaxed. (P08, T1, male, radiotherapy)

The latter part of this quote highlights how there appears to be a lack of understanding with some participants on the purposes of this procedure and how only by coming through the procedure can they understand it. This theme was also underlying in P06's quote as he was "quite prepared for the mask once it had been made", suggesting that he did not understand the procedure fully until he had experienced it. He also highlights how the attitude and confidence of the staff carrying out the procedure helped him cope. For example:

I was quite prepared for the mask, once he'd made it. It was peculiar having it made, but once it was made it didn't matter so much, you know, again, it depends on the person that's operating the thing, who's doing it, they talk away and all. (P06, T2, male, radiotherapy)

The skills and attitude of the radiography staff were crucial to some participants as it enabled them to cope, allowing them to complete their treatment. P20 had suffered a panic attack when she first attended to have the mask made due to the attitude of one radiographer, as demonstrated in the following quote:

I took one panic attack, oh, that was the first one, aye, the nurse was raging at me... what a time for to spend with one patient. They're no nice, I'm telling you they're no. I took a panic attack, mind, it was the nurse's fault, I realised that later into it, but this one wuman – smart

arse in her fifties, she went "I'll dae this masel, I'm good you know," but I didnae realise that 'cause it was my first time that put me into the panic attack 'cause she was taking so long, open one side and then going away roond, it's supposed to be two aw the time! (P20, T2 chemo-radiotherapy)

Her quote highlights how she had no prior knowledge to understand this procedure "as it was *the first time*" with a lack of care and empathy shown by this member of staff which influenced her perception of an overall lack of "caring" by them being "*not nice*". Although she initially had a poor experience, she highlights how the skills and caring attitude of other members of staff helped her to complete her course of treatment:

The wee boy and lassie that done me the full seven weeks were absolutely fantastic, you couldnae have took a panic attack wi' them because they done it the right way and they were quick. (P20, T2, female, chemo-radiotherapy)

Some commented on how seeing the mask helped them understand the procedure as they had no prior understanding or knowledge, highlighted by P18 and her husband:

You werenae prepared for that type of mask until you had seen it, eh no?" (C18, husband of P18, T4 laryngectomy)

I did not think it would be so big. (P18, female, T4, laryngectomy)

Thus, their quotes highlight a lack of information and understanding on this procedure, as they had no concept of what the mask would look like; a common response by those who received radiotherapy after their laryngectomy. They

reported receiving no information about “the mask” and found it to be a painful and traumatic experience, as described by P13:

Naebody explained that tae me, what kind of mask it was, oh Christ, ah says, “Ah don’t want tae see it again.” I’ll tell you one thing that is the worst bloody part of the whole treatment being bolted to a table. It was bloody painful for the last two weeks, it’s doubled up. (P13, T3, male laryngectomy)

It is interesting to hear how someone who has come through a laryngectomy can perceive “the mask” to be the worst part of his treatment. This man highlighted in section 5.4.3 that he was prepared for his treatment based on the verbal information from the CNS, thus identifying a gap in his knowledge and understanding of his full treatment pathway.

In summary, leading up to their radiotherapy treatment starting, many participants discussed the value of information from professionals (MDT & CNS) and ex-patients to help them prepare for and understand what to expect during their treatment. However, for some, the information received was not enough to help them manage the reality of “the mask”. It seemed as if there was a lack of information from the radiography staff or an underlying assumption with them that participants knew what to expect and understood this procedure. Many appreciated the care, skill and attention of the staff during this time and the time they gave to help them cope and complete their treatment which, to them, illustrated a “culture of caring”. However, some experienced a lack of caring due to their specific needs not being addressed at this time, with the need for simple pieces of information identified that could have alleviated some of the fear and anxiety evident with this procedure. For

those who had laryngectomy then radiotherapy, there seemed to be a gap in the provision of information for this group, at a time when they were adjusting and coping with the challenges associated with this type of surgery. Many reported the benefits of “seeing the mask”, suggesting that a picture or video may help some patients to “know” what to expect when attending for this procedure as many commented on having no understanding on the “size” of the mask.

6.2.2 Impact of treatment

Once the mask was fitted and the treatment plan was complete, participants attended radiotherapy daily, for between four and six weeks. Participants discussed how they received and used information from health professionals, friends and fellow patients on the effects of their treatment and how best to manage them and to cope with the impact of their treatment in the context of their lives. It was evident how patients and their families moved between the different categories of information, sourcing specific information over the course of their treatment to tailor information specific to their needs based on their experiences of treatment.

It is not surprising that patients discussed receiving a lot of information from health professionals on the side effects of their treatment due to the complex clusters of symptoms they experience and how best to manage them, as addressed in Chapter 3. For example, P11 highlights how he knew what to expect from the professional information:

Well, they said “We’re really going to give you laryngitis, it’s a good big dose so don’t expect you’re going to get away with eh, eating the way you would normally.” (P11, T2, male, radiotherapy)

Others discussed how over the course of their treatment they had built up a relationship with the radiography staff which allowed them to ask questions regarding their treatment and on any minor issues they were experiencing, thus providing a culture of caring, as highlighted by P11:

Tell you what, you develop, obviously you develop a relationship with the girls that are doing radiotherapy and that’s a daily thing for six weeks just now, so that, I’m comfortable with going in there and any questions and that come to mind I just ‘em, ask them at the time. They either say I’m to ask at the next clinic or here’s an idea or whatever, so that’s fine, so there’s a continuum. (P11, T2, male, radiotherapy)

Similarly, P10 comments on how the staff were very good with him and how they had told him that the pain in his throat was to be expected:

Aye, they [radiographers] are very good, they jist give you the treatment. I asked them the other day, I mentioned my throat and they said it would get worse before it gets better, it’s just to do wi’ the treatment. (P10, T3, male, chemo-radiation)

A good number of participants discussed how they were beginning to experience the very unpleasant effects of treatment and how they were beginning to struggle. For example, P01 said:

I've had mair problems fae I've been getting ma treatment, it's, it's sore now; it's killing me, my throat. I think the treatment is worse than the disease. (P01, male T3, Chemo radiotherapy)

For those recovering from laryngectomy the impact of this treatment was profound through not only the physical impact of the surgery but also the psychological impact, evident in the following account. This participant gave me her written account of her first few days after surgery:

Day 1

All I feel is pain. Husband was with me all the time but I didn't know.

All I feel is pain.

Day 2

Still in so much pain, the worst pain in my life. My daughters come to see me and I feel like I am animal in a zoo. They talk to me and I can't talk back. I feel scared; I just want to scream at someone. Nurses at me all the time, even during the night - I have never slept. It's the worst pain in my life. My face feels swollen and sore. I can't talk have to write everything down, I just keep asking, "What do I look like?" I still keep trying to talk but I am not supposed to in case I hurt myself.

Day 3

Doctor looking at me again today said I am doing really well; I don't feel like it. Everything's been so quick I can't take it in. Doctor and nurses were in at me during the night checking my wires and for any

swelling. I feel pain when everything gets tighter and I get painkillers. The days go so slowly, all I do is lie on the bed looking into space and think about how I ended up like this. I am glad that I made it through the operation, for a minute I didn't think I would because of my breathing, it was so bad that the doctor had to put the trachea in first I was awake when he did it and it only took seconds. My face looks a mess now you think I've been battered. I hate this tube. Sister said not to use it at all anyway. I still haven't cried, can't get it out. I will never go through anything like this again. I don't know what I am going to do – what's my life going to be like now. I don't get tea or breakfast, I just watch everyone else I miss cups of tea. I have to learn to clean this tube; I can do it ok but find it hard getting it back in. I miss being normal, eating and drinking.

Day 4

I've had a pain in my side since this morning and am not feeling so good today. I feel like I don't want to go through much more. They gave me something for my bowels but now I can't stop going. I just feel drained and no energy. I have had a shower and managed myself but I don't think I can take anymore, just want to lose the head all the time. I am so angry and frustrated.

Day 5

The nurse tried to take blood today it hurt so much I jumped back. She told me she would let the doctor know. I am covered in bruises where I've been poked and prodded. I can't wait to get to my own

comfy bed, I have to sleep sitting up and I can't get comfy. I sit most days myself staring into space.

Day 6

I am still running to the toilet all the time, it's driving me nuts. I can't even wash my hair when I go in the shower. I just want to go home and be in my own house. I get so mad because I can't do things myself. Got staples out today felt a bit sore but not as bad as I thought it would be. Heard there is MRSA in ward – I am scared don't want to get a bug next don't think I could get better from that. Went for a walk with the physio and she said I am doing really well. So do the nurses, I am eating and drinking better.

Thus, the extract shows the profound impact that this type of surgery has on the individual. Not only do they experience the pain and physical impact of the surgery but the emotional and psychological disruption that is evident in the account. The sense of pain in the account is both physical and psychological with the process of loss evident in many areas of her life. The loss of voice is both physical and emotional, as she cannot communicate her anger and fear; she has to suffer in silence, to try to make sense of what is happening. She has no experiential knowledge to draw on and the information from health professionals that she is progressing does not resonate with her understanding as she cannot achieve the basic things in life, like having a cup of tea or washing her hair. She is searching to gain a “sense of normality” but finds herself in a “reality of uncertainty”; a theme that will be discussed further in the follow-up phase. She does not know what the future holds and how she will manage this process or be “normal” again. Although health professionals

provide her with information on her progress, what information can they provide that could prepare her for this surgery and help her manage the impact of the symptoms, both physical and psychological, that this account demonstrates?

In their interview, P18 and her husband highlighted how she discharged herself from hospital as she was tired and needed time to adjust to her surgery and was struggling with the prospect of attending for her radiotherapy:

Had enough. (P18 T4 laryngectomy)

She'd had enough and came home in her jammies and aw that. But that was when she got the dates for the Beatson and I don't know, doon in the dumps but you never missed one treatment. We got you through it, it didnae matter how awful you felt. (C18)

"After operation just wanted home for a few weeks, was so wishing I had not gone through with it [surgery], had enough. (P18, T4 laryngectomy)

Thus, these quotes show the fatigue, weariness and fear that laryngectomy patients experience knowing that they still have their course of radiotherapy treatment to go through when they are still adjusting to this life-changing surgery.

Going for radiotherapy treatment, many commented on how radiography staff were a source of daily information which helped them cope and relax, especially as their treatment progressed. The staff provided participants with information on the progress of their treatment, information on treatment side effects and information on how to manage the side effects.

However, participants also discussed attending a formal weekly meeting with clinicians, who assessed their pain, weight and neck burns, and discussed any issues they were experiencing. All participants found these meetings helpful and informative, but some suggested that their specific needs were not addressed, which left them unsure of what to do and how best to manage them.

Although many received plenty of information and “goodies” (medicines and creams) to help them to manage their symptoms, mixed messages on aspects of care on things like burns to their neck caused more problems, as described by P11:

No problems there and eh, useful advice each time about how your getting on eh, and ladling out various goodies. But then at the last clinic but one they said, “Oh, you know, you’re better not to take too much of water on,” on what was by now getting to be quite a sunburned neck. Which hadn’t really been the case until relatively recently, but because it was becoming more aggravatingly sore meant that I was applying this aqueous cream more and then because of the fact that my skin is fairly dry anyway it was eh drying up overnight and of course the cream would almost harden. It was getting really quite sore and the difficulty was being able to get rid of it because on the one hand they were saying “well you can use a cream and it’s aqueous but on the other hand you weren’t to use water,” so that the logical thing would have been to take a face cloth to the whole thing before it got eh, scabby and just clear and start again with the cream but em, there was a slight inconsistency there.

(P11, T1, male, radiotherapy)

This was also evident with C08, who describes the issues she experienced concerning her husband's neck and perceived a lack of detailed information that would have been helpful at this time:

His neck, I didn't realise until I happened to look at it the other night, I don't know how often he's meant to get this cream on, tae me, maybe cold water and dab it off. I said, "Why are you taking it off and putting more on?" You're just meant tae, I don't know how, he seems to be putting millions on it. I don't whether he's just tae pat it on, cause it always looks white. I assumed it would absorb or sink in, I don't know. I didn't expect it to get infected I must admit. I knew that it was going to be painful and I knew it would break out in sores and em [friend] told me all that. But no I actually assumed that, well, they told him how much cream to put on and then how often to put it on and that. (C08, wife of T1, radiotherapy).

Others discussed how they reported difficulty in swallowing during the clinic but received no information on how best to deal with this, as described by P10:

Well, it's when I swallow, Anne, it's sore but no, they say it'll go away once the treatment stops. Well, I spoke with the nurses and I seen a doctor today, I was telling him and he says, "That will, when you stop your treatment, it'll gradually go away." (P10, T3, male, radiotherapy)

Linked with the pain on swallowing were the challenges that many faced trying to eat and maintain their weight, which is crucial over the course of their treatment. Although many participants said that they had received plenty of

advice and information on what to eat, for some, the information and advice they received did not always work. A good example of this is provided by P16:

The dietician who is the diabetic dietician says to me, "Forget diabetes, forget anything about it," she says, "what ye want tae dae is starting eating cheese, butter, full cream milk, aw the stuff that will build yae up." She says, "never mind your diabetes, your diabetes is the least of your worries, take stuff that will build ye up." But I mean, I'm trying tae eat, it's just ma throat's that sore I cannae get anything doon, it sticks to it and that stuff they gave me, that doesnae help. See they gave me stuff and ye take that and it's supposed to put a lining on yer throat, it doesnae. As soon as you eat bread or something it takes it off it. Ye know, so I am trying to eat but I don't want to go in and get a tube in, I just don't fancy that idea. I'd rather struggle on and try and eat masel you know? (P16, T2, male, radiotherapy)

Similarly, others discussed how they perceived the written information to be wrong as they could not eat anything from the dietary information provided in the booklet due to the side effects of their treatment and knew the potential consequences of losing too much weight. For example, P20 highlights:

Told to eat puddings, it's the worst thing you can eat. As soon as you put pudding in your mouth it congeals. It (booklet) says eat custard, as soon as you put custard in your mouth it turns tae glue right away cause you've nae saliva, you've nae and the custard just goes like glue. He [CNS] just kept trying to keep me in cause o' ma

weight loss, I just keep running away from him. I mean the leaflets are all wrong. (P20, T2, female, chemo-radiotherapy)

These quotes would suggest that there are disparities between the information patients receive from health professionals and the reality of trying to follow that information in the context of their lives. It was apparent that these patients were using the information provided but through their actual experience of symptoms, it did not resonate with their understanding and expectations of what their symptoms should be.

Spouses, particularly wives, talked a lot of trying to support their husbands' eating, but sometimes felt a lack of detailed information to help them. For example, C11 said:

It's a tiny little quibble, I'm actually quite an enthusiastic cook so it was a challenge to me to ensure that he didn't lose too much weight. But, because I enjoy cooking it wasn't a challenge to produce different homemade soups full of lentils and chickpeas and loads of vegetables every day and then cook fish with different sauces every night but if I weren't a cook I think that might be quite difficult to make sure that the right food is going in, that it's all mashed or pureed or whatever. But there was no assistance about that apart from the CNS saying feed him on all things you've probably never fed him on like double cream and butter and stuff. (C11, wife of T2, male radiotherapy)

Thus, the information on dietary advice appears to be broad and generic with no specific information on what to feed patients on, with the challenges

associated of having the skills, knowledge and support to achieve the appropriate meals. Whereas, others described having different experiences and receiving advice and information from both professionals and friends to help them, as described by C15:

We have got a very good speech therapist here. She came with lists of things to eat and things that were suitable. But everyone is so full of ideas, even our butcher last week, he gave me two lovely recipes because I was running out of something to do. (C15, wife of oesophagectomy and laryngectomy)

From the above quotes, many reported receiving an “acknowledgement” from professionals at the clinic regarding their swallowing and/or eating difficulties conveying the message that it was to be expected over the course of their treatment. However, there appeared to be no “actual” information or guidance given by professionals addressing their specific needs in the context of their lives, with some spouses reporting a need for information on specific dietary advice.

Based on the lack of information from health professionals that resonated with some participants’ experiences of symptoms, many discussed how they accessed the appropriate information from fellow patients. They did not discuss going and actively seeking information from fellow patients, but rather, how they accessed information through informal discussions whilst attending for their treatment. The information exchanged during these conversations was invaluable in clarifying, or filling in the gaps, that helped this group of patients and their spouses manage and cope with the treatment and its side effects.

The interactions with fellow patients also seemed to provide reassurance and support as “*they were all in the same boat*” and there to help one another, as the following quote puts into context. When participants started treatment, they reported feeling like the “*new kid on the block*”, not knowing what to expect, where to go and who was who. Through the informal conversations with other patients they gathered these types of information which helped them to settle into the routine of treatment. The information from fellow patients in the first few days of treatment was invaluable and many described how it was reciprocated as they gave new patients similar information at the start of their treatment, as highlighted in P08’s account:

I mean, the first day I was like the new kid on the block if you like, because everybody more or less has the same time and you get to talk to them and you get to know them, let’s face it, we’re all in the same boat. A lot of new people in yesterday and I’m introducing, “How you doing, is this your first day? You’ll be fine.” ‘Cause you’re trying tae you know, a lot of people are, they’ll be the same as me as I was two weeks ago, a bit o’ what’s going to happen here, what’s - and you try and put them at ease, the way these people put me at ease and it’s a bit o’ camaraderie if you like, “You’ll be fine, you’ll be fine.” (P08, T1, male, radiotherapy)

Others talked about being “part of a club” with their fellow patients in which they exchanged stories and practical information as they arrived for treatment at the same time, providing them with reassurance and support, as described by P06:

Em, it so happens that we go with the same bunch practically every day, part of a club, you know, members, too, sort of thing, but you

know, it's good I think, that matters. Well, you're talking to people with similar complaints. I mean, on the one hand I'm talking to someone who is in exactly the same situation as me, on exactly the same programme, and he's had similar experiences right through, you know, it's quite nice to compare notes. (P06, T1, male radiotherapy)

For spouses, some of whom had no direct contact with professionals during their partners' treatment, information from other patients and *their* spouses was their main source of information. For example, P06 highlights how the interactions helped her fill the gaps on practical information that helped her manage the impact of her husband's treatment in the context of their lives:

I say you get the other information from the other people, you know, sort of we're filling in the gaps sort of thing. We're talking about what they're eating and how things like that, how they're sleeping. For instance, you didn't know anything about getting a thing for your throat, you hadn't heard about that and one of the people was getting it, so he could ask for that, you know. They're all a nice bunch of people and you know we tell each other things and things that perhaps, you know, ideas for food and things like that. (C06 wife of T1, radiotherapy)

Information from fellow patients was tailored to their specific needs, in contrast to the information from professionals, which appeared to be more generic. This extract from P20 makes this point:

I'm getting ma information aff eh, other patients. I've been awful sick and I was sitting talking tae this wuman in the radiotherapy and it's big clogs o' yella stuff aw stick tae it. She says, "Get a nebuliser that breaks aw that up," that's no even in the leaflets and it's naewhere tae be seen. So I went oan to my ain nurse up at the surgery, she goat me a nebuliser. Eh, and that stuff that they says freezes it I didn't know anything about that. Another patient there, I said, "This is murder," he said, "Take your medicine fifteen minutes," I said, "I don't get any medicine," so naebody had mentioned to me that you can get this. (P20, T2, female, radiotherapy)

The nature of the information provided by other patients seemed to be held in high regard because it was based on direct and personal experience, as highlighted by P09:

Having spoken to a lot of patients, especially when I was in for the five days at a time, you get to know everybody, sharing experiences, different things. I found it a big help, a big help. Well, I didn't realise at the time there's as much help about until you start speaking to these guys that have been in for longer than what I have and even their wives, they come in, they'll say, "My wife will tell you, you more about it [benefits]," plus what they went through and what you're about to go through prepares you better. (P09, T2 N3 male, chemo-radiotherapy)

Thus, receiving information from fellow patients based on their direct personal experience helped many participants manage and cope with their experience of treatment. This information resonated with their own experiences, therefore

they could relate to and understand the information in the context of their lives. However, not all participants wanted to share their experiences with other patients. P17 highlights how he was anxious to tell other patients about his poor experience of radiotherapy in case he frightened them or put them off going for the treatment, as highlighted in the following quote:

Up in the hospital and people get their operation then they go for radiotherapy, you know, and they were sayin' to me, "How is it?" I said, "Everybody's ...," I didn't want to tell ma experience in case ah put them aff it. I just said, "It was alright, you'll feel a wee bit ill," and I just said they might just get through it wi'out being. I said, that it was different for some people there, you wouldnae know they're ill. Some were ill and some werenae, they walked through it, it was a walk in the park tae them. (P17, T2, male, laryngectomy for recurrence)

This would suggest that patients who have had positive experiences of treatment or have had a positive outcome from their treatment feel happy to share their experiences with others. Patients may frame their own experiential information of treatment in a positive manner to maintain others' optimism, or minimise the amount of information exchanged to reduce anxiety and fear of the reality of the side effects of their future treatment.

P09 nicely illustrates how information from fellow patients helped him to make sense of and understand what was happening to him regarding his treatment. Knowing others are there who can understand and relate to the fear and shock of being diagnosed and the reality of what he was now experiencing was reassuring. Again, having "time" to reflect on the different types of

information is an important factor in allowing patients to adjust and manage the impact of their treatment:

I found a lot eh, sitting, talking at night, especially with him [man in next bed], because most of the guys were the same as myself, they were in for the first time but eh, speaking tae the patients that's been through it before is a big help. Well you get booklets and leaflets and you're still a bit confused in your mind trying to take everything in, you know, it hits like you a ton of bricks you know, when you're first diagnosed, speaking to someone in the hospital as you're going through, in a relaxed atmosphere at night, when you're sitting having your tea at night before turning in, you start to take it in a lot better, especially if you are lying in bed at night and all that sort of things just go through your mind. (P09, T2 N3 male, chemo-radiotherapy)

In summary, based on the information participants received from health professionals leading up to and during their treatment, many could initially manage their symptoms. However, as time progressed and the impact of their symptoms was beginning to affect their daily lives, many had to reinterpret them and seek confirmation from the health professionals involved in their care (Dingwall 1976). Many perceived that the information received conveyed mixed messages as it did not resolve the issues they were facing, which caused confusion and anxiety about the best way to manage their symptoms in the context of their lives. Others reported how they received an acknowledgement that their symptoms were indicative of their treatment and to be expected, with no "actual" information or guidance given by the health professionals at this time.

Although many attended the “formal weekly clinic” to have their symptoms assessed and their specific needs addressed, based on their experiences, many participants reported how the information was generic and not tailored to their specific needs as it did not resonate with their actual experience of managing their symptoms in the context of their lives. This is where the informal discussions with fellow patients helped fill in the gaps and rectify the inconsistencies through their experiential information gained from having direct experience of similar events. This type of information was invaluable to participants as it helped them to manage and make sense of their symptoms in the context of their lives by addressing their specific needs at this time. Those who experienced laryngectomy did not discuss drawing on experiential knowledge from fellow patients as many had “no voice” and were unable to communicate their need for information based on their experience of treatment. In addition, many were embarrassed by their appearance at this time and were still struggling with the psychological impact of their surgery, thus unlikely to communicate confidently with other patients at this time.

6.2.3 Myths and misconceptions

Although many participants discussed using information from fellow patients and found the information invaluable, the information conveyed is influenced by their own direct experiences and lay understandings of illness and disease, which may not always portray the correct or “true” facts about specific issues. This was evident in one person’s account who discussed the types of information, in his opinion, that all patients should receive when starting their treatment. His account highlighted the myth and misconception that he associated with radiotherapy and how this information was exchanged

through the informal “camaraderie” amongst patients whilst attending their treatment. This participant experienced inconsistency in the advice given and found that the information was not detailed enough for him and suggested exactly what would be good for patients to know about their treatment and the impact this would have on them:

I feel that, see, every patient that's diagnosed, they should be took in and explained and that, I mean, as I say, I'm cynical. I can live wi' it. I can work ma way through it, [but] there'll be people totally confused; but see, if they come in and sat doon, especially if they had somebody wi' them, a lot of them have goat somebody wi them, and explained to them exactly what's the matter wi' them, what's going to happen wi' the treatment, how the mask's gonnae work, how it's going tae affect them getting the mask oan 'cause aw the nurses say putting the mask on is the hardest thing for a lot o' people, especially wi; the throat cancer. Explain tae them what that's like, when it's going to be and then explain tae them what's going tae happen wi' the treatment. What's going tae happen tae their neck, how they are basically being cooked. There's people starting, arrived, the same ones we aw go in at the same time and they say, “You're first,” they say, “You're nuked, it's my turn tae get nuked,” and people don't know, they're going like, “What does he mean by nuked?” They don't realise that's exactly what's happening. It's radiation treatment, you are getting nuked. (P07, T1, male, radiotherapy)

This quote highlights his lay understandings or lay perceptions of radiotherapy due to a lack of knowledge associated with this treatment. This participant was unhappy and dissatisfied with his lack of involvement in his treatment decision during the MDT, as discussed in section 5.4.3. The lack of discussion and information provided by the team at that time could have perpetuated his lack of understanding of this treatment and his perception of how he was being “cooked” and “nuked”. His quote illustrates that, although there may be inconsistencies in the information provided by professionals, there can also be inconsistencies in the information provided by fellow patients, an issue that needs to be considered by others when using or relying on this source of information only.

Similarly, there were misconceptions associated with some participants’ understanding of their chemotherapy treatment. For some, their accounts identified how there was a lack of information on this process from professionals as both participants recalled how they had no understanding of what chemotherapy was and how they would receive it. In the following extract, P02 and his wife highlight the lack of knowledge and understanding they both had leading up to his first course of treatment and the impact this had on them. I had asked him if he had felt prepared going in for his treatment; he replied:

Not in the least. Hadn’t a clue. Hadn’t a clue.

I asked, “What would have helped you?” He replied:

I think the only thing, Anne, that would have enlightened me as to this is what you’re going to get is to be physically shown it on film on a ward of folk getting chemotherapy. But I’ve since even ... I’ve

since learned because I'm attending the clinic there are various types of chemo.

His wife continues:

See, I was ... I just thought chemotherapy was chemotherapy, it was a' the same.

He continues:

I thought that as well. But I didn't realise there's various ways ... maybe it is the same, there is one chemotherapy but there are various ways of administering it, that's what I couldnae figure out. I mean ... that Friday I went in for chemo I was overnight I had seven different bags, whereas the wee wifey I speak to in the morning at the other clinic, she's upstairs for two hours, goes back down, gets her radio treatment and buggers off home. How can I no dae that? Obviously, my case is totally different, you know. Any time I get chemo it's a long, drawn out process. Really, I didnae know anything about these, this wee stand I would have beside me constantly wi' a wee pump purring away a' the time keeping me wakened a' night. And this stuff going dripping into my body. I hadn't even an idea what I was going in for but I think the only thing ... I don't think anybody could have explained that to me to be honest. I think I would need to have been shown it or a film animate or something, a picture o' a woman standing wi' this thing wouldnae have helped me. I would need to have seen it, I would really need to have seen it. Again, as I said, I'm no the bravest man in the world but I can put up

*wi' a lot o' things you know. Whatever it is we'll handle it, you know.
I did, but I was greeting. (P02, T2, chemo-radiation)*

Similarly, P09 highlights how he had no concept of what chemotherapy was and how it was a fellow patient who informed him that he had received his first chemotherapy treatment:

See when I started my chemo, I didn't realise that chemo was done through the drip. It was a mystery tae me. I mean, it wasn't until one o' the other lads that was in the bed alongside me says, "How do you feel after your first chemo?" I says, "Whit chemo?" He says, "That wis your chemo you had." I didn't know that 'cause you were getting drips for dehydration an all that sort of thing. They [staff] were just coming in and changing it over and putting you in and giving you a jag, away they would go, I didn't even realise. (P09, T2, N3, chemo-radiation)

These quotes illustrate, at first glance, a lack of information and explanation given to these participants by health professionals involved in their care as they were unaware of how the process of this treatment works. The comment by P02 that he would need to have "*seen the chemo being given*" and "*it was a mystery*" by P09, suggests that when a concept is so unfamiliar to a patient's lay knowledge, the information does not resonate as they do not have the knowledge to understand it. I doubt that these participants did not receive any information regarding their chemotherapy treatment but suggest that due to their lack of knowledge or limited knowledge of chemotherapy they could not draw on any prior knowledge to try and understand the information from health professionals, similar to some participants' experience of "the mask".

Equally, the description given by P02, about *“the purring of the machine and this stuff dripping into my body”* shows the profound effect this treatment had on him due to a lack of knowledge and understanding, causing him *“to greeet”* (to cry). A lack of knowledge was highlighted because he did not know exactly what was *“dripping into his body”*, with P09 highlighting, *“I didn’t know that ‘cause you were getting drips for dehydration an all that sort of thing”*, illustrating the implicit trust that these participants placed in health professionals and the *“illusion of certainty”* their knowledge provided.

This data show that there is a lack of information about chemotherapy treatment from health professionals that patients understand, which can have a profound effect on their view of this treatment.

There were also misconceptions identified on the use of analgesia from the information provided by health professionals and how it was situated in the context of participants’ lay knowledge and understanding of pain relief. As discussed earlier, many had trouble with swallowing due to the pain in their throat as their treatment progressed and had been prescribed analgesia to alleviate and help with this pain. However, there seemed to be misunderstandings around how best to use their analgesia, as illustrated by P01:

P01: I’ve been taking eh, paracetamol, painkillers, but you’re only supposed to take eight o’ them, I’m taking eight o’ them in the morning, if you know what I mean. So by the time the night comes I cannae take anymore and it’s just, feels worse.

Interviewer: Have you spoken to anyone about your pain?

P01: Naw, I'm going to speak to them the morra when I go into the hospital and tell them. (P01, T3, male chemo-radiotherapy)

The quote highlights how this participant did not understand how best to manage his analgesia or how he was on the wrong analgesia to control his pain. Others discussed a lack of clear instructions from professionals associated with their fear of drug addiction. For example, P02 reported being very anxious about taking morphine due to the vagueness of the instructions and his lay knowledge and understanding of its association with drug addiction:

It [throat] was sore aye, I think that's when they put me on the Severadol, eh breakthrough pain and it was, it was a bit vague, em, how many of these I could take and I was a wee bit worried. I mean, I've never been into drugs or anything like that apart from medication. I was taking them and they were working but I was worried about them and I went to the GP and I asked him "How many of these can I take?" And he said "Blah, blah, blah," to cut a long story short, "Four a day so all you've got to do is space them out," it wisnae enough and then we had to go back and see CNS and the doctor. They were quite adamant about that, "I don't want you having pain, the pain relief is to stop the pain, you know," and she [CNS] virtually says "As many Severadol as you need." She explained, "You'll not get addicted to morphine as long as you're in pain, the morphine will do its job. You'll get addicted if you take morphine wi' no pain, then your body will get used to it." I still don't like this much morphine I'm having. (P03, T1 chemo-radiotherapy)

The extract highlights how he did not fully understand the information he initially received about the amount of tablets he should take, with the GP providing cautious information that did not alleviate his pain. This information, in combination with his lay knowledge and understanding of morphine linked with drug addiction, prevented him from taking more tablets than he thought was socially acceptable. It was only when he received the sanction from the CNS and the doctor, "*they were quite adamant*", that he felt justified to take as many tablets as he required to ensure he was pain-free, knowing then that he would not become addicted.

The myth and misconception of addiction to morphine was also identified with P09, not from his lay knowledge or understanding, but from the inconsistent information from nursing staff, which made it difficult for him to manage and understand what he should be doing, as highlighted in the following quote:

Aye, I mean the soreness and that, I've accepted that's part o' the course you know, they've told me this will happen and the CNS will tell me to go back on the morphine but in the hospital they [ward staff] were telling me, they were trying to cut down on the morphine. I thought it was just their opinion you know but then when I was saying to someone, "Oh naw," she says, "it can be addictive," but if you go downstairs then the other wee nurse was saying "By all means take that," and they give me more to take home. In my opinion, if somebody asked me advice on electrical I'd give them advice, so I believe in what they say, so you can only presume that

they know what they're saying, but some I don't. (P09, T2 N3, male chemo-radiotherapy)

His quote highlights how the inconsistency in the provision of information from the CNS and ward staff made him question the reliability of the information. He implies that he knows his job; therefore, they should know theirs and provide the correct information to patients as they possess the knowledge to know best. It is surprising that the myth and misconception of addiction to morphine is still evident. This highlights a lack of education with some members of staff, which the CNS is in a prime position to address.

In summary, these data suggest that there are myths and misconceptions surrounding treatment regimes and analgesia with this group of participants. A lack of lay knowledge and understanding of the process of radiotherapy and chemotherapy prevented some patients being able to situate the information from health professionals in the context of their knowledge, leading to misconceptions and misunderstandings. This highlights the need to look at innovative ways to communicate information to patients, specifically with regards to chemotherapy, so that they can understand these treatments in the context of their lay knowledge and understanding to resolve the misconceptions associated with them. Equally, there is a lack of knowledge and understanding with some members of ward staff regarding the addictive nature of morphine that needs to be addressed with the CNS in the best position to inform and educate members of ward staff.

6.2.4 Limbo

This sub-theme describes how many participants felt prior to completing their treatment due to the lack of clear information and communication on what to expect over the coming weeks and months in the follow-up phase. The lack of clear information caused many to feel anxious and to experience a feeling of being in “Limbo”, as described by P11:

The one thing that they are a bit diffident about, and you can understand why because it must depend very much on the individual case or the severity of their symptoms and so forth was, well, obviously, one knows exactly when the treatment is coming to an end, i.e. Monday, em, what they're not prepared to say is, “Oh yes, it'll be a fortnight after that before you'll be eating your steaks and drinking your red wine again,” or anything like that but eh, when you push them they say anything, “Oh, it could be two weeks, it could be four weeks,” and they vary, to be honest, the assessments of that, but basically, that's the deal and they've been clear about that but in the intervening period between now and then is just limbo again. I think the next what I call “big pow-wow” is going to be at the ENT and that's fine, the only question marks that are on the horizon is what happens between now and then. (P11, T1, male, radiotherapy)

“What happens between now and then” was a worry for many, as they talked again about the disparity between the information they had received and what their actual experience could be. For example:

The nurse told me yesterday when I was getting ma treatment the next week tae ten days is going to be the worst bit even though my treatment's finished. I thought, OK, a fortnight after aw that redness would be away, naw, naw, naw, up tae six weeks, maybe longer. I mean these are aw things you've goat tae be told. (P07, T1, male, radiotherapy)

Although some knew they would continue to experience symptoms once their treatment was finished, they did not know what to expect initially, post-treatment:

I've been told it'll be like after the ... six-and-half weeks after that before the radium sort of leaves your body and that's the day we don't know what's going to happen after that. I'm hoping this team, they'll be able to say "Right, next week's your last." I presume I'll come back in a month or something like that and have a talk. I understood right at the beginning, I think it was the CNS, so after the radiotherapy treatment is that when we'll know the yeah or nay? "No," she said, "there's another six weeks after that," because I didnae think. I just thought radiotherapy, oh right they can blast it or whatever but she said, "It's a build-up," I think, and it's still even though you're not receiving it, it's still doing its job. (P02, T2, male chemo-radiotherapy)

Similarly, P20 knew this was the "worst time" from the written information, but the lack of clear information on what would happen and who to contact caused her to feel apprehensive and unsupported:

I know exactly what I'm going through the now is the worst time; I knew that by going by the leaflets, this is actually worse than getting the treatment. They [treatment staff] just said "cheerio" tae me and then I got a letter saying I was to go back up to the outpatients. CNS at the treatment centre did say that I was handed back ouer to ma first CNS. No had any contact fae her. CNS just told us that we [daughter and patient] would get sent there and never telt us what would happen, didnae even phone. (P20, T2, female, chemo-radiation)

The lack of clear information and communication from professionals at the end of treatment caused many to feel vulnerable, as they were experiencing treatment side effects becoming worse with no source of information or contact evident. After an intensive phase of treatment and information from a variety of sources, there was a sudden void of information and support to help them make sense of and understand what was going to happen. At the end of treatment, participants understood that their symptoms would, "*get worse before they got better*" based on information from various members of staff during their treatment. However, many reported a lack of detailed information from professionals about what to expect post-treatment leading to their first follow-up appointment. After receiving a wealth of both verbal and written information from a wide range of health professionals and fellow patients, many finished their treatment feeling apprehensive and unsure; they were leaving a place of security and entering into "*limbo*".

In summary, I have described participants' accounts of the information they received and used over the course of their treatment under the

broad theme of “Culture of Caring”. Many discussed how the written and verbal information received prior to treatment had not prepared them for the reality of their treatment experience, specifically the mask and, for some, chemotherapy. Many commented on how the attitude and skills of treatment staff and the way in which they had provided the information had reassured them and provided them with a caring and supportive environment. However, as treatment progressed and participants’ symptoms were affecting their daily lives, much of the information received did not resonate or match with their actual experiences and many commented on how the information did not meet their specific needs at that time. Although many received an acknowledgement of their symptoms, the information given by health professionals informed participants that their symptoms were to be expected in the context of their treatment.

In contrast to the prescriptive manner of the information from health professionals, information from fellow patients was subjective and specific to their needs, focusing on support and the practical aspects of managing the side effects of their treatment in the context of their lives. Many participants talked of incorporating information from professionals and from fellow patients to help make sense of and manage the impact of their treatment. The information from fellow patients filled gaps and inconsistencies, suggesting that information from professionals is not consistent and may not be imbued with such a trust as that based on actual, verifiable, experience. However, it was noted that information from fellow patients can include misconceptions and misunderstandings that need to be addressed and dispelled by health professionals so that correct information is conveyed and understood in the context of lay knowledge and understanding on aspects of their treatment. Over the course of treatment,

participants had access to, and were able to, source a wealth of different types of information depending on their needs which provided them with security and reassurance. However, at the end of treatment it became evident there was a lack of information and communication from health professionals as many participants commented on how they did not know what to expect, leaving many feeling uncertain and vulnerable and perceiving they were entering “limbo”.

Follow-up

6.3 Introduction

The second interview took place approximately six months after participants had completed their treatment. Two patients died during the follow-up phase. During this interview, I asked participants to discuss how things had been since the first interview, what information they received into and during follow-up, and their view of the information they had received since their diagnosis.

Many talked about their experience of symptoms initially post-treatment and how they managed them based on the information they had received from both health professionals and fellow patients during their treatment. Many had attended several outpatient appointments by this time and discussed the different types of information they had received from the consultant and their CNS. Participants' accounts differed and were influenced by their experience of symptoms initially post-treatment and the information they had received from the consultant in combination with the consequences of

their treatment in the context of their lives. All of these factors influenced how they reflected on the information they had received since their diagnosis and the reality of their actual experiences.

Three broad thematic headings describe and explain how participants used both categories of information (experiential and professional) to try to help them make sense of the impact of their treatment and their experience of post-treatment symptoms in the context of their lives in this phase. It was evident at this point in the pathway that there was a relationship between themes discussed earlier in their trajectory and the reality that they were now experiencing. In many ways, participants discussed a continual “search for normality” to explain their post-treatment symptoms in the context of their lives. In contrast to the “illusion of certainty” that so many had perceived at diagnosis, many now experienced a “reality of uncertainty”, with the information received from health professionals being vague and ambiguous, leading to a sense that information was “lost in translation”. All of these factors led many to experience a diminished “culture of caring” as they experienced feelings of frustration and disappointment because their actual experiences did not resonate with their expectations based on the information received at diagnosis and during treatment, leading some to experience living in a constant “reality of uncertainty”.

6.3.1 Search for Normality

This theme describes the different strategies that participants adopted to explain and understand their physical experience of post-treatment symptoms in the context of their experiential knowledge and understanding

gained through their direct experiences of treatment and the information they had received during this time. At this stage, many seemed to “normalise” the severity of their symptoms based on the information they had received from health professionals in addition to drawing on others’ experiential knowledge. Under this theme there are two sub-themes showing how people affected by laryngeal cancer responded to their experiences of post-treatment symptoms to interpret what was happening and what they understood in the context of their lives. These are: “worse before it gets better” and “time”.

6.3.1.1 Worse before it gets better

From the accounts given by participants, it was clear that many assumed their initial post-treatment symptoms were normal or to be expected in the context of their treatment. This assumption was based on their new experiential knowledge and understanding gained from the information they had received from health professionals and their direct experience of their treatment. Through the process of recognising, interpreting and responding to their physical symptoms, participants responded by perceiving them to be “normal” based on the information that their symptoms “*would get worse before they got better*”. Few participants recognised their post-radiotherapy symptoms as serious enough to lead them to seek information from their CNS or treatment centre staff initially after completing their treatment. Some participants reported experiencing severe symptoms, which they assumed was an inevitable part of the treatment based on their understanding of this information, as P17 highlights:

For six weeks after it [radiotherapy] I was ill, violently ill, and I thought it was just part o' the treatment. I couldnae eat, and pain – oh. I had nae appetite, some days were murder. (P17, T2, male, radiotherapy 1st, laryngectomy for recurrence)

Others tolerated and suffered severe symptoms initially post-treatment, oblivious of their severity, which required admission to hospital:

My valve was leaking and they took it out in outpatients [at treatment centre] and put feeding tube back in. Of course, when I came home I went to see CNS at my review and she wanted to keep me in there and then. She [CNS] took me into ward because I had grade four burns. I was having my neck dressed morning and night and after two weeks in hospital I was home again. (P14, female, T3 laryngectomy & radiotherapy)

C02 highlighted how the impact of her husband's post-treatment symptoms meant he had to be admitted and have a nasogastric tube inserted:

He [doctor] says "I think we need to get you in, I think it would be best for yourself to get you in." That was because he had got his throat, it was so sore at this point he couldnae swallow, he couldn't swallow. He couldn't even take a drink of water by that point and because he wasnae able to eat enough to, you know, so that was the reason they put it [ngtube] in. (C02 wife of T1, chemo-radiation)

P16 and P02 highlight a general comment made by many about how they did not expect their post-treatment symptoms to be as severe. They understood that their symptoms would get "worse before they got better" but did not

appreciate how severe they would become, based on the information received over the course of their treatment:

I didnae think it would be as bad, naw, naw I didnae think it would be as bad as it was, because I burnt aw ma neck as well. (P16, T2, male radiotherapy)

If he [consultant] said to me well, maybe he told us in no certain terms that you can actually feel worse after the treatment for anything up to six weeks, eight weeks you could feel really bad, I mean the burns, the dry mouth, you know these things, it was never made clear what sort of nick my throat would finish up in. (P02, male, T1, chemo-radiotherapy)

Thus, the information and knowledge gained to this point, allowed many participants to experience and cope with severe symptoms based on the information that their symptoms “would get worse before they got better”. Many suffered in silence, perceiving their symptoms to be “normal”, even though they were affecting their physical functioning and affecting their daily lives. This is in stark contrast to how participants responded to their initial experience of symptoms in the pre-diagnosis phase. Based on their experience of post-treatment symptoms, participants did not respond by actively seeking information from others, even though their symptoms were affecting their physical functioning and causing pain and discomfort. They explained their symptom experience based on the information gained from health professionals that they would experience their symptoms becoming worse, thus normalising them in the context of their experiential knowledge gained through their

treatment, and continued to suffer and cope, adopting a wait-and-see strategy until they were “officially” reviewed (Dingwall 1976).

Participants commented on how they had to endure their experience of post-treatment symptoms much longer than they had expected based on the information given by health professionals. P16 and his wife described how, on reflection, this information does not give a true account of the reality of their actual experiences:

Aye, but they, what they did say to me was, when I asked them about the dry mouth, “Oh, that will clear up in six to eight weeks,” and I mean, that’s away [meaning more time has passed than that] ...pfft!! It’s still there, it’s no as bad as it was but I’ve still got it, eh. Even ma own doctor said to me that “It doesnae stop working, it works oan yae for months and months.” I says, “Well, they didnae tell me that.” You see, if they don’t gie you the information, I think they should tell you how long. (P16, T2, male radiotherapy)

C16: You felt angry at the idea, they told me it it’d be away in six weeks, how is it no away in six weeks?, now I would say about six to eight months. (C16, wife of T1, radiotherapy)

There is a big difference between being prepared to suffer treatment side effects for six to eight weeks in comparison to suffering them for six to eight months. The account shows the interaction between couples drawing on the information from professionals to try to understand their symptoms or “normalise” them in the context of their understanding. It also illustrates the impact on carers when the outcome of treatment is not what was expected

based on the information they received. The length of time patients experienced their post-treatment symptoms played a major factor on how they used information as they discussed drawing on others' experiential knowledge to try to regain a sense of normality at this time. The following sub-theme highlights the challenges that this presented to them and the impact this had in the context of their lives.

6.3.1.2 Time

The length of time participants experienced post-treatment symptoms made them question whether their symptoms would become part of their lives and become the "norm" that they would need to deal with in the future. As the quote from P20 highlights, even though she had received information that had been explained to her about her symptoms, due to the length of time she and others had experienced their post-treatment symptoms, she perceived she would be experiencing these symptoms for the rest of her life and that this would become her "normal":

Oh, aye, oh, aye it was all explained but I didnae think it would, would have went oan as long. I mean there's a man went through it two year ago, I'm in contact wi' him, he's still sair efter two year and I'm like, "Flippin hell!" Efter two year? Naw, they don't tell you how long. So to me it's just a thing you've got to have for the rest of your life really fae the sounds o' it anyway. (P20, female, T2, chemo-radiotherapy)

Similarly, P08 highlights how he drew on experiential knowledge from others who had suffered similar experience of symptoms since their treatment to help him realise that he would have a “sense of normality” through time:

I know people that's had it done, the same, I spoke to people and their voice is back to normal. People three, four years ago that's went through it, but their voices are back to normal. People I know that's had the same, they're plagued with mouth ulcers as well and I'm hoping it's just gonna be in time, I don't know. (P08, male, T1 radiotherapy)

With P02, highlighting how the prospect of suffering post-treatment symptoms for many years frightened him and how this could become his “normal” drawn from the experience of knowing others:

There was one guy in a wee pub I used to go into, used to go in, eh, he had throat cancer about 15 years ago but trying to get a sensible word out of him, it's no easy, he just kept saying, “Oh, it takes a hell of a time, takes a hell of a time.” The thought of this, Anne, for the rest of my life, it frightens me, it does frighten me. (P02, male, T2, chemo-radiation)

The accounts highlight how participants drew on others’ experiential knowledge to gauge how long their symptoms may last to try to regain a sense of normality or to understand what may become their normal. Their experience of symptoms was contrary to their expectations based on the information received from health professionals. Due to the fear associated with the prospect of experiencing post-treatment symptoms for a long time, many participants

needed information from health professionals to clarify or help them make sense of their situation; there was a real sense of uncertainty for the future in so many of their accounts.

However, the reality for many was that information from health professionals was vague and non-committal, as no one could provide them with exact information on the length of time they would experience their symptoms. Participants at this point needed definitive information from health professionals to know how long their symptoms would persist or last, in order to know what to expect in the future. Many discussed how they received “weak” explanations, blaming their treatment, like P02 and his wife, and how that information was viewed as “vague” which caused anxiety and worry for the future:

Yeah, radiation, everything gets blamed on radiotherapy, might get better, it might not, everybody's different, it's just a matter of time, vague, extremely vague. I don't understand, there's nobody wants to say "next September you'll be fine." (P02, male, T1 chemo-radiotherapy)

His wife continued;

That's our kinda worry at the moment; if somebody could say, "Right, you'll be like this for a year and then it'll get better," but it's just the vagueness. (C02, wife of T1, chemo-radiotherapy)

From the quotes above, it was evident how there was a disparity between the information provided from the health professionals and the reality of many of the participants' actual experiences in relation to the time they suffered the effects of their treatment. Living with the long-term consequences of treatment

and receiving vague information from health professionals led many to question and doubt the information they had received because it did not resonate with their expectations drawn from the information received, leading some to feel disappointed, as highlighted by P08:

Fine, back to work, back to work coping very well, great to be back but disappointed that my voice after six months down the line isn't really any better. I'm disappointed in a lot of things to be honest, Anne, I've got a swelling I've been concerned about and I've been to see the consultant, they never told me about it. I've now got to sleep with a plastic bucket at the side of my bed because there's, no easy way of saying this, the crap I bring up during the night is terrible, emm, and as I say, my voice, I would thought six months down the line after the radiotherapy it woulda been a lot better. (P08, male, T1 radiotherapy)

The disappointment is evident in this quote, as this participant had adopted a strategy of going back to work to try to regain a sense of normality. However, due to the length of time he experienced symptoms, in addition to suffering symptoms that he did not expect which had a major impact on his life, in conjunction with his voice not being back to normal, led him to feel a deep sense of disappointment. This disappointment was based on his actual experience of symptoms and how they did not resonate with his expectations of being “back to normal” based on his understanding of the information he had received. His wife highlights how they had both expected everything to be “back to normal” based on the information they had received since his

diagnosis and during the follow-up consultation and how disappointing the reality they were experiencing was at this point:

I think he's disappointed in the fact that he has come through the radiotherapy, he assumed then that when he got the all-clear that was him. I think he thought immediately he'd be back to normal and his voice isn't great either. I actually think it has got worse now than when it was a couple of months ago. As I said, I think he expected and so did I, to be frank, that it would get, as the weeks and months went on, everything would go back to normal. I was with him the day it was all clear, the tumour had gone from his vocal cords. (C08, wife of T1, radiotherapy)

The point made in the latter part of this quote highlights the association made between being told they were “clear” and how everything therefore should be back to normal. This is linked to the “illusion of certainty” that many had perceived from the information they had received at the MDT, that their life would be back to “normal” after finishing their course of treatment and that their cancer would be “cured”. For a small number of participants, this was the case, as highlighted in the following quotes:

All going according to what they told me it would be like. I know I'd be grating, and they told me I might lose my voice altogether, so that didn't happen, so I was ahead of the game. (P06, male, T1 radiotherapy)

They [MDT] told me, they told me you will be cured, within 30-40 days and he [consultant] was really, he says “Ah promise ye that,” and he was spot on. (P05, T1, male radiotherapy)

In many ways, the information they had received at their diagnosis had met their expectations and cancer was not dominant in their lives any more, as highlighted by P19:

I've been getting good feedback from the hospital, I was there last week and Mr X who performed the operation had a good look about and everything seems fine. Aye, quite pleased about the way things have went, feel a lot at ease now after getting the, think when I'd been in for the second, everything was looking good down there and I was sort of relieved. So I just get on with things now. The novelty has worn off, don't think about it as much now. (P19, male, T1, laser surgery)

However, this was not the case for the majority of participants and, due to their prolonged experience of treatment side effects, in conjunction with a mismatch of information from the health professionals involved in their follow-up care that did not resonate with their actual experiences, they were propelled into a “reality of uncertainty”.

6.3.2 Reality of Uncertainty

This theme describes how the information many participants received at their diagnosis and during their follow-up from health professionals, in combination with their actual experience of symptoms, caused them uncertainty and ambiguity for their future. There seemed to be a mismatch

between the information they received and what they were actually experiencing, therefore, the information did not resonate with their understanding. This mismatch and ambiguity could be partly explained by the use of two words that influenced how many participants perceived the outcome of their treatment, “cure” and “clear”.

6.3.2.1 Cure versus Clear

As highlighted in the introduction (6.3), many had attended follow-up clinics where they had been told they were clear and everything looked fine, as illustrated by P09:

The radium, oh aye, aye ... I finished all that obviously and eh, they gave me the all-clear, aye I'm, I'm still attending that ... the hospital, but eh, he [consultant] gave me the all-clear... and said that eh, he couldn't find any traces o' a cancer and that he was quite happy with it. (P09, male, T2, N3, chemo-radiation & surgery)

However, for those participants who were still experiencing post-treatment symptoms, being told they were “clear” did not resonate with their expectations or understanding leading them to experience a sense of uncertainty. This was linked with their actual experience of symptoms at this time in combination with being told at diagnosis that their cancer would be cured, as illustrated by C08 and P20:

I mean, I don't know if I've still got cancer or if I'm in remission, I don't know. I don't know if they've cured the cancer....so I don't know if it's cured or if it will come back, I just live from day to day. (P08, male T1, radiotherapy)

I've no picked up, no the weight loss or anything, they've no picked up in any way. They just put the camera doon and look at it. They don't really say anything, they just say, "Right, that's fine," they've just said that they're happy with it. (P20, female, chemo-radiation)

Thus, being informed that "it is clear" but still experiencing symptoms leads to uncertainty, a concern that did not seem to be addressed by health professionals involved in their care at this time. In many ways, participants expected to be told that the cancer was cured but being told everything was clear, in combination with their experience of symptoms, led many to experience a reality of uncertainty. The "reality of uncertainty" during the follow-up phase was very evident with those who had had laryngectomy. The impact of their post-treatment symptoms was profound and the uncertainty they experienced evident due to the lack of clear information from health professionals on what the future outcome would be, as highlighted in the following quote by P12:

Sometimes I wonder if I will ever get rid of the tube in my stoma, I feel it will always be there as no one says any different at clinic when I go to appointments. (P12, female, T3, radiotherapy first and laryngectomy for recurrence)

Thus, when information is not received from health professionals to explain or clarify what is happening or going to happen, then patients will draw on their own experiential knowledge in an attempt to minimize the uncertainty they face. This experience led some participants to feel that information conveyed by health professionals and from them to health professionals involved in their care at this time was lost in translation.

6.3.2.2 Lost in Translation

This sub-theme describes how information from the MDT at the participants' diagnoses was "lost" due to the amount and timing of that information and how carers and the CNS played a vital role in filling in the gaps and providing and clarifying information. However, at this point in the pathway it was apparent that information was "lost" due to the use of professional language not resonating with the patients' understanding based on their actual experience of symptoms or that the language conveyed by participants was not heard by the health professional in order to provide clarity or explain their experience of symptoms at this time.

For example, P20 gave an account of a consultation she had and how the language used by the professional was too medically orientated, as she did not know what the word "benign" meant, therefore did not understand the information she received, which left her uncertain of her future care:

I was at the thyroid clinic a couple o' weeks ago and I got the ultrasound and aw' that but they don't tell you nothing either, he just says that eh, "The nodule's still there, it's solid but it's no grew in any way." That's aw they tell yae, they've no said if I've to get it oot, when the operation is, they just done the ultrasound and I says "What's happening?" He says, "Eh, well, the nodule's still there", it's still a solid nodule but it's no grew since April fae I first got the ultrasound but I think it's benign but I don't know, don't know what that means. So, so I don't know what they're going tae dae wi' it.
(P20, female, T2 chemo-radiotherapy)

Her opinion, “*they don’t tell you what’s happening*”, clearly emphasises a lack of knowledge and understanding due to the language used. There is a lot of clinical information conveyed in this account but, due to her lack of knowledge and understanding, the information does not mean anything to her, causing her to feel uncertain of her future care. In many ways, this participant was expecting to be told that she required surgery to remove the thyroid based on information she received at her diagnosis (see section 5.2.2.1, p. 170). The quote highlights how the health professional used language that did not resonate with her experiential knowledge and understanding and did not ascertain during the consultation whether the patient had understood the information, thus leading her to the opinion that “they don’t tell you anything”, which left her with uncertainty, as was evident in this account.

In contrast, others described how *they* perceived that the health professionals did not understand the language *they* used based on their prolonged experience of symptoms. P02 describes how he continued to have post-treatment symptoms that were affecting his daily life and sensed a lump when swallowing. He perceived that the consultant did not believe him based on the repetitive comment of “it’s fine, it’s healthy”:

Still get pain yet, and swallowing is, I keep telling them I think there’s a lump there or some sort of ridge or ledge or something, but eh, I don’t think they ever believe me. Mr X [consultant], he’s put the camera down, he’s happy that the inside is fine, is healthy. There’s something there, well, I feel there’s something in there, you know. Although the radiation also affected my thyroid gland on one half, it’s no working right and it’s swollen. This possibly could be what I’m

feeling resting in my throat, I don't know. (P02, male, T2 chemo-radiotherapy)

The quote emphasises how being told everything is “fine” by the consultant did not relieve the uncertainty he was experiencing as it did not resonate with his actual experience of post-treatment symptoms as he was not “fine”. The consultant appears to focus only on the terms “clear and healthy” and not on the “uncertainty” that the other symptoms were causing this participant in the context of his life. It could be suggested that P02 was drawing on his experiential knowledge, gained through the direct experience of his treatment, to know that something was wrong, thus causing the uncertainty and the feeling of scepticism of being told that he was fine.

Similarly, P20 highlights in the following quote how her experience of symptoms had not improved and how the information from professionals involved in her care was not helping her to progress and manage her symptoms. Being told everything was “fine” did not resonate with her experience, as she was not “fine” through her inability to eat:

I've no picked up, no the weight loss or anything, they've no picked up in anyway. They just put the camera doon and look at it. They don't really say anything, they just say, "Right, that's fine," they've just said that they're happy with it, I mean, it's terrible, I can take porridge but everything else is hopeless and it's no for the want o' trying and at the hospital aw they dae is send yae tae the dietician. She just sits and tells you the same thing over and over again; she just sits there and talks a lot of twaddle. I mean we awe know what kind o' food that's oan it [leaflets] we aw know we can dae that, I feel

*like saying tae her “look I’m no f***** stupid, I don’t need somebody to tell me **what** to eat, I need somebody to tell me **how** to eat. (P20, female, T2 chemo-radiotherapy)*

She describes how she was told “*what*” to eat but not “*how*” to eat, which was her main need at this point. She had experienced these symptoms for many months with no obvious progress and needed practical information and advice from the dietician to help her manage her symptoms in the context of her life. It is evident from the quote that she had used the information provided by health professionals in an attempt to improve her weight loss. However, the dietician had not explored her specific experience of symptoms and appeared to provide generic information that did not help her manage her symptoms, i.e. learning to swallow again, thus the information from the dietician was lost in translation as it did not resonate with her understanding or help her to manage her actual experience of symptoms.

In addition, who to contact seemed to be “lost in translation” as there was a lack of communication and information from health professionals in the follow-up phase in contrast to the level of information and communication that participants reported drawing on at their diagnosis and during their treatment phase. Many reported how they called the CNS to clarify information on aspects of their treatment or to check on treatment appointments and, at times, as C06 said, “*answer the quirky things*”. This was not evident with the majority of participants during the follow-up phase which will be discussed in more detail later in this section. At this time point there seemed to be a lack of understanding of “who to contact”, as highlighted by C08:

It's just now when he's finished, as I say, I'm more than happy with the treatment and he's been, you know, happy about it, but the only thing, as I say, is just after the treatment finishes, when it doesn't all fall back into place a hundred percent, then it would be nice just to phone somebody up and say, "Look, is this normal? or, "When can I expect his voice to get back to normal?" or, "Can I expect his voice to get back to normal?" (C08, wife of P08, T1 radiotherapy)

Her quote illustrates the "uncertainty" and anxiety experienced "*when it doesn't all fall back into place*" with the need for information and support to help them manage this challenging phase. Not having information and support from health professionals with knowledge can lead some to experience a feeling of being alone and isolated as they are dealing with issues that are beyond their knowledge and understanding. This was evident in the following quote by C18:

In between that period when we were oan oor own, she [wife] just wanted to die and when I phoned the doctor [GP] saying I couldnae get her tae eat or drink or aw that, he wis as good as a chocolate tea pot, cause he wouldnae even come. They just kept threatening saying that they'd come and take her away and aw that, take her into the hospital, ken whit I mean? And that was making her worse. (C18, husband of P18 T3 laryngectomy).

His comment "*we were on our own*" highlights how he felt isolated and alone with a lack of support available to help him care for his wife. His perception of the GP highlights that he had no support, at a time when he needed help from health professionals who could care for his wife, provide them with correct information, and support them at this fragile time.

At this stage, it was evident how participants responded to their experience of symptoms differently to the pre-diagnosis and treatment phases based on the information they had received. During the earlier stages, participants responded by actively seeking information from health professionals to explain their experience of symptoms, whereas during the follow-up phase, many suffered and experienced symptoms in silence, leading many to feel lost. This led some participants to question the information that they had received and the expectations that they had developed based on that information.

6.3.2.3 Experiences versus Information

This sub-theme describes how participants discussed and viewed the information from health professionals in the context of their actual experiences over the course of their trajectory. At this stage, many were living in a reality of uncertainty due to their experience of post-treatment symptoms, with few knowing when they would regain a sense of normality in their life. For those patients who received laryngectomy, they discussed how information from health professionals in many ways could not prepare them for the reality of this type of surgery and the physical and psychological impact they experienced. Patients and carers both discussed the reality of their experiences and the sense of loss and uncertainty they experienced since the surgery. Many commented on how information had not and could not prepare them for the reality they experienced and for some provided them with false expectations of what was ahead.

P15 highlights the importance of receiving information and the improvement he has witnessed over the years. However, the use of the word “blissfully” in the following quote would suggest that there is something quite nice about not knowing all the details of what lies ahead:

It's all history now ... but I think it is better knowing than not knowing like the old days you waited to have your operations, blissfully unaware of what was ahead. (P15, male, T4, oesophagectomy & laryngectomy)

With P14, highlighting that the information she received was based on everything going to plan, alluding to the fact that she was not given information on the things that could potentially go wrong:

Information in my eyes is alright – I was just unlucky as CNS said, if anything, I had everything that could go wrong go wrong, I suppose if I had not had an open wound that took weeks to heal maybe the information I was given would have been alright. (P14, female, T3, laryngectomy)

This would suggest that a more realistic account of what could happen post-treatment is required, as discussed in C12's quote, who perceived that the information they received provided them with unrealistic expectations:

I think that it would have been a good thing for us because, as I say, we aw like to be positive but reality isnae positive and happy and good, do you know, cause I say we were of the opinion wi' the first bit she's going to be fine, she'll be back to her normal self and then she wisnae. Then the second bit, right, this is taking it [cancer] away

and I think maybe that was just us being disillusioned, it's the cancer that's making my mum no well, but then after it, see when I thought there's nae cancer, it's the treatment that's making her no well and then well the cancer's back again, right, so it's the cancer, so once that's away ... everything going to be fine, which wisnae, it wisnae the case, no. (C12, daughter of P12, radiotherapy (first laryngectomy for recurrence)).

However, P13 highlights how information cannot prepare anyone for the reality of the surgery and treatment:

It cannae be done, Anne, they can tell you main the bits ... I think it is important to tell you straight ... but at the back of ma throat I know exactly what they have done, aw the radium... and aw that crap wis tae make sure that it doesn't come back. That wis the whole challenge [making sense of what lay ahead]. (P13, male T3, laryngectomy)

Making sense of what is ahead is the challenge for this group of patients and, as P18 highlights, although they can “tell you”, i.e. provide the information on the surgery, patients cannot understand what is going to be like:

It all happened so quickly and it was done before I kent what it was going to be like. But you dinnae realise how bad it's gonnae be till you're in it. Although they tell you, you cannae see it in your mind you know, you've gone through it. I never thought I was going to be as bad as this. (P18, female, T4 laryngectomy)

The accounts above highlight again, that when a concept or treatment does not resonate with their level of understanding drawn from their own and others' experiential knowledge, no amount of information can provide them with the knowledge to understand what is ahead. The inability of some to understand what is ahead is evident in the personal account of P18 on the impact of her surgery. The psychological impact of this type of surgery through the physical changes, linked with facial disfigurement and loss of voice and the inability to participate in the normal aspects of life, is evident in the following account:

Day 3

Took out my drains and I saw my FACE, I jumped back from the mirror, I don't want to see it. I look like something out of Star Wars. I just keep thinking about everyone seeing me like this. I don't want to scare people. I still haven't cried, can't get it out. I will never go through anything like this again. I don't know what I am going to do – what's my life going to be like now.

Day 4

I can't stand looking at my face when I go to the toilet I cover my face with a towel. I can't imagine my grandchildren seeing me like this and not being able to talk to them.

Day 7

Went for x-ray today felt like everyone was staring at me, first time I have been off the ward and it felt strange. Doctor watched me all the time and watched when I swallowed something so they could check everything is ok inside. They told me it was fine – I have little pain. I

am confused; I really want to go home but don't want people to see me like this. How will I manage? Speech therapist came and changed my tube to a talking one but told me not to use it until my treatment is finished. Things are getting a little better so hopefully I can go home soon.

The extract shows the rollercoaster of emotions that this individual experienced and the experience of “loss” is profound. Her whole sense of identity was lost in a matter of hours. Her inability to communicate, to participate in any part of normal life, is gone, as she highlights, “*I am never going to be the same person*” with her “*voice going further away*”, highlighting a physical sense of the loss she feels for her voice. The concerns noted in the extract of how she will manage, how she will cope and the fear and embarrassment of everyone looking at her “*looking like something out of Star Wars*”, raises the question: what information from health professionals could prepare someone for this type of surgery?

Similarly, P12 highlights in her written account how she knows her life will never be what it was:

I get upset at times when I can't speak, cry when people look at me and realise I can't speak, am I feeling sorry for myself or just need to cry at times. I wonder if I am the only person who feels that I am not coping very well with my cancer, will I ever be told it is no longer there, it has been 3 years in September since I was first diagnosed and so much has changed in my life and I know it will never be what it was like. I miss a lot of things, like meeting a neighbour when shopping and having a wee gab, being given a box of chocolates

which I could eat in one and really enjoyed, talking to my grandchildren. I miss all of these things and more.

Before going to hairdressers, I wash my own hair in case I get water in the stoma. I have to wear a plastic bib even in the bath I have to do the same, it is frustrating at times, all the little things that mean so much to me that I can't do or enjoy anymore. I eat but only what I can eat not what I want to eat. Am I being selfish because of the changes in my life or should I be glad to be alive and get on with it, as there are a lot of people worse off than me.

I think when I go back to ENT in June I will ask what is going to happen about helping me to speak if I ever will that is. I don't know if I will accept it if they tell me I won't ever get a voice again. It is hard when you pull out pad and paper for people to read. I think some people struggle to read or just can't be bothered and walk away. I am very self conscious of the straps round my neck and as much as I try to cover them with a scarf sometimes they still show and I see people looking at me, children seem to be the worst but I know that they are young and don't understand what it is. I get angry when adults stare they should know better, children are curious. (P12, T2, radiotherapy/laryngectomy)

These accounts demonstrate vividly the sense of loss experienced by participants who receive laryngectomy. Life will never be and can never be the same for these patients, with massive changes evident to the simple aspects of their lives, “*gabbing with a neighbour, eating a box of chocolates, chatting with their grandchildren*”. The challenges they experience are profound and life-

changing with the information from health professionals only able to inform them of the physical changes of the surgery. What type of information can health professionals provide to prepare these patients for the loss they experience that is evident in the above accounts? Potentially, P13 is correct in his assumption that you “*cannae*”, that is the challenge, you *just need to get through it*. P18 received the exact same words from an ex-patient prior to her surgery, therefore it could be suggested that it is not necessarily the provision of information that is required by this group of patients but the provision of psychological support or counselling pre- and post-surgery to alleviate the uncertainty they experience and help them progress to a new normality.

In summary, the “reality of uncertainty” was common for most participants due to the impact of their post-treatment symptoms, and the effect they had on the individual in the context of their lives. The quotes highlight the many challenges that participants faced with the uncertainty of knowing whether they would ever regain a sense of normality, with a mismatch evident with the communication of information from health professionals leading some information being “lost in translation” which compounded the uncertainty many experienced. This led many participants to question the information they had received as it did not resonate with their actual experiences at this time, allowing some to develop false expectations on the outcome of their treatment. This was evident for those patients who received laryngectomy who highlighted that no amount of information could prepare them for the physical and psychological impact that this type of surgery has on the individual.

6.3.3 Culture of Caring

At this point in the pathway, many participants were living with the reality of the outcome of their cancer, coping and managing the consequences of their cancer in the context of their lives. They had evolved from an “illusion of certainty” at diagnosis into a “reality of uncertainty” and now needed information and support to help them manage at this time. This is where the role of the CNS was discussed again and how she provided them with core information and support that they needed at this time. However, there were gaps identified and some patients and their carers “flew under the radar” and suffered initially post-treatment due to a lack of caring and understanding by health professionals involved in their care. Carers of those who had laryngectomy discussed the challenges they faced and experienced with the input from health professionals across the team varied and dependant on the level of support they required. During the 2nd interview, carers did discuss their specific needs, especially when *“everything doesn’t fall back into place”* which was the first time in the pathway that many carers discussed having specific needs of their own. I describe and explain the role of information at this stage under two sub-themes: “limbo” and “carers’ needs”.

6.3.3.1 Limbo

This sub-theme describes the impact that the lack of information had on some participants. Similar to their experience of “limbo” at diagnosis and at the end of treatment, participants needed information from health professionals to help them know what was ahead and how best to manage the consequences of their treatment. Various aspects of care were discussed relating to the

practical information many required to help them manage and cope with the reality they were experiencing and the long-term consequences of the treatment. However, due to a lack of information and support from health professionals, some carers experienced a feeling of being in limbo as they did not have the knowledge to carry out the care required or have the knowledge to know where or who to access information from. This was more evident with those participants who were caring for patients recovering from laryngectomy.

To put this into context, leakage from the speaking valve after laryngectomy can be common in the early stages and the main concern is that fluid will leak from the valve site into the lungs leading to a chest infection. In addition, if the leakage continues there can be prolonged issues with speech restoration. P17's daughter describes how they did not receive information from professionals about the importance of checking the valve and looking out for leakage. She explains how they did not have access to a computer or knew anyone else with laryngectomy and therefore could not draw on these sources of information to help them manage these difficulties:

Ye never really got told, he's never really been told aint ye about how tae care, he hasnae even got a computer tae look up. Ye should be mair told about these, we didnae even know anybody, he wasn't even told how tae, see the valve at the back o' his thingwy, aye we clean it, but they [professionals] never said tae look for leakage. Even the speech therapist said, "That's ridiculous that ye got out the hospital without knowing this." Naebody telt us, an it wis leaking, it's scary, leaking into yer lungs, a mean, come on. Trial an

error, innit, we've just tried ourselves. (C17, daughter of P17 laryngectomy)

She also discussed how she did not feel that she had received adequate information and training from health professionals to care for her father on discharge. She describes contacting a nurse on the ward but not receiving supportive information to provide the necessary care. She points out how the written information was useful but only in conjunction with being shown or trained how to provide the appropriate care:

Ah phoned the ward when I was bolus feeding him, because it's very important tae have it ye know right, ye need tae check his Ph balance an that cause again, if it's no in his stomach it's very serious, you know, so on that day the Ph wasnae right. A phoned up an' a says, "Am just concerned, ye know, 'cause ah read aw ma wee manuals and told me that, you know, what ah mean, don't risk it." She [nurse] says, "Och, I don't know nothin' about they tubes." An' you think if they were for to work as a nurse for to know these wouldn't they? This first time we got leaflets for the bolus feeding but you've gotta be showed it in practice. (C17, daughter of P17, laryngectomy)

In contrast, P12 reports how she had received training and was provided with the right level of support and information to care for her mum at this time, as highlighted in the following quote:

Everything they'd take me through it and they sent out the Abbott nurse to give us training ... so she came out and showed us how to

set all this up and things and then if there was a problem with that she came back out again, again, they've been very, very good in that sense. And the hospital contacted the district nurses as well and they've be great as well. Once we went to give her an antibiotic through her tube and tube was blocked, she was only in the house an hour and the tube was blocked, so I phoned Ward 2C, "This is what's happened - what do I do?" "Try and put juice in," it wisnae happening, my mum got really upset that night, took her away back over to Ward 2C and it took them about an hour to unblock it, they were going to put a new tube in, but they pumped and pumped and eventually managed to get it. Did that em, and then she got home again, but hadnae been sleeping and the, the machine starting beep, beep, beeping and the machine messed up, phoned up Abbot, sent oot another machine, and that machine didnae work and last Saturday my mum was just for saying, "I'm no daing it; stuff aw this," you know, kinda thing. Eh, so CNS she came out, we phoned up and CNS came out, was it Monday, mum? ... CNS came out on the Monday and says to us, "Right, we've goat another machine, we can try this." (C12, daughter, P12 T2, radiotherapy then laryngectomy)

These quotes show how there was a disparity between these carers' experiences due to the information and training received from health professionals and the impact this had on them. P17 perceived that it was "trial and error" caring for her dad, as she had not been provided with the correct information on how to care for his valve with a lack of knowledge and understanding on who to contact or how to source information at this time.

Equally, when she did ask for advice from some one who should possess the knowledge, she experienced a lack of support and guidance identifying a lack of care for them at this time leading to her to live in limbo unable to provide the appropriate level of care to her dad.

In contrast, C12 had received information, training and support to allow her to have the knowledge to care for her mum at home at a time when her mum was still fragile and vulnerable. The need for information and support provided by those with the knowledge is crucial. C12 highlights how her mum was saying “*stuff all this, had enough*”, demonstrating the need for health professionals to understand the trauma and anxiety that these patients and their families experience, therefore requiring their knowledge and skills to alleviate some of the stress at this time.

Similarly, C18 describes how it was only after the CNS saw his wife that they received the correct information and support to provide the correct level of care to his wife at this time. From the quote below, it is evident how this couple had been left in limbo without adequate support and information to help them manage at this crucial time:

CNS seen that, she'd goat a fright didn't she? And she goat oan tae the phone right away tae the surgery and that's when Dr X [another GP] started coming up and that's when you started, turned around. Cause she [wife] was that bad and the GP came in and she went ballistic eh? She [GP] says that wife was trying to cope wi' everything herself, even though she's seeing Mr X [consultant], he's just a surgeon, he cannae help wi' depression or anything like that

and well, eventually it started tae get sorted oot. (C18, husband of P18, laryngectomy)

The quote implies that the consultant surgeon and the initial GP did not address the needs of this individual patient and her husband and that there was an evident gap in her care. The lack of understanding by the initial GP and lack of insight by the surgeon highlights the need for proper assessment of this group of patients from the “proper” members of the multi-disciplinary team with a range of knowledge and skills. It also highlights the important role that the clinical nurse specialist plays to ensure patients and their carers experience a “culture or package of care” at a time when they are vulnerable, fragile, and coping with the major consequences of this type of surgery in the context of their lives. Addressing the needs of patients and their family members is fundamental to ensuring they experience a culture of caring where their needs are at the centre of their care.

Others discussed how a lack of practical information, such as accessing medication and equipment to help them manage initially post-treatment, caused them anxiety and frustration, as described by C12:

The hospital would prescribe morphine for my mum and I'd go to the chemist, “Oh, we don't have that, you'd need to go to a palliative care chemist.” “Where is a palliative care chemist?” and then they would say, “We don't have it in just now, I can get it for you the morra morning.” I'm like, this is somebody who's in major pain and so uncomfortable, and that I found really frustrating. A lot o' ma mum's things as well, the doctor [GP], “No, we don't prescribe that,”

and I'm like, "Why don't you prescribe that? Wi' the straps and things?" (C12, daughter of P12, laryngectomy)

The quote highlights how there is a need for practical, day-to-day information that allows the transition from hospital to home to be as smooth as possible for those caring for family members with laryngectomy. They are also adjusting to massive changes in their lives in caring for their family member and require practical information and support to help them achieve this as it is often the small and simple pieces of information that are forgotten but can cause the most stress and the sense of being in limbo without the appropriate support and information.

As this interview was six months after completion of treatment, many participants reflected on the care and information they had received since the diagnosis and the consequences of treatment in the reality of their lives. Many commented on how attentive all the staff were, how the care they had received was appreciated and how the information did help up to a point, as highlighted by P02:

We found it helpful, oh aye, it helped us understand what I was going through oh aye, it did say that would happen, aye I'm wondering why is my throat, why is my throat like, oh look, that's why, I mean it did, that was quite informative, so you knew where, what was goanna happen. (P02, T2, chemo radiotherapy)

The quote highlights how knowing what was going to happen is important to this group of participants as it allows them to understand and manage the symptoms or consequences of their treatment. When information is not

provided it is evident how they experience a feeling of being in limbo as they do not have the knowledge or understanding to manage the complex symptoms or know where to access information from. Limbo at this time point in the trajectory was similar to participants' experience of limbo leading to their diagnosis, as they needed information from health professionals to help them move from a state of unknowing to knowing in order to provide the appropriate care.

At this time point there was a change in the culture of caring in comparison to other time points as some participants did not have their specific needs met or did not perceive that their needs were at the centre of their overall care. This was more evident within carers of those who had laryngectomy due to the complex needs of this type of surgery. In the second interview this was the first time carers identified that they have specific needs of their own that needed to be addressed.

6.3.3.2 Carers' needs

This sub-theme describes how family members discussed in this interview how they had personal needs of their own and that they themselves needed to be cared for, a subject that had not be raised in the first interview. Their need to be cared for could be explained by the experiential knowledge they had gained from their involvement in the whole experience. As we know, hindsight is a wonderful thing. The general opinion given by many, was that if *"he/she was okay then they were okay."* However, some carers commented on the importance of being "formally" invited into consultations and of feeling involved and an integral part of the consultations. As C03 highlights, they are a

partnership and therefore he equally has to know what is and might be going to happen to his wife:

They just talk to the patient, I think they should [talk to both] because we're a partnership. And I'm obviously every bit as concerned as ... I cannae be as concerned as her because it's happening to her, but it's my wife, but when he [consultant] saw you I got in then, I went in then anyway and he never objected. (C03, husband, to wife who had chemo-radiation (first) and laryngectomy for recurrence)

This quote shows how spouses need to feel involved in all aspects of care and to know that they are welcomed as part of the consultation as cancer does not only affect the individual but also the wider family network. The impact of treatment and managing the consequences of treatment on the family network was highlighted by C16. She talked about the importance of professionals providing specific information and support to family members on the impact that treatment can have on a couple's relationship. C16 suggested how a "drop-in centre" during treatment could help others discuss any issues or problems they were experiencing and receive information and advice from professionals at this time:

Well, I think they [MDT] should take you, take you in and say, "Listen," you know, and, "We know you are going through a hard time, and he's going through a hard time, so the two o' yous will just have to kind of grin and bear it, and you know, probably he'll say things and you'll say things that you don't really mean it, but it's the illness, so just try and kinda turn a deaf ear tae it." Ah mean there's days that you can and then there's other days that you cannae, but I

think maybe if he [consultant] explained to us, "Well, you know yourself he's ill, but he's going to get through it and he needs your help to get through it, but you also need the support o' the two o' yours to get through it and you also need your break away fae one another." Where, in the hospital you think, I think they should have something like that, I think there should be somebody there, if you've really got something worrying, worrying you it should ... well, if there's nobody there and he went in for treatment could I go and talk to somebody because you're going over there and you've got this on your mind you know ... I wonder if they could help me wi' this and, and maybe you could ask questions if, if hubby wisnae there. I mean they were aw nice, they're aw good tae yae, I mean I, I've no one bad word to say about any o' the staff that way, it's just I, I would have just, like if they had some place you could go and chap oan the door. (C16, wife of P16, T2 radiotherapy)

The quote highlights how family members need care and support as well as the patient as they are the ones who are dealing and managing the consequences of treatment in the context of their lives. This issue is supported by C11, who had no direct contact with the CNS or other health professionals during her husband's treatment, which prevented her from receiving information to help her manage and cope with the side effects of his treatment. The lack of direct information and contact meant that she had to access information from other sources:

Well, I've found ways of getting round it and getting the answers, well, as I say, I would go to the internet or I would find a friend that

had some dealings with cancer patients, to that extent we're quite lucky, you know, we've got medical friends. I would go and quiz them on subjects and eh, get my answers and I did have a trip to the Maggie's Centre [re his diet post-treatment], I arranged to go along to see the dietician and she was absolutely super. (C11, wife of T1 radiotherapy)

Thus, based on her need for information, C11 actively sought information from others to ensure that she was providing the best care, i.e. nutrition, to her husband at this time. These accounts highlight the importance of health professionals providing a supportive and caring environment for carers and how they need to be involved in discussions and consultations where their own needs are assessed to ensure they can provide the correct level of support and care to their loved ones.

Many participants talked about how there was not the same level of information available to them in follow-up, which forced them to re-evaluate the information they had received. Many experienced that the outcome of treatment did not meet their expectations in combination with the lack of and vagueness of information from health professionals involved in their care. Many reported using the written information as a reference guide, to help them try to make sense of and manage the side effects in the post-treatment phase. However, the lack of professional, and for some, experiential information to draw on during follow-up left many feeling vulnerable and disillusioned about the information they had received, which is illustrated nicely by the summary given by C02:

What information we've been given I think we have used it to the best of, to the best of we can use it. You know, we have had rules to follow if he says [consultant], "Right, we'll do that, that'll help, we'll do that," then, you know, but I think we coulda maybe had more information, but then that information we get really is, it's no like personally for you, that information really has a broad spectrum and it could cover maybe a lot of people with head and neck cancers, so it ... maybe some might no have suffered as much as Eddie, maybe some have suffered more than Eddie, they can only give you this overview, but we read it and I mean, I haven't obviously looked at it recently but all through his treatment and at the end of treatment I kept referring to it and thinking, oh right, next week Eddie, maybe you should be feeling a bit better, cause it says in the book that you [laughs], it didnae happen, but it's only probably cause it's general.
(C02, wife of P02, T2, chemo radiation)

The quote shows how written information can play a guiding role for some participants to help them explain and understand their experience of symptoms, especially during their treatment. In addition, it helps to explain why some participants focus on the length of “time” they should experience their symptoms as discussed in section 6.3.1.2, and how their symptoms should be improving over the course of weeks rather than months. However, the quote suggests that written information does not seem to be applicable in the follow-up phase as C02 “hadn’t looked at it recently” and the content was deemed generic and not relevant to their specific situation. This highlights the importance of health professionals providing information and support to patients

and their family members in the follow-up phase and their need for information that is tailored to their specific experience of symptoms at this time.

In summary, participants viewed the information from health professionals at diagnosis and through treatment as positive and talked about the “illusion of certainty” it provided. However, for those participants who experienced long-term side effects of their treatment they had to reevaluate the information in the context of their actual experiences during the follow-up phase. Many experienced the continual search for normality to make sense of their symptoms in the context of their lives but experienced a “reality of uncertainty”. This was linked with the length of time they had experienced their symptoms mixed with the vagueness and ambiguity of the information received from health professionals at this time point. Compounding this sense of uncertainty was the physical and psychological loss those participants who had had a laryngectomy endured and the challenges that both they and their family members experienced. Due to the challenges they experienced many needed a “culture of caring” to ensure that their specific needs were addressed and met by the health professionals involved in their care. However, some experienced a diminished culture of caring and experienced a feeling of being in limbo as they did not have the information and understanding to provide the appropriate care required. This led some to view the information from health professionals as generic, prescriptive, and not specific to their needs at this time, leading to a disparity between the information received and the reality of their experience. During this phase, carers identified that they also needed to be cared for, as they were dealing with the side effects of treatment and managing the reality of cancer and its consequences in the context of their lives. Practical and

supportive information was required as well as the need for health professionals to be aware that they are involved in the whole experience and therefore require some care and attention, especially when *“it all doesn’t fall back into place”*.

6.4 Summary

In Chapters 5 and 6, I have presented a rich description and thematic explanation of the role of professional and experiential information based on the experiences of people affected by laryngeal cancer across their trajectory. From the findings, it was evident how this group of participants seemed to draw on both categories of information with differential patterns of use depending on their perceived level of need and understanding based on their experiences at different time points across their trajectory. The four main themes, in combination with the sub-themes, provided a description and explanation of the role of information and the factors that influenced how patients and their family members sourced and used information and how this changed over time based on their actual experiences.

In the following chapter, I will revisit my research questions and discuss the findings of this study in relation to relevant literature drawing on Dingwall’s (1976) illness action model, discussed in section 4.4. I will go on to illustrate the changing role of both categories of information over the cancer trajectory using the four thematic headings in the context of a thematic model and how the role of information and the knowledge this provides is influential in how people respond to their experience of symptoms and overall illness experience.

Chapter 7

Discussion and Conclusions

7.1 Introduction

This study set out to explain the role of information with people affected by laryngeal cancer based on their experiences from diagnosis through to follow-up. Based on these experiences, I aimed to describe and explain the types of information they sourced, why and in what ways they used those types of information, and what factors were influential in how they used information at key stages over their cancer trajectory. Four broad thematic headings were identified from the analysis that encompasses the experiential and professional information that this group of participants sourced and used. It was evident that there were relationships between the broad themes at different points across the cancer trajectory with the over-arching theme of “Search for Normality” identified across the whole trajectory. This over-arching theme illustrates how participants adopted different strategies in response to their physical experience of symptoms in an attempt to normalise them in the context of their knowledge and understanding of illness. Due to the strategies that participants adopted in response to their illness experience, Dingwall’s illness action model (1976) was appropriate to explain and situate the data.

In this chapter, I will revisit my research questions and discuss the study findings in relation to relevant literature and Dingwall’s (1976) illness action model. I will illustrate how the role of information changes over the

course of the trajectory through the development of a thematic model using the four main thematic headings developed from the analysis. Finally, I will present my conclusion and the implications of the findings for policy, practice and future research.

7.2 Overview

Chapter 1 discussed how information plays an important role in helping people manage the impact of a cancer diagnosis and their treatment, with many policies over the last decade identifying the importance of the provision of information and that the central providers of this information should be health professionals from across the various sectors in the NHS. A core element of many of these policies is the central tenet that “people should have access to accurate, high quality, comprehensive information delivered in the way they want; have their personal information needs considered and discussed at every contact with health professionals and receive as much support as they want to access and understand information” (DOH 2004). Therefore, I suggested that patients and their families affected by laryngeal cancer should expect and experience a uniformly high quality service with the provision of quality detailed information, specific to their needs, along with a seamless pathway from diagnosis through treatment and into follow-up care. The term “information need” was discussed in Chapter 3 by Adams et al (2009), who commented on the need for greater clarity of the term to ensure that the reader was clear that it is the information needs of the patient or the carer being addressed and not those of health professionals involved in their care, with Timmins (2006) defining information needs as “expressed needs” as they are subjective and unique to the individual based on their actual experiences.

In addition, Chapter 3 highlighted the lack of qualitative studies exploring the experiences of the individual patient over the whole cancer trajectory (McQuestion et al 2011; Semple et al 2008; Semple 2001) with a dearth of studies exploring the experiences of their family members noted. Many studies have focused retrospectively on the impact of treatment and not the whole treatment experience, with little known of the experiences of patients beyond that phase (Wells 1998b). This study provides an in-depth account of the experiences of this group of patients, carers and their families over key stages of their cancer trajectory and explains how different types of information from different sources helped people affected by laryngeal cancer try to understand their experiences in the context of their lives.

The findings from this study show how people affected by laryngeal cancer used two main categories of information: experiential information from self and others, or what Abel and Browner (1998) called “embodied knowledge”, and information from a range of health professionals. As discussed in Chapter 3, section 3.5, experiential information of illness is gained through past and present experiences of similar symptoms or knowledge of others with similar symptoms, developed from a wider cultural understanding to explain illness (Young 2004; Lawton 2003; Abel & Browner 1998; Locker 1981; Kleinman et al 1978; Borkmann 1976). For this study, information from health professionals is defined as verbal, non-verbal and written information from any health professional across the multi-disciplinary team as described in Chapter 4, section 4.3.1. Both categories of information are broad and encompass many health professionals from across the multi-disciplinary team with sources of experiential information encompassing one’s own and those of family, friends

and fellow patients. It was evident from the data how both categories provided specific types of information to participants across the cancer trajectory to help them try to make sense of their cancer and its effects in the context of their lives. Both categories of information were used in different ways and at different time points depending on their perceived level of need based on their actual experiences and understanding. However, over the course of the trajectory both categories became inextricably linked and influenced how people affected with laryngeal cancer made sense of their overall experiences.

My research questions were:

- What are the experiences of people affected by laryngeal cancer across their cancer trajectory?
- In response to their experiences, what information do they need and use?
- Why do they need these types of information?
- In what ways are they using these types of information?
- Are there factors that influence or inhibit their need and use of information?
- Is information being tailored to their individual needs based on their experiences?

I will address these questions using the four key stages identified in Chapters 5 and 6.

7.3 Explanation of findings en route to diagnosis

En route to diagnosis it was evident how participants' experiences were based around their physical experience of symptoms. It was evident how their knowledge and understanding of their physical experience of symptoms influenced the types of information they sourced. Many responded to their experience of symptoms by initially drawing on their own and others' experiential knowledge of illness to "normalise" them, assuming that they were a consequence of everyday common ailments. At this time point, few participants recognised or interpreted their symptoms to indicate anything being seriously wrong as they could initially explain them in the context of everyday illness explanations. Inherent in this group's illness explanation was how the absence of pain indicated that nothing was seriously wrong.

Previous research has suggested that patients affected by head and neck cancers may ignore their experience of symptoms due to fear and thus delay seeking help and advice (Tromp et al 2004; Andersen et al 1995). However, recent research has found that patients affected by lung cancer delayed seeking professional advice due to their lack of knowledge and understanding of their physical symptoms to interpret them to indicate anything serious, i.e. cancer (Wyke 2011b; Corner et al 2006, Corner et al 2005). The findings from this study would support these results, as many of the participants did not attribute any great significance to their initial experience of symptoms and based their understandings on their own and others' experiential knowledge of common illness explanations in combination with the initial information they received from the GP (throat infection). Relating these findings to Dingwall's model, "It is only when there is an imbalance in our normal bodily

function due to a biological disturbance or problematic experience, we use our stock of knowledge of health and illness to interpret what the problematic experience could mean (1976: 93). This statement suggests that people will draw on their own experiential knowledge and understanding of illness to interpret and explain their experience of symptoms which was evident with this group of participants.

It was only when the participants' physical symptoms became enduring, affected their quality of life or did not respond to their initial treatment that they actively sought information from a professional. Again, these findings concur with previous research, which shows how ambiguous or vague symptoms are experienced for many months before the participants would seek professional advice, as they tend not to evoke worry. It is only when the symptoms persist or worsen, or when additional symptoms develop, that the normalising strategies that people use break down, thus triggering the individual to seek professional advice (Wyke 2011b; Corner et al 2006; Corner et al 2005; Smith et al 2005, Zola 1973). Therefore, once an individual cannot explain their experience of symptoms drawing on their own and others' stock of knowledge of illness, then they will respond by sourcing information from someone who can provide them with the appropriate knowledge (Dingwall 1976). Many responded by sourcing further information from the GP as they could not "normalise" their experience of symptoms in the context of their own stock of knowledge of illness. At this stage in their trajectory many participants seemed to tailor information to their own needs based on the experience of their symptoms and the significance they attached to them.

However, due to the length of time over which many experienced their symptoms, in combination with the information from the GP and ENT consultant, many became suspicious that the symptoms were indicative of something being wrong or “something being there”. They responded to this information by needing a caring and informative environment from health professionals, as many had become anxious and worried, needing information to explain their symptoms and to know what could be done. The time between being told there was “something there”, having a biopsy and getting their results was an anxious time due to a lack of practical and supportive information from health professionals and a lack of understanding and knowledge on the process and outcome of biopsy by some participants. Thus, information provided by health professionals at this time point caused a response of anxiety and worry in participants as they did not possess the knowledge or understanding to explain what their symptoms indicated leading up to their diagnosis, leaving many with a sense of living in “limbo”.

7.4 Explanation of findings at diagnosis

Previous research has shown the anxiety and threat associated with a cancer diagnosis leads many to seek information as a strategy to help them cope and manage (Rutten et al 2005; Costelloe & Nelson 2004; Lazarus & Folkman 1984). Depending on how an individual responds to their cancer diagnosis will influence the types, sources and amounts of information they seek (Lambert & Loiselle 2007; Llewellyn et al 2005; Leydon et al 2000).

At diagnosis, participants talked at length about the information they received at the MDT clinic as many were anxious and worried about what the

outcome would be. Although some commented on a lack of information around biopsy, it was evident how they were provided with a wealth of verbal information on their diagnosis, prognosis and treatment pathway from the “experts” in an honest and straightforward manner, which meant it was to be trusted, as they would know best. This provided many with an “illusion of certainty” that their cancer was curable which gave them relief and hope for the future. It was evident how some participants relied heavily on the biomedical information at this point and the “illusion of certainty” this provided, in comparison to the experiential knowledge they drew upon leading up to their diagnosis, with many accepting the treatment offered unquestioningly. Due to the level of information provided at this time, many participants did not need to source further information as the health professionals had provided them with information specific to their stage of tumour and the appropriate treatment pathway, giving them hope for their future, which was their main need at this stage.

The findings from this study strongly resonate with previous research, which shows the implicit trust and confidence patients affected by head and neck cancer have in their consultant (Davies et al 2010; Pollock et al 2008), and how they prefer an honest and open discussion with health professionals (Pollock et al 2008; Timmins 2006; Rutten et al 2005; Ankem 2006; Feber 2003). Newell et al (2004) reported how participants accepted the treatment offered by the doctor based on the knowledge that “he was the expert” and “he would know best”, with many patients commenting on “being presented” with their treatment option in the study by Pollock et al (2008). Davies et al (2010) suggests that the severity of the illness and experience of

symptoms could explain why patients affected by head and neck cancers do not appear involved in discussions about their treatment decisions. They found that patients facing serious illness, defined in their study as a patient who has “considerable pain, discomfort or alteration to complete daily activities and fears imminent death” (2010:2444), relied on the information from the physician as the expert. This finding could be linked to the perception of those people affected with advanced head and neck cancers, who experience such severe symptoms that they must take the treatment option offered by the consultant or they will die (Davies et al 2010; Pollock et al 2008; Newell et al 2004) which was evident with those patients who required laryngectomy in this study.

However, from the findings, it could be argued that the lack of apparent discussion around treatment options could be due to some patients drawing on their experiential knowledge of knowing others’ experiences, specifically with laryngectomy. It was evident in the data how some participants used experiential knowledge and the information this provides in a subtle way that influenced how they viewed the treatment pathway offered. It was apparent how some participants used both categories of information to inform their decision-making regarding their treatment, specifically concerning laryngectomy. Experiential knowledge and the information this provides enabled some participants to know and understand the outcome of this treatment and the impact it would have on their lives. Based on that knowledge there was either relief that another treatment option had been offered or a refusal of treatment, showing the influence that experiential knowledge can have on patients’ treatment decision-making. Although there was no apparent discussion reported around treatment options during the MDT clinic, the data

suggests that some participants may make their treatment decision prior to attending the MDT clinic drawing on their experiential knowledge of knowing others' experiences.

There is a wealth of research focusing on the benefits and challenges of patients participating and being involved in their treatment and care decisions (Power et al 2011; Collins et al 2007; Bugge et al 2006; Entwistle et al 2004) with the expressed need for information certainly associated with preferences in relation to involvement in decisions. Lambert et al (2009) found that for patients affected by breast, prostate and colorectal cancer, most active information-seeking behaviour was around treatment options, with many commenting on the frustration and anxiety this caused, with the burden experienced by patients having to make choices at this emotionally difficult time highlighted by Power et al (2011). They discussed how patients can adopt biases and shortcuts in their reasoning at this time based on the information they receive, which can lead to "bad" decision-making. This anxiety was evident with some patients in this study who were offered laryngectomy and perceived their treatment decision was to live or die which affected how they coped with the overall outcome of their treatment.

Through the information exchange, patients should understand the risks associated with their treatment choice, and have their own values considered with health professionals involved in their care, which is challenging for those patients who do require laryngectomy as they perceive the biggest risk is to die and "who wants death"? This would suggest that those patients who require laryngectomy are emotionally burdened at this particular time which would inhibit or influence their need and use of information when they

perceive their treatment choice is between life and death. However, the findings from this study would suggest that, for the majority, there is no expressed need for information from health professionals as many may well have made their decision regarding their treatment prior to attending the clinic. Relief that they do not require a laryngectomy could explain the unquestioning acceptance of other treatment options by the majority evident in this group of patients. This is an area that requires further investigation to aid better understanding of the influence of experiential knowledge in response to decision-making with this group of patients.

The amount and timing of information delivered to patients can also influence their involvement in decision-making as previous research has shown that patients can forget between 40 and 80% of medical information provided during consultations with poorer levels of recall where large amounts of information are provided (Kessels 2003). Some participants did experience being overwhelmed with the amount of biomedical information given during the MDT clinic and indicated how some information was “lost in translation”. This is where the role of spouses and the CNS were influential in providing clarity or filling in the gaps of the information they had been given. It was evident how the interaction between couples at this time helped them to make sense of the situation in the context of their lives, tailoring information to their specific needs at his time. These findings resonate with previous research showing how carers are an important source of information to patients through the different types of information provided by health professionals which allows many carers to cope and feel involved in the cancer experience and be prepared for what lay ahead (Ankem 2006; Feltwell & Rees 2004; Morris 2001, Eriksson 2001).

The amount and timing of information is a common complaint found with people affected by head and neck cancers (Newell et al 2004; Stafford et al 2001), with a lack of time to assimilate the amount of information given at diagnosis found by Llewellyn et al (2005). In their study, they found participants did not want too much detailed information in the pre-treatment phase as they reported an inability to absorb the information due to the lack of time between their diagnosis and their treatment starting which is contrary to the findings from this study. Participants in this study reported having “time” or “time out” between their diagnosis and starting treatment as crucial as it gave them time to absorb the information they had received from professionals in combination with experiential information gained from others, i.e. ex-patients, to make sense of their diagnosis and impending treatment, with those having laryngectomy needing some time to help them prepare for the challenges ahead. The presence of the clinical nurse specialist (CNS) and the support she provided at this time was influential in how participants viewed their diagnostic experience. Many discussed how they were treated as “a person and not a number”, where their needs and concerns were addressed at a time when many felt fragile and vulnerable. It was evident at this point how many perceived that their specific need for information and support was addressed and tailored to their needs. This finding supports previous research showing the important role that clinical nurse specialists play in helping people affected by head and neck cancers adjust and cope with their diagnosis and ensuing treatment through the provision of information, support and reassurance (Wells et al 2007; Larsson et al 2007, Semple 2001; Wells 1998b).

However, not all participants discussed being reassured by the written information provided by the CNS at this time. The findings demonstrated that there was a prescriptive approach to the provision of information adopted by the CNS, as the written information was not tailored to the individual's specific needs as some commented on not requiring or wanting to read the written information. In many ways some of the participants could be classed as "blunters" as they did not want to know too much detailed information on specific aspects of their treatment, whereas others could be classed as "monitors" as they actively sourced information from the internet or ex-patients after meeting with the CNS. These findings show the challenges faced by health professionals on ascertaining the amount and types of information individuals want and need at their diagnosis and how proper assessment of the individual's need for information is required at this time point.

Previous research has shown how written information supports and confirms the verbal information that patients and their families receive (Hubbard et al 2005; Birchall et al 2002; Leydon et al 2000; Hope et al 2000; Mills & Sullivan 2000), with studies reporting how people affected by head and neck cancer want more written information to be available (Pollock et al 2008; Balmer 2005). The findings in this study highlight that for some this was the case, however, the need for health professionals to clarify what types and how much information patients and carers want at this point in the trajectory needs to be a continual process of assessment. Previous research has identified carers as actively seeking information at diagnosis and through treatment to know and prepare for what is ahead (Semple et al 2008; Ankem 2006, Hubbard et al 2005; Feltwell & Rees 2004; Morris 2001). The findings from this study

would support these findings but also suggest that people's own knowledge of cancer is influential in the strategies they adopt to either seek or ignore further information depending on their level of experiential knowledge and understanding of cancer and its treatments.

Relating these findings to Dingwall's model (1976), participants arrived at the MDT clinic needing information to help them understand and have the knowledge of what their symptoms indicated and what could be done. The information provided by the MDT allowed them to gather new information that could explain and help them begin to make sense of their diagnosis and ensuing treatment. For many, the information provided enough new information and knowledge to know what was ahead and what the outcome of their treatment would be, therefore, they did not need to source any further information. Some had drawn on their own stock of knowledge of laryngectomy and it was evident how this knowledge influenced how they viewed the treatment options offered. Others, however, required further information, they wanted to know "the worst case scenario" and responded by sourcing experiential information from ex-patients and the internet to provide them with the level of knowledge they required to make sense of the information they had received and what lay ahead. At this point it was evident how participants tailored information in response to their needs and began to interweave both categories of information. They had developed a new stock of knowledge of cancer and its treatments that would help them explain and respond to their experience of symptoms over the course of their treatment.

7.5 Explanation of findings at treatment

Although many participants discussed feeling prepared for their treatment or knowing what lay ahead around their diagnosis, over the course of their treatment pathway it became apparent how the written and verbal information received from health professionals had not prepared them for the reality of their treatment experience, specifically the mask and, for some, chemotherapy. The findings highlighted how there was a lack of specific information from health professionals that patients understood about the mask and chemotherapy treatment, which had a profound effect on some participants' experience of their treatment. Participants seemed to lack experiential knowledge and understanding of the processes of these aspects of treatment, which prevented them from being able to situate the information from health professionals in the context of their own knowledge and understanding (Dingwall 1976).

Due to this lack of knowledge and understanding, misconceptions and misunderstandings occurred with the need for clear information from health professionals evident, as "myths, misconceptions and uncertainties surrounding cancer are fertile grounds for creating unnecessary anxieties and in producing inappropriate responses" (McCaughan & McKenna 2007:2097). Some participants experienced increased anxiety and responded by suffering panic attacks and entering into chemotherapy "blind". Many discussed sourcing information from treatment room staff in response to their anxiety to help them understand the various aspects and outcomes of their treatment. These findings highlight the need for health professionals to explore with patients and carers their understanding of these treatments or find innovative ways to

communicate information to patients regarding the different aspects of these treatments that they can understand in the context of their lay knowledge and understanding. The anxiety that many experienced due to these aspects of their treatment may not be completely reduced but it may improve their knowledge and understanding of the process and side effects of them to help them better manage and cope with the outcome (Schofield et al 2008).

Many commented on how the attitude and skills of health professionals and the way in which they cared for them reassured them and provided them with a caring and supportive experience that is expected by cancer patients and their families. However, as treatment progressed, their experiences changed because the information from professionals did not seem to resonate or match with participants' actual treatment experiences with many commenting on how the information did not address their specific needs, as their treatment symptoms were affecting their daily lives. In response to their experience of symptoms, many attempted to source professional advice and information but received an acknowledgement that their symptoms were to be expected and understood in the context of their treatment.

Previous research has widely documented the side effects of radiotherapy (Moore et al 2004; Larsson et al 2003; Rose-Ped et al 2002; Rose & Yates 2001; Larsson 1999; Wells 1998b; Whale 1998), with more recent studies identifying the increase in toxicities associated with new treatment regimes, such as chemo-radiation (Logan 2009; Verdura et al 2005; Rose-Ped et al 2002). It was evident how the side effects of treatment had a profound impact on patients with the clustering of symptoms affecting their daily life, thus affecting the individual in complex ways and therefore should not be treated in

isolation but rather treated as a cluster (Logan 2009). However, the findings from my study would suggest that treatment symptoms were treated and managed in isolation using the biomedical model, which “tends to disregard the significance of the experience and impact of illness, and concentrates instead on symptoms as indicators of disease or tolerance of treatment” (Wells 1998a: 841).

