Cancer Patients Experience of Perceived Diagnostic Error: An Interpretative Phenomenological Analysis

Thesis submitted in part fulfilment of the degree of

Doctorate in Clinical Psychology
(DClinPsy)
University of Leicester

By

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Declaration

I, Tim Siggs, can confirm the research contained within this thesis is my own work and has not been submitted for any other academic award.
Cancer Patients Experience of Perceived Diagnostic Error: An Interpretative Phenomenological Analysis

Tim Siggs

Thesis Abstract

Literature Review

Qualitative evidence of the experience of doctors in training encountering clinical errors was synthesised following a systematic literature search. A meta-ethnographic approach to metasynthesis was used to develop two third order themes which were novel to the existent literature; i) in error trainees revealed as being betwixt and between and; ii) professional assimilation at a cost. These findings captured the psychological and emotional experience of error as being situated within a wider context of medical culture and learning for participants as they acclimatized and internalized socially available response to error. Implications for practice and future research are considered.

Research Report

The experience of 6 participants who believed they had experienced diagnostic error (missed, delayed or incorrect) prior to a correct diagnosis of cancer. An Interpretative Phenomenological Analysis (IPA) approach was undertaken. Three superordinate themes were identified; i) diagnostic error as invalidating; ii) shifting appraisals of diagnostic error during the cancer journey; and, iii) seeking reconstruction of the self. Themes were considered in relation to their contribution to current understanding of diagnostic error and cancer survivorship research. Clinical implications and critique were identified in addition for future directions for research.

Critical Appraisal

The researcher’s account of the research process, reflections, personal learning and critique are offered.
Acknowledgements

I would like to firstly acknowledge my gratitude to the six participants who took part in this research study. Without their willingness to share openly what were difficult experiences I would not have been able to conduct this research.

I would also like to thank my supervisor, Dr Noelle Robertson, for her support and guidance over the last three years; the encouragement and prudent reflections provided throughout have enabled me to bring this research project to fruition.

I would also like to thank my family, most notably my wife and son, for the tolerance, motivation and inspiration they have provided during our collective DClinPsy experience, this would not have happened without them!
# Word Count

Total word count for main text:

**Literature Review:**
- Abstract: 299 words
- Full text (excluding tables): 6683 words
- References: 1701 words

**Research report:**
- Abstract: 251 words
- Full text: 11562 words
- References: 1813 words

**Critical appraisal:**
- Full text: 3575 words
- References: 190 words

Total word count for thesis main text (excluding references): 21820 words

Total word count for mandatory appendices: 4107 words

Total word count for non-mandatory appendices: 3992 words
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Andrew
Audrey
Mary
Mike
Susan
Tina

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Abstract

Doctors in Training Experience of Clinical Error: A Meta-ethnography

Tim Siggs

CONTEXT
Experiencing medical error is associated with adverse implications for healthcare professionals. Less is known about how doctors in training who are at a formative stage of their career experience error. This review seeks to synthesise qualitative evidence exploring the impact of clinical error for doctors in training.

METHODS
A systematic search of the literature was undertaken to identify research specifically examining the experience of errors by doctors in training. Four databases (Medline, PsycINFO, Scopus and Web of Science) were used, in addition to patient safety specific sources and contacting researchers in the area. Reference and citation searches were also carried out for included studies. Identified studies were chosen according to selection criteria. Findings from included studies were extracted and each study was appraised for quality. A meta-ethnographic approach was used to interpretively integrate findings, expressed using a Lines-Of-Argument synthesis.

RESULTS
Seven studies met the criteria for this review from 446 identified from search results. Three super-ordinate themes of were identified: i) intense and co-constructed emotional response; ii) in error trainees revealed as being betwixt and between and; iii) professional assimilation at a cost. Themes (ii) and (iii) offered novel additions to extant literature and are the focus of this review.

CONCLUSIONS
The findings from this review demonstrated a process of acclimatization with, and internalization of, available responses to clinical error as doctors in training seek to manage the impact caused. Such responses were shown to typically be defensive and void of considering the emotional and psychological consequences of experiencing error.

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3 The review is presented according to the author guidelines for submissions to the Medical Education journal (Appendix A)
1 Introduction

1.1 Background Literature

Error in clinical contexts (often termed medical error) can be defined as “an act of omission or commission in planning or execution that contributes, or could contribute to an unintended result” (Grober & Bohnen, 2005, p.42); and encompasses both process and outcome (Reason, 2001). Whilst healthcare procedures can produce iatrogenic injury, errors are defined as adverse events which were preventable (Brennan et al., 1991), and incidents in which an error was made but did not lead to harm are considered to be a near miss (Barach and Small, 2000). Harm may be physical, emotional or psychological.

Medical errors place significant burden on patients, healthcare workers and delivery systems. Approximately 1 in 10 patients experience harm due to adverse events (Health Foundation, 2011) with retrospective case review suggesting 5.2% of English hospital deaths were preventable (Hogan et al., 2012), a substantial number attributable to diagnostic errors. Patient safety incidents are estimated to cost in excess of £3billion annually to the NHS (National Audit Office, 2005), with clinical negligence claim costs in 2013/14 (including damages and legal fees) close to £1.2 billion (NHS Litigation Authority, 2014). These adverse impacts have been formally acknowledged in recent years with the establishment of such entities as the National Patient Safety Agency (since disbanded) (DH, 2000, 2010). Medical error is clearly a costly phenomenon which requires sustained efforts to minimise its impact.

Whilst impacts of medical error are undoubtedly most detrimental to patients, there are also adverse implications for healthcare providers. The term second victim describes those healthcare professionals involved in an error to reflect the harm they experience; the first victims are considered to be the patient (Wu, 2000). Defined more fully

‘Second victims are healthcare providers who are involved in an unanticipated adverse patient event, in a medical error and/or a patient related injury and become victimized in the sense that the provider is traumatized by the event’. (Scott et al., 2009, p.326)
Estimates of the prevalence of second victims have varied, in part due to the self-report nature of data collection, the timeframes and definitions provided. However recent prevalence data offer estimates of between 10.4%, and 43.3% of clinical staff affected (Lander et al., 2006; Wolf et al., 2000; both as cited in Seys et al., 2012).

A circumscribed literature to date has suggested that second victims report diverse emotional responses with anxiety, shame, fear, depression and self-doubt prominent (Aasland & Forde, 2005; Fisseni et al., 2007; Newman, 1996; Schelbred & Nord, 2007; Seys et al., 2012; Sirriyeh et al., 2010; Waterman et al., 2007). Further distress (such as guilt and fear) may be engendered if the clinician is unable to resolