

The lived experience of being diagnosed and treated for lung cancer in the outpatient departments of an acute care hospital: a psychosocial phenomenological study.

A thesis submitted in partial fulfilment of a Master of Nursing Science (Oncology Nursing).

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Signed Statement

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

I give consent to this copy of my thesis, when deposited in the School of Nursing Library, being available for loan and photocopying.

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Abstract

Aim

The aim of this project was to research participants' lived experiences of being diagnosed and treated for lung cancer in the outpatient departments of an acute care hospital, particularly in relation to whether they reported lung cancer related psychosocial distress and secondly to analyse whether the participants felt that they had received appropriate psychosocial care from the hospital staff.

Background

Lung cancer is the leading cause of cancer death worldwide with only 12% of people diagnosed surviving for more than five years beyond their diagnosis and few surviving for more than one year (Australian Institute of Health and Welfare 2011). Consequently, receiving a lung cancer diagnosis is a source of high emotional and psychosocial distress, which research suggests, is often not detected or treated by health professionals with appropriate levels of supportive care. More research is needed to identify the barriers that exist in the outpatient setting, particularly from the patients' perspective, which undermine best practice psychosocial care.

Methods

The fundamental position of phenomenological research is that human understanding is only accessible through inner subjectivity and that each person and their understandings are inseparable from the context of their environment. This approach allows open expression and exploration of patients' lung cancer experience within the health care context. For this study, Heidegger's hermeneutic phenomenology has been used for its interpretive approach, as it allows the researcher to use theories, knowledge and pre-understanding when interpreting the participants' subjective experience.

Results

A very high level of unrelieved psychosocial distress and concern was expressed by some of the participants with late stage lung cancer and most participants, regardless of stage, reported ongoing fear of recurrence. Some evidence of barriers which prevent supportive care from occurring became apparent. The findings developed during the research included some simple health care approaches that practitioners can adopt in order to help reduce the psychosocial distress of this group of people. These include ensuring continuity of care, improving empathetic communications, early referral and reflection on professional attitudes. It is hoped that this research will improve understanding and empathy for lung cancer patients, so that detection and treatment of psychosocial distress can be improved.

Chapter 1 Introduction

Background

Lung cancer is the leading cause of cancer death worldwide, for both men and women and the fourth most common cancer in Australia, with 9,703 new cases diagnosed in Australia in 2007 and 7,626 deaths (AIHW 2011). Mortality from lung cancer is high, with only 12% of people diagnosed surviving for more than five years beyond their diagnosis and few surviving past one year (AIHW 2011). Consequently, receiving a lung cancer diagnosis is a time of high psychosocial distress (Gonzales & Jacobsen 2010; Ftanou et al 2014; National Breast Cancer Centre & National Cancer Control Initiative 2003; National Comprehensive Cancer Network, 2003) which is often not detected or treated by health professionals with appropriate levels of supportive care (Ball 2013; Gonzales & Jacobsen 2010; Hill et al 2003; Li & Girgis 2006; Neron et al 2007; Sanders et al 2010; Schofield et al 2006; Temel et al 2010; Ugalde et al 2012). This study researched these issues with a sample of people who received their lung cancer diagnosis and treatment in the outpatient departments of an acute care hospital; in order to detect psychosocial distress and review the care they received to address this problem.

Statement of the problem

Many authors state that lung cancer patients tend to have amongst the highest psychosocial distress levels of any cancer group, particularly around the time of initial diagnosis, diagnosis of recurrence and when diagnosed late stage (Cohen & Bankston 2010; Ftanou et al 2014; Jones et al 2003; Li & Girgis 2006; NBCC & NCCI 2003; Ugalde et al 2012). Other authors report that lung cancer patients diagnosed late stage and with a poor prognosis, actually experience sustained psychosocial distress throughout the illness, as long treatment regimens, side effects and symptom burden negatively affect psychological well-being (Aketchi et al 2006; Sanders et al 2010; Ugalde et al 2012).

Disturbingly, recent research also indicates that psychosocial distress amongst lung cancer patients is often not detected or treated by health professionals with appropriate levels of supportive care (Ball 2013; Gonzales & Jacobsen 2010; Hill et al 2003; Li and Girgis 2006; Neron et al 2007; Temel et al 2010). Even though multidisciplinary care is considered the gold standard management for lung cancer and has been broadly embraced (NBCC 2005), focus on staging, curative treatments and physical symptoms still dominate over psychosocial, existential and palliative concerns (Lehto & Therrien 2010; Li and Girgis 2006; Rolke, Bakke & Gallefoss 2008; Temel et al 2010; Zakowski et al 2003). Additionally, although a growing body of research investigates psychosocial distress associated with other cancers, there has been little research to understand and treat these issues in the

field of lung cancer (Gonzales & Jacobsen 2010; Hill et al 2003; Li and Girgis 2006; National Cancer Control Initiative 2003).

This study discusses the various barriers in health care settings, reported in the literature, which appear to prevent people diagnosed with lung cancer from having their psychosocial needs adequately met (Li and Girgis 2006; Rolke, Bakke & Gallefoss 2008; Schofield et al 2006; Temel et al 2010; Zakowski et al 2003). Although somewhat abstract constructs these barriers are reported to exist in the realms of institutional and interpersonal health contexts. Schofield et al (2006) for example, describe the two categories of barriers as interpersonal barriers: such as lack of knowledge, beliefs, values and attitudes; and secondly institutional barriers: such as lack of time, negative unit culture, insufficient training and resources.

More recently and possibly more importantly, there has also been a growing body of research which analyses and critiques the insidious role of smoking related stigma and nihilism in compounding overall distress, delaying early detection and possibly reducing the amount of treatment being offered to lung cancer patients (Ball 2013, Cataldo et al 2011; Chambers et al 2012; Else –Quest et al 2009; Sarna 2002; Weiss & Ramakrishna 2006).

Another barrier identified to good psychosocial support of metastatic and end stage lung cancer, is the reluctance of health care practitioners to refer patients to Palliative care teams (Temel et al 2010). This is thought to be due to practitioners belief that patient's must be days away from death before a referral can be made. Palliative care studies however, have recently demonstrated promising evidence that early introduction of palliative care (even during active treatment) can effectively reduce psychosocial distress, whilst actually prolonging survival (Temel et al 2010).

Unfortunately, these barriers and delays have been linked with increased depression, desire for early death, suicide and poor adherence to treatments; as well as increased health care costs and hospital admissions (Cohen & Bankston 2010; Ftanou et al 2014, Jones et al 2003; NBCC & NCCI 2003; NCCN 2003). Good psychosocial care, on the other hand, has been found to improve quality of life, reduce hospital admissions and lower health care costs (Bultz & Carlson 2006; Ftanou et al 2012; Goodwin 2003; Holland & Bultz 2007; Schofield 2006; Temel et al 2010). Further research is required to enhance recognition of the barriers to detection and treatment of psychosocial distress.

Study purpose, aims and objectives

Purpose

The purpose of this thesis was to develop an interpretive hermeneutical phenomenological research project, which explored the participants' lived experience of being diagnosed with and treated for lung cancer, in the outpatient departments of an acute care hospital.

Objective

The objective of the study was to research whether the participants with lung cancer have experienced the phenomenon of lung cancer related psychosocial distress and how they reflect on the care they have received from their treating staff. Many barriers have been reported as standing in the way of adequate psychosocial care for lung cancer patients and this study set out to examine if this phenomenon was evident in the outpatient setting. To understand and detect these barriers, this study used a phenomenological approach, in order to ask the patients to share their experiences and thoughts freely and without coercion or fear of retribution. This research discusses and analyses participants' lung cancer related experiences within the context of the currently recommended clinical guidelines for appropriate psychosocial and palliative management.

Aims

The research aimed to illuminate participant experiences of being diagnosed with and treated for lung cancer within the context of the outpatient setting through open ended semi-structured interviews; whilst simultaneously narrowing the research focus to reports of lung cancer related psychosocial distress through analysis and interpretation. This method of research allows the illumination of one person's feelings and perceptions to be universally understood as something any human being might experience and feel in the same circumstance (Husserl 1970). Dissemination of the results will help to further reveal how participants experience their cancer health care and what areas need to be improved.

Statement of the research question

Will the participants' experiences of being diagnosed and treated for lung cancer in the outpatient department, reveal the phenomenon of lung cancer related psychosocial distress and will participants' reflections contain information that suggests they have received appropriate psychosocial care and support from the hospital staff?

Significance of the study

Few current day studies report the subjective experience of lung cancer patients in regard to their psychosocial concerns, particularly within the context of the outpatient departments of acute care hospitals, where the majority of lung cancer patients now receive their diagnosis and care. This study discusses the various barriers thought to impede lung cancer patients from having their psychosocial needs met, particularly in light of emerging stigma and nihilism research. The most recent systematic reviews and recommendations of non-invasive psychosocial interventions and palliative care underscore the context of the results and interpretation of the participants' experiences. Recommendations for improved psychosocial care for people with lung cancer were able to be made from combining previous research with the sharing and interpretation of participants' lived experiences.

Definitions of Terms

What is lung cancer

Lung cancer is a malignant tumour starting in the lungs. A malignant tumour has the ability to spread to other parts of the body, which is called metastasising. If the spread is unable to be stopped it can result in death (AIHW 2011). There are two main types of malignant lung cancer which include Small Cell (SCLC) and Non-Small Cell (NSCLC).

Stages of lung cancer

Very generally, stage at diagnosis refers to extent or spread of cancer at time of diagnosis. There are four stages of lung cancer, stage one and two being the earliest and possibly amenable to surgery; stage three often being treated with radical chemoradiotherapy; and stage four being late and usually treated palliatively. Treatment depends on overall wellness of the person, stage of cancer and doctor referral. The patients in this study were all discussed in the lung cancer multidisciplinary team meeting and recommendations from the meeting guided their staging and treatment outcomes. Lung cancer staging in this hospital setting, was guided by the multidisciplinary lung cancer team using the revised International Staging System, published by the International Union against Cancer (IUAC) and the American Joint Committee on Cancer (AJCC) 7th edition (Vallieres et al 2009).

Recurrence of lung cancer

Recurrence of lung cancer after curative intent treatment usually occurs within two years and needs to be restaged and retreated according to the recommendations and the patient's wishes. Cases of recurrence are usually re-presented at the multidisciplinary meeting but are usually not for curative treatment and are then treated with a palliative approach (The South Australian Department of Health (SA Health 2013) *South Australian Lung Cancer Pathway Optimising outcomes for all South Australians diagnosed with Lung Cancer*). News of recurrence is known to be a time of very high psychosocial distress for lung cancer patients (Sanders et al 2010).

Distress

Distress, a term used in oncological nursing literature to describe a normal human reaction to having cancer, has recently been promoted as the 'sixth vital sign' (Bultz & Carlson 2006; Goodwin 2003; Holland & Bultz 2007; NCCN 2003). The word distress in this context covers the expected feelings such as anxiety, fear, loss, depression, social isolation and existential angst about impending death, which are caused by having cancer.

Psychosocial distress

The term psychosocial distress is used in this context not only to describe the psychological aspects of cancer related distress but also the social, financial, geographic and cultural aspects that correspondingly compound the problem (Goodwin 2003).

Angst

The word angst has been used in this context as it most aptly depicts the extreme feeling emanating from some of the participants' relaying of their experience of living with lung cancer. The term angst, an existential concept largely attributed to the philosopher Soren Kierkegaard (1844 cited by Clark 1991), is often used to describe a transcendent emotion which combines anguish about uncertain but impending death, freedom of choice and the struggle to maintain hope and find meaning. Kierkegaard identified the problem of being human as both enjoying the freedom of choice over our lives, whilst also finding it overwhelming and terrifying (Clark 1991).

Smoking related stigma

Smoking related stigma is defined as a personal perception of social isolation, rejection, self-blame or lowering of self-esteem that comes from the perception of an adverse social judgement about smoking or being labelled as a smoker (Cataldo et al 2011; Link & Phelan 2001).

Therapeutic nihilism

This is a construct that is thought to occur when health professionals limit the amount of treatment they offer to people with lung cancer, possibly because of multiple factors such as blame for having smoked, poor overall prognosis, limited treatment outcomes and high health costs (Ball and Irving 2000; Chambers et al 2012).

Phenomenology

Phenomenology, according to Husserl (1931, 1970), is a philosophy, a theory and a method, which attempts to disclose the essential meaning of human experience through interpreting inner subjectivity. Husserl believed that reflecting on life's experiences revealed truth and promoted understanding (Dahlberg, Drew & Nystrom 2001). Most phenomenology uses open ended or semi-structured interviews to collect rich supplies of data from participants' lived experiences of a situation. Husserl's phenomenological theory requires researchers to 'bracket' or withhold their prior knowledge in order to more fully appreciate the participants' subjective experience and for this reason has not been used for this study.

Heidegger's Hermeneutic Phenomenology

The phenomenological approach used for this thesis is that of Heidegger's (1962) hermeneutic interpretive approach, which allows lived experiences collected as data to be analysed and interpreted by the researcher using preconceived knowledge and literature (Flood 2010).

Summary of the chapter

This chapter introduces the topic of lung cancer related psychosocial distress and discusses how this study is designed to explore this. It describes the high prevalence and mortality of lung cancer and begins to situate the research as it sets out to discuss the problem of unmet

psychosocial needs of lung cancer patients, particularly in the context of the outpatient or non-overnight admission setting. It defines and discusses the significant terms to be used throughout the study and clearly states the research question, aims and objectives.

Conclusion

Mortality from lung cancer is very high, with only 12% of people diagnosed surviving for more than five years beyond their diagnosis (AIHW 2011) and few late stage patients surviving beyond one year (AIHW 2011; NCCI 2003). Consequently, receiving a new lung cancer diagnosis, a diagnosis of recurrence or a diagnosis of imminent progression to death, are times of high emotional and psychosocial stress. Added to this can be the burden of debilitating physical symptoms, protracted treatment regimens, as well as demographic and cultural isolation from home during treatments for rural patients, which all compound distress. Unfortunately, according to recent research, psychosocial distress amongst lung cancer patients is often not detected or treated by health professionals with appropriate levels of supportive care (Gonzales & Jacobsen 2010; Hill et al 2003; Li and Girgis 2006; Sanders et al 2010; Temel et al 2010). Although a growing body of research investigates psychosocial distress associated with other cancers, there has been little research to understand and treat these issues in the field of lung cancer. Various barriers continue to exist in the health care setting, which appear to prevent people diagnosed with lung cancer from having their psychosocial needs adequately met (Li and Girgis 2006; Schofield et al 2006). This research project aims to improve empathy and understanding for people with lung cancer, so that recognition of the barriers to detection and treatment of psychosocial distress can be enhanced.

Chapter 2 Literature Review

Introduction

The literature review identifies and discusses previous research about lung cancer related distress and briefly investigates the history of current issues such as; poorly addressed fear of imminent death from a life limiting illness and the barriers that prevent adequate treatment of distress, particularly in light of new research concerning the possible effect of smoking related social stigma. It also reviews some of the recommended nursing, psychosocial and palliative care measures which have been recommended to address some of these problems.

Findings from previous studies will be organised in the literature review in order to inform the reader about how the study question arose. This study uses previous assumptions and literature to underscore the examination of the extent of lung cancer related psychosocial distress in this group of eight participants with lung cancer and the care they received. Additionally it seeks to research if this group, similar to the literature, report, recognise or refute stigma and whether they remember having their distress levels checked or received counselling. The literature review will also link previous literature such as expert clinical practice guidelines and systematic reviews of the latest research in order to describe why the study is important and to compare if guidelines are being carried out.

The search strategy for this review used the online databases: CINAHL, COCHRANE, PubMed, PsychINFO and SCOPUS with the following key words: lung cancer, lived experience, phenomenology, psychosocial, stress, distress, anxiety, depression, nursing, and stigma. The search discovered studies using quantitative and qualitative data. The search strategy suggested by search experts (Barroso et al 2003; Flemming & Briggs 2007) included searching of bibliographies of all final articles, hand-searching of qualitative research journals, a grey literature search, and other activities such as contacting topic experts.

A second search using qualitative filters was also used to check more broadly for phenomenological qualitative studies (Wilczynski, Marks & Haynes 2007). Examples of the use of qualitative filters used came from Wilczynski, Marks & Haynes (2007, p706) work on qualitative search strategies and include search terms such as 'data saturation', 'audiotaped', 'lived experience' and 'focus group'; whilst text words such as 'narratives' and 'interviews' were 'exploded' (meaning including all of this term's similar terms).

Unmet psychosocial needs in people with lung cancer

Sanders et al (2010) study of unmet needs in patients with lung cancer, found that nearly 40% of participants had distress and depressive symptomology that met clinical depression and anxiety diagnostic criteria with 91.4% expressing a need for at least one supportive care

service and 51.4% endorsing help from a psychological service (i.e. to help with depression, anxiety, counselling or support groups). Questions have been raised, in a small amount of literature, about the factors that may contribute to higher levels of distress such as age, education, socioeconomic status, stage of cancer, length of treatment, time since diagnosis and so on (Lehto & Therrien 2010; Sanders et al 2010). Sanders et al (2010) reported, for example, that patients who suffered higher physical symptoms and side effects of treatment were more likely to suffer from intrusive distress, be less satisfied with the quality of their health care and require higher levels of psychosocial supportive care.

Other research has suggested that psychosocial distress amongst cancer patients is thought to occur in peaks and tends to be highest around the time of initial diagnosis, diagnosis of recurrence and when diagnosed late stage (Cohen & Bankston 2010; Jones et al 2003; NBCC & NCCI 2003). Aketchi et al (2006) on the other hand and similar to Sanders et al (2010) purports that the majority of lung cancer patients, 75% of whom are diagnosed late stage and with a poor prognosis, experience sustained psychosocial distress throughout the illness, as poor prognosis, long treatment regimens, side effects and symptom burden negatively affect psychological well-being.

Distress

The definition of distress is crucial at this point in order to highlight the complex issues involved in recognising and treating the psychosocial issues involved in lung cancer care. Distress, a term recently used in oncological literature to describe a normal human reaction to having cancer, has recently been promoted as the 'sixth vital sign' (Bultz & Carlson 2006; Goodwin 2003; Holland & Bultz 2007; NCCN 2003). The word distress in this context covers such feelings as anxiety, fear, loss, depression, social isolation and existential angst about impending death, which are caused by having cancer. More broadly, the term psychosocial distress is also used in this context to describe the social, financial, geographic and cultural aspects of cancer distress. The terminology of distress has been recommended in the literature to identify psychosocial difficulties without the implications of full spectrum clinical mental health syndromes (Goodwin 2003).

Existential death related concerns

Due to being given a poor prognosis, many people diagnosed with late stage or metastatic lung cancer, suffer from existential death-related concerns and intense emotional turmoil (Lehto & Therrien 2010). Additionally, Lehto and Therrien (2010) state, that the lung cancer illness context, particularly in the treatment setting, suddenly asserts a death construct on the individual for which they may be totally unprepared to accept. Uncertain death related fears frequently lie behind psychoses and contribute to poor emotional coping (Yalom 2008 cited by Lehto & Therrien 2010). Adequate assessment and treatment of these concerns, the literature suggests, have been hampered by health providers who have problems discussing end of life and death concerns, as well as institutional barriers and constraints (Fitzsimmons et al 2007; McSkimming et al 1999; Schofield et al 2006). Good management

of death concerns, on the other hand, contribute to enhanced meaning and better quality of life (Fitzsimmons et al 2007; Le May & Wilson 2008; Temel et al 2010).

Distress Screening

Ugalde et al (2012) assert that people with inoperable lung cancer experience more psychological distress and physical disease burden than any other tumour type, and particularly report unmet needs regarding psychological/emotional and medical communication. Despite useful clinical guidelines being developed for best practice psychosocial care, lung cancer patients continue to report high unmet needs, so careful examination of possible enduring barriers is essential. Schofield et al (2006 citing Detmar et al 2000 and Maguire 1985) for example, found that some health professionals believe patients will spontaneously raise psychosocial concerns without being specifically asked. Ironically, Schofield et al (2006) point out, patients actually expect clinicians to initiate discussions about psychosocial concerns, and feel uncomfortable bringing them up without being asked. This miscommunication, as Schofield et al (2006) conclude, may further compound the clinician's misguided belief that patients only expect the provision of physical medical care.

The issues of appropriate psychosocial referral versus ensuring the person with lung cancer that their concerns are a normal reaction to their illness, presents an ongoing assessment challenge. In response to this assessment problem and others, distress screening tools have been developed by cancer experts. Roth et al (1998) invented the *Distress Thermometer* (DT) a self-report measure which asks the respondent to rate their distress over the previous week from 0-10. Jacobsen et al (2005) found that the DT demonstrated high sensitivity and specificity for assessing clinically significant distress in cancer survivors.

The National Cancer Control Network (NCCN) (2003) and others also endorse distress assessment tools which guide the health care worker through a tiered model of referral process, with higher scores requiring referral to a psychological professional (Chambers et al 2012; Hawks et al 2010; Holland & Bultz 2007; Jacobsen et al 2005). The South Australian Department of Health (SA Health 2013) *South Australian Lung Cancer Pathway Optimising outcomes for all South Australians diagnosed with Lung Cancer* recommends that a screening tool such as the NCCN Distress Thermometer (2003) be used as an initial assessment of psychosocial distress and again at regular intervals along the cancer trajectory.

Neron et al (2007) also found psychological distress and depression as high as 49% in their study of newly diagnosed stage 3 and 4 patients with Non-Small Cell lung cancer but interestingly reported that semi-structured interviews by health care professionals were more effective in detecting clinically significant depression than self-administered questionnaires. One of the theories suggested by Neron et al (2007) for this difference was that advanced lung cancer patients have a number of physical symptoms and side effects of treatment, which make it difficult for them to recognise if they are becoming depressed.

They also suggested that results vary according to the type of screening tool used. The study did show a strong correlation between lower performance status and increased psychological stress, with no lessening of distress over the period of 7-8 weeks of starting chemotherapy.

Despite this growing body of research and recommendations however, the use of formal psychosocial distress screening tools has not been broadly incorporated into clinical practice. More research is needed to determine what barriers affect recognition of psychosocial concerns, frequency of referral and access to professional multidisciplinary and psychological supports (Ball 2013; Schofield et al 2006).

Barriers to recognition and treatment of distress in lung cancer patients

Regrettably, recent cancer research has found that efforts to understand and resolve the needs of lung cancer patients have largely remained unmet in clinical practice (Ball 2013; Cancer Council of South Australia & South Australian Health 2010; Cohen & Bankston 2010; Hill et al 2003; Lehto & Therrien 2010; NBBC & NCCI 2003; Sanders et al 2010; Rolke, Bakke & Gallefoss 2008; Ugalde et al 2012; Zakowski et al 2003). Various barriers are thought to exist that prevent the busy health care worker from discussing patients' existential and psychosocial concerns, particularly around how illness, death and dying will affect their lives (Deafner & Bell 2005; Lehto and Therrien 2010; Leung & Esplan 2010; Schofield et al 2006). Some of these barriers are thought to be lack of time, feeling out of their depth, lack of psychosocial counselling training, not wanting to upset the patients and their families during consultations, smoking related stigma and therapeutic nihilism (Ball 2013, Deafner & Bell 2005; Gonzalez & Jacobsen 2012; Lehto and Therrien 2010; Leung & Esplan 2010).

Time restrictions and giving bad news

Lack of time is often cited as a reason for why health care workers are reluctant to raise psychosocial issues with patients (Butow et al 2002; Leung & Esplan 2010). In order to expedite waiting times and service large patient numbers, most lung cancer patients are given their diagnosis and prognosis in busy over packed outpatient clinics, often in time allocations of only 20 minutes (Temel et al 2010). Clinicians may feel rushed to cover all of the physical symptoms and side effects of treatment, as well as feeling unable to cope with emotional issues without immediate psychological resources being available.

The Australian Government and National Health and Medical Research Council (2004) have set out recommendations for best practice in regard to giving bad news, which require lengthy appointment times to achieve. These guidelines recommend a comprehensive thirteen step process as part of an ideal patient doctor consultation, including such things as: active listening, assisting patient understanding, facilitating informed decision making, providing diagnostic and interventional information, use of patient advocates, use of interpreters and informing patients about alternative sources of information. Of particular

significance, the 'Communicating Bad News' section of the guidelines recommends special consideration of a peaceful environment, increased time and the need for a support person of the patient's choice to be present. It also recommends that immediate or rapid access to additional counselling and support services may need to be addressed if distress is suspected. Follow up consultations within a prompt time frame were also recommended to allow patients to absorb information and think of more questions, particularly when the bad news involved sustained treatment, permanent impairment or death. Further research into patients' impressions of these issues will reveal areas for improvement.

More resources and time need to be allocated to lung cancer outpatient clinics so important diagnostic and prognostic conversations can occur in a compassionate manner. Many authors argue that actually taking the time for open discussion of psychosocial stresses can actually bring about enhanced acceptance, improved coping skills, lower health costs and shorter hospital stays (Lehto 2012; Lehto & Therrien 2010; Newel et al 2002).

Lack of psychosocial education and not wanting to upset patients

Improved education and training are important, as health care workers have reported feeling uncomfortable or out of their scope of practice discussing psychosocial issues and therefore tend to focus on physical symptoms (Lehto & Therrien 2010; McSkimming et al 1999. Kubler- Ross (2002) (cited by Lehto and Therrien 2010) found that death concerns were often not addressed by health professionals who were overly focused on curative treatment. Although addressing physical symptoms is important, poorly managed psychosocial concerns in the acute care setting, may actually inhibit patients' ability to consume information, result in higher pain levels, poorer physical functioning, worsening adherence to treatments and consequently increase hospital stays (Schofield et al 2006).

Schofield et al (2006) cites studies which found that 70% of oncology health professionals expressed interest in advanced psycho-educational oncology training, which they were not receiving. Lansdell and Beech (2010), after developing a skills program aimed at improving staff delivery of psychosocial care to end of life patients, reported a measurable increase in confidence of staff to be more responsive to patient cues and prompts, even when the subject area was difficult. Other studies have shown the benefits of communication training programmes which are longer in duration, learner-centred and combine theoretical knowledge with practical simulations (Gysel et al 2005; Wilkinson et al 2008).

Smoking related stigma

Another disturbing barrier for people diagnosed with lung cancer in receiving an equitable amount of psychosocial health care, is smoking related stigma. People diagnosed with lung cancer, regardless of whether they have smoked or not, often experience the social stigma of having a tobacco related disease, as modern societal values tend to imply the disease is self-inflicted (Bertero 2008; Else-Quest et al 2009; Gonzalez & Jacobsen 2012; Stuber, Galea & Link 2008).

The key focus of international public health efforts to reduce the lung cancer burden has been to work towards decreasing the incidence of the disease through tobacco control and although this has effectively increased the number of people quitting smoking, it has also lead to stigmatisation of smokers and people with a smoking related disease (Chambers et al 2012; US Department of Health and Services, 2012). Concern has arisen as to whether this stigmatisation influences the illness experience of people who develop a smoking-related disease (Cataldo, Jahan & Pongquan 2012; Stuber, Galea and Link 2008).

Health related smoking stigma issues such as social isolation, shame, self-blame and poor self-image have begun to be investigated in relation to their impact on people with lung cancers' ability to equitably access health care (Cataldo et al 2011; Cataldo, Jahan & Pongquan 2012; Link & Phelan 2001; Weiss & Ramakrishna, 2006). Early studies investigating the stigma around HIV, epilepsy and mental health have defined health related stigma, as a personal perception of social isolation, unfavourable stereotyping, rejection, self-blame or deflation that comes from adverse social judgement (Cataldo et al 2011; Link & Phelan 2001). Interestingly, it is thought that if the perception or recognition of stigma is not accepted by the intended target, then the devaluing effect of stigma has less power (Cataldo, Jahan & Pongquan 2012; Link & Phelan 2001). This is where health care practitioners can assist with education and empowerment over this effect to help people with lung cancer overcome what could otherwise be a persistent and burdensome psychological symptom (Cataldo, Jahan & Pongquan 2012; Link & Phelan 2001).

The concept of stigma is multifaceted in that participants may not be aware or able to articulate the feelings or perceptions involved. Some stigma has been categorised as self-blame or internalised, for example, rather than blame being externally applied from others (Cataldo et al 2011). Lung cancer related stigma was reported by patients and health professionals in a systematic review by Chambers et al (2012) and was related to poorer quality of life and higher psychological distress in patients.

Therapeutic Nihilism

This is a construct that is alleged to occur when health professionals limit the amount of treatment they offer to people with lung cancer in association with factors such as poor overall prognosis, limited treatment outcomes, high health costs and blame for smoking behaviour (Ball and Irving 2000; Chambers et al 2012). Many authors have commented on this phenomenon which is thought to impede peoples' ability to ask for and accept help as well as insidiously influence how much treatment (and compassion) is offered by health care workers (Ball 2013; Else-Quest et al 2009; Link & Phelan 2001; Raleigh 2010; Sarna 2002; Stuber, Galea & Link 2008). Ball (2013) also reiterated that smoking related stigma might underscore such barriers as medical and consumer nihilism, problems with lack of resources, treatment delays, limited access to multidisciplinary opinion and inconsistencies in treatment decisions.

In attempting to understand the issues behind this complex medical argument Chambers et al (2012) cite Star's (1982) classical medical definition of nihilism as the belief that medical science is limited, potentially harmful and that some illnesses are safer left to nature. Chambers et al's (2012) systematic review found that apart from some patient and practitioners' perceptions reported in qualitative data, no empirical studies or instruments had yet directly measured therapeutic nihilism and suggested this may be due to problems in actualising and measuring this concept. The hidden nature of medical stigma towards patients' make recognition and reversal particularly difficult and is not something that can be ethically tested via randomised clinical trials.

The reasons for why lung cancer patients do not always accept or access full recommended treatment are of course multifactorial, including socioeconomic disadvantage, geographic distance from treatment centres, comorbidities, cultural beliefs, patient choice and patient/doctor beliefs about treatment as futile, undeserved and expensive (Chambers et al 2012). As lung cancer stigma research is still in an emerging stage and is extremely complex, additional phenomenological focus on the lung cancer patients' lived experience will hopefully further illuminate whether patients perceive and articulate this phenomenon in the health care they receive and guide further recommendations.

The specialist lung cancer nurse as an aid to coordination of care

As nurses are immediately present in the outpatient clinic at the time of diagnosis or bad news of recurrence, a nurse cancer coordinator role is recommended in order to assist both the patient with lung cancer and the physician giving bad news. Advanced cancer nurse specialist roles have been recommended for large diagnostic and treatment centres in the Australian setting (NBCC & NCCI 2003; NHMRC 2004; Peters 2013; Yates 2004).

As well as attending busy outpatient clinics, patients and their families face many organisational frustrations, such as the complex maze of diagnostic testing, prolonged waiting times and numerous cancer treatments, which may involve multiple treatment centres and health care practitioners (Maguire & Pitceathly 2003; Peters 2013; Yates 2004). In response to these problems there has been a growing volume of research which now supports the cancer nurse specialist as a central cancer coordinator and an important member of the multidisciplinary team, a trend which is underpinned through leading cancer state and federal organisational guidelines (Aranda & Yates 2009; Cancer Council of South Australia & SA Health 2010; Clinical Oncology Society of Australia & The Cancer Council of Australia & NCCI 2003; NBCC & NCCI 2003; Maguire & Pitceathly 2003; Moore et al 2002; Peters 2013; Sheldon et al 2008; Yates 2004).

Level II evidence presented as early as 2003 in *The Clinical Practice Guidelines for Psychosocial Care for Adults with Cancer* (NBCC & NCCI 2003), indicated that specialist breast care nurses improved understanding and provided continuity of care for women with breast cancer. It is hoped that the model of the breast care nurse can be adapted to lung

cancer specialist nursing, but little research has been done in this area (Moore 2002; Peters 2013). Advanced cancer nursing education is evolving in order to assist cancer nurses in working to the full extent of their capabilities within emerging specialist roles (Aranda and Yates 2009).

A study in the UK found that nurse practitioner led follow up after lung cancer treatment had been completed actually led to a beneficial effect on patient satisfaction, increased radiotherapy treatment without survival decrease, over doctor led follow up (Moore et al 2002). The Australian Government and Cancer Australia's *Clinical Guidelines for the Treatment of Lung Cancer* (Ftanou et al 2014) also reported level C recommendations for non-invasive nurse-led programs with a focus on managing physical symptoms and treatment related toxicities to optimise quality of life.

Delays in the type and amount of nursing and medical research have been effected by problems with conducting ethical clinical trials on humans and human behaviour which present obvious challenges when withholding recommended care from control groups. Further research of the patients' perceptions and needs about their treatment experience in the clinical area needs to be done in order to understand and enhance cancer nursing for people with lung cancer.

Evidence for non-invasive psychosocial interventions

It is important for the improvement of psychosocial care that barriers are identified and effective interventions are recognised in an evidenced based informed way, so that a more pro-active attitude can be developed towards treating lung cancer related distress. The Cancer Council of Australia's Lung Cancer Guidelines Working Party (Ftanou et al 2014) has reviewed the latest empirical research in treatments for cancer related depression, mood and anxiety with promising results.

Treatments for cancer related depression

The Cancer Council Australia's' Lung Cancer Guidelines Working Party (Ftanou et al 2014), sites three examples of systematic reviews and one meta-analysis which review the effectiveness of non-invasive psychosocial interventions for the treatment of depression and mood in a mixed group of cancer patients.

Of these Barsevick et al (2002) in a systematic review of 36 studies, recommended that psycho-educational interventions did help cancer patients. Barsevick et al (2002) summarised that 70% of behaviour therapy studies, 66% of counselling studies and 58% of studies of counselling combined with cancer education were effective. A second systematic review of 13 trials conducted by Uitterhoeve et al (2004), specifically for patients with advanced cancer stated that behaviour therapy enhanced mood in 12 out of the 13 trials. The third systematic review by Newel et al (2002) and a meta-analysis by Osborne et al (2006) recommended that cognitive behaviour therapy was effective in the short-term

management of depression in cancer patients. Ftanou et al (2014) also looked at studies about group versus individual counselling for depression but reported that the results were less certain as discussed in the next paragraph.

Group Therapy versus individual counselling of depression

Ftanou et al (2014 cites Newell et al 2002) reports cautious support, from the literature review, for a combination of group therapy, education and structured counselling to reduce depressive symptoms in cancer. Ftanou et al (2014) highlight the inconsistencies in the reviews about whether group therapy is as effective as individual therapy, stating that mixing heterogeneous sample characteristics in empirical studies, such as comparing early stage cancer survivors with advanced cancer patients with multiple problems may give misleading results.

Group Therapy for anxiety

Reviews of group therapy interventions for anxiety suffered by cancer patients remain mixed, according to Ftanou et al (2014) who reported on a recent RCT by Breitbart et al (2010) of 90 patients with either stage III or stage IV Non-small cell lung cancer. These patients were randomly assigned to either Meaning Centred Group Psychotherapy (MCGP) or Supportive Group Psychotherapy (SGP). Whilst the patients assigned to MCGP did show improvements in anxiety, spiritual well-being and sense of meaning, the patients assigned to SGP showed no improvements at all.

Cognitive Behavioural Therapy for anxiety

Ftanou et al (2014) report that reviews in the treatment of anxiety specifically for lung cancer patients are very limited and conflicted. According to Newell et al's (2002) systematic review of cognitive behaviour therapy (CBT) for the treatment of anxiety in advanced cancer sufferers', reliable evidence was not found for its use. Moorey et al (2009) conversely, found in a randomised control trial of 80 patients that CBT (compared with usual care) did show evidence of decreased anxiety over time. Obviously, more research with greater rigour is needed in these areas to assess the effectiveness of these therapies; however researchers are faced with many difficulties, particularly due to the high morbidity and mortality of this patient group. There is also the ethical problem of withholding recommended psychosocial care to the control group or providing only 'usual care', when clinical guidelines stipulate otherwise. For these reasons a qualitative interviewing style of research has been used in this study to illuminate participants' experiences.

Palliative care can help with quality of life in late stage cancer

Literature from leading experts recommends early palliative care referral as a solution to high levels of distress in late stage lung cancer patients (Hill et al 2003; Lemay & Wilson 2008; McSkimming et al 1999; Temel et al 2010; World Health Organisation, 2013). Patients with advanced stage non-small cell lung cancer are often informed that their median survival may not be more than 12 months and for patients with small cell lung cancer this figure can be 3 to 6 months (AIHW 2011). The South Australian Lung Cancer Pathway (SA Health 2013) recommends that early palliative care referral should be considered for poor prognosis late stage lung cancer. The WHO (2013) also recommends palliative care as an approach, which will improve quality of life through the prevention and relief of suffering, by treating pain, and other physical, psychosocial and spiritual problems.

When to introduce palliative care to patients and their families is always a challenging issue for health care providers, as many people may associate this with impending death, end of curative treatment and possibly the active hastening of death, for which they may not be psychologically prepared. This is particularly problematic when people are just being told they have lung cancer and may already have advanced symptoms such as bone metastasis, spinal cord compression, or severely obstructed airways. Existential concerns arising from confronting mortality are reported to be just as serious as physical symptoms in determining quality of life (Hill et al 2003; Lemay & Wilson 2008; McSkimming et al 1999; Temel et al 2010; WHO 2013). Additionally, Temel et al (2010) suggested, that treating oncologists (and others) may feel that palliative care should be their responsibility but are in reality unable to fulfil all of what is required and thus do not refer early enough for dedicated palliative care services to be fully effective.

Leading global experts from the World Health Organisation (2013) clearly state that palliative care can be 'introduced early in the course of illness, in conjunction with other therapies that are intended to prolong life' and may positively influence the course of illness. In addition, the WHO 2013 definition statement purports that palliative care neither intends to hasten or postpone death' but supports life and regards dying as an ordinary process. Temel et al (2010) in a study of 151 patients with Non-Small cell lung cancer published in *The New England Journal of Medicine*, found that patients' who were assigned to early palliative care had a better quality of life than patients assigned standard care (98.0 vs 91.5: P 0.03) and that fewer patients in the palliative care group had depressive symptoms (16% vs 38%, P 0.01). Interestingly, despite fewer patients in the palliative care group receiving aggressive end-of-life care (33% vs 54%, P 0.05) median survival was lengthier among patients receiving early palliative care (11.6 months vs. 8.9 months, P 0.02). More patients in the study tended to have their end-of -life wishes for resuscitation documented, were able to decline aggressive chemotherapy at the end-of- life and were offered longer hospice care (Emanuel et al and Earle et al cited by Temel et al 2010).

Importantly, palliative care aims to integrate the psychological and spiritual aspects of being human in the world and importantly offers a support system to help patients and their families at home; in the hospital or in hospice care, during illness and bereavement (WHO 2013).

Summary

The literature review identifies and discusses recent research about lung cancer related psychosocial distress and briefly investigates the background issues such as: the barriers that may prevent adequate treatment of distress and the possible effect of smoking related social stigma on patient and health care outcomes. It also reviews health care measures, which have been recommended to address some of these problems such as non-invasive psychosocial therapies, care coordination, education and counselling, as well as the important role of palliative care for late stage lung cancer.

Conclusion

The literature review grounds the research and begins to formulate questions about how lung cancer patients are affected psychosocially when they are given a lung cancer diagnosis and what happens to them as they move through their treatments and disease progression. Most importantly, the literature review introduces the idea that lung cancer patients are suffering from high psychosocial distress levels, which are not being assessed and treated with adequate levels of care. Alarming, the literature review suggests that poorly managed psychosocial concerns in the acute care setting, may actually contribute to desire for early death, suicide, aggressive treatments, exacerbated suffering and increased hospital admissions. The literature recommends that better psychosocial distress assessment and treatment, can contribute to improved quality of life and coping for lung cancer patients, but many complex issues are intertwined in this discussion. Further research is required to illuminate the lung cancer patient's experience in order to enhance understanding and improve health care delivery.

Chapter 3 Phenomenological Methodology

Introduction

Phenomenology

The fundamental position of phenomenological research is that human understanding is only accessible through inner subjectivity (Flood 2010; Husserl 1970; Thorne 1991) and that each person and their understandings are inseparable from the context of their environment (Burns & Grove 1999). Epistemologically, phenomenology focuses on revealing meaning which is able to be shared with the researcher and other readers through mutual knowledge of culture, history and language (Van Manen 1997). To better understand and remain true to phenomenological methodology, the philosophic foundations of phenomenological analytic style need to be further explained.

Husserl's descriptive phenomenology

Phenomenology attempts to disclose the essential meaning of human experience (Husserl 1931; 1970). Husserl believed that reflecting on life's experiences revealed truth and promoted understanding (Dahlberg, Drew & Nystrom 2001). Husserl (1970) asserted that scientists often compromised their scientific enquiry by their preconceptions and prior knowledge (Drew 1999). In response Husserl developed descriptive phenomenology, which requires researchers to 'bracket' or withhold their own ideas in order to more fully appreciate the participants' subjective experience (Drew 1999).

Heidegger's Hermeneutic Phenomenology

For this research different theoretical and philosophical stances of phenomenology underscore the methodological process required. Of the two main phenomenological approaches: Descriptive and interpretive, Heideggerian (1962) hermeneutics (interpretive) has been used for this research. A crucial difference between Husserl's descriptive phenomenology and the philosophical stance used for this research of Heideggerian (1962) hermeneutics (or interpretive) is that it allows the researcher to use theory and knowledge from pre-existing literature. Heidegger (1962) disagreed with the idea of bracketing; rather asserting that it is impossible to not know what you already know and that the researcher needs to be able to acknowledge prior knowledge of the subject under investigation. Heidegger (1962) further developed hermeneutic theory into an interpretive ontological approach, which questions how phenomenon is understood, through experience of the phenomenon, within the context of the person's environment. The theory provides a framework to describe people and how they view their being- in their- world or 'dasein' and includes the researcher as integral to the research (Flood 2010, p9).

The outpatient clinic as the embodiment of the social, cultural and political context

Essential to illuminating the lived experiences of these participants in the outpatient setting, is Heidegger's (1962) belief that individuals are not free to do whatever they want but are circumscribed by the particular circumstances of their lives. Heidegger (1962) asserted that humans are so entrenched in their social, cultural and political contexts that their subjective experiences cannot be viewed without this understanding (Leonard 1999). Heidegger (1962) suggested that the exploration of the lived experience or 'dasein' (the situated meaning of a human in the world) should be the focus of phenomenological research rather than the person or phenomena in isolation (Thompson 1990). Heidegger (1962) believed that hermeneutics goes beyond mere literal description of common practices to look for hidden or implied meanings in the text, with a view towards further revealing truths and creating fresh understanding (Lopez and Willis 2004).

The Hermeneutic Circle

Gadamer (1976), further advanced this theory by suggesting that a dynamic Hermeneutic circle between the participant and researcher needs to occur, where the phenomenologist not only examines the language of the participants' stories but also incorporates understandings from their own experience. Additionally readers of the research will be able to identify with the common experiences described and the meanings extrapolated by the researcher. Flood (2010, p10) highlights that Gadamer (1976) described the resulting amalgam of meanings articulated by the participant and interpreted by the researcher as a 'fusion of horizons'. Gaenellos (2000) also alludes to Gadamer's horizon analogy, stating that the art of interpretation will always be circumscribed by the interconnecting horizons of researchers and participants. Hermeneutic phenomenology researches and interprets a phenomenon, which has been experienced in the everyday life of the participant through phenomenological reproduction and text analysis (Flood 2010; Osborne 1994).

Ricoeur and Van-Manen's textural reflection

Similarly, Ricoeur (1991) stated that understanding existence is mediated by interpretation, thus aiding the understanding of the phenomenon of being human within a social-historical reality. Furthermore, Van-Manen (1990) importantly purported that human science research and understanding is meshed within language and text, or in other words, textural reflection creates and defines meaning.

Audiotaped semi-structured interviews

In order to gain understanding of the participants lived experience of being diagnosed with and treated for lung cancer; audiotaped semi-structured interviews were conducted by the principal researcher. The experiences expressed by the participants were audiotaped and the direct quotes transcribed verbatim as text (also by the principal researcher). During this process it was important to the phenomenological style of the research that the data or descriptions of the phenomenon were obtained from the participant by the researcher,

using open style questions and that the researcher did not interfere, interrupt or coerce the participants' descriptions.

Literal and metaphorical interpretation

After the audiotape was transcribed, the researcher interpreted the transcript from its literal meaning to produce a metaphorical meaning (Ray, Hutchinson & Wilson, 1994). This approach was influenced by the writings of Ricoeur (1991) who believed when performing phenomenological research, the researcher undertakes a set of activities that focus on the phenomenon being investigated or in this instance the lived experience of the participants being diagnosed and treated for lung cancer in the various outpatient areas of an acute care hospital. These activities involved writing, reflecting and interpreting, in pursuit of an advanced illumination of the phenomenon, which remain grounded in the original participants meaning of their experience.

Data into core themes

Data analysis through the hermeneutic phenomenological approach is a process of description, thematic interpreting and metaphoric insight (Van Manen 1990). Ricoeur (1991) developed a theory of interpretive methodology, which allows interpretation of data that helps to reveal phenomena. Ricoeur (1991) believed that all human perceptions and understandings are interpretive and that interpretation precedes understanding. His theory allowed practical steps for hermeneutic methodological data analysis which included the steps of 'Distanciation', 'Engagement' and 'Appropriation' which is further explained in the chapter called 'Methods'.

Chapter 4 Methods

Introduction

The Study setting

Initially when thinking of the cancer patient's journey, the word labyrinth springs to mind but to the researcher this only describes a single, non-branching unambiguous pathway to the centre and back. A maze, on the other hand, is more synonymous with the lung cancer trajectory, as it refers to a complex branching puzzle with choices of path and direction which is deliberately designed to be difficult to navigate. Whilst health care providers do not deliberately set out to complicate the lung cancer patient's pathway of care, the multiple settings and practitioners the patient experiences, require special understanding.

Although the immediate setting where the interviews took place was in the Thoracic Medicine outpatient department, the research area of interest or context is more broadly set within all of the departments involved in cancer diagnosis, staging and treatment. These included the Thoracic Medicine, Cardiothoracic Surgical, Medical Oncology and Radiation Oncology departments. This intentionally allowed patients' to recall their whole range of experiences from being diagnosed with and treated for lung cancer from GP referral to completion of treatment and ongoing surveillance.

Stage one and two surgical patients

To further briefly explain the lung cancer pathway of treatment, for example, participants with stage one lung cancer who had received successful surgical resection, were generally diagnosed by Thoracic Medicine and, operated on by the Cardiothoracic Surgical Unit. Patients whose surgery was found to be incomplete post operatively, usually went on to experience the Medical and Radiation Oncology areas for adjuvant treatments, followed by Thoracic Medicine for surveillance.

Stage three and four patients

Stage three and four patients' generally experienced Thoracic Medicine, Medical Oncology and Radiation Oncology departments with various degrees of radical to palliative treatments and follow up. Some late stage patients were also referred to their local palliative care team and may access palliative treatments from the oncology teams as well as being monitored by Thoracic Medicine and their General Practitioner. Often patients were seeing two or three multidisciplinary outpatient teams at the hospital at once, whilst still living at home and trying to manage side effects, psychosocial concerns and maintain their independence. Table 1, demonstrates some of this complexity. Although the research was originally focused on asking patients how their diagnostic and treatment episodes were experienced

in the past, some of the patients who volunteered for the research project were still undergoing current treatments.

Table 1. Participants' TNM stage, gender, age and treatments

Participant	Age	Time from Diagnosis	Stage	Surgery	Chemo-therapy	Radio-therapy
1. Male	79	2 years	1	Yes [#]	No	No
2. Male	83	5 years	1	Yes [#]	No	No
3. Female	61	7 months	2*	Yes	Yes	Yes [#]
4. Female	70	7 months	2*	Yes	Yes	Yes [#]
5. Male	61	1 year	3	No	Yes	Yes [#] @
6. Female	66	8 months	3	No	Yes	Yes [#]
7. Male	67	4 months [†]	4	No	No	Yes [#] Palliative Care
8. Male	79	6 months	4	No	Yes	No [#]

[#] Plus Thoracic follow up ^{*} Staging increased to 3 at time of surgery [@] Hosp in the Home [†] Died 1 month later

Sample, Inclusion and Exclusion Criteria

Inclusion criteria for the sample group involved 8 patients who had been given their diagnosis of primary lung cancer in one specialist thoracic outpatient area (at least three months prior) and treated in the surgical and oncology areas of an acute care hospital. Newly diagnosed patients were not approached, as they are usually too acutely distressed. Table 1. displays the Tumour Node and Metastasis (TNM) stages and treatment regimens of the 8 participants.

The study sample was purposively chosen to represent a 'symbolic representation' of the phenomenon under investigation (Ritchie, Lewis & Elam 2003, p. 83). This involved patients who were hoped to be 'information rich', meaning those who were most likely to talk openly and at length about their experience and who were also able to provide a wide and illuminating view of the topic (Guest, Brunce & Johnson 2006).

Data saturation (or when no new information arises) was the goal and the deciding factor over how many participants were required (Guest, Brunce & Johnson 2006; Morse 1995). Both male and female genders were included. Age of participants was guided by the majority of lung cancer patients being usually between the ages of 60 to 80 (AIHW 2011). Due to issues of informed consent, patients with cognitive deficiencies, such as those arising from brain metastasis and dementia, which involve confusion and disorientation, were not approached for the study.

Recruitment and participation

Participants were selected by the researcher and recruited by their treating doctors after their clinic appointment was completed; if the doctors considered them to be relatively stable and not too acutely distressed. Patients approached did not have a prior relationship with the researcher. Patients who agreed were given an information sheet, consent form and a revoke consent form (to use if they decided to revoke permission later) to read and sign. Participants could pick the place and time of their interview, with most participants wanting to do the interview in the clinic straight away. One patient, for convenience reasons preferred to do the interview in her home. A few patients declined, usually stating because of 'time, parking and transport' issues; if they offered a reason, but were not questioned about reasons for refusal.

Ethical considerations

The study was approved by the Royal Adelaide Hospital Ethics Committee (see Appendix 1) and has been conducted in an ethical manner, according to the National Health and Medical Research Council's National Statement on the Ethical Conduct of Human Research (2007). Site Specific Assessment (SSA) approval was also given (Appendix 2) from the Government of South Australia, Central Adelaide Local Health Network Research Governance office for the study to be conducted at the Royal Adelaide Hospital until the project was completed or according to Section 9 of the SSA. Notification was also given to the University of Adelaide Ethics Committee. According to NHMRC (2007) guidelines the principles of integrity, respect for persons, beneficence and justice have been applied to the research process and results.

Recruitment of eight participants by their treating doctors occurred in one outpatient clinic during patients' appointments. Due to high distress and shock levels experienced by newly diagnosed patients on the day they receive their diagnosis or diagnosis of recurrence, these patients were not to be approached for the study. Patients, who received their diagnosis at least three months prior or more, were approached if their prognosis was stable. A participant information form (Appendix 3), an informed consent form (Appendix 4) and a consent revoke form (Appendix 5) were supplied to the participants, after they had been fully verbally informed by their doctor during clinic visits and had agreed to participate.

The interviews were carried out by the principle investigator who was also the Lung Cancer Support Nurse from the clinic, with full disclosure written in to the study design, verbally explained and given in writing to the participants. Participants who had no previous relationship with the researcher were chosen in order to avoid coercion and conflict of interest. Confidentiality and anonymity were assured by de-identification of personal details in the results. Interviews were audiotaped and then stored confidentially according to hospital protocol. Any distress generated or noted during the conducting of interviews, as was explained to the participant prior to signing the consent, would have resulted in the interview being stopped and referrals being made back to the treating doctor for

appropriate psychosocial counselling or referral. No participants complained of distress during or after the interviews, although one patient requested support group information and a referral to Palliative Care. Another patient refused clinical psychology referral, in favour of speaking with his usual treating physician. Patients were informed verbally and in writing of their right to discontinue in the study at any time.

Interviews

Due to study time constrictions and the high level of the patients' illness and distress as described in the literature review, each participant was interviewed only once. As per the phenomenological reflective approach (Flood 2010), interviews were semi-structured, using open-ended questions, and lasted 20 minutes, with the option of extension if the participant wanted to talk longer. The participants were asked to choose the timing and location of the interviews and were free to terminate the interview at any time. Participants' experiences were explored using reflection, clarification and active listening (Jasper cited by Flood 2010). Journal notes were made immediately after each interview to capture immediate impressions and feelings of the researcher towards the participant and the interview. Interview audiotapes were transcribed verbatim straight after or soon after the interviews.

Data analysis

Data analysis through the hermeneutic phenomenological approach is a process of description, thematic interpreting and metaphoric insight (Van Manen 1990). Ricoeur (1974) developed a theory of interpretive methodology, which allows interpretation of data that helps to reveal phenomena; his theories allowed practical steps for hermeneutic methodological analysis and are described under the terms of 'Distanciation', 'Engagement' and 'Appropriation'.

Distanciation

Firstly, Ricoeur's (1991) reflective dialectic of 'Distanciation' or viewing of the text without pre-suppositions to illuminate reality was achieved via a literal transcription of the actual interview into text. The principal investigator using Microsoft Word[©] documents, transcribed audiotaped interviews verbatim.

Engagement

Ricoeur's (1991) term of 'Engagement' (or interpretation of the experience through analysing the text) was then achieved through the reading and re-reading of the interview transcripts and from this reading, the central meaning of the transcript as a whole was developed. The transcripts were then read and re-read to find and code the core themes and subsequent sub themes.

Appropriation

Ricoeur's (1991) phase of 'Appropriation' where understanding of a phenomenon is achieved through linguistic analysis and interpretation occurred through the researcher actively producing metaphoric connotations from the participants' descriptions and literal meanings. In this way central themes emerged and were illuminated in metaphorical interpretations presented in the 'Results' section. This process discussed in the 'Discussion' section included literature from the original literature review and some additional new literature as fresh meanings and advanced topics emerged.

Credibility, transferability and dependability

Credibility has been maintained by faithfully recording and transcribing verbatim the participants' experiences into text. Metaphorical interpretation by the researcher stayed grounded in the participants' experiences but used insights from the literature. During analysis by the principle researcher participants paragraphs of expressions were kept together to maintain as much meaning as possible, rather than being stripped into individual words or sentences. Transferability has been achieved by all conclusions remaining true to the original data and interpreted using Heidegger's hermeneutic phenomenological methodology (Guba & Lincoln 1989; Koch & Harrington 1998). Themes interpreted by the principle researcher were checked by the researcher's supervisor and co-researcher for transferability and reliability (Koch 1994). The research represents believable themes and concepts of meaning, which can be empathetically shared between the participants, the researchers and the readers of the research, as experiences that are recognisable and common to human existence (Guba & Lincoln 1989; Koch & Harrington 1998; Van Manen 1990). Hammond et al (1991, p.21) purports that 'when something is evident, it is certain; and it excludes doubt in the sense that in experiencing something as certain, one does not at the same time experience it as doubtful'.

Conclusion

Qualitative research rigour is often described in terms such as credibility and trustworthiness (Guba & Lincoln 1989; Koch & Harrington 1998). Credibility has been maintained by the faithfully recorded account of experience from the participant, the literal description transformed into text and finally by the metaphorical interpretation of the researcher. The research has produced believable themes and concepts of meaning, which can be empathetically shared between the interviewees, the researcher and by the readers of the research, as experiences that are recognisable and common to human existence, in order to improve health care for people with lung cancer in the future.

Chapter 5 Findings

Introduction

In order to review the findings through the phenomenological hermeneutical lens, the reader must be reminded of the research question and its context which is: when hearing participants' experiences of being diagnosed and treated for lung cancer in the outpatient department, will the phenomenon of lung cancer related psychosocial distress be reported by participants and will participants report that they have received appropriate care and support from the hospital staff?

As the goal of phenomenological qualitative study is not to provide a large number of positivist numerical or statistical evidence but rather to illuminate the phenomenon under question, it is only necessary to show examples that highlight the main themes in the results. The themes highlighted through the participants lived experiences portray issues common to most human understanding through cultural, historical and social parallel meaning (Gadamer 1990).

The approach used to present the findings has been guided by Ricoeur's (1981) interpretive theories. Ricoeur believed that all human perceptions and understandings are interpretive and that interpretation precedes understanding. His theories allowed practical steps for hermeneutic methodological analysis, which he called Distanciation, Engagement and Appropriation. The findings are coded themes that whilst representing segments of the answer to the question 'do participants report lung cancer related psychosocial distress', also form a collective answer, which will be presented in the 'Discussion' section. The core themes are presented as 'Angst', 'Living with the fear of recurrence', 'Reflecting on Treatment', 'Death Concerns', 'stigma' and 'Therapeutic Relationships' (divided into sub themes of Satisfaction and Dissatisfaction).

Themes are a coding device of qualitative study that are used to break down the material into organisable pieces but importantly must stay true to the original data, whilst also answering the research question. The results address the research question in two parts: firstly whether lung cancer patients report psychosocial distress in their experiences of being diagnosed and treated for lung cancer in the outpatient departments: and secondly searches for and reflects on their impressions of the health care they received during this time. The setting or context encapsulates the various outpatient departments involved in the diagnosis, staging and treatment of lung cancer so that a wide variety of experiences could be presented.

The order of the themes are presented, not in the order of how frequently they were expressed or by how many out of the eight participants expressed them, as they would be in a positivist empirical study, but rather in order of severity of psychosocial distress

illuminated in the text, according to the principle researcher (NCCN 2003). Expressions of satisfaction with care were included as a counterbalance to the dissatisfaction section and serve as a model of good patient service.

Figure 1. Core and Sub Themes



Theme 1: Angst

The word angst has been used in this context as it most aptly depicts the extreme feeling emanating from the participants' relaying of their experience of living with lung cancer. The term angst, an existential concept thought to be developed by the existential philosopher Soren Kiekegaard (1844 cited by Clark 1991), is often used to describe a transcendent emotion which combines anguish about impending death, the freedom of choice and the uncertain hope of surviving (Clark 1991). Kiekegaard is remembered as identifying the problem of being human as both enjoying the freedom of choice over our lives, whilst also finding it overwhelming and terrifying (Clark 1991). In the context of this research angst is the term used to describe the theme that most accurately portrays the participants' awareness of their poor prognosis, possible imminent death and the struggle to maintain hope and find meaning.

Example 1

Researcher: Can you remember what it felt like when you were first diagnosed with lung cancer?

Participant: Ok, well it was a very mental pressure. I wasn't sure as to where I go from here. What can be done and what can't be done. So it was mentally straining. Even now, as it is about a year since I got my diagnosis, I still have my rollercoasters

mentally. Psychologically, some days I feel very depressed. Other days I sort of escape it by, I suppose it's a denial. Not to think about it. Whilst I'm home I'm safe, but when I come to hospital I see other people that are patients and it exacerbates it. And when I do have clinical appointments, I'm always anxious, very, very anxious, as to what the doctors are going to say. My life is in their hands. (Participant No 5, page 1, line 3).

Literal Meaning: Learning he had lung cancer caused a lot of 'mental strain' which is ongoing and alternates in intensity levels. Some days he recognises the feeling as 'depression' and is able to escape by using what he calls 'denial'. He feels 'safe' at home because he is able to stay in the denial state but is reminded about his lung cancer when he has clinic appointments. He describes very high levels of anxiety when attending cancer check-up appointments (where possible news of recurrence may occur). He recognises the power the doctors have over his life.

Metaphorical/Interpretation: Angst, a word first attributed to Danish existential philosopher Soren Kierkegaard (Ostenfield & McKinnon 1972) describes a deep seated feeling of turmoil, anxiety or fear and is very predominant in this participant's experience. The feelings he describes at this point in time, are for him, ongoing and relentless with horrible periods of exacerbation. His reports of elevated anxiety, which first occurred at diagnosis and reoccur before cancer reviews, reflect the research that possible news of recurrence is a very frightening time (Cohen & Bankston 2010; Jones et al 2003; NBCC & NCCI 2003). His statement 'my life is in their hands' demonstrates the absolute trust and feeling of power he attributes to his doctors. In terms of analysis this passage demonstrates all of the themes of angst, fear of recurrence, death concerns and therapeutic concerns but has the prevailing and most concerning theme of angst and has thus been preserved as a full paragraph in order to be faithful to the meaning conveyed at the time of the interview.

Example 2

Researcher: Can you remember what it felt like when you were first diagnosed with lung cancer? You were saying earlier that the reaction from friends has been disappointing since your diagnosis.

Participant: yes they've sort of disappeared since I was diagnosed. They say "oh don't worry about it, you'll be right". I haven't heard from them. I sit at home and when I ring up they have always got excuses why they can't see me. They promise to ring back but don't. We've done a lot together and it makes me wonder what I have done wrong. I only have my 2 dogs. They look at me and they know something is wrong. But with friends, I can't depend on them.

It's like when I had my heart attack this hospital had rehabilitation where there were regular meeting in groups where you saw people face to face and a nurse visited you

at home afterwards. Whereas lung cancer well lots of people say they will help you but actually...

I get upset pretty easily now. Things I used to laugh off. Now I'm reaching for the bloody tissues. What's going wrong with me? I used to be macho, macho man. Then all of a sudden I've gone to a softy (Participant no 7, page 1, line 4).

Literal Meaning: He is lamenting loss of support from friends and the hospital since diagnosis. He mentions gaining support and understanding from his dogs. He reports losing his ability to cope with things by using humour and is crying often. He feels embarrassed about his emotional state and can't seem to control the sadness.

Metaphorical/Interpretation: this participant is potentially suffering from the effect of smoking or lung cancer related stigma from friends and family in society who appear to have deserted him, although he is not actually articulating in the language of stigma (Bertero 2008; Cataldo et al 2011; Cataldo et al 2012; Else-Quest et al 2009, Gonzalez & Jacobsen 2012). Most overwhelmingly, his comments illuminate psychosocial distress and sadness at a very high level and warranted further referrals for professional help and palliative care (Temel et al 2010). On a practical level a previous referral to Palliative Care had not been actualised (possibly due to cross institutional communication breakdown between providers), so the referral was remade for ongoing care at home. He also asked for support groups he could go to where face to face contact could occur and this was provided.

Theme 2: Living with the fear of recurrence

Example 1

Researcher: Do you feel anxious or fearful when a lung cancer review appointment is coming up, that the cancer may have come back and that is why you bring someone with you?

Participant: Yes like lately I have had a cough and that was one of the main symptoms prior to my diagnosis so that does cause a worry in the back of my mind. Having my stepdaughter/s support at each check-up really helps (Participant no 1, page 2, line 35).

Literal meaning: Even minor symptoms such as a cough remind him of when he was first diagnosed with lung cancer and provoke fears of recurrence.

Metaphorical/Interpretation: Doctors reviews (usually with fresh CT scans) and minor symptoms provoke fear that the cancer may be coming back but he is proactive and takes a family member along with him to appointments for support.

Example 2

Researcher: Do you think you can see a light at the end of the tunnel now that your radiotherapy and chemotherapy is nearly finished?

Participant: Yes, but now I am anxious about the next CT. But I'm happier with my new doctor (dissatisfied with previous doctor and had to change). It still feels that there is a lump of coal in my lung. The doctor thought that might be 'the healing'. The scar still hurts in the cold weather and has a strange numbness in parts. But I'm not sure what treatment is causing what. Sometimes I get dark thoughts, especially when a cough comes along. Its healing now but I will get anxious waiting for the CT result. Especially now the films are electronically transferred to doctors so I won't be able to read the result. I'm afraid they'll say it's doubled in size again (Participant No 3, page 3, line 204).

Literal Meaning: She feels happier getting through her treatments of concurrent chemoradiotherapy after asking to change her doctor but is worried about the restaging post treatment CT which is when the doctor will tell her if the treatment has been effective.

Metaphorical/Interpretation: Small symptoms cause doubt and worry that the lung cancer is progressing in spite of adhering to a gruelling treatment regime. She has a surgical scar which causes pain and numb sensations but is not sure if the adjuvant treatments are also causing side-effects or if this could be the cancer growing. Private radiology companies transfer films electronically straight to the doctors and do not provide a written report to the patient (which she used to be able to read, before the doctors) so she experiences this

as a source of disempowerment and increased anxiety (with lengthy waits to doctors review appointments).

Theme 3: Reflecting on treatments

Example 1

Participant: Hopefully no more chemo. I wouldn't wish it upon my worst enemy. You start off thinking it's alright and then you're tired and over sleep. My husband would cook me a meal and then I would go and bring it up. I always knew 3 days after chemo I would feel lousy and sleep all day. Then a week off and start again. I was there in chemo Day Centre for 5 hours most days when other people seemed to be coming and going quicker. I just want to forget it. I felt that they were pumping extra into me at the end. Especially the radiotherapy, there was that long walk down the corridor, it used to be an effort for me to walk but there was no way I was going to resort to a wheelchair (Participant 4, page 1, line 5).

Literal meaning: Patient who experienced surgery, chemotherapy and radiotherapy reflecting back on treatment with dread that she may have to have more treatment. She is remembering the effects, feelings, side effects of treatment, nausea, vomiting and fatigue with absolute dread.

Metaphorical/Interpretation: She fears recurrence news at next doctors post treatment review, as she doesn't want to have any more treatments. She remembers the physical and visceral sensations of tiredness, fatigue, nausea, and vomiting as well as long chemotherapy sessions in the chair (longer than other people). 'The long walk down the corridor' of the radiotherapy department (after 6 weeks of daily treatments) which physically does resemble a long dark draughty tunnel in real life, was an 'effort to walk' with the main motivation being to avoid becoming wheelchair dependant.

Example 2

Researcher: Do you remember being in the chemo day centre. And if any of the other patients or staff talked to you?

Participant: No, not much, one or two maybe. It was a very depressing place really. So many young people with cancer, lots of young women, I suppose with breast cancer I presume (not sure). Yes very depressing and sad to see. It was very sad.

Researcher: Did you see social workers walking around in the Chemo Day Centre?

P: I think I saw one SW earlier in the piece.

R: Did you think they could have done more about providing Social Work for you?

P: No not really she did a good job.

R: Did they ever give you a distress thermometer screen to fill in?

P: Yes I remember that.

R: But you didn't feel as though you needed any extra help?

P: No, I had the country cancer coordinator helping at home and I stay with my daughter in Adelaide. I just hope I've still got time to get through this now. I didn't have to come until Oct but my doctor made an apt for me because I'm not well (Participant no 6, page 1, line 25).

Theme 4: Death concerns

Example 1

Participant: I felt unwell and I'd lost my voice with pains down the side. I went to my GP and he did an x-ray and said there was a little spot there. He ordered a CT, but I had to chase up the result myself. It was about 3 weeks later I went to the flying doctors. She told me that I had cancer. She told me I had it in my shoulder, and my lung and she said 'I want you to go to Adelaide and I think they will find it in your head and your neck. I thought oh no I'd better make my funeral arrangements. She referred me to Thoracic and when they did the tests it wasn't in my shoulder, head or neck just my lung so I had that treated. I felt angry about that delay and misinformation. I used to walk easily but now I can hardly walk for 5 minutes. I have pain as well and a cough at times. I just hope I've still got time to get through this now. I didn't have to come until Oct but my doctor made an apt for me because I'm not well (Participant 6, page 1, line 1).

Literal: Originally the participant experienced death concerns when first over-staged but then relief when it wasn't as bad as predicted. Is again faced with possible bad news of recurrence and is also suffering from dyspnoea, cough and hoarse voice.

Metaphorical/Interpretation: The participant was expressing lack of confidence in her doctors when they initially over-staged her cancer and she went through a stressful period of thinking she was going to die quickly. She also is angry with the local rural doctors for not chasing up her CT results and having to follow it up herself. Now after treatment she is experiencing increased cough symptoms and fear of recurrence at this appointment as a new lesion may have appeared. She hopes she still has time left to live.

Example 2

Participant: Sometimes I get dark thoughts, especially when a cough comes along. Its healing now but I will get anxious waiting for the CT result. Especially now the films

are electronically transferred to doctors so I won't get to read the result. I'm afraid they'll say it's doubled in size again (Participant no 3, page 6, line 150).

Literal meaning: A cough and a CT review post treatment cause fear and remind her of when she was first diagnosed.

Metaphorical/Interpretation: The mention of 'dark thoughts' can be interpreted as the fear of recurrence and death being attached to symptoms and doctor reviews. Additionally she feels disempowered by the situation when she can't read the radiologist report of her CT and has to wait for her appointment with the doctor.

Theme 5: Stigma

Example 1

Note: The word 'stigma' was not used in the interview questions to avoid leading the conversation

Researcher: Did you notice any bad effects against you because of the association between smoking and lung cancer? Like when you say you've got lung cancer do people automatically ask you if you're a smoker?

Participant: No, but I already know deep down that smoking had a lot to do with it. I just don't listen to that sort of thing. They still sell cigarettes even though they know it was causing cancer. I think the governments might be a bit hypocritical by not banning it altogether. I tried to stop. I probably tried to stop 6 times before. I finally stopped and haven't had a cigarette now for 4 and half years. Yes some people are bit funny like when I lost my hair and had a scarf on, some people would just stare at me and they knew me but it was too much of an effort to say hello (Participant 6, page 2, line 46).

Literal meaning: The participant understands the link between smoking and lung cancer but has given up 4 years ago and is able to brush off any comments about smoking. She has quite an advanced understanding of the smoking related issues, although didn't use the word stigma.

Metaphorical/Interpretation: The participant has accepted that her smoking has probably had a large role in her getting lung cancer. She is aware of stigma comments, but gave up '4 years ago', so is able to discard negative smoking related stigma comments from other people and does not seem to suffer from internalised stigma (Cataldo et al 2011; Hamann et al 2014; Link & Phelan 2001).

She expresses anger at the government for still selling addictive cigarettes, a positive response referred to in the stigma literature as disavowal or a defence mechanism which effectively buffers against internalised stigma (Leventhal, Brissette & Leventhal 2003 cited in

Hamann et al 2014). She also expresses irritation and hurt that people she thought were friends didn't bother to talk to her when they saw that her hair had fallen out, which fits with perceived (or felt) stigma (Cataldo et al 2011; Hamann et al 2014; Link & Phelan 2001). Also the delay in getting her CT result from the doctor of three weeks and having to chase results from another doctor could be suspected of representing some kind of medical nihilism (Ball 2013) but could also have been an accident or unintended delay caused by (rural) health care resource deficiencies. Ball (2013) suggested, however, smoking related stigma and nihilism possibly underscores health care deficiencies, thus representing the complexity of this issue. According to a current systematic review by Chambers et al (2014) nevertheless, there is no empirical evidence or test to measure or prove medical nihilism, but there are qualitative patient reports about this issue.

Example 2

Researcher: Was it a shock to you when your GP first started investigating your lungs?

Participant: I think it was. The first thing he said was "you're a smoker". I used to smoke reasonably heavy. I opened a lot of packets of cigarettes in a week but never smoked one whole one. I ran a business and when a customer came in I'd put the cigarette down and I'd light another one and another one... I gave it up 40 years ago and yet this was only diagnosed 2 years ago so I still say it's just the luck of the draw and had I not given up 40 years ago it may have been a hell of a lot worse and I may not have been here now. The nurses were very attentive. Everything throughout being diagnosed and through the surgery went forward without a hitch. There was no condemnation like 'you bloody smoker' none of that like 'serves you bloody right', no. I could not fault the whole attitude of everybody. I was a smoker but I gave it up 40 years ago (Participant no1, page 2, line 40).

Literal: Discusses GP labelling him 'a smoker' as the reason why he first developed lung cancer and smoking history. He stated that he didn't feel any discrimination from the hospital staff. He still feels worried 2 years after surgery about his CT reviews with the doctor and brings his daughter for support.

Metaphorical/interpretation: Although the doctor initially labelled him as 'a smoker' he reflects that he did smoke heavily at a time when smoking was a cultural norm (Australia in the 1970s prior to indoor smoking restrictions) and he gives the example of smoking in his office in-between customers, but proudly reports that he gave up '40 years ago', so is not self-blaming or suffering from perceived or internalised stigma (Cataldo et al 2011; Hamann et al 2014; Link & Phelan 2001). Although he accepts his history of smoking, he no longer sees himself as 'a smoker' and as his lung cancer has been removed surgically feels very lucky and glad to have given up. The effect of smoking related stigma has no power over him (Hamann et al 2014; Link & Phelan 2001).

Theme 6: Therapeutic relationships

Sub themes: Satisfaction and Dissatisfaction with care

These are quite numerous and self-explanatory, but useful for service improvement so have been presented in quote form only and are included in the context of the final discussion.

Dissatisfaction Quotes

Example 1 Dissatisfaction with clinical psychology

Interviewer: Do you think it would help if you had counselling from a social worker or psychologist?

Participant: Yes it was recommended by the hospital, last year about 3 months after the diagnosis. I saw a so called psychologist twice.

Did you find that helpful?

Participant: No I didn't. They were trying to make me accept something that I needed to accept in my own time. Yes I felt very much like a number there, and they didn't really know me. Um I felt more comfort with someone who knows me. Yes, a couple of times I thanked them for their time and that I would contact them if I needed any more assistance. Not really (laughing). I can't remember what therapy they offered me psychologically but they were trying to balance my thoughts in my favour of course and it wasn't working. I felt aggravated and angry. I thought they were trying to coerce me. Or force me into thinking what I wasn't ready to accept at that stage. And now I don't know. I have no intentions of seeing them again. At that stage I felt very aggravated and irritated as they were trying to teach me into how I should think through this. But I'm an individual like they are and I think differently. I thought this individual here; the time they were spending with me would have been better spent with someone else. I'm not ready to accept their professionalism, because my psychology is erratic at the moment. It's aggravating (Participant no 5, page 2, line 46).

Example 2 Dissatisfaction with the nurse

Interviewer: Can you tell me about your experience of being diagnosed with lung cancer?

Participant: It was fine until after the procedure when I was regaining consciousness. The nurse, the RN who was supposed to be watching me, I was coughing and trying to get her attention (there was no buzzer), and I couldn't talk and she was too busy talking to the other nurses. Another nurse or technician came in from the other room and noticed I needed help. And after that the RN didn't appreciate me, as I think someone might have mentioned something to her, as she had her back to me

for most of the time I was there. But I just thought thank goodness I won't have to see her again (Participant no3, page 1, line 8).

Example 3 Dissatisfaction with surgery

Interviewer: Can you tell me about the surgical experience?

Participant: I finally got into surgery and the day it was supposed to happen, 2 junior doctors came in and without introducing themselves said "we're not doing the surgery because it had doubled in size" and didn't explain why. The doctors said this wouldn't happen before the surgery (Participant no 3, page 1, line 18).

Example 4 Dissatisfaction with surgery

Participant: Within a week I was back in and they did the operation, took half a lung out. But they didn't get it all, I found out later from my radiation doctor (not from the surgeons) (Participant no 3, page 1, line 30).

Example 5 Dissatisfaction with Medical Oncology

Participant: Then we got to chemo. At this stage they said 'who sent you to us' and I said 'how do I know'. I assume the surgeons, I don't know. They were talking about this really aggressive chemo every day. And then he explained everything to me. Then he said I'll get my boss (consultant) to talk to you. Hours later and the registrar apologised and said the consultant won't be coming and it's too late to put you on the Monday meeting (Multidisciplinary Team Meeting) so if you ring up in a week's time we might have a final answer for you. Then on the 8th they still didn't have a firm decision and didn't appear to have discussed it at a meeting. I don't think they knew I existed (Participant no 3, page 2, line 38).

Example 6 Dissatisfaction with Medical Oncologist

Participant: I said to the registrar I want to change consultant and he said 'why he is the head of our unit'. And I said I don't have any confidence in him and explained why. He didn't explain things and answer questions. Often he would just stare at his computer and not answer my questions. He didn't even look at me. I don't think he had even read my notes again. He took a few calls during my appointment without apologising. I was reduced to tears about this issue (Participant no 3, page 3, line 86).

Interviewer: Do you have any particular spiritual beliefs or ways of coping?

Participant: I think I mainly use humour and it was important for me to be in control of changing my doctor. After that I felt much happier, because I didn't have any confidence in him. The radiation doctor said 'oh but he is very nice, give him another try', so I saw him twice. But when I found out I had to keep seeing him, I thought, no. This is the only issue that really made me cry. Yes I would have put up with it, but I just couldn't trust him (Participant no 3, Page 3, Line 118).

Example 7 Dissatisfaction with lack of home support from the hospital

Participant: It's like when I had my heart attack this hospital had rehabilitation where there were regular meeting in groups where you saw people face to face and a nurse visited you at home afterwards. Whereas lung cancer well lots of people say they will help you but actually...(Participant no 7, page 1, line 22).

Satisfaction quotes

Example 1 Satisfaction with General Practitioner, Thoracic Medicine and Cardiothoracic Surgeon

Interviewer: I would like you to think back to when you were first received your diagnosis of lung cancer in this department and how that experience was for you.

Participant: It started with bronchitis. After x-ray and CT scan, into the doctor here (Thoracic from GP referral) they said 'you're into the surgeon next week. I was really amazed how quick this was happening. It was decided although a small cancer they would remove it by taking a section of the lung. I was home within the week after surgery and I have had no trouble since. I have regular doctors' visits (yearly Thoracic) and this relatively new GP to me, has done a marvellous job. I reckon I was very lucky to have possibly the best surgeon in Australia and I just feel great, especially, when I look at other people with lung cancer. Had it not been found it would have grown bigger and bigger and I would have been in real trouble, everything's fine (Participant no 1, page 1, line 3).

Interviewer: And when you came to the Clinic for your results did you find that that was done nicely and sympathetically when the doctor was giving you the diagnosis?

Participant: The diagnosis was not confirmed until I'd seen Dr ... and he referred me to the surgeon and to have a PET scan. After that I had a second visit to check the PET scan and then went to see the surgeon. After talking to the surgeon in his office he said right we'll get this done next week. "I couldn't believe it". I think I went in on the Thursday and was home on the following Tuesday.

Interviewer: so you didn't have much waiting?

Participant: No, no waiting and that's the part that really surprised me. You hear these days some people have to wait but that is one thing I cannot do is criticise the health system (Participant no1, page 2, line 27).

Example 2 Satisfaction with having the same treating doctor and 'Hospital in the Home'.

Participant: It's very much about seeing the same treating doctor who knows you. I don't think you could offer anymore. When I got out of hospital I caught a bug and had to be on antibiotics on a drip it was suggested I would be better off at home

because of the germs. Then I had the drainage from the lung and I had Hospital in the Home for antibiotics. Really the health care in this country couldn't be better. We are very lucky. Now I don't have the pleural drain, I just have the district nurse come to my home for bandages etc. what more could you want? (Participant no 5, page 2, line 40).

Example 3 Satisfaction with nursing care

Interviewer: How did you find the nurses attitudes towards you?

Participant: The nurses gave me a lot of useful information. Especially, when I had febrile neutropenia and had to be admitted. They were very organised and helpful. I can't fault anyone. The hospital has been great (Participant, no 4, page 1, line 18).

Example 4 Satisfaction with Thoracic Medicine and Cardiothoracic Surgical nursing care

Participant: yes the nurses were very attentive. Everything throughout being diagnosed and through the surgery went forward without a hitch (Participant no1, page 2, line 40).

Example 5 Satisfaction with nursing

Luckily a friend of mine's son who had worked as a nurse in the RAH recovery came to see me and explained it (her surgery). Everyone said if you want better answers ask the nurses (Participant no 3, page 1, line 26).

Example 6 Satisfaction with Radiation and Medical Oncology nurses

Then chemo and radiotherapy started on the same day. A nurse showed me a pamphlet and took me into the radiation room and picked me up and then took me to chemo. The nurses do all of the important information and coordinating care between treatments (Participant no 3, page 1, line 54).

Example 7 Satisfaction with family support

Participant: The family used to come with me for support all along. They just turned up; I didn't have to ask them. Some were living interstate, even leaving 3 kids at home with their father. My husband came to every appointment with me. At the end of the treatment they all held a party for me to celebrate (Participant no 4, page 2, line 32).

Example 8 Satisfaction with Thoracic Medicine nursing and family support

Interviewer: Did you have much memory of the nurses in the clinic when you first came in?

Participant: I remember them going through the bronchoscopy information with me but when I got my diagnosis I was busy holding myself together for the children. Even the older adult one, I know was very upset, and he had his baby daughter with him, so I had to think of them rather than myself (Participant no 3, page 1, line 188).

Example 9 Distress Screening and family support

Interviewer: Did you think that you needed extra counselling at any stage through the treatments from the social worker or psychologist?

Participant: Well I saw a cancer lady near the end with a form where I had to say if I needed help (distress screen?), but I just said that I had the support of my husband and the kids. I said I had cancer and I think it's all gone. I had to sort of get that in my mind and get through it. I just hoped I was through with it (Participant no 4, line 35).

Example 10 Spiritual support

Researcher: Is there anything else you would like to tell me about your lung cancer experience?

Participant: I should tell you that I'm a Christian and a lot of my strength comes from my faith and belief in god. Yes, that's right; the church community has helped me spiritually and for support a great deal (Participant no 2, page 3, Line 94).

Example 11 Support from dogs

Participant: I only have my 2 dogs. They look at me and they know something is wrong. But with friends I can't depend on them (Participant 7, page 2, line 42).

Example 12 Support from dogs

Participant: After surgery and chemoradiotherapy, walking the dog helped clear my lung congestion. 20 minutes around the oval everyday now with the dog. She is always with me and she knows when something is wrong (Participant 3, page 4, line 520).

Conclusion

As the results demonstrate, distress was evident in varying degrees for most of these participants and ranged from very severe and unrelenting to a quieter background, but never the less, ongoing fear of recurrence and death. It is important to clarify here that none of these patients were involved in formal complaints and probably would not have brought forward their experiences if not for this study, so the interview process has been very rewarding. Many participants also expressed gratitude and appreciation for the care and support they had been given. The next chapter will discuss the results and the researcher's interpretations in more detail and conclude the research.

Chapter 6 Discussion

Introduction

This research set out to study the phenomenon of lung cancer related psychosocial distress by highlighting the lived experiences of people being diagnosed with lung cancer in the setting of their diagnostic and treatment outpatient clinics.

High psychosocial distress

As suggested in the literature review, research has reported that psychosocial distress amongst lung cancer patients is thought to occur in peaks around the time of initial diagnosis, diagnosis of recurrence and when diagnosis is at a late stage (Cohen & Bankston 2010; Jones et al 2003; NBCC & NCCI 2003). Alternatively, Aketchi et al (2006) state that lung cancer patients diagnosed late stage and with a poor prognosis actually experience sustained psychosocial distress throughout the illness, as poor prognosis, long treatment regimens, side effects and symptom-burden, negatively affect psychological well-being. It is the appearance of the latter distress, which has been most concerning in this study: that of sustained burdensome and prolonged anxiety and depression, as described by some of the participants.

Psychosocial needs

The literature review also reported that psychosocial distress amongst lung cancer patients was often not detected or treated by health professionals with appropriate levels of supportive care (Ftanou et al 2014; Gonzales & Jacobsen 2010; Temel et al 2010; Zabora et al 2001). This research aimed to see if the participants firstly experienced psychosocial distress from having lung cancer and secondly whether they reported having received appropriate psychosocial care. The two participants who had expressed a high unrelieved level of psychosocial distress, had been referred separately, one to clinical psychology and the other to palliative care as per clinical recommendations, but both strategies had not been effective. The participant who had clinical psychology input had found it unsatisfactory and the participant who had been referred to palliative care at another regional hospital had not been contacted (4 weeks after referral) and needed to be re-referred. The other 6 patients mainly managed their psychosocial concerns with the help of their treating physicians, cancer nurses, families and local church and spiritual supports. Although some preliminary assessment and referral of high levels of lung cancer related psychosocial distress was evident, overall the findings were in line with the literature in confirming that more needs to be done.

Phenomenological research for illuminating deep understandings

Phenomenology was used for this research in order to highlight the deeper understandings obtained from the participants' experiences of being diagnosed and living with lung cancer. Although early recognition, screening and referral for treatments are recommended for psychological management and improving quality of life for most other cancer patients, there is a dearth of research about psychosocial management of this cancer group (NBCC & NCCI 2003; Neron et al 2007). Ftanou et al (2014) suggest that this is due to the difficulties of doing randomised control trials on the lung cancer population, which include small sample sizes, heterogeneous samples, high morbidity and mortality and consequent high attrition rates. Although phenomenological research uses a small number of participants, it is able to highlight participants' experiences in a way that can produce profound meanings.

Profound phenomenological findings

This study revealed that profound meanings from distress were evident in varying degrees for most of these participants. The distress ranged from very severe and unrelenting anxiety and depression, to lesser ongoing fears of recurrence and death. Only one of the participants who had stage IV lung cancer, actually reported being referred to a hospital clinical psychologist and described finding this experience as extremely annoying and unhelpful. This reaction seemed to be related to the psychologist trying to talk to him about an issue he wasn't ready to discuss, which may have been his poor prognosis and possible imminent death, although he didn't elaborate any further. It was important that the delicate balance of what the patient was ready to discuss was not over ridden by what the researcher thought needed to be discussed (NBCC & NCCI 2003; SA Health 2013).

Continuity of care issues were revealed by this participant in his statement that he 'felt like the psychologist didn't know him' and he 'felt like a number there'; also that when he saw different doctors he also felt that they 'didn't know him' and he would rather speak to the same doctor at each visit. Although continuity of care has been a recommended philosophy throughout health care, the importance this patient placed on seeing the same treating clinicians struck me as a new and profound meaning. Despite his ongoing angst about the effect cancer was having on his life and his disappointment with clinical psychologically, continuity of care was the one thing he thought could help him the most.

Continuity of cancer care

Institutional problems, such as constantly seeing different practitioners at each visit to the same clinic or across treatment settings, is something that can be recommended from the study as a care improvement for cancer patients (King et al 2008). A Cochrane review (Aubin et al 2012) of cancer follow up interventions, designed to indirectly improve continuity of care, found that the 51 included studies contained too much heterogeneity and lacked firm evidence to make any conclusions, other than to recommend that a standard instrument to

measure continuity of care needed to be developed. This tool needed to be consistent and able to be used along the trajectory of the whole cancer experience. Relevant to this study, the review questioned the effectiveness of measuring physical and mental health improvement outcomes in cancer patients, when regardless of the quality of care, people with cancer often face severe disability and imminent death (Aubin et al 2012).

More positive outcomes were reported in a primary mixed method study across 5 UK hospitals by King et al (2008), which found that higher reports of continuity of care foretold lower unmet needs for care, (after adjustment for other possible causative factors) and cautiously predicted that improved continuity may reduce health care costs. Interestingly, of the 28 patients (7 of whom had lung cancer), involved in the qualitative section of the study; 13 patients nominated a GP from primary practice and 10 nominated a secondary practice specialist, 7 of whom were specialist cancer nurses. Some of the relevant results were that clinical nurse specialists were very aware of their important roles in trust and continuity of care and that family members and carers were more unsatisfied with perceived delays and service providers than patients, who tended to just accept the care they were given. Consistency of services was reported as the most common patient concern, in particular whether the health care provider remembered them and whether there was good communication about what to expect in the future (King et al 2008). Also crucial to the ongoing discussion about psychiatric referral for cancer patients versus maintaining 'normality', the patients reported that managing the effects of treatment and maintaining 'a feeling of normality was crucial' (king et al 2008, p 4) and at times patients wanted to forget the cancer in order to achieve this sense of normality.

Again, if we look at the experiences of participant no. 5 who rejected clinical psychology; he stressed the importance of seeing the same treating doctor who 'knew him' and mentioned the importance of being able to forget about the cancer for a while when he was at home. His lived experience is that he seeks a sense of normality in his health care. His requests, expectations and preferences are from an individual trying to cope with a catastrophic illness and imminent death. The profound understanding gained from his experience, is one that any human in a similar situation can relate to. The clinical implications of the need for continuity, although a simple concept, presents many challenges for change in public outpatient clinics, where rotating health care practitioners provide care for patients with lung cancer.

Participants' predominant clinical concern - good therapeutic relationships

Apart from the dependence of the participants on their therapeutic relationships with their treating physicians was the trust and appreciation they expressed for the other hospital staff. Nurses have been generally appreciated as efficient, helpful, and knowledgeable and reliably working in the background, keeping everything running and sometimes going 'above and beyond' to keep patient's spirits up. Only one patient reported an incident where she felt unsupported by a particular nurse during a critical procedure and this highlights the

need for vigilant care. It is also interesting that the participant felt comfortable reporting this incident in a confidential research interview but had not lodged an official complaint. A formal complaint form was offered to the participant but she declined the offer, saying she would like to see her contribution in this research instead.

A participant who was unhappy with her treating medical oncologist was able to change doctors, and expressed much greater happiness and coping with her treatments. Although troubled and upset by the service delivery, she had felt empowered by changing physicians and was coping well with family support. The therapeutic relationship with the doctor was perceived as vital because the news they gave was critical. While participants had a great deal of trust and faith in their doctors, they were very anxious before attending review appointments, because they worried about what was about to be said to them. As one participant said "...when I do have clinical appointments, I'm always anxious, very, very anxious, as to what the doctors are going to say. My life is in their hands." (Participant No 5, page 1, line 3).

Surgical patients feeling 'cured' expressed lower unmet needs

Two participants with early stage one lung cancer reported being told that their surgeon had successfully removed the lung cancer and apart from a low level fear of recurrence, did not seem to have high levels of cancer related psychosocial distress. Consequently they did not need more than family support and usual care for their surveillance periods. The profound finding from interviewing two of these participants and from previous experience with other patients is that they no longer think of themselves as having lung cancer or being a lung cancer patient. The other participants, however, who had incomplete surgery with adjuvant chemotherapy, more intense and protracted chemoradiotherapy or palliative treatments, reported much higher levels of psychosocial and physical symptoms. Further research into these two rather disparate groups of Non-Small Cell Lung Cancer patients is required and these two groups need to be considered separately.

Lived experiences which led to deeper insights

Significantly for this phenomenological study, it is essential not to try to apply the results of a small sample group to the overall lung cancer population but rather to appreciate the illumination that comes from improved understanding and empathy of the participants' experiences. The lived experiences of these eight people with lung cancer were varied and yet held elements of similarity. The people who had been given a short prognosis and had already experienced various life limiting symptoms expressed the most psychosocial distress ranging from anxiety, depression, fear, dread and angst to quiet resignation. It was distressing to hear that efforts such as clinical psychology, offers of social work, distress screening, counselling and so on had either not been offered, not been taken up or were not effective in relieving distress. Further research needs to be done to examine these issues and improve care.

Unfortunately for one of the participants, whose experience included severe psychological distress, a high burden of symptoms and very little social and hospital support, an earlier referral to palliative care services at a regional hospital had not yet been enacted. It was unknown how this occurred or whether it was a resource problem but at this late stage in his life, there were severe consequences for him. He described feeling that no one had time or cared for him since he was diagnosed with lung cancer. He lived alone with his dogs for support, and waited for someone from the hospital to contact him. He described being so short of breath he couldn't walk his beloved dogs anymore and not being able to even get to the shops for food. This breakdown in clinical transfer care from hospital to home was confounded by his usual family and friends no longer keeping in contact with him; a process he described as active social avoidance since his diagnosis. He was re-referred to Palliative Care from the interview and died one month later, only four months after receiving his diagnosis. Palliative care support at home, in the hospital or hospice can give reassurance to patients and this service needs to be actively facilitated for people with lung cancer.

Stigma and nihilism

Although none of the participants used the language of stigma, their lived experiences of lung cancer related problems could be interpreted as being associated with possible stigma and therapeutic nihilism. For some of the participants these experiences included feeling that their treating clinicians didn't care about them, feeling ill informed, wishing for continuity and waiting for palliative care follow up. Therapeutic nihilism, a theoretical construct that is alleged to occur when health professionals limit the amount of treatment they offer to people with lung cancer in association with factors such as poor overall prognosis, limited treatment outcomes, high health costs and blame for smoking behaviour (Ball and Irving 2000; Chambers et al 2012) is as yet unmeasured (Chambers et al 2012). Further research needs to be done on whether patients perceive stigma in health care settings and if it affects their ability to ask for and receive appropriate health care.