Tolerance to treatment was evident as many participants discussed how health professionals focused on their experience of weight loss, neck burns and pain with disparities evident between having their own specific needs addressed based on their actual experiences and the prescriptive approach that many perceived the health professionals adopted at this time. This prescriptive approach influenced how participants perceived their experience of treatment and how they had to source other types of information to help them make sense of the side effects of their treatment. Those who experienced laryngectomy discussed not being prepared for the impact of their surgery and a lack of information on their radiotherapy treatment. These patients were recovering from the impact of this type of surgery, with no voice, which would ultimately inhibit how they sourced and used information and led many to have poor experiences over the course of their treatment. These findings resonate with previous research, which suggests that the information needs of patients and carers across all treatment modalities and on the side effects of treatment were generally unmet (Newell et al 2004; Feber 2003; Feber 1998; Edwards 1998). Larsson et al (2005; 2003) and Wells (1998b) identified more communication from health professionals at this time. However, the findings from this study would suggest that it is not necessarily about the provision of more information

but exploring the specific needs of patients based on their actual symptom experiences. Through continual assessment and discussion, health professionals need to find out how patients are managing and coping with the side effects of treatment drawn from their own knowledge, understanding and experience. This may reduce the disparity that many participants experienced in this study and allow them to explain their experience of symptoms drawn from their own knowledge gained through their direct experience of their treatment symptoms.

This disparity influenced how participants used information as many discussed sourcing information from fellow patients which was subjective and tailored to their specific needs and was more focused on the supportive and practical aspects of managing the side effects of their treatment in the context of their lives. Many participants talked of incorporating information from professionals and from fellow patients to help them “fill in the gaps”, allowing them to make sense of and manage the impact of their treatment. This finding would suggest that the information from health professionals is not always coherent and in line with the actual experiences of individual patients and their families. The use of fellow patients as a source of information on various aspects of treatment has been highlighted in previous research (Pollock et al 2008; Atkinson et al 2002; Leydon et al 2000), thus showing how people respond to their experience of symptoms by actively sourcing information from those with the knowledge to help them explain and understand their symptoms (Dingwall 1976). However, those with the knowledge may not always be a professional, as the findings from this study highlight and show how fellow patients play an integral and influential role in the exchange of information,

helping each other make sense of their treatment symptoms in the context of their daily lives. Health professionals need to be aware of this information source and explore patients' and carers' understanding to ensure the right information and knowledge of treatment is being exchanged. The information exchanged between patients and carers enables a better understanding as the information is drawn from direct experiences of treatment and coping with the side effects of treatment in the context of their daily lives.

Feber (1998) found in her early work how newly diagnosed patients with laryngeal cancer requiring laryngectomy benefited from the peer support and information provided by post-laryngectomy patients. She found that the information and experience ex-patients provided to the newly diagnosed patients aided in their understanding and future adjustment. These findings from Feber's study were also evident in my study as some patients found it beneficial to speak and see other patients with laryngectomy and described how this helped them begin to understand the outcome of their surgery. However, the findings from this study would suggest that meeting with ex-laryngectomy patients may have a negative impact on individuals, causing initial fear and anxiety due to the reality of "seeing the stoma", leading to a level of expectation of having voice, eating and drinking, with a sense of normality in their life again post-surgery. The findings would suggest that this is not always the case as several patients suffered and experienced loss of voice, eating and drinking problems and the continual search for normality, far beyond the treatment phase. Therefore, the reality of their experience did not resonate with their expectations based on the experiential information given by ex-patients which influenced how they viewed the outcome of their overall treatment.

It was apparent over the course of treatment how participants sourced a wealth of different types of information depending on their experiences, providing them with knowledge and understanding leading to a sense of security and reassurance at this time. However, as the end of treatment approached it became evident how there was a lack of clear instructive information and communication from health professionals as many participants commented on how they did not know what to expect in the post-treatment and follow-up phase, leaving many feeling uncertain and vulnerable and perceiving they were entering “limbo” again.

7.6 Explanation of findings in follow-up

It was at this point in the trajectory that participants’ use of information and the strategies they adopted changed. Coming through diagnosis and treatment, participants had received a wealth of information from various sources that they could tailor to their specific needs in response to their actual experience of physical symptoms. The use of experiential information in combination with information from professionals was “interweaved” along with the “other experiences and sources of expertise” (Lippmann 1999:270) to make sense of their experiences in the context of their lives. Based on this new knowledge, what became evident was how information gained up to this point allowed many participants to experience and cope with severe symptoms based on the knowledge that their symptoms “would get worse before they got better” in the early post-treatment phase. Many suffered and managed their experience of complex symptoms in silence, perceiving their symptoms to be “normal”, even though they were affecting their physical functioning and affecting their daily lives. This is in stark contrast to how participants responded

to their initial experience of symptoms in the pre-diagnosis phase. Based on their experience of post-treatment symptoms, participants did not respond by actively seeking information from others who could provide them with knowledge because they could understand and explain their symptom experience based instead on the information gained from health professionals that they would experience their symptoms becoming worse (Dingwall 1976). This information meant that they normalised the severity of their symptoms in the context of their new experiential knowledge and continued to suffer in silence until they were “officially” reviewed.

Patients affected by head and neck cancer are known to suffer in silence and are accepting of their symptom experience without asking for help, showing a resilience in coping with the changing side effects of treatment on a daily basis (Moore et al 2004; Wells 1998a) leading to feelings of loss of certainty about their future health and life. The findings from this study suggest that patients are experiencing and suffering severe symptoms in silence because they understand from the information received from health professionals and the new knowledge gained that their symptom experience is normal in the context of their treatment and to be expected. If this is the case, then innovative approaches to symptom management are needed in the post-treatment phase to ensure that the severity of post-treatment symptoms is closely monitored to reduce the poor experiences some patients endure unnecessarily. Severe post-treatment symptoms left unmanaged lead to feelings of uncertainty with this group of patients and carers as identified in previous research (Pollock et al 2008, Wells 1998a).

The feeling of uncertainty highlighted in previous research was evident in this study and influenced by participants' experiences of long-term side effects of treatment, as their experience of symptoms did not resonate with the information they had received and understood across their trajectory. Many had to re-evaluate the information from professionals to try to regain a "sense of normality" in the post-treatment and follow-up phase but many also experienced a "reality of uncertainty" with information from health professionals viewed as vague and ambiguous at this point. These findings resonate with Pollock et al (2008) who found that the impact of post-treatment symptoms in the context of participants' daily lives was a cause for concern due to the ambiguity and lack of consistency in the written and verbal information they had received. This would suggest that information provided earlier in the trajectory is not a true reflection of the reality experienced by patients and their carers at this stage, compounding their feelings of uncertainty.

Due to the ambiguity and vagueness of information provided at this time, many patients affected by head and neck cancer have reported the need for specific information on knowing what to expect as they feel vulnerable and lost, leading to an increase in their psychological distress (Llewellyn et al 2005; Newell et al 2004; Feber 2003). The feeling of being "left alone" to manage and cope with the problems experienced post-treatment with an overall lack of information provided at this time, having unanswered questions and the provision of information being a "one-way process", seems to be a common experience by this group of patients (Larsson et al 2007; Edwards 1998). Over a decade ago, Edwards highlighted the poor experiences of this group of patients and their carers during the post-treatment phase, with Wells (1998a)

commenting on the profound disruption treatment symptoms had on the individual and how they were experienced well beyond the treatment phase.

Clinical pathways have changed with a seamless care pathway for patients and their carers from diagnosis through treatment evident in this study with a wealth of information from various sources accessible. However, there is a gap in service delivery and care for this group of patients in the post-treatment phase that needs to be addressed. The need for clinical teams to support and communicate with patients in the initial post-treatment phase was highlighted over a decade ago, with Wells suggesting how health professionals need to “support the return to normal life, and to help restore self-confidence which is so vital to the renewal of social acceptance” (1998b:846). The findings from this study would suggest that this group’s experience of ambiguity and a sense of loss are based on the knowledge gained from the information received over the cancer trajectory. Many knew that they would experience post-treatment symptoms for a certain length of time, however, the reality for many was that they experienced symptoms much longer than they expected and as this did not resonate with their new knowledge and understanding, many experienced feelings of uncertainty for their future.

Due to the challenges this group of patients experience post-treatment and during follow-up, they needed a caring environment to ensure that their specific needs were addressed by health professionals involved in their care. However, in contrast to their experiences at diagnosis and treatment, contact and communication with health professionals was scarce at this time and participants were reluctant to contact health professionals or know whom to contact to help them manage. It was evident how some carers

responded to their need for information by using the written information to try to understand when the treatment symptoms would alleviate or improve, but there was a consensus that this information was generic, prescriptive, and not specific to their specific needs at this time. It was evident how participants had to change their strategies at this time as they could not source information to tailor to their specific needs, compounding their feelings of uncertainty and isolation.

Those who suffered laryngectomy experienced major challenges with the profound changes to their facial appearance, the fear and embarrassment associated with this type of surgery along with the psychological distress that was evident in the data. Many patients post-laryngectomy initially fear looking at themselves due to the fear and uncertainty of what they will look like (Llewellyn et al 2005), which is compounded by the loss of their natural voice. Newell et al (2004) suggest that only a minority of patients affected with disfigurement will have meaningful contact with a health professional and receive the information and support required at this time. Cartwright and Magee (2006) noted that although health professionals were aware of the need to provide patients with information at this time, patients and carers reported that they did not always receive the specific information they needed when they needed it, leaving them with questions and worries unanswered. The findings from this study support these findings with a lack of information and support evident for patients with laryngectomy and their carers. However, I would argue that there is a limit to the information that health professionals can provide that could prepare patients for the physical and psychological impact of this type of surgery. There is a move towards a more

psychosocial rather than biomedical approach of care for this group of patients and their family members across the cancer trajectory (Penner 2009) as it is evident that the symptoms are complex and not only associated with physical function. The findings from this study would support this approach and strongly recommend that for laryngectomy patients and their families there is a need for psychological or counselling interventions to be integrated into their care pathway, starting at diagnosis, to help them cope and manage with this life-changing surgery and enhance their return to normal life.

The consequences of treatment for head and neck cancers are evident to the world and cannot be masked or covered and where patients have to learn to negotiate their way through new treatment regimes, changing bodies and managing a disrupted life (Mathieson & Stam 1995). For the individual diagnosed with a head and neck cancer and their family, learning to adjust and cope with a changing body and the physical disruption that treatment can have on their body goes far beyond the treatment phase and can fundamentally change their social world forever. The need for health professionals to provide continuing information and support is essential to both the patient and their families as the impact of treatment will be influential in how patients respond and source information to help them manage and cope. Previous research has shown that survivors with psychosocial issues and diminished quality of life are those suffering from chronic physical symptoms, physical impairment, or change in appearance or function (Holland & Weiss 2008).

Semple et al (2008) identified the important role of social support at this time to ensure the return to normality enabling this group of patients to adjust in the post-treatment phase and achieve social acceptance. Participants

in their qualitative study identified the important role that family and friends played in helping them cope and adjust to the changes and challenges that they experienced from their treatment. The interaction with family and friends and the different types of information and support they provide was evident in this study. The findings support the important role that family and friends provide to patients, not only in the post-treatment phase, but also across the whole of the trajectory, which has implications for those patients who live on their own or have poor social networks.

The lack of studies exploring the experiences and information needs of carers and families affected by head and neck cancer was noted in this study. Although research has shown that the information needs of carers run parallel with the information needs of patients across the cancer trajectory (Harris 1998), they do have specific information needs of their own that need to be addressed (Adams et al 2009; Morris & Thomas 2002). The findings from this study would suggest that carers' information needs do run parallel with the patients' needs up until the post-treatment phase. At diagnosis and during treatment, in many ways, carers adopted the philosophy "as long as he/she was fine then they were fine", and the different types of information they received and sourced from both health professionals and fellow patients allowed them to manage and understand what was ahead and how best to manage the initial impact of treatment. Thus, information at this point provided them with new knowledge to understand what was going to happen and what lay ahead (Dingwall 1976).

However, their need for information changed in the post-treatment and follow-up phase due to the experience of post-treatment symptoms they

endured. Carers identified that they also needed to feel “cared for”, as they were dealing with the long-term side effects of treatment and managing the consequences of these in the context of their lives. Carers of those with laryngectomy described not having or being provided with information to help them manage and care for aspects of the laryngectomy and commented on the lack of sources they could access. Practical and supportive information was required at this crucial time due to the distress and adjustment this group of carers were experiencing. Carers require specific information to allow them to provide the appropriate care and attention from health professionals to ensure they have the skills and knowledge available (Morris & Thomas 2002). Due to a lack of practical and educational information from professionals, carers did not have the knowledge available to give the appropriate care required at this time and many suffered poor experiences. This has strong clinical implications as carers of patients with laryngectomy need to be provided with the correct knowledge to allow them to provide the appropriate care and understand the consequences of that care. At a time of change and adaptation for both patient and carer due to the physical and psychological impact of this type of surgery, carers need to be provided with the information and support to know what to do or where to source the appropriate information. The clinical nurse specialist can take the lead through communication and education in addressing these specific issues.

Many carers had perceived an “illusion of certainty” at diagnosis and through treatment based on the information they received and were also propelled into a “reality of uncertainty” due to the long-term experience of symptoms and the consequences of those symptoms in the context of their

lives. Again, perception was based on the assumption that all would be back to normal after the treatment had finished, based on their understanding of the information provided at diagnosis and during treatment and the new experiential knowledge gained. Previous research has shown that carers affected by head and neck cancer experience increased levels of distress and anxiety due to the functional and social impairment of their spouses in the acute post-treatment phase (Ross et al 2010; Baghi et al 2007; Verdonck-de Leeuw et al 2007). This psychological distress is reported to be associated with the lack of specific information given to carers on the impact and outcome of treatment which is evident in the findings from this study. However, the findings from this study would suggest that this is partly true, but the psychological distress experienced by carers could also be related and explained by the knowledge and understanding gained from the “illusion of certainty” at diagnosis, based on the information given by health professionals at that time. The reality did not meet their expectations, therefore causing distress and fear for the future.

Based on the lack of specific information to address the needs of carers at this time, other research has shown how carers access information from other sources such as support networks or telephone help lines (Rutten et al 2005; Morris 2001). However, the findings from this study differ, as many of the carers did not describe sourcing information from these areas, with only one reporting accessing the internet and attending the Maggie’s Centre for further information. The findings would suggest that carers of people affected with laryngeal cancer seem to rely heavily on the information from professionals and the “illusion of certainty” this provides in combination with experiential information gained from others to help them make sense of their spouses’

treatment and the consequences of treatment. This study has identified that there is a need for health professionals to assess and address the specific needs of carers across the cancer trajectory. Carers are involved in the whole cancer experience and are an integral part of the patient's world and therefore cannot, and should not, be separated from it. Their need for information and support is evident, specifically in the post-treatment and follow-up phase when *"it all doesn't fall back into place"*.

7.7 Summary

The findings from this study show how people affected with laryngeal cancer use information from professionals and their own and others' experiential information to make sense of their experiences across their cancer trajectory. These categories of information become inextricably linked as people affected by laryngeal cancer move through their trajectory drawing on them both to explain and understand their experiences of cancer and its treatment. Both categories of information are "woven into cohesive, internally consistent 'embodied' knowledge, with received 'biomedical' information merely one strand in this complex fabric" (Lippmann 1999:269). This strand builds up over time and is integrated into experiential knowledge through the direct experience of diagnosis, treatment and living with post-treatment symptoms and the information these experiences provide. The findings support previous research showing how patients' and carers' needs for information changes as they move through their trajectory and how they move along a continuum of professional and experiential information where they seek information according to their perceived need based on their actual experiences (Lambert et al 2009)

At the time points of diagnosis and treatment, patients and their carers moved between the information provided by health professionals, family members and fellow patients, tailoring it to their specific needs based on their symptom experience. It was evident from the data how they weaved together both categories of information based on their actual experiences and developed a new knowledge base of cancer, its treatments and outcomes. However, it was evident as participants completed treatment and entered into follow-up how there was a lack of information, communication and contact with health professionals and fellow patients. The lack of communication and contact inhibited how they sourced information to make sense of their experiences at these times. The new knowledge gained from the information received could not explain the reality of their experiences in follow-up and with limited sources to access information from, many experienced anxiety and uncertainty for their future.

Four broad thematic headings were developed from the analysis that encompasses the changing role of information across their trajectory. An explanatory model was developed to illustrate the inter-relationships between the themes and to demonstrate how both categories of information are used at key stages in the trajectory. From the model it is evident how participants started and ended their journey drawing on their own and other's experiential knowledge of health and illness to interpret the significance of their symptoms. However, how they explained and understood the significance of their symptoms altered over the course of their trajectory, based on the information they received and the knowledge gained from it. This thematic model is illustrated in Figure 3 below.

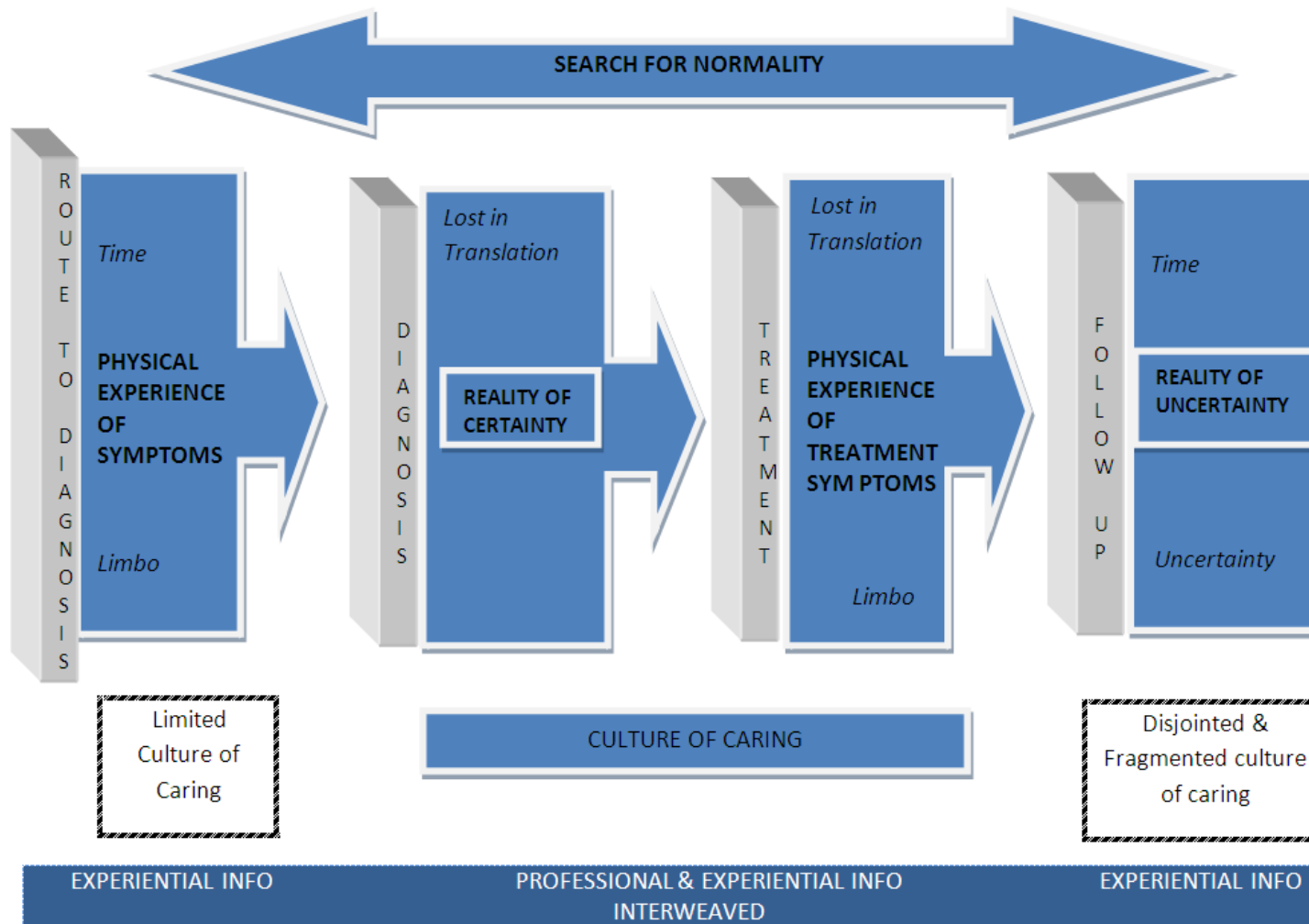


Figure 3: Thematic Model

7.8 Thematic Model

The over-arching theme of “search for normality” describes the strategies that participants adopted to normalise their experiences over the course of their trajectory. Participants predominantly focused on their experience of symptoms and sourced information accordingly to help them explain and understand them in the context of their own and others’ experiential knowledge. Leading up to their diagnosis, participants searched to normalise their experience of symptoms using common illness explanations by drawing on their own and others’ experiential knowledge of health and illness. It became evident how time influenced how they interpreted the significance of their symptoms and many responded by sourcing information from someone who possessed the knowledge to help them explain and understand them. Based on this information, many became anxious as they realised that their symptoms were indicative of something being there or something being wrong. As they had not formally entered the cancer arena there was no real “culture of caring” evident since much of their care was based on an outpatient basis. Many perceived their care and the information provided at this time as limited, leaving many with a feeling and sense of being in limbo.

However, once participants received a diagnosis of cancer and they entered the cancer arena, they were provided with a wealth of both verbal and written information from various sources across the multi-disciplinary team. Many participants had been anxious and fearful leading up to their diagnosis and therefore relied heavily on the information from professionals and the

knowledge this provided. The way in which the diagnostic, prognostic and treatment information was given, within a “culture of caring” from health professionals who possessed the knowledge and expertise, provided many with a “reality of certainty” that their cancer would be cured and life would be back to normal after completing their treatment. However, some commented on how the information they received was too much and they talked about how it was lost in translation with their spouses and the CNS being crucial in filling in the gaps or clarifying aspects of their future treatment and its outcome. Participants talked about how they normalised or made sense of their diagnosis through the use of cultural understandings, family history or lifestyle behaviours strongly associated with cancer.

Prior to the start of treatment, many were certain that they understood from the information they received and sourced that they were prepared for the reality of their treatment. It was evident how they combined both categories of information to help them understand what was ahead. However, over the course of treatment, what became evident was how aspects of participants’ treatment and their experience of symptoms did not resonate with their new experiential knowledge as many could not normalise them in the context of their understanding. Based on this experience, many responded by sourcing information from various health professionals and fellow patients to aid their understanding and knowledge, showing again how participants sourced both categories of information to understand and normalise their experience of symptoms. Both categories of information were easily accessible as participants were immersed in a culture of caring with a range of health

professionals and fellow patients available to provide information specific to their needs as required. However, many noted how the amount of information and communication tapered off as they moved towards the end of treatment as many perceived they were entering limbo again as they did not know what to expect in the early post-treatment and follow-up phase.

The model aims to illustrate the seamless forward movement that participants experienced over the course of their trajectory through the use of the arrows. I specifically used no arrows at follow-up as many participants had no real forward vision or hope for their future due to the reality of uncertainty they were experiencing at this time. Participants had moved through their trajectory weaving both categories of information into “internally consistent “embodied” knowledge, with received “biomedical” information merely one strand in this complex fabric” (Lippmann 1999:269). This strand had built up over their trajectory and was now integrated into experiential knowledge through the direct experience of diagnosis, treatment and now living with post-treatment symptoms and the information these experiences provide.

Participants at this stage had come full circle where they drew heavily on their own and others’ new experiential knowledge of cancer, its treatment and outcomes. However, how they responded and sourced information at this point differed from the other time points and was influenced by their experience of symptoms, their understanding of those symptoms and the disjointed and fragmented culture of caring that many experienced at this time. Participants talked about how they normalised their initial experience of

symptoms based on the knowledge and understanding they had gained from the information they had received up to this point. Based on this information, many initially suffered severe post-treatment symptoms as they understood them to be normal and part of their treatment experience. Again, time influenced how many interpreted the significance of their symptoms and where earlier in their trajectory they responded by sourcing information specific to their needs they could not access or did not know who to access information from at this time. Many experienced a disjointed and fragmented culture of caring as there appeared to be no one available to provide the specific information they required or they received information that they perceived was vague and ambivalent as it did not resonate with their actual experiences or expectations. Due to these factors, many experienced living in a “reality of uncertainty” as they were living with the long-term consequences of their treatment that they did not understand or expect gained from the information they received across their cancer trajectory and the knowledge this provides.

7.9 Strengths and Limitations of the Study

This study is one of the first prospective longitudinal studies explaining the role of information based on the experiences of people affected by laryngeal cancer. It incorporates the experiences of patients and carers, a group previously under-researched, and how and why they use information to make sense of their experiences based on the information they receive. This study provides a detailed account of the experiences of people affected by laryngeal cancer across the cancer trajectory illustrating how their need for

information is based on their actual experiences and how their need and use of information changes as they progress across their trajectory. This study identifies how carers play an integral part in the patient's trajectory and have specific needs of their own that previous research has acknowledged but not fully explored.

This study adds knowledge to the practical and methodological issues of joint and single interviews and provides justification for future prospective longitudinal studies with this group of patients and their carers, as attrition from this study was low. This study shows how this group of patients and carers made sense of their illness experiences, drawing on experiential knowledge in combination with information from health professionals, thus adding to this body of work from both a clinical and sociological perspective. Drawing on Dingwall's Illness action model (1976), the findings from this study have shown how this group of participants respond to their physical experience of symptoms in the context of their knowledge and understanding gained from the information they receive across the cancer trajectory, thus explaining the role of information. However, as this was an explorative qualitative study, the sample is small and covers a range of treatment pathways, therefore caution is needed on interpreting the results to the wider head and neck population. The sample recruited was predominantly male, therefore no comparison can be made on gender differences with regards their use of information based on their actual experiences.

Due to the data collection methods adopted in this study, the findings are based solely on the personal accounts of the participants involved and cannot be verified against the actual exchange of information during the consultations with health professionals involved in their care. How participants discussed their overall experiences across the trajectory, particularly in the second interview, will have been influenced by the outcome of their treatment given in their retrospective account. Many participants gave their accounts through joint interviews, which could suggest that the accounts given may not be a “true” account of their personal experiences as couples may withhold or minimize their experiences to protect each other from the emotional impact of their experiences over the cancer trajectory.

7.10 Conclusion and Recommendations

This study has explained the role of information based on the experiences of people affected by laryngeal cancer across the cancer trajectory. Two broad categories of information were identified: experiential information drawn from experiential knowledge, and information from health professionals. These categories of information were inextricably linked, with one source not viewed as more important than the other with both being used separately and in combination at different time points across the cancer trajectory depending on the perceived level of need of the individual based on their actual experiences.

This study has shown that participants receive a wealth of both verbal and written information at diagnosis and through treatment from a range

of health professionals involved in their care, in combination with experiential information from family, friends and ex-patients. Through their experience of symptoms, many participants responded by seeking information from those who could provide them with the knowledge to help them understand and explain their symptoms and achieve a sense of normality. Based on the information many received at diagnosis, they perceived an “illusion of certainty” that their life would be back to normal and their cancer would be cured after treatment. However, the reality for many was uncertainty as their experience of symptoms did not resonate with their new knowledge and understanding based on the information received. Many searched for normality but experienced a sense of loss and ambiguity for the future. The wealth of information that participants received at diagnosis and through treatment from the various sources provided many with a culture of caring which appeared to dwindle in the post-treatment and follow-up phase with many not knowing who to contact and where to seek further information that could explain their experience of treatment symptoms. Many commented that the written information from health professionals during follow-up was prescriptive and vague as it did not resonate with their actual experience of symptoms at this time, leaving many living in a reality of uncertainty. The findings from this study raise issues that need to be addressed by policy makers, clinicians and future research.

Most policy documents and NHS directives over the last decade have dictated the need for health professionals to provide information to people affected by cancer that is “tailored to their individual needs” to ensure that they understand and know what is happening at key stages over their cancer

trajectory. This development has seen a plethora of information booklets and information sources relating to various aspects of diagnosis, treatment and the outcome of their treatment. However, the data from this study would suggest that the verbal and written information provided to patients and their families by health professionals is not always coherent and reflective of their actual experiences with information at diagnosis and through treatment still being prescriptive and generic, and focusing mainly on the stage of tumour, treatment pathway and the management of treatment side effects. These types of information are important and need to be provided, however, the data from this study would suggest that the information provided by health professionals, especially at diagnosis, allows many patients and their carers to have unrealistic expectations of the outcome of their treatment. This prescriptive approach, where the health professional gives and the patient receives information, needs to change to a holistic or patient-centred approach where the exchange of information is a two-way process. Only through this process will health professional be able to explore the experiential knowledge that patients and their families are drawing on to explain and make sense of their symptom experience. People affected by laryngeal cancer experience complex clusters of symptoms, therefore how they manage and understand them will depend on the information they have received. The need for clear, accurate information from health professionals, for example, on the length of time many patients experience symptoms, must be addressed as 6-8 weeks was found not to be a true reflection of the majority of participant's experience in this study. The need for continual assessment across the trajectory is required to ensure

the needs of this group of patients are met, especially in the post-treatment and follow-up phase.

There has been an emphasis placed on the need and implementation of patient needs assessment tools which would allow health professionals to obtain information to provide a consistent and comprehensive system, through which a patient's range of needs for information, support and care could be explored. A needs assessment tool would enable health care professionals to understand the specific needs patients would like to be met by health professionals involved in their care at clearly defined points in their cancer trajectory (Richardson et al 2011). The data from this study have shown how patients' and carers' needs change over the trajectory based on their actual experiences, therefore supporting the use of needs assessment tools at key stages over the cancer trajectory within clinical practice to identify their changing needs. However, a recent evaluation of embedding needs assessment tools into clinical practice has found that clinical nurse specialists perceive that they are time-consuming and a bureaucratic exercise more than a clinical tool, possess a lack of knowledge of specific tools to use and that many perceived that they knew which patients required formal assessment and those who did not (Seerha & Hughes 2011). My data would suggest that this is not the case as many patients experienced their needs being unmet due to the lack of assessment and continuity of care many experienced beyond the diagnostic phase. I would recommend that all patients and their main carer are formally assessed at diagnosis, during their treatment, at the end of active treatment and early in the post-treatment follow-up phase. Only by doing this will health

professionals understand and address the specific needs of the individual patient and their families and provide the appropriate care or services to help them manage at these times.

Continuity of care is deemed important to patients and their families, especially in the follow-up phase where many feel vulnerable, isolated and uncertain of their future (Foster & Fenlon 2011). Continuity of care is a multifaceted concept with Haggerty et al (2003) identifying three types of continuity that are central to patients and their families from across different sectors of the health service. Firstly, they highlight how information is the common thread that links care from one provider to the next and bridges the gaps between different episodes of the illness or “separate care events” (2003:1220). This information can be disease- or person-orientated, but the important factor is that the patient’s preferences and values are taken into context by the health care provider to ensure the care received by patients is responsive to their needs. Secondly, they discuss management continuity and the importance of shared care plans or protocols, especially in the management of chronic or complex diseases where there are several health care providers involved in a patient’s care. Continuity of care is perceived by the patient to be when the appropriate service is delivered in a complementary and timely manner with flexibility embedded to cater for their changing health care needs. Thirdly, they discuss relational continuity and the importance that patients place in having consistent contact with core members of staff who provide them with a sense of predictability and coherence to their care (Haggerty et al 2003). Relational continuity allows patients to know that their past and present illness

experiences are known to, and will be considered by, the health professionals involved in their care and in the future planning of their care to meet their actual needs.

What Haggerty and her colleagues allude to is not difficult to achieve or understand, especially in today's health care service where there are seamless care pathways for patients already established and multi-disciplinary teams working together, especially within cancer care. People affected by laryngeal cancer have complex needs due to the complexity of their treatment and the outcome of their treatment, especially those that require laryngectomy, which require continuity of care from the health professionals involved in their care. By adopting needs assessment tools and developing care plans based on the specific needs addressed, the care plan can be shared across the team, altered and further developed by the various health care professionals involved in their care at the key stages over their trajectory. By adopting these approaches to the management and long-term care of people affected by laryngeal cancer it would alleviate the challenges that many experience, especially in the follow-up phase. As Haggerty and her colleagues state, "processes designed to improve continuity – for example, care pathways and case management – do not themselves equate to continuity. For continuity to exist, care must be experienced [by the patient] as connected and coherent" (2003:1221).

This study has shown that at points in the cancer trajectory people affected by laryngeal cancer experienced a "connected and coherent" approach

to their care, where their specific needs were addressed and they perceived they were being cared for. This was more apparent at diagnosis and initially starting treatment. However, it was very evident how the coherency and connectedness dwindled when many participants left active treatment and entered follow-up which can lead many patients and their families to report higher health care needs in the future (King et al 2008). Follow-up is a phase which, in general, is poorly understood and relatively neglected for many cancer types (DoH 2007) with new initiatives and political drivers set up to explore and understand what the issues are for people that have and are surviving cancer (DoH, Macmillan and NHS Improvement 2010). Five-year survival rates from cancer have continually improved over the last few decades, especially for people affected with breast and colorectal cancer, however, due to the impact of their treatment, many patients are now living with and managing a chronic illness.

Although survival rates are improving, there is a growing concern that the physical and emotional needs and service delivery for cancer survivors are not improving and not being adequately met (Richardson et al 2011). This concern has prompted the National Cancer Survivorship Initiative (NCSI) to call for a fundamental shift in the way cancer survivors are supported by encouraging a move away from the biomedical model to an individualised model of care, one promoting recovery, health and well-being in survivors (Richardson et al 2011). Survivorship has been interpreted in many ways, but the most common definition is someone who has completed initial cancer treatment and has no evidence of active disease, or is living with progressive

disease but is not in the terminal phase of their illness or has had cancer in the past (Macmillan Cancer Support 2008). This definition would imply that patients should be receiving individualised supportive care on leaving active treatment and that this care is planned and organised based on the preferences and values of the individual's needs at that time.

However, in their scoping review, Richardson et al (2011) found that although there is a wealth of research exploring survivorship issues, these are in relation to pain, depression and fatigue with surprisingly little evidence on the physical, financial and relational issues associated with cancer patients. In addition, they highlight that most of the research has been carried out with women affected by breast cancer with little research carried out with less prevalent cancers, such as head and neck cancer, even though there is evidence on the physical, psychological and social issues this group of patients experience due to the impact of their cancer and its treatment.

Based on these new initiatives, the findings from this study would strongly recommend a collaborative project between head and neck cancer clinicians and researchers to explore the long-term issues (i.e. six months to five years post-treatment) that this group of patients and carers experience. I would advocate that interventions need to be tested and developed on both patients and their carers across the whole of the cancer trajectory to ensure that their ever-changing and complex needs are met. For example, some of the questions raised from this study are:

1. Are there interventions that can be developed to aid head and neck cancer patients' understanding of the mask and chemotherapy?
2. What interventions can be developed to assess and monitor the psychological distress with patients undergoing laryngectomy?
3. What interventions can be developed or are available to assist patients to manage their post-treatment symptoms?
4. What interventions can be developed to monitor and assess patients' and carers' needs in the post-treatment and follow-up phase?

In addition, the findings from the study raise further areas for exploratory research, such as:

1. Does experiential knowledge of laryngeal cancer influence newly-diagnosed patients' treatment decisions?
2. Are people affected by laryngeal cancer told that their cancer will be cured from the information provided at diagnosis?
3. Does patient recall of information at diagnosis reflect a "true" account of the information provided at the MDT clinic?

From the findings of this study, it is evident that an individual does not enter the health care system as a blank sheet but comes with a life history of events and experiences. These events and experiences influence how they understand and manage the information they receive in the context of their experiences of illness and its symptoms in the context of their lives. The information and the knowledge gained from the informal and formal exchanges

with others is through a shared language, as language is fundamental to how we discuss, describe and make sense of their experiences. As highlighted in Chapter 1, as a nurse, communication is core to finding out the explicit needs of the patient and their family in the clinical setting, therefore only through discussion can we know what people's needs are in the context of their understanding as the sharing of information is central to all aspects of our lives. Only by sharing information can health professionals provide the right information that will be situated and understood in the context of patients' and their families' lives, leading to a reduction in the uncertainty that this group experienced, specifically when *"it all doesn't fall back into place"*.

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Appendices

Appendix 1: Interview 1 Topic Guides



**UNIVERSITY OF
STIRLING**

Title of Study

What are the information needs of people affected with cancer of the larynx?

Cancer Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling FK9 4LA Scotland
Telephone: +44 (0)1786 849260
Facsimile: +44 (0)1786 460060

Topic Guide for First Interviews - Patient

Ideally, the patient and carer interviews will be carried out separately. All of the interviews will be patient-centred which means that respondents will be encouraged to define their own experiences and information needs.

Each subsequent interview will build on the previous one. The following outline is designed to be used in a flexible manner, responding to the patient's verbal and non verbal cues.

First Interview – this interview will explore the patient's route to diagnosis, their needs for information leading up to diagnosis and during treatment.

Questions

Can you start at the beginning and tell me what has happened? How did you come to be diagnosed?

[Prompts to be used if the respondent does not say much or finds it difficult to articulate]

Can you tell me what was happening to you before you were diagnosed?

What were your symptoms?

Had you experienced them long?

[If no GP consultation previously mentioned]

Did you ever consult a GP about your symptoms?

- What prompted you to do so?
- What happened?
- Why was that?

Can you tell me what happened at the hospital?

Who did you meet at the hospital? What were you told?

Appendix 1: Interview 1 Topic Guides

Can you tell me your experience of being told that you had cancer of the larynx?

- Tell me about the information you received at your diagnosis?
- Who gave you the information?

Is there anything else you would like to say about the information you received when you were diagnosed?

Exploring the experiences of the patient during their treatment phase and their needs surrounding the provision of information at this time

When did you find out what treatment you were to have?

- Who told you about your treatment?
- How did they tell you?
- Did they give you any written information?
- Did you understand the information?
- Could the information provision be better – if so how?

Can you tell me how you are finding your treatment?

- Explore issues such as
 1. Communication/speech
 2. Dietary intake
 3. Body Image
 4. Provision of information surrounding these issues
 5. Who would say is central in the provision of information since your diagnosis?
why?

Do you think you have been provided with enough information throughout your treatment?

- Who has provided you with this information?
- What types of information have they provided you with?
- Could the provision of information be improved?

Is there anything else you would like to say about your information and support needs during your treatment?

Thank you so much for taking part in this study.

Appendix 1: Interview 1 Topic Guides



**UNIVERSITY OF
STIRLING**

Title of Study

What are the information needs of people affected with cancer of the larynx?

Cancer Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling FK9 4LA Scotland
Telephone: +44 (0)1786 849260
Facsimile: +44 (0)1786 460060

Topic Guide for First Interviews – Carers

Ideally the patient and carer interviews will be carried out separately. All of the interviews will be patient-centred which means that respondents will be encouraged to define their own experiences, information and support needs.

*Where **xxxx** is marked the patient's name will be inserted.*

First Interview – this interview will explore the patient's route to diagnosis and their needs for information and support at this point.

Can you start at the beginning and tell me what has happened? How did xxxx come to be diagnosed?

[Prompts to be used if the respondent does not say much or finds it difficult to articulate]

Can you tell me what was happening before xxxx was diagnosed?

Did he/she have any symptoms?

What were they?

Had he/she had them long?

[If no GP consultation previously mentioned]

Did xxxx ever consult a GP about his/her symptoms? What prompted xxxx to do so? What happened? What was said?

Did you have any questions at that time? Were they answered? By whom?

How long from seeing the GP was it before xxxx was seen at the hospital?

Appendix 1: Interview 1 Topic Guides

What happened when you attended the hospital?

Can you tell me your experience of being told that **xxxx** had cancer of the throat/larynx?

What were your thoughts and feelings at this time?

Were **you** provided with enough information at this time?

- Who provided you with that information?
- In what format was that information provided?
- Did you understand the information?
- How could the provision of information be improved?

Is there anything else you would like to say about the information you received when **xxxx** was diagnosed?

Experiences of the carer during their partner/relative's treatment phase and their needs surrounding the provision of information at this time.

When did you find out what treatment **xxxx** was to have?

- Who told you about **xxxx**'s treatment? How did they tell you? Were you there when **xxxx** was told?
- Did they give you any written information? Did you understand the information?

Can you tell me how you are finding **xxxx**'s treatment?

Have you been provided with enough information throughout **xxxx**'s treatment?

- Who has provided you with this information?
- In what ways have you used the information?

Is there anything else you would like to say about your information needs during **xxxx**'s treatment?

Thank you so much for participating in the study.

Appendix 2: Interview 2 Topic Guides



**UNIVERSITY OF
STIRLING**

Title of Study

What are the information needs of people affected with cancer of the larynx?

Cancer Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling FK9 4LA Scotland
Telephone: +44 (0)1786 849260
Facsimile: +44 (0)1786 460060

Topic Guide for Second Interviews - Patient

Second Interview: Follow up care – this interview will explore the experiences of the patient now that active treatment has stopped and explore what their information needs/support is in follow up care?

How have you been since we last met?

Can you tell me what happened when you finished your treatment?

What information were you given by the hospital when you finished your treatment?

- In what format was the information?
- Who provided this information?
- Was it enough information?
- Did you understand the information?
- Could it be better – if so how?

Have you seen any health professionals since you have finished your treatment?

What have you been told since finishing your treatment?

What do you think of the information?

In what ways have you used the information you received since your diagnosis?

In your opinion is there anything else that you think needs to be done/improved with information for future?

If you had the opportunity, what would you tell someone in your position now? What would be helpful to them?

Is there anything else you would like to discuss?

Thanks so much for taking part in this study.

Appendix 2: Interview 2 Topic Guides



**UNIVERSITY OF
STIRLING**

Title of Study

What are the information needs of people affected with cancer of the larynx?

Cancer Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling FK9 4LA Scotland
Telephone: +44 (0)1786 849260
Facsimile: +44 (0)1786 460060

Topic Guide for Second Interviews – Carer

Second Interview: Follow up care – this interview will explore the experiences of the carer now that active treatment for the patient has stopped and explore what their information needs are in follow up care?

How have you been since we last met?

Can you tell me how things have been since **xxxx** finished his/her treatment?

What information were you given by the hospital when **xxxx** finished his/her treatment?

- Who provided this information?
- Was it enough information?
- Did you understand the information?
- Could it be better – if so how?

Can you tell me how **you** are feeling now that **xxxx** has finished his/her treatment?

Have **you** seen any health professionals' since **xxxx** finished his/her treatment?

What types of information did they give you?

What do **you** think of the information since **xxxx** was diagnosed?

In what ways have you used this information?

Can you tell me if **you have** been provided with enough information?

With regards information– in your opinion is there anything else that you think needs to be done/improved for future?

Is there anything else you would like to discuss?

Thank you so much for taking part in this study.

Appendix 3: Ethics Approval

Multi-Centre Research Ethics Committee for
Scotland

Secretariat
Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Telephone 0131 536 9026
Fax 0131 536 9346
www.corec.org.uk



Mrs Anne Taylor
CRUK Nursing Research Training Fellow
Cancer Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling
FK9 4LA

Date: 2 October 2006
Your Ref.:
Our Ref.: 06/MRE00/89

Enquiries to: Walter Hunter
Extension: 89026
Direct Line: 0131 536 9026
Email: walter.hunter@lhb.scot.nhs.uk

L

Dear Mrs Taylor

Study title: **An exploration of the information and support needs of patients and carers affected by cancer of the larynx from diagnosis through to supportive care**

REC reference: **06/MRE00/89**

The Multi Centre Research Ethics Committee for Scotland, Committee A reviewed the above application at the meeting held on 28 September 2006. Thank you for attending to discuss the study.

Ethical opinion

The Committee noted that this was non-therapeutic qualitative research. It was a student project for a PhD. The Committee had no major ethical concerns. There were some inconsistencies relating to length of data retention and indemnity. Ms Taylor confirmed that the data retention would be 10 years for all groups, and agreed to correct the erroneous information sheets. The Committee suggested that either tape recordings should be kept securely for the duration of the study or that the participants should be given the opportunity to check and approve transcripts of the interviews with the transcripts being retained for 10 years. This was accepted by Ms Taylor. The Committee also suggested that a joint interview as well as individual interviews with carers and patients would be useful for the aims of this study, but this was not considered an essential requirement for approval: Ms Taylor agreed to consider this suggestion. In response to questions about the approach to potential participants and accessing records Ms Taylor assured the Committee that the clinical nurse specialist would make the initial contact and only when the patient had consented would their name be passed to her. The accessing of records would be by a member of the treating team and not the researcher. The Committee also agreed that the study should be exempt from site specific assessment.

Chairman Professor Kennedy Lees
Vice-Chairman Dr George Masterion



Offer of Research Training Fellowship		07 July 2005
Participant Registration Form	1	05 September 2006
Carer Registration Form	1	06 September 2006

Research governance approval

You should arrange for all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research at a NHS site must obtain research governance approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number: 06/MRE00/89-Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

✓ **Professor Kennedy Lees**
Chairman
cc: Jen Shearer
Research Office
University of Stirling
Stirling FK7 8PW

Appendix 4: NHS Sites Approval



R&D Department
Lochiel Court
Monklands Hospital
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date 16th February 2007

Mrs Anne Taylor
Cancer Care Research Centre
Department of Nursing & Midwifery
University of Stirling
FK9 4LA

Enquiries to Margaret Stewart, R&D Support Officer
Direct Line 01236 712445
Email Margaret.Stewart@lanarkshire.scot.nhs.uk

Dear Mrs Taylor,

An exploration of the information and support needs of patients and carers affected by cancer of the larynx from diagnosis through to supportive care – PROJECT ID: 732

Thank you for sending your amended R&D application form for the above study in response to my letter of 13th December 2006.

R&D Management Approval has been granted for the study and an honorary contract to allow you to carry out the research within NHS Lanarkshire Acute Division is currently being arranged. This will be forwarded to you for your signature.

Once your honorary contract is in place, the research can then be conducted within Lanarkshire Acute Division on the understanding that you will follow the conditions set out below.

Conditions

- You have been granted ethical approval for the research (if required) and supplied the R&D office with a copy of your letter of approval or letter to confirm approval not required
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: <http://www.show.scot.nhs.uk/cso/> or the Research & Development Intranet site: <http://intranet/lah/ClinEffect/Research>)
- You notify the R&D Department of any future amendments to the protocol
- You notify the R&D Department if any additional researchers from Lanarkshire Acute Division becomes involved in the project
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely
- You provide the R&D Department with a copy of the results of your research once complete.

I trust these conditions are acceptable to you.

Yours sincerely,

J.C Rodger MD, FRCP
Director of Clinical Effectiveness



LAT100

Acute Services Division

Diagnostics Directorate



Research & Development Office

5th Floor I.N.S. Southern General Hospital, 1345 Govan Road Glasgow G51 4TF

Professor D J Wyper: R&D Director
Mrs Sonia Whyte: R&D Co-ordinator
Dr Susan Graham: R&D Co-ordinator
Mrs Carolyn Stewart: R&D Officer

Tel: 0141 201 1890
Fax: 0141 201 2060
email: sonia.whyte@sgh.scot.nhs.uk

Our Ref: R060163/SW

19th February 2007

Mrs. Anne Taylor
CRUK Nursing and Training Fellow
Cancer Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling
FK9 4LA

Dear Miss Taylor,

Title: An exploraton of the information and support needs of patients and carers affected by cancer of the larynx from diagnosis through to supportive care

The above project has undergone registration with the R&D Office and I am satisfied that all necessary arrangements have been set in place. Therefore on behalf of **Greater Glasgow and Clyde Health Board** I am writing to confirm approval is given, to allow the project to commence at:

Southern General Hospital,
Royal Alexander Hospital,
Gartnavel Royal Hospital,
Beatson oncology
and Primary Care Services.

Please find enclosed a reimbursement form, which should be given to GP's who agree to participate. Research and Development are obliged to offer support if the study is eligibly funded. The general costs are GP first hour - £51 second hour £39. **This is not billed to you** but will be paid to GP's that participate, by R&D.

Appendix 4: NHS Sites Approval

Acute Services Division

Diagnostics Directorate



Please send completed forms to:

Mr. Brian Rae
Research and Development Manager Primary Care
Gartnavel Royal Hospital
1055 Great Western road
Glasgow
G12 0XH

It is important that you advise the R&D office of any changes i.e. to the protocol, recruitment numbers, and staff. I wish you every success with your study. Please don't hesitate to contact me should you require any further assistance.

Yours sincerely,

A handwritten signature in black ink that reads 'Sonia Whyte'.

Mrs. Sonia Whyte
Research & Development Co-ordinator

Enc: Honorary Contract
NHS Greater Glasgow Practice Reimbursement form

CC: Dr. Judith Godden, R&D Gartnavel and Beatson Oncology
Mr. Brian Rae, R&D Primary Care
Miss Emma Cuthbertson, R&D RAH

Appendix 5: Information Letter to Consultants



**UNIVERSITY OF
STIRLING**

Title of Study:
Information and support needs of people affected with
cancer of the larynx?

Cancer Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling FK9 4LA Scotland
Telephone: +44 (0)1786 849260
Facsimile: +44 (0)1786 460060

3rd of July 2007

Dear [Consultant Name]

I am trainee nursing research fellow funded by Cancer Research UK based at the Cancer Research Centre at Stirling University and I am currently carrying out a three-year study exploring the information and support needs of people affected with cancer of the Larynx.

The study is longitudinal and I plan to recruit 20 patients and their main carer (if they agree) from diagnosis through treatment and into follow up care. Recruitment is being carried out throughout the West of Scotland and all consultants have been written to and informed about the study. I have spoken with the clinical nurse specialists across all sites who are supportive of the study.

Two interviews will be carried out with the patient and their main carer; one towards the end of the patient's treatment and one during follow up care to explore the patient's and carers experiences and perspectives of information and support through these stages.

I have recently met with the clinical nurse's specialists, Ewan and Frances at the Beatson and feel that it is appropriate to inform you of the study as I will be accessing patients from the Beatson. The study has been approved by MREC A ethics committee and R&D approval has been obtained.

Please feel free to contact me if you would like any further information about the study. My contact details are – a.d.taylor@stir.ac.uk or 01786 849260

Hope this meets with your approval and thank you for your time.

Kind Regards

Anne Taylor CRUK Nursing Research Training Fellow

Appendix 6: Patient Information Sheet



**UNIVERSITY OF
STIRLING**

Study Title:

What are the information needs of people affected by cancer of the larynx?

Cancer Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling FK9 4LA Scotland
Telephone: +44 (0)1786 849260
Facsimile: +44 (0)1786 460060

Participant Information Sheet (Patient)

Invitation

I am inviting you to take part in this research study. Before you decide whether to take part, it is important for you to understand why the study is being done and what it involves. Please take some time to read the following information and discuss it with family or friends if you wish.

What is the purpose of this study?

The purpose of this study is to find out what are the information and support needs of people affected by cancer of the throat/larynx from diagnosis, during treatment and after treatment has finished.

To allow me to carry out this study I have been awarded a nursing research training fellowship for three years which will form my PhD thesis.

Why have you been chosen?

You have been chosen to take part in this study as you have recently been newly diagnosed with cancer of the throat/larynx and your experiences and views are important. I hope to recruit 20 newly diagnosed patients into the study.

Do I have to take part?

It is up to you to decide whether or not take part in the study. This information sheet is yours to keep what ever you decide. If you decide to take part in the study and then change your

Appendix 6: Patient Information Sheet

mind, you can withdraw at any time without giving a reason and the care you receive will not be affected. **You do not have to make any decisions about the study today.**

Who is organising the study?

The study has been funded by Cancer Research UK and is being led by myself, Anne Taylor. The study has been approved by MREC A research ethics committee

What happens next?

The nurse specialist has given you this information sheet on my behalf and you will inform her/him if you permit them to pass on your contact details to me. If you have given permission I will contact you over the next two to three days to give you time to consider whether you wish to take part in the study. When I contact you, I will discuss the study with you and answer any questions you may have. If you are considering taking part in the study I will arrange to meet you either at your home or at your next hospital appointment. At that meeting I will speak with you about the study again and check that you are still willing to take part, if you agree I will then ask you to sign a standard consent form and you will be given a copy of this to keep.

What will taking part in the study mean for me?

Taking part in the study will mean that you and I will meet twice for an interview which will last between thirty minutes and two hours depending on how much you have to say. The first interview will take place towards the end of your treatment to discuss your experiences of information and support needs surrounding your diagnosis and through your treatment. The second will be 6 months from completing your treatment to discuss your experiences of information and support through out this time. **The interviews will be arranged at a time that suits you and at a place where you feel most comfortable, whether that is at your home or at the hospital.**

Will I benefit from taking part?

I cannot promise that taking part in this study will be of direct benefit to you but by telling me of your experiences of information and your support needs since your diagnosis will help give nursing research a greater understanding of what the information and support needs of people affected with cancer of the larynx are which may help other people in the future.

Appendix 6: Patient Information Sheet

Are there any risks involved in taking part?

It is unlikely that you will come to any harm as a result of taking part in the study, and no special arrangements have been put place for compensation. If you have any concerns about the way you are approached or treated during the course of the study, please contact either myself or my supervisor Dr Gill Hubbard at Stirling University (01786 849260) or alternatively you can contact the normal National Health Service complaints mechanisms which will be available to you.

Will my taking part be kept confidential?

Any information which is collected about you, or that you provide during this study, will be kept strictly confidential. Your personal details will be removed so that you will only be identifiable by a project number and the researcher and her supervisory team will only have access to your details. All information will be held securely for a period of 10 years, as required by the university. However, any tape recorded information from you will be destroyed once the project is complete. I will send your GP a letter to let him/her know that you have agreed to take part in the study however if you do not wish me to contact your GP for any reason then please let me know.

What will happen to the results of the study?

When the results of the study have been analysed, a report will be prepared that I will send to Cancer Research UK and will also prepare the results for publication and presentations at conferences. A summary of the results of the study will also be available to you if you wish; we can discuss this at your final interview.

Thank you for taking the time to read this information.

If you would like to find out more about the study please feel free to contact me –

Anne Taylor

Cancer Research UK Training Nursing Research Fellow

Tel. 01786 849260

Email: a.d.taylor@stir.ac.uk

Appendix 7: Carer Information Sheet



**UNIVERSITY OF
STIRLING**

Study Title

What are the information needs of people affected by cancer of the larynx?

Cancer Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling FK9 4LA Scotland
Telephone: +44 (0)1786 849260
Facsimile: +44 (0)1786 460060

Participant Information Sheet (Carer)

Invitation

I am inviting you to take part in this research study. Before you decide whether to take part, it is important for you to understand why the study is being done and what it involves. Please take some time to read the following information and discuss it with family or friends if you wish.

What is the purpose of this study?

The purpose of this study is to find out about the information and support needs of people affected by cancer of the throat/larynx from diagnosis, during treatment and after treatment has finished.

To allow me to carry out this study I have been awarded a nursing research training fellowship for three years which will form my PhD thesis.

Why have you been chosen?

You have been chosen to take part in this study as you are a partner, close family member or carer to someone who has been diagnosed with cancer of the throat/larynx and your experiences and views are important. I hope to recruit 20 “family members/carers” to take part in this study.

Who is organising the study?

The study has been funded by Cancer Research UK and is being led by myself, Anne Taylor. The study has been approved by MREC A research ethics committee.

Appendix 7: Carer Information Sheet

Do I have to take part?

It is up to you to decide whether or not take part in the study. This information sheet is yours to keep whatever you decide. If you decide to take part in the study and then change your mind, you can withdraw at any time without giving a reason and the care your partner receives will not be affected. **You do not have to make any decisions about the study today.**

What happens next?

The nurse specialist has given you this information sheet on my behalf and you will inform her if you permit them to pass on your contact details to me. If you have given permission I will contact you over the next two to three days which will give you time to consider whether you wish to take part in the study. When I contact you, I will discuss the study with you and answer any questions you may have. If you are considering taking part in the study I will arrange to meet you either at your home or at your partner's/family member's next hospital appointment. At that meeting I will discuss the study again and check that you are willing to take part, if you agree I will ask you to sign a consent form and you will be given a copy of this to keep.

What will taking part in the study mean for me?

Taking part in the study will mean that you will meet with me twice for an interview which will last between thirty minutes to two hours depending on how much you have to say. The first interview will be during your partner's/family member's treatment to discuss your experiences of information and support during this time and the second and final interview will be in the follow up phase when treatment has stopped; again this interview is to discuss your experiences of information and support needs at this time. **The interviews will be arranged at a time that suits you and at a place where you feel most comfortable, whether that is at your home or at the hospital.**

Will I benefit from taking part?

I cannot promise that taking part in this study will be of direct benefit to you but by telling me of your experiences of information and your support needs during this time, will help give nurses and other health professionals a greater understanding of what the information and

Appendix 7: Carer Information Sheet

support needs of people affected with cancer of the larynx are which may help other people in the future.

Are there any risks involved in taking part?

It is unlikely that you will come to any harm as a result of taking part in the study, and no special arrangements have been put place for compensation. If you have any concerns about the way you are approached or treated during the course of the study, please contact either myself or my research supervisor Dr Gill Hubbard at Stirling University (01786 849260) or alternatively you can contact the normal National Health Service complaints mechanisms which will be available to you.

Will my taking part be kept confidential?

Any information which is collected about you, or that you provide during the study, will be kept strictly confidential. Your personal details will be removed so that you will only be identifiable by a project number and the researcher and her supervisory team will only have access to your details. All information will be held securely for a period of 10 years, as required by the university.

What will happen to the results of the study?

When the results of the study have been analysed, a report/thesis will be prepared that I will send to Cancer Research UK and submit to the University of Stirling. I will also prepare the results for publication and presentations at conferences. A summary of the results will be sent to the nurses and their teams at your hospital and a summary of the results will also be available to you if you wish; we can discuss this at the final interview.

Thank you for taking the time to read this information.

If you would like to find out more about the study please feel free to contact me –

Anne Taylor

Trainee Nursing Research Fellow

Tel. 01786 849260

Email. a.d.taylor@stir.ac.uk

Appendix 8: Consent to Contact Form



UNIVERSITY OF STIRLING

Title of Study

What are the information needs of people affected by cancer of the larynx?

Cancer Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling FK9 4LA Scotland
Telephone: +44 (0)1786 849260
Facsimile: +44 (0)1786 460060

Consent for potential participants contact details

The nurse specialist has discussed with you today about the possibility of you taking part in the above study. However before I can contact you I need you to sign this form to say that you agree for the nurse to pass on your contact details to me.

The only details that will be passed on to me are your name and a contact telephone number. I will contact you over the next few days to have chat with you about the study. This will give you time to read over the study information sheet which the nurse has given to you.

BY SIGNING THIS FORM DOES NOT MEAN THAT YOU AGREE TO TAKE PART IN THE STUDY.

I agree for the nurse specialist to pass on my details to Anne Taylor

Please sign and print your name below

.....
.....

Telephone number -

Thank you

Anne Taylor

Appendix 9: Patient Consent Form



**UNIVERSITY OF
STIRLING**

Cancer Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling FK9 4LA Scotland
Telephone: +44 (0)1786 849260
Facsimile: +44 (0)1786 460060

CONSENT FORM (PATIENT)

Title of Study: What are the information needs of people affected by cancer of the larynx?

Please read the statements below tick each box and sign at the bottom if you agree

1. I confirm that I have read and understand the study information sheet (dated .xxx)
and I have had the opportunity to ask the researcher questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that I will take part in three interviews as part of the study and that the interviews will be audio-recorded.

4. I understand that any information I provide will be treated in the strictest confidence. This information will be held securely for 10 years and will only be available to the researcher. Information will be destroyed after this time.

6. I give permission for the information I provide to be used for research purposes (including reports, publications and presentations) with strict preservation of anonymity.

7. I agree to take part in the above study.

Name of Patient

Date

Signature

Researcher

Date

Signature

Appendix 10: Carer Consent Form



**UNIVERSITY OF
STIRLING**

CONSENT FORM (CARER)

Cancer Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling FK9 4LA Scotland
Telephone: +44 (0)1786 849260
Facsimile: +44 (0)1786 460060

Title of Project: What are the information needs of people affected by cancer of the larynx?

Please read the statements below tick each box and sign at the bottom if you agree

1. I confirm that I have read and understand the study information sheet (dated .xxx)
and I have had the opportunity to ask the researcher questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

3. I understand that I will take part in three interviews as part of the study and that the interviews will be audio-recorded.

4. I understand that any information I provide will be treated in the strictest confidence
This information will be held securely for 10 years and will only be available to the researcher. Information will be destroyed after this time.

5. I give permission for the information I provide to be used for research purposes (including reports, publications and presentations) with strict preservation of my anonymity.

6. I agree to take part in the above study.

Name of Patient

Date

Signature

Researcher

Date

Signature

Appendix 11: Thematic Matrices Sample

Detailed analysis P08

61 year old male diagnosed with T1 laryngeal cancer – had 4 weeks radiotherapy – ex smoker of 5 years and heavy alcohol intake – in employment and in owned property. - Lives at home with wife and 2 daughters.

Summary of what happened	Experiential info	Professional info	Patient interpretation
<p>Symptoms –</p> <p>1 - Experienced a change in voice over a period of 12-13 weeks</p> <p>2-Attended GP – given antibiotics but antibiotics didn’t work</p> <p>3 -Next GP was a friend and he gave him more antibiotics</p> <p>4 -Voice not getting better and impacting on work</p> <p>5 -Contacted GP again and asked to be</p>	<p>1a-“I’ve normally got a gravelly voice, I have had all my life but my voice was getting worse and worse” (14)</p> <p>3a-Symptoms continued</p> <p>4a-“I do presentations all the time and it was getting a bit embarrassing , even my boss was saying what’s wrong wi’ your voice” (14)</p> <p>5a-“I know my body and I know there was something</p>	<p>2a-“reckoned it was laryngitis – so he gave us a course of antibiotics”(14) (<i>outcome info</i>)</p> <p>3b-“now at that time it was a Dr BD who I have known all my life...he’s been very good and he said if this second set of antibiotics doesn’t help then I’m going to refer you” (14) (<i>procedural and outcome info</i>)</p> <p>5b-“he says no bother....he says</p>	<p>3c-“Fair enough” (14)</p>

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient interpretation
<p>referred – told it could take 3-4 months for appt and he wasn't prepared to wait that long as he was worried and he decided to go private</p> <p>6 -Contacted Ross Hall and was seen 2 days later – surgeon had a look via endoscopy</p>	<p>not right”</p>	<p>roughly 3-4 months to see and ENT specialist.....that's the best thing if your worried about it” (14) (<i>procedural and outcome</i>)</p> <p>6a-She says “yeah there's something there” (26) (<i>outcome info</i>)</p> <p>6b -“She said it could be a cyst, a wart” (34) (<i>outcome info</i>)</p>	<p>5c-“ I know my body myself” (22) and that is why he went private</p> <p>6c-“I was a bit taken a back I must admit, I knew there was something there but....you always say...ach, it might be nothing” (34)</p>
<p>Wife –</p> <p>1 -hubby had suffered laryngitis for a month or two and had got a couple of prescriptions from the GP – he kept saying that “this isn't right , I need to go back , he said I think there's something sort of worse going on...I'm going to make an appointment to see a consultant” (16c)</p> <p>2 - Came back from appt and said that there was something there</p>	<p>1a -“I said well I think your not giving the antibiotics enough time to work” (24)</p>		<p>1b - “I thought he was being hysterical about all these things...I think you are just wasting your money....because G is very impatient right and wants things cured immediately” (16/20c)</p> <p>“oh here we go again...you know he's wishing something else to be wrong with him” (32)</p> <p>2a - “I felt that size I must admit, you know I really felt as though, you know I'm always kind oh....”right” but this time I wasn't” (24)</p> <p>“I thought oh here well this , there must be more to this than I've actually given, you know given credence for all along, so em....then I kinda felt guilty” (32)</p>

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient interpretation
<p>Biopsy – 1 - attended for biopsy with his wife and had the biopsy done in the morning and spoke with the surgeon in the afternoon.</p> <p>2 - Attended for CT scan</p>		<p>1a -She says “ come in on the morning we’ll operate, we’ll have a look, we’ll get it removed, we’ll do a biopsy blah blah” (42) <i>(procedural info)</i></p> <p>1b-“She said that’s the tumour in your vocal cords and she says we’ve removed it.....they didn’t want to go any closer with the laser, so she’s says em hopefully...” (46) <i>(outcome info)</i></p> <p>2a --“she says they think they’ve got it all, it certainly hasn’t spread , they scanned my lungs as well” (46) <i>(outcome info)</i></p>	<p>1c-“ they reckoned they had got it all” (46)</p> <p>2b-“because I’ve got to admit I was a heavy smoker for 40 years, 40 cigarettes a day for 40 years and eh I was totally surprised when there was nothing in my lungs and it hasn’t spread anywhere else” 46/50</p>
<p>Wife – 1 - Hubby attended for biopsy and she hoped that it would be fine.</p>	<p>1a -“ och it could be a cyst...as I say I’m always very much the optimist ...you know get up and get on with things type thing, G tends not to be like that”(48)</p>		

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient interpretation
2 - Awaiting formal diagnosis things were tense and G was feeling down	2a-“you know me still thinking , oh it’ll be fine, it’ll be fine just a wee growth or polyps or something like that” (52)		2b - “his whole life was thinking this em, he was either depressed or he was em scunnered, or he was em “aye, its awright for you, its not happening to you, you don’t care, your not caring.....its not that I don’t care...its just that I deal with it” (96)

Summary of what happened	Experiential info	Professional info	Patient interpretation
<p>Formal Diagnosis –</p> <p>1 - Given formal diagnosis and how they aim to cure the cancer.</p> <p>2 - Discusses the treatment plan and his attitude towards the treatment.</p>		<p>1a -She says “just to be on the safe side G I want you to see Dr R , the oncologist down at the Beatson – he says right just to be perfectly safe em I want tae you know go through radiotherapy for 4 weeks, 20 sessions plus thewell 20 sessions plus the planning” (50) (<i>procedural info</i>)</p> <p>2a - “they’ve told me there’s three cancers, there’s terminal cancer, there’s cancer that they can keep at bay and there’s cancer they can cure, so they’ve told me they can cure me” (50) – (<i>prognostic info</i>)</p> <p>3a -“They says go on holiday</p>	<p>1b -“I said fine lets be up for it ...eh its got to be done, if its got to be done, its got to be done, they just want to be absolutely sure that they’ve caught it in time” (50)</p> <p>2b -“so I hope they’re right you know.....so I’m going through this therapy just now” (50)</p> <p>3b-“I was glad that they let me go on holiday”</p>

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient interpretation
<p>3 - Allowed to go on main summer holiday and highlighted that before going on holiday there was a letter sent explaining the procedures involved prior to him starting his treatment – his interpretation highlights how he used the holiday to absorb what had happened and prepare for what lay ahead</p> <p>4 - Highlights how he was very anxious about attending the mould room for the mask and I asked did no-one explain the procedure to you – his interpretation of what he was told</p> <p>5 - Discusses the shock at being told his formal diagnosis</p> <p>6 - Discusses how he met up with an ex</p>	<p>4a -“it was the unknown” (58) – “ while I was waiting to go into get the CT scan I had to go to the toilet and I was physically sick with not known”</p> <p>5a -“you know when they told me it was cancerous I was gob smacked “oh dear” you in the back of your head is it going to be a cyst or is it going to be a wart, is it going to be something, is it going to be benign but naw” (104)</p> <p>6a - (Other exp info) – he told me exactly what its all about and you’re saying “<i>what</i>” and he told me, he</p>	<p>cause I mean there is a bit of planning work to do before you come in and you just can’t get in the Beatson right away and get radiotherapy there is probably a waiting list (58) (<i>procedural info</i>)</p>	<p>(58) “it gave me time, I thoroughly enjoyed it...ate like a pig, had a few drinks, good company at night and eh but I says the last couple of days I says right, down to reality” (320) “ I know what I’ve got to come back to, lets get on and get it over and done with”(324) 4b -“they they did yeah they did but its alright saying right I didn’t know if there was going to be a plaster cast or if there was going to be this plastic that they use and eh, I said to he....I says you know not app....apprehensive is the word , not knowing”(68)</p> <p>5b -“I mean I just couldn’t take it in for the first week to be honest, but I had my holiday too look forward tae and I’m saying right, went on holiday I knew what I was coming back tae then.....was I angry probably not...probably not. I had come to accept that I had cancer” (104)</p> <p>6b -“oh it helped, he didn’t mince his words” (136) – “at the beginning it was certainly a big help....he told me all about the mask, the</p>

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient interpretation
<p>patient of 3 years and how that prepared him for what lay ahead</p> <p>7 -Discussed what the health professionals told him about going</p>	<p>didn't tell me any lies, he says G sometimes you'll feel very , very low and eh he had 6 weeks- he was that low he didn't want to go in on the last week – he told me I was going to be down , he's told me I'm going to have a sore throat, he's told me all the unpleasant things...he...I could be sick; so far I haven't been. He says the worst thing is you'll get very tired, he says but radiotherapy makes you like that (116/120/136)"</p>	<p>7a - "they say don't smoke, keep yourself well nourished and you know there are no two patients the same.....some people can sail</p>	<p>mask was worrying me" (380) – "it was one of the first things he asked me how was your scan, CT scan? They're saying its clear, its not in your lungs, its not...its not...glands was the word" (544)</p> <p>"it's alright nurses and doctors and consultants and oncologists saying...now your getting that and this is what's going to happen, I think its better coming from the horses mouth if you like, people that have gone through what I'm you know what I'm currently going through and eh, yeah I think it would be a great benefit, a great help to at least know but I didn't want to know all the, you know I wanted the truth, you know I wanted the crap times and he told me you'll not even know that you're going through radiotherapy for the first couple of weeks and he says then it, it can hit you like a hammer, you'll feel unwell, you'll feel this, you'll feel that and but at least I knew that, I says rights that's me" (612)</p>

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient interpretation
<p>through treatment and the types of information that they gave to him at this time point – the CNS highlighted her role and how he needed to look at his lifestyle to ensure he got the most out of the treatment.</p>		<p>through it, other people that’s maybe not so well nourished or not eating or still smoking they wont come through it as well (140) (<i>treatment info</i>)</p> <p>7b - “When T (CNS) said to me G look if you want this to go right and you, you want to get the benefit of it all then stop drinking. Don’t drink lager, don’t drink anything gassy and don’t drink any spirits” (172) (<i>procedural info</i>)</p> <p>7d -T gave me the booklets (240) (<i>treatment info</i>)</p> <p>7f- “After I had seen Dr R and Miss McG she called me into a separate room and she says look take as long.....did you understand this? Did you</p>	<p>7c -“I mean I did drink a lot I must admit in my social life, in my work side....I mean I was going over the top a wee bit eh, I liked lager and I like a few drams, believe me a few drams at the weekend (172)</p> <p>7e - “I mean it was, when I started reading it...all about radiation and about you know cancer of the larynx I’m saying “oh god do I need to go through all this you know...em but I think its better knowing...what’s in front of you yeah, so it doesn’t come as a surprise then, it doesn’t come as any surprise.” (244/260</p> <p>7g - “ I says well I understand but it was taking it in , it went over my head and she couldn’t have done enough for me, she gave me a phone number” (268)</p>

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient interpretation
<p>8 - Highlights the importance of having someone to contact if required and how he contacted her a couple of times re his alcohol intake – <i>interesting how he needed to find out how much alcohol he could have through the treatment – is this the same with other cancers or specific to this group?</i></p>		<p>understand” (268) (<i>clarifying info</i>) and she said (CNS) I’m your contact just now until after you get into the Beatson, if you need anything...if you want any information...just phone me (<i>procedural info</i>)</p> <p>8a - She said “aye, but don’t go nuts. Don’t go nuts and drink water....have a glass of wine...a glass oh water, because as the treatment goes on it will irritate your throat” (272) (<i>symptom management</i>)</p>	
<p>Wife – 1 - On holiday with a girlfriend and two daughters when husband was diagnosed - she had arranged to call him late afternoon on the Thursday once he had been to the clinic. She called him from</p>			

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient interpretation
<p>the beach – and was shocked initially when he told her it was cancer - “he said I’ve got good news and bad news – it was cancerous and he said the good news is it hasn’t spread anywhere else - I’m going back in on Friday to see the oncologist” (96c)</p> <p>2 - Called him back on the Friday and he told her that it was radiotherapy.</p> <p>3 - She then discusses the worry and anxiety that G displayed about the treatment and going on holiday even though the clinical staff had told him to go and how she coped with it in her own way</p>	<p>3c - “that, that kind of doesn’t wash with me you know what I mean, that kind oh negative behaviour and that...its terrible but as I say I sound like a bitch but its just the way I cope with things” (96c/100c)</p>		<p>1a- “I thought ...oh my” (96c)</p> <p>2a - “oh that’s good then if that’s all...you’ve had it removed and its not chemotherapy. I thought radiotherapy – great, you know up for that” (96c)</p> <p>3a - “he was really worried cause it was the unknown, he had no idea what was going to happen to him, what the side effects were blah, blah and then he started saying oh I don’t know whether we should go our main summer holiday and I said but they’ve told you that you can, cause after the operation there’s nothing to stop you going, the radiotherapy won’t start till you come back and then it was “ oh I don’t know whether I’ll be up for it and all that” (96c)</p>

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient interpretation
<p>4 - she highlights how the holiday was a roller coaster of emotion and how the holiday was very different – not the normal type of holiday that they would normally have and how that impacted on her</p>			<p>4a -“it was different because some day he would waken up and be really angry, really och really angry em, I said right are you going to the beach and that “nut, nut I don’t want to go to the beach and em I say why not – aye its awright for you but the way I’m feeling” and aw that and everything and em and he say “why me why me” I said why you G – you smoked 60 cigarettes a day since you were 14, you drink like a fish, you know...why not you – you are a prime candidate “ (100c)</p> <p>“so as I say some days he was “why me” other days he was up...”oh I’m going to beat this and you know it won’t hold me down and aw that so and other days he was weepy” (156c)</p> <p>“I just went with the flow (160c) –“ it wasn’t normal full of life, you know sort of joining in with everybody holiday em, so G he didn’t feel like it and because he had this radiotherapy hanging over his head and also the fact that his voice wasn’t normal, (164c) “it wasn’t normal at all and he was getting some nights he was getting frustrated, other nights he was just getting tired and em some</p>

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient interpretation
<p>5 - She discusses the booklets that he had been given and how she realised that he was a prime candidate for this type of cancer but how he had some form of denial and goes on to discuss his consumption of alcohol over their married life</p>			<p>nights he didn't want to speak to anybody at all, whereas normally he and I are in the thick oh the crowd and up dancing and having a drink and all that and everything changed (168c)</p> <p>5a - "When I read the booklets that they had given him and it said one of the cause em it was em, I cannae talk I'm a smoker....."excessive smoking and drinking", I immediately said there's your answer"no I don't believe that , I mean it could happen to anybody" He just has got a denial, as much as he didn't do it to himself (104c)</p> <p>"he maybe won't like me saying this but G drank to excess, see this month when he's going through radiotherapy and he's not allowed alcohol, its been fabulous" (108c)</p> <p>"see prior to his starting radiotherapy he just used to get smashed you know of a night just to take his mind off it" (136)</p> <p>"but then even before he had cancer, G could sit and get smashed you know three or four nights a week.." (140c) "and he didn't have a problem at all and then sometimes he would get quite nasty in drink, some...he used...your kninda all tip toeing round about him a lot of the time" (144c)</p>

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient interpretation
<p>6 - Her girl friend that she was on holiday with gave her and their daughters information about the impact of the treatment and that helped them</p> <p>7 - She goes onto highlight the importance that the word “curative” had and how that helped her and in an indirect way helped G to cope with the diagnosis and the subsequent treatment along with the written information – <i>in a way the information given gave her a valid reason for G being diagnosed with this type of cancer due to his excessive smoking and drinking</i></p>	<p>6a - (Other exp info)“she was saying that the radiotherapy could be.....she filled me in on how her, her dad had it and she said it can be very unpleasant, she said he’ll break out all in sores and things like that, she kinda gave me all the, the kinda worst scenario...(256c/260c)</p>		<p>6c - “I said but they’ve told he they’ll cure him, I said and that’s the main thing”(264c)</p> <p>7a - “when it comes to things like this G sometimes as I say initially it’s all “oh woe is me” you know “oh poor me, I’m ill and I’m this and that but when push comes to shove he’s a fighter and I knew for a fact the minute they told he they would cure him he’ll be up for it and he has been. Em I didn’t, I must admit....I, when he told me then he had had it, I just – oh my God – got cancer. And eh, but having read the leaflets and things like that I realised well he was kinda prime candidate to have it, no that you wish it on anyone. Em but no I, I accepted it right away (264c) “I think I did, and I thought well they’ve told</p>

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient interpretation
			<p>him they'll cure him, so lets just go get this show on the road type of thing" (268)</p> <p>"...I thought what ever it takes, they've told him it's not going to be in remission, it's not terminal – <i>they will cure him</i>. And I thought well as long as they've said that, I mean they're not going to say that willy-nilly type thing, I thought that's what we've goat tae focus on, that's always what we've goat to focus on" (276c)</p> <p>"well the type of cancer lets say that G has, I didn't crumble, I didn't cry I....because I knew I would get through it....I don't know how I would have reacted had it been terminal" (696c)</p> <p>"I just got up and got on with it, but only cause I knew at the back oh my mind that its going to be cured....." (700c)</p>

Summary of what happened	Experiential info	Professional info	Patient/Carer interpretation
<p>Treatment – The Mask -</p> <p>1 - Very unsure about getting the mask fitted – lack of knowledge of what to expect – very unpleasant experience and found the whole process initially barbaric. "mould clinic, the plaster em, which I</p>	<p>1a - Ex – patient – "at the beginning it was certainly a big help, it was a big help at the beginning saying right....he told me all about the mask, the mask was</p>		

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient/Carer interpretation
<p>wasn't looking forward to I've got.....I must admit and then going in on the Thursday to get the mask fitted and the CT scan with it on now that that wasn't pleasant, it was the unknown" – "it was the unknown, not knowing and while I was waiting to go in to get the CT scan I had to go to the toilet and I was physically sick " (58)</p> <p>"I couldn't open my eyes, I couldn't close my eyes and it was horrible" (72)</p> <p>"I found it totally barbaric" (388)</p> <p>2 - "so I'm lying down on the bed and right OK lets go on wi thisand I'm going what is he wanting a couple oh colleagues and its literally as soon as they put it on its hot you feel as if your suffocating but your not but its just the initial shock oh the heat....in fact that has been the worst experience out of having cancer" (388)</p> <p>3 - "I says look I'm , you know a bit, not app.., apprehensive is the word, not knowing, I says cause I don't breathe through my nose to well" (68)</p> <p>4 -Once they had sorted the mask and</p>	<p>worrying me" (380)</p> <p><i>(even after discussion with this ex patient he was still unsure of what to expect and as is evident in his account anxious)</i></p> <p>3b -"I was so relieved after that" (68)</p>	<p>2a - "They said do you know what this – we immerse this in the hot water and then eh we'll get a hold oh your face and your shoulders – he showed me the size of the clips" and he went and got some of his colleagues." (388)</p> <p>3a - "she says well don't worry about it cause there's a place for your mouth, your nose <i>and</i> your mouth" (68)</p>	

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient/Carer interpretation
explained what the purpose of the mask – he was fine			4a -“now I realise its so that they can get the laser perfect and not be you know eh, burning you if you like anywhere else. But once I found out that, you know I could breathe through my, my nose and my mouth and they eventually cut out the eyes....the holes that I could see what I was doing I mean it was a weight off my shoulders, I was so relaxed, so relaxed now at going I don’t even think about it” (412, 420)

Summary of what happened	Experiential info	Professional info	Patient/Carer interpretation
Treatment Phase			
<p>PATIENT – 1 - He discusses different aspects of his treatment and how the influence of an ex patient prior to him starting treatment helped to prepare for what lay ahead.</p> <p>The combination of this information and information from health professionals helped him understand his treatment and the physical impact of his treatment.</p>	<p>1a - Ex patient of 3 years – “I met a lad who’s gone through the same thing as me three years ago....and he told me exactly what its all about, he didn’t tell me any lies, he says sometimes you’ll feel very, very low and eh he had 6 weeks of it. I mean he didn’t mince his words, he told me you know I was going to be down, he’s told me I’m going to have a sore throat,</p>		<p>1b - “Its nice to be able tae talk tae somebody that’s going through the same thing” (132) Its helped.....oh yeah its helped” (136)</p>

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient/Carer interpretation
	<p>he's told me all the unpleasant things.....heI could be. sick: so far I haven't been. He says the worst thing is you'll get very tired but radiotherapy makes you like that (112, 116, 136).</p> <p>He places how important it was that he didn't tell him any lies and that the truth of what lay ahead obviously is important</p> <p>2b - "I'll handle it as best I can I'm sure I will" (112)</p>	<p>2a - "They said that the radiotherapy is at its highest 4 weeks down the line, eh probably not going to brush my teeth, I'm going to break out in a rash, I'm going to have a really sore throat, I'm going to have a dry mouth.....I've read all about it...I mean they've (Beatson staff) been fantastic they've let me know what's going to happen, they've given mouthwashes em,</p>	<p>2 - "I know its going to get worse before it gets better I understand that cause they (health professional) told me that last week.....its not going to be very pleasant for maybe a couple oh months, your going to be very tired but so far so good - If I want to be here this time next year I've got to get thought this" (112)</p> <p>He comes across prepared for the worst and knows that it will be short-term</p> <p>2c - " but albeit I don't know I hold out a lot</p>

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient/Carer interpretation
<p>He discusses the importance of being able to assist other people that are going through the same treatment as him and through his own experiential knowledge he can help others – I like</p>	<p>4 - “I mean I’ve met some people in there and eh that’s what they’ve been saying its soup and ice lollies and ice cream and jelly....I mean the first day I was like the new kid on the block if you like , because</p>	<p>they’ve given me creams for when it breaks out...They actually told me ...you’ll not halfway through it, three quarters through it, you’ll not want to drink anyway, he says your body will tell you what you want and what you don’t want” (176) <i>symptom info</i></p> <p>3 - “and the girls (radiography staff) cant be nicer, I mean they tend to put you at ease as ...you know just having a laugh. But they all I mean they’re also saying if you’re not feeling well let us know and you’ll see the nurse before your away. So naw they can’t do enough for you” (228, 232) “I mean they’ve told me it starts building up in your system” (264) <i>treatment info</i></p>	<p>of hope that they’ll really sort it to be honest...you know cause they are burning you, you know I mean my, my throats going to be a mess for a wee while...em....however as I said earlier its got to be done; its got to be done but if you want better well take the pain the now, no pain – no gain, it’s a s simple as that” Ref 26 – psycho) 2d -“ I mean I have learned, you know now that the last two weeks, I mean drink means nothing to me now you know” (176)</p> <p>3a – You know I thought its maybe just a couple of blasts of radiotherapy and your out the door but its not like that, it’s the planning it all, wearing the mask, so they know they’re zapping you exactly where they want to zap you, I didnae, I wasn’t aware that the radiotherapy is a constant , whether it be a constant 20 sessions, I thought you go in, I mean you can have a blast of radiotherapy and that’s you your fixed, but it doesn’t work that way cause it builds up seemingly in your body and eh so now I understand that (264)</p>

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Summary of what happened	Experiential info	Professional info	Patient/Carer interpretation
<p>He discusses the psychological impact of cancer and how you have to remain positive through this section of the transcript and through discussion with other patients and reading the literature he realised it is not a “death sentence” “you know the cures and what I read about it.....eh cancers came a long way, its not the, before I think eh, when the word cancer was mentioned it was a death sentence but I think they’re doing so much more nowadays in the treatment of cancer and they’re finding more and more cures” (Ref 21 – psycho)</p> <p>Helping to reassure him that things are progressing in a positive way</p>	<p>I’m going to beat this, I’m not going to lie down to this” (Ref 10 – psycho)</p>	<p>5a - “They’ve told me though that they will keep a close eye on me for the next, after this over, em they’ll have me back in again, they’ll put me to sleep have a look down just to make sure everything is okay and then they will keep a close eye on me for the next 5I couldn’t believe it ...for five years down the line...just to male sure” (272)</p> <p><i>procedural info</i></p>	<p>5b - “I’m very confident aye maybe two or three, maybe a couple of months down the line I’ll be on the mend” (Ref 4 psycho)</p> <p>“ I mean I’ve got another chance here, cause I want to be like (ex-patient) talking about it three years down the line” (Ref 25 – psycho)</p>
<p>WIFE – She discusses how a close friend told her about the impact of the treatment and what to expect</p>	<p>1 - “(M a friend) she was saying that the radiotherapy could be ... she had filled me in on how her, her dad had it ... and she said it can be very unpleasant, she said he’ll break out all in sores and things like that, she</p>		

Appendix 11: Thematic Matrices Sample

Summary of what happened	Experiential info	Professional info	Patient/Carer interpretation
<p>She then discusses how well her husband has coped with the treatment as she never expected it</p> <p>2 - “I must admit, he’s been absolutely fabulous. Em, the first ... I think they said it, was it maybe into the second or the third week he would be ill and really he’s been great, I must admit, he’s gone in every single day on his own” (284)</p>	<p>kinda gave me all the, the kinda worst scenario” (256, 260)</p> <p>2a - “I thought he would be ill, I, I, must admit. I thought he would, would be milking this from day one” (788)</p> <p>“cause that’s the type oh guy he is wi' an illness. I really thought he would, but he hasn’t, he's been wonderful, absolutely marvellous” (792)</p>		
<p>She discusses how he viewed his cancer and how in some ways he did not take responsibility for his lifestyle and how this has impacted on them all her married life and their daughters lives – she has learned to cope with everything that life deals because her husband is in may ways</p>	<p>3 -“he was like “did you read those booklets?” – uhh uhh, mmm mmm, “what do you think?” and I said oh they're very informative and that and. I said em, did you see that bit about em,</p>	<p>3a - “. I would prefer it if someone said to him, you know it’s probably, its no going to happen, if somebody said, well I don't think you should ever touch whisky again and knew what your going through. You</p>	<p>3c “no dad’s saying he's no going to touch whisky after that (treatment), and he's sitting in the chair and he's saying ... I didn’t say I wasn’t going to touch it, I mean I’ll maybe have a couple here and ...</p> <p>– he can't do that - Yes, he knew that himself, and I think once when we went to the AA one day and he came back and he</p>

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Summary of what happened	Experiential info	Professional info	Patient/Carer interpretation
<p>(in my opinion) is selfish and focuses very much on himself – very heavy drinker but will not do anything about it –</p> <p>She highlights that although the booklets were informative – she needed to contact someone one night but there were no numbers available in the book and how she was unsure and him of how much cream to apply to his neck –</p> <p>4a - “his neck as I say, I didn’t realise until I happened to look at it the other night though when he was ... I don't know how often he's meant to get this cream oan, tae memaybe cold water and dab it off, I said and why</p>	<p>where it said “excessive smoking and drinking?” – didn’t want to know” (physical 540)</p> <p>4b - “Em, I didn’t expect it to get infected, I must admit ... as I say I knew that it was going to em, be painful and I knew</p>	<p>know, I need somebody professional” (660 psycho) Highlights the need for professionals to discuss the impact of alcohol on the cancer diagnosis/prognosis and the wider issues – to assess impact on life</p> <p>4 “by the Saturday night he was in absolutely agony in the stomach, and he said I need to phone someone, so I looked through all these useful contacts as it said in the booklet, but it was just gaps that he was supposed to have filled in everybody’s phone number, there was nothing in it at all he didn’t have anybody’s phone number” (312,</p>	<p>said och I'm not going back there they're all like sitting like, you know like tramps and down and outs and all that, and I said well do you think cause you wear a suit and you’ve got a big fancy merc out there it makes you any different? But he didn’t think he had ... you know fall into that category ... but he knew himself that had a problem” (physical, 560, 636)</p> <p>I asked is this a wake up call – 3d - “I hope so, I don't know, because I say, he said he didn’t miss it, was just a habit and he wasn’t going to touch it again and yet at the weekend there he said och, he can probably have a couple” (physical 640)</p>

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Summary of what happened	Experiential info	Professional info	Patient/Carer interpretation
<p>are you taking it off and putting more on? Your just meant tae ... I don't know how I'm, he seems to be putting millions on it. I, I don't whether he's just to pat it on cause it always looks white I assumed it would absorb or sink in, I don't know" (728, 732)</p> <p>In summary here she highlights how they have coped/not coped and her coping mechanisms are highlighted in the next few quotes</p>	<p>that it was going to break out in sore and em,M told me all that and I was also expecting him to get thrush in his mouth and em, but thankfully, touch wood he hasn't had that. But no I actually assumed that, well they, they told him how much cream to put on and then how often to put it on and that, but as say he's taken it off and its still white" (736, 740)</p> <p>5 – "do you know so ... sometimes as I say he, he doesn't want the "pandering", but he'd, he'd rather sit and talk about it and talk about it and talk about it, now to me talk about it solves nothing ... when, when, when the action is needed I'll be there, I'll do what I, what I think he needs</p>	<p>316) Don't know if patients are told this as part of the course but shows how they didn't think to contact a GP as it may have something to do with the radiotherapy</p>	

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Summary of what happened	Experiential info	Professional info	Patient/Carer interpretation
	<p>or what he asks me to do or whatever, I don't want to sit and talk about it ..(236, 240 psycho)</p> <p>5a -"So that's what I mean by saying – cancer, well the type of cancer lets say that G has, I didn't crumble, I didn't cry I ... because I knew I would get through it, cause I've got through it 30 years of life of dealing with everything. I don't know how I would have reacted had it been terminal or remission, do you know what I mean, I don't know how I would react because remission's just ongoing like, as in forever, terminal's a totally different ball game, do you know what I mean (696, 700 psycho)</p>		<p>5b - ". I just got up and got on with it, but only cause I knew at the back oh my mind that its going to be cured ." (700 psycho)</p>

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Summary of what happened	Experiential info	Professional knowledge/info	Interpretation patient/carer
<p>Follow –up Patient – Relieved that his treatment is over and that he is back to work however disappointed he has been left with a swelling under his chin and his voice is not back to anything like normal. He was asked to attend speech therapy but said no – his work is his priority as they were good to him when he was off -</p> <p>1 – “Fine, back to work, back to work coping very well, great to be back, but disappointed that my voice after six months down the line isn’t really any better. I was at a speech therapist last week and she wants me to go through an intense six or seven or eight week programme with a lot of homework at night, and at this moment in time I’m back to my work and I’ve decided at this moment in time, not at the moment, I’m more concentrated on my own job company they’ve been very, very good to me and I want to try and pay them back” (9) shows the response of gratitude to his employer for being supportive since diagnosis.</p>	<p>1a – “I’m disappointed in a lot of things to be honest I’ve got a swelling I’ve been concerned about and I’ve been to see Miss McG, they never told me about it, I’ve got to now sleep with a plastic bucket at the side of my bed because – there’s no easy way of saying this – the crap I bring up during the night out of my throat is terrible, emm, as I say my voice, I would have thought six months down the line after the radiotherapy it woulda been a lot better” (9, 17)</p> <p>1b – “I know people that’s had it done the same, I spoke to people and their voice is back to normal” (17exp)</p>		

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Summary of what happened	Experiential info	Professional knowledge/info	Interpretation patient/carer
<p>He is disappointed in this and highlights that he was not told to expect this post radiotherapy – he admits that at diagnosis you are more concerned whether you are going to live or die – but there was no mention of this long term side – effect.</p> <p>He has a large mouth ulcer which is causing him great concern and he is anxious that it is cancer – he tries to explain that if it is normal then he will learn to live with it but at present he is very anxious.</p>	<p>2 – “my main concern to be honest is that I’ve got an ulcer, a massive ulcer in the inside of my mouth and it just won’t go away” (17 prof)</p> <p>2c – “So I’m concerned about that, in the light of things [pause] I know a lad that’s the same and they took a biopsy of it and it was just the radiotherapy” (17 – exp)</p> <p>2f – “I’ve learnt to live with it but it’s not normal. I knew when I had the tumour in my throat, I didn’t know it was a tumour but I knew it wasn’t laryngitis. I knew, eh really it shouldn’t be there, it</p>	<p>2a – “I’ve been at my own doctors and Miss McG, seven or eight weeks ago, “does that come and go”, I said then, it does, [pause] and I’ve got to be perfectly honest, it just won’t go away. My best mates a GP, and we tried Corlin, we’ve tried something and orabase to try and get rid of it but it just won’t go away” (17 – prof)</p> <p>2d – “She (CNS) says you’ve no idea what the radiotherapy does, it just burns a lot down here” (21 - prof)</p> <p>2e “Disappointed, aye I’m, well, what’s the difference Anne, if they tell you right your ducts, the ducts, you know your clearing ducts, they’ll never work the same again and you’re gon’nae have fluid [pause].....gathering all night and you get up in the morning but at night it goes away gradually, and during the</p>	<p>2b – “All be it I’ve learned to live with it, I can’t take hot tea anymore, hot soup anymore but I live with it but you see round the side of my mouth, I can see it in my mouth and you wonder and you say could this be another tumour I got” (17 – prof)</p>

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Summary of what happened	Experiential info	Professional knowledge/info	Interpretation patient/carer
<p>He is annoyed that he wasn't told about the swelling but is very grateful to the staff for their care during his attention – he compares himself to others that have been through the same and hoping that through time all will settle down.</p>	<p>shouldn't be there and this shouldn't be there" (69 – exp) –emphasising the importance of listening to the patients understanding of their symptoms 2g – “People I know that's had the same, they're plagued with mouth ulcers as well and I'm hoping it's just, right ok, if I've got to put up with this ulcer” (73 – exp) – hoping that it is all part of the treatment 3 – “But I've known people three, four years ago that's went through it. I've met people but, their voices are back to normal, whether it's gonna be in time I don't know it” (149, 153)</p>	<p>day it goes away gradually, but I mean the booklets they issued, I found I was more worried at the time [pause] am I gon'nae to live, am I gon'nae to die? (29, 33 - exp) This highlights that there was no information about long term side effects of treatment and that at the beginning his concern was is he going to survive</p> <p>3a – “At the end of (treatment) CNS gave me so much creams ...mouthwashes, potions, lotions, I mean he gave me a carrier bag more or less to take away and he says, I'm always at the end of the phone. Emmm, I can't praise him enough Anne to be honest I can't praise him enough ...if he'd a told me, you know, but everybody's different” (137, 141, 145</p>	<p>3b – “you know I thought, ah but, you know this...I've still, you know, it's there at the moment and that's six or seven months down the line and I've still got the swelling, I didn't know all that but at the same time, everybody's different” (149)</p>

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Summary of what happened	Experiential info	Professional knowledge/info	Interpretation patient/carer
<p>He has been told that radiotherapy burns everything and that the lump might never go away – he explains how this is impacting on his working life.</p> <p>He is philosophical about life now and that he doesn't think whether you smoke or drink – it is destiny whether you get cancer or not</p> <p>He finished off the interview by highlighting he was very satisfied with the information that he received from diagnosis through treatment. After care the help was there if you needed it</p>	<p>4a – “it's very difficult, I never arrange meetings in the morning, if I have meetings it's in the afternoon” (229 - prof)</p> <p>5 – “I know people and to be honest who don't smoke and don't drink have got cancer. I mean, you go to the doctor; “do you smoke”? Aye, “well stop smoking, do you drink”? Aye, “well stop drinking”. Do you know what it's called, it's called destiny it's called, we all know how we got</p>	<p>4 – “I had to phone T and then ehh, <i>ohhh, you've slipped through the net</i>, and I was disappointed in that. And I went in to see Miss McG and everything was clear, all be it it was still swollen but Miss McG didn't reckon it (the swelling) would settle because the radio it destroys they say, it's a bugger of a thing right, hopefully it's cleared the cancer... but in the process it does a lot of damage, it does a lot of damage” (229, 233)</p>	<p>4b- “I mean I don't know if I've still got cancer or if I'm in remission, I don't know. I don't know if they've cured the cancer...so I don't know if it's cured or if it will come back, I just live from day to day” (253, 261 exp)</p> <p>Lack of understanding and information from health professionals re “clear”and “cured”</p> <p>5a – “it changes your whole life... this year hopefully it'll maybe turn the year round, I mean life's got to go on, life's for the living, no for the dead, simple as that. I try as best I can to be very positive, all be it in the back of my mind I'm worried. I wouldn't knock it, they (staff) were very, very good, from diagnosis all the way through, yeah.....Yes, oh aye, oh aye, but I mean after I was diagnosed, after I'd seen Miss McG the oncologist, CNS took me through, “do you understand?” was what she</p>

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Summary of what happened	Experiential info	Professional knowledge/info	Interpretation patient/carer
	<p>into the world, we don't know how we're going out of it, I mean it's called destiny, I mean I reckon your path is there for a reason" (337, 341, 345 - exp)</p>		<p>said because a lot of it really does go over your head because it <i>oh what the hell is this, have I got cancer</i>. No they couldn't have been more helpful, the Beatson, I wouldn't knock it. The aftercare, if you needed it, it was there, if you phoned them, it was there, I wouldn't knock anything about it, honestly emm, I'm thankful and finishing off I'm just here today, simple as that and that's the way I would like to end it (373, 377)</p> <p>Highlighting that his out look has changed, he is grateful to be alive. His comment about the aftercare being there highlights that it was there if you needed it but they were not forthcoming with information and support during this phase.</p>
<p>Wife – follow up Overall she is amazed at how well G coped since his diagnosis and with his treatment – however she is also disappointed and anxious about the long term impact of the effects of treatment – she highlights that the main thing that kept her going through the whole thing was that they had told him that they would cure him but things are still not back to normal – an ex patient did tell</p>	<p>1 – “I think he’s disappointed in the fact that he has come through the radiotherapy, he assumed then that when he got the all clear that was him. I think he thought immediately he’d be back to normal and his voice isn’t great either. I actually think it has got</p>	<p>1b – “I was with him that day, it was all clear, the tumour had gone from the vocal cords, and emmm, she (CNS) said, “well all this fluid lying there, it will take a while to clear and she says you can massage it during the day, it will be worse in the morning and it’ll get better at night but by that time your’e back in bed</p>	<p>1c – “I gave him an extra pillow but he’s not sleeping well cause he’s not used to having too high pillows, but as you say, it’s the lesser of two evils. You know it either means he’s trying to get a more decent sleep or just sleeping with his normal kind of flattish pillow and emmm, I don’t think it makes any difference whether they’re up or down” (16)</p>

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Summary of what happened	Experiential info	Professional knowledge/info	Interpretation patient/carer
<p>her that you never get back to 100% after the treatment. 1a – “But emm, no he’s coming on, I mean he’s looking well enough, eating you know and all that again but as I say I just think he’s worried, he’s worried now, even he’s going in this Friday and he said the other day, <i>I think I’m going to get bad news</i>, and I said, look you haven’t, they’d have told you that the last time you were in there five or six weeks ago but he’s quite, it does get him down, there’s no getting away from it” (16)</p> <p>The main cause of worry for them was a large mouth ulcer which was not going away – she highlighted that G can look on the negative side of things however</p>	<p>worse now than when it was a couple of months ago.... as I said I think G expected and so did I to be perfectly frank, that it would get, as the weeks and months went on everything would go back to normal but then somebody said to me, oh well actually it will never be back to normal, it’ll never, you’ll, maybe that was somebody else that had it, a chap that he had met and he said that it does change your life and you’re never one hundred per cent the same as what you were” (12, 41)</p> <p>This shows the disappointment and the expectation that people have after treatment and the sue of other info from patients</p> <p>2 – “As they said the last time, you don’t have cancer any more, emmm,</p>	<p>she says, you can raise his pillows up” (16) – <i>outcome and symptom info</i></p>	

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Summary of what happened	Experiential info	Professional knowledge/info	Interpretation patient/carer
<p>he is not helping himself through his lifestyle. She is keen for him to find out what exactly is the long-term plan at his next clinic appt.</p> <p>2a – “It was going to be cured (AT) “that was the bit that always kept me going, aha, the whole time yes, aha, I must admit I thought, now I don’t know, you see that’s the thing I think he should be asking on Friday, will all this sort of you know mucus and everything eventually clear from my throat, will I get rid of these mouth ulcers” (97 - exp)</p> <p>Highlights lay interpretation by the health professionals saying curative at the beginning they assumed that it meant cured and back to normal</p> <p>She goes onto discuss with hindsight she would have liked to attend the clinics with G but that there was their choice and gives a reason why she should have gone.</p>	<p>this will be a kinda side effect which will only last ex amounts of months or things like that I’m sort of pedantic, I like things you know, one, two, three, four, five, that’s it, whereas G tends to home in on the negative things that they tell him”` (57 – prof)</p> <p>3 – “I would have like to have gone in with him then, to actually hear it from the horses mouth, cause sometimes I think</p>	<p>2b – “I think he’s worrying now cause the last time he was in Miss X had said that there was a coming and going but now I think they’re (ulcers) just there all the time and what he had said from that a couple of times he said Miss X said she would be more concerned if they weren’t going away at all, but they haven’t gone away” (97 – outcome info) – which shows that she is beginning to worry if there is something wrong</p>	<p>2c – “I’m thinking to myself, is he going to have this forever, do you know what I mean, is he going to be up and down all night in the bathroom clearing his throat, clearing his throat, I mean sometimes he can hardly talk because of all these mouth ulcers all over his mouth, I thought well that’s not pleasant for anybody but then again he is still here, know what I mean” (157 - impact)</p>

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Summary of what happened	Experiential info	Professional knowledge/info	Interpretation patient/carer
<p>She highlights that she found the booklets informative and that helped her cope but they informed them through out the treatment not in the follow up and there are gaps.</p>	<p>as well when one person goes in, because it's happened to them, it affects them more and you can't take in everything they tell him whereas if they're two of you there what they remember and what you remember can be two different things" (137 - exp)</p> <p>3b – "I think it definitely helped me cope, definitely helped me cope. I read all the literature and that that they gave out, cause G read it all at first and I think he was afraid when he read it, obviously because he was the patient, it's totally different for me reading it...but no it did take you literally through all the stages, what will happen, it's just now when he's finished I just feel as</p>		<p>3c – "Aha, but the strange thing is, see when in retrospect see when he was going into get his bypass [pause], the two of us went into see him (professor) and I sat and listened to everything he was going to do and all the recuperation things and everything would be fine and you would get your date and all that and everything but I haven't been in as I say once because G didn't want me. It's strange because I mean a bypass is a big operation too and I've never been to that consultant, but no, as I say G just didn't want, I think, I don't know I think it's just the stigma of cancer. You hear lots of people who have bypass's, I don't know percentage but a high percentage come through them, but</p>

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Summary of what happened	Experiential info	Professional knowledge/info	Interpretation patient/carer
	<p>though he's oh, when anything does go wrong, <i>will I phone the doctor, will I phone the Beatson or the Gartnaval</i>, he's not really sure you know what direction to go in" (209 – exp)</p> <p>3d – “no as I say I'm more that happy with the treatment G's had and he's been you know happy about it but the only thing as I say is just after the treatment finishes, when it doesn't all fall back into place a hundred percent then it would be nice just to phone somebody up and say, look is this normal or when can I expect his voice to get back to normal or can I expect his voice to get back to normal" (377 – exp)</p>		<p>with cancer, it's just the unknown know what I mean I think part of it initially when G went was the fact that if it was a bad diagnosis, he wanted to deal with it himself, do you know what I mean, maybe he didn't want me to see him upset, I really don't know but part of me maybe thinks that to cause I mean cancer is just like you know a death sentence to most people [pause] and I was the same initially too until they did the what do you call it, the biopsy and things like that, that was fabulous after that" (249 - exp)</p>