Recommended psychosocial clinical guidelines

Significantly for clinical practice, there are psychosocial clinical guidelines describing best practice. The Psychosocial Guidelines for Adults with Cancer (NBCC and NCCI 2003) recognised that stage III and IV lung cancer patients suffer from multiple factors such as anxiety, depression, fatigue and poor prognoses, that make them vulnerable to increased distress and in need of special psychosocial consideration. A recent review of research by the Cancer Council Australia's Lung Cancer Guidelines Working Party (Ftanou et al 2014) , involving small heterogeneous sample sizes, questionable methodologies and mixed groups of cancer patients; cautiously recommended that psychological interventions can help advanced lung cancer patients improve psychological well-being. Of these interventions combinations of supportive and unstructured therapies, psycho-education, relaxation and cognitive behaviour therapy have shown evidence of effectiveness (Ftanou et al 2014). Additionally, health care professionals need to acknowledge and involve the help of

palliative care services, as research has shown early referral to be effective in improving quality of life and relieving suffering (Hill et al 2003; Lemay & Wilson 2008; Lehto 2012; Lehto & Therrien 2010; McSkimming et al 1999; Temel et al 2010; WHO 2013).

Study limitations and Recommendations for further research

Although this study provides valuable insight and illuminates the psychosocial aspects of these participants' lived experience, it is only a brief window into what will be their total cancer experience. Larger longitudinal studies over the whole cancer trajectory where the same participants are reinterviewed at regular intervals are needed to see how their coping and feelings might have changed and possibly highlight again what strategies of care they thought were successful or lacking. Unfortunately, due to time constrictions, disease morbidity and mortality, this has not been possible. Additionally, people with different stages of lung cancer, late stage versus early stage for example, seem to have markedly different levels of unmet psychosocial needs and may need to be considered separately.

Conclusion

In conclusion the study has been instrumental in highlighting the participants' psychosocial and clinical experiences, whilst being diagnosed and treated for lung cancer in the context of the outpatient clinics of an acute care hospital. Broadly the level of psychosocial distress reported in this study reflected what previous research has suggested: that a high level of distress is often experienced at initial diagnosis, news of recurrence and end of life prognosis (Cohen & Bankston 2010; Jones et al 2003; NBCC & NCCI 2003). However for at least two and to a lesser extent four of the later stage (III to IV) participants as Aketchi et al (2006) reported, psychosocial distress was sustained at a high and unrelieved level. Of these participants, some remembered and reported efforts to assess and treat the distress by their doctors, nurses and clinical psychologists with varied results. Continuity of cancer care, particularly wanting to see the same treating physician, feeling 'known' and maintaining a sense of normality were predominant concerns for some patients.

In terms of levels of distress, according to stage and level of curative treatment, the two stage one patients who had experienced complete resection surgery, had much lower levels of concern re possible recurrence, mixed with good family and spiritual support and subsequently didn't need professional psychosocial supports. Additionally, three out of four surgical patients reported being informed by the surgeon that 'we got it all out' and patient's generally believed this to be the case. This difference between early and late stage lung cancer, in terms of how they view their cancer and themselves and the amount of psychosocial distress they may experience, needs to be taken into account when comparing or aggregating studies about psychosocial needs.

The main phenomenological understanding gained from these participants' experiences, is that psychosocial distress in people with lung cancer; particularly in people diagnosed late

stage is omnipresent and can be severely distressing. Disturbingly, it appears as though either psychosocial distress, in the worst cases, is either not being assessed and treated, or the treatments are not yet successful. Barriers to effective psychosocial assessment and treatment for people with lung cancer, although discussed in the literature and clinical guidelines, are still insidiously prevalent throughout the participants comments about their experiences in the outpatient clinical environment.

Another essential phenomenological understanding gained from the participants' experiences include the importance of good continuous therapeutic relationships and the suffering caused to patients when they feel that their health care providers do not really care about them. Simple improvements in communication, such as taking time to listen, maintaining eye contact and providing reassurance, can help patient's endure their illness and treatment regimes. Additionally, institutional service provision and resource issues in regard to time, psychosocial services and education and other resource barriers need to be addressed with evidence based research and clinical practice guidelines.

Overall the findings from this study of lived experiences are those of severe psychosocial distress related to initial diagnosis, diagnosis of recurrence and the poor prognosis and high mortality of late stage lung cancer. Prevalent needs arising from analysis and interpretation included the need for continuity of care; the need for awareness about lung cancer related stigma; the need for understanding about fear of recurrence and the need for urgent psychosocial and palliative care services. It is hoped that this research will enhance understanding and compassion for people living with lung cancer in the future.

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Appendices

Appendix 1: Ethics approval letter



Government of South Australia
SA Health

Approval Date: 10 June 2014

Ms M Oborn
Department of Thoracic Medicine, Chest Clinic
ROYAL ADELAIDE HOSPITAL

Dear Ms Oborn,

HREC reference number: **HREC/14/RAH/218**

Project Title: **“The lived experience of being diagnosed with and treated for lung cancer in the outpatient areas of an acute care hospital: a psychosocial phenomenological study.”**

RAH Protocol No: 140608.

Thank you for submitting the above project for ethical review. This project was considered by the Chairman of the Royal Adelaide Hospital Human Research Ethics Committee. I am pleased to advise that your protocol has been granted full ethics approval and meets the requirements of the *National Statement on Ethical Conduct in Human Research*. The documents reviewed and approved include:

- **LNR Application: AU/15/ CBA71144**
- **Research Proposal, Version 1, 3 April 2014**
- **Participant Information Form, Version 1, 3 April 2014**
- **Participant Consent Form, Version 1, 3 April 2014**
- **Revocation of Consent Form, Version 1, 3 April 2014**
- **Letter of Support, Dr Peter Robinson, 29 May 2014**

Please quote the RAH Protocol Number allocated to your study on all future correspondence.

GENERAL TERMS AND CONDITIONS OF ETHICAL APPROVAL:

- Adequate record-keeping is important. If the project involves signed consent, you should retain the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them in the future if necessary. The duration of record retention for all clinical research data is 15 years.
- You must notify the Research Ethics Committee of any events which might warrant review of the approval or which warrant new information being presented to research participants, including:
 - (a) serious or unexpected adverse events which warrant protocol change or notification to research participants,
 - (b) changes to the protocol,
 - (c) premature termination of the study.
- The Committee must be notified within 72 hours of any serious adverse event occurring at this site.
- Approval is valid for **5 years** from the date of this letter, after which an extension must be applied for. Investigators are responsible for providing an annual review to the RAH REC Executive Officer each anniversary of the above approval date, within 10 working days, using the Annual Review Form available at: <http://www.rah.sa.gov.au/rec/index.php>
- The REC must be advised with a report or in writing within 30 days of completion.

Should you have any queries about the HREC's consideration of your project, please contact Ms Heather O'Dea on 08 8222 4139, or rah.ethics@health.sa.gov.au.

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a SA Health site until separate authorisation from the Chief Executive or delegate of that site has been obtained.

This Committee is constituted in accordance with the NHMRC's *National Statement on the Ethical Conduct of Human Research* (2007). The HREC wishes you every success in your research.

Yours sincerely,

A/Prof A Thornton
CHAIRMAN

Central Adelaide Local Health Network
Royal Adelaide Hospital Human Research Ethics Committee
Level 3, Hanson Institute, IMVS Building
Royal Adelaide Hospital
North Terrace
Adelaide South Australia, 5000
Telephone: +61 8 8222 4139
Fax: +61 8 8222 3035
Email: rah.ethics@health.sa.gov.au

Appendix 2: Site Specific Assessment Review confirmation letter



Government of South Australia
SA Health

Central Adelaide Local Health Network
Research Governance Office
Level 3, IMVS South Building
Frome Road, Adelaide SA
Australia 5000
T : 08 8222 3839
F : 08 8222 3414

23 June 2014

Ms Maree Oborn
Chest Clinic,
275 North terrace,
Adelaide, 5000, SA

Dear Ms Oborn

HREC reference number: HREC/14/RAH/218

SSA reference number: SSA/14/RAH/261

Project title: The lived experience of being diagnosed with and treated for lung cancer in the outpatient areas of an acute care hospital: a psychosocial phenomenological study.

RE: Site Specific Assessment Review

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to commence at the following site: **Royal Adelaide Hospital**

The following conditions apply to the authorisation of this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval to this project:

Please note the following conditions of authorisation:

1. Authorisation is limited to the site/s identified in this letter only.
2. Project authorisation is granted for the term of your project outlined in Section 9 of the SSA, or until the project is complete (whichever date is earlier).
3. The study must be conducted in accordance with the conditions of ethical approval provided by the lead HREC, SA Health policies, and in conjunction with the standards outlined in the *National Statement on Ethical Conduct in Human Research (2007)* and the *Australian Code for the Responsible Conduct of Research (2007)*.
4. The Coordinating Principal Investigator is responsible for notifying the institution via this Research Governance Office of any changes to the status of the project within a timely manner:
 - a. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the HREC for review, are copied to this research governance office;
 - b. Proposed amendments to the research protocol or conduct of the research which only affects the ongoing site acceptability of the project, are to be submitted to this research governance office;
 - c. Proposed amendments to the research protocol or conduct of the research which may affect both the ongoing ethical acceptability of the project and the site acceptability of the project are to be submitted to this research governance office after a HREC decision is made.
5. A copy of this letter should be maintained on file by the Coordinating Principal Investigator as evidence of project authorisation.
6. Notification of completion of the study at this site is to be provided to this Research Governance Office.

If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.

Should you have any queries about the consideration of your Site Specific Assessment form, please contact this Research Governance Office. The SSA reference number should be quoted in any correspondence about this matter.

Yours sincerely

Bernadette Swart

Manager Research Governance, IP and Contracts
Royal Adelaide Hospital and SA Pathology
Ph: 8222 3890
Email: bernadette.swart@health.sa.gov.au
Email: rgipc@health.sa.gov.au

Appendix 3: Participant information form

The lived experience of being diagnosed and treated for lung cancer in the outpatient areas of an acute care hospital: a psychosocial phenomenological research project.

Principal researcher: Maree Oborn

Associate researchers: Dr David Foley, Dr Peter Robinson and Dr Phan Nguyen

1. Your Consent

You are invited to take part in this research project.

This Participant information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record

2. Purpose and Background

The purpose of this exploratory research project is to discover how you experienced being diagnosed with and treated for lung cancer throughout various outpatient areas of the Royal Adelaide Hospital. We are interested in your perception and understandings of this period. Your personal story and interpretation of this time are important to us and will help us to improve our care of current and future patients. The interview will be mainly about your personal story and guided by some semi-structured open ended questions with a focus on your psychosocial experience and the treatment you received during this time.

3. Possible Benefits

The information that we gain from this study may help to foster empathy and understanding of the experience of being diagnosed and treated for lung cancer and advise future care for lung cancer patients. This would benefit the patients and the hospital to better care for lung cancer patients. The process will also provide participants the opportunity to express their lung cancer storey in a safe and confidential manner.

4. Possible Risks

There may be a risk of participants becoming upset or distressed discussing previous experiences to do with their lung cancer diagnosis or treatment. If this occurs you will be referred back to your treating doctor for counselling and further referral as required.

6. Privacy, Confidentiality and Disclosure of Information

Appropriate participants will be identified by their treating doctors who will invite them to take part. Acceptance or refusal to participate will not affect your medical care in any way. Any information obtained in connection with this project and that can identify you will remain confidential, stored within the Department in a manner similar to the storage of medical records as per the Royal Adelaide Hospital protocol. It will only be disclosed with your permission, except as required by law. You may access your information and correct any errors. Your identity will not be disclosed in any publication of the research project results.

7. Results of Project

You may, if you wish, receive a copy of the research project results once the project is completed.

8. Further Information or Any Problems

If you require further information or if you have any problems concerning this project, you can contact Maree Oborn during working hours by telephoning 82225694. Contact details are also listed at the bottom of this page.

9. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

10. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research* (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

This study has been reviewed and approved by the Royal Adelaide Hospital Ethics Committee. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make an independent complaint, you can contact The Human Research Ethics Committee, via the Royal Adelaide Hospital Switchboard (82224000)

11. Reimbursement for your costs

Unfortunately you will not be paid for your participation in this project.

Appendix 4: Consent Form

Full Project Title:

The lived experience of being diagnosed and treated for lung cancer in the outpatient areas of an acute care hospital: a psychosocial phenomenological research project.

Principal Researcher: Maree Oborn

Associate Researchers: Dr David Foley, Dr Peter Robinson and Dr Phan Nguyen

Department of Thoracic Medicine Royal Adelaide Hospital

Version 1, Dated 3/04/2014

I have read and I understand the Participant Information version 1 dated 3/04/2014

I freely agree to participate in this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

I would like a copy of the results of this study. (Delete if not required)

Participant's Name (printed)

Signature

Date

Name of Witness to Participant's Signature (printed)

.....

Signature

Date

Researcher's Name (printed)

Signature

Date

Note: All parties signing the Consent Form must date their own signature.

Appendix 5: Revocation of consent form

Maree Oborn
The Department of Thoracic Medicine
The Royal Adelaide Hospital
North Terrace
Adelaide 5000
(08) 8222 5694

Full Project Title:

The lived experience of being diagnosed and treated for lung cancer in the outpatient areas of an acute care hospital: a psychosocial phenomenological research project.

I hereby wish to WITHDRAW my consent to participate in the research proposal named above and understand that such withdrawal WILL NOT jeopardize my relationship with ***The Royal Adelaide Hospital***

Completion of this form is not a mandatory requirement of withdrawal.

Participant's Name (printed)

Signature

Date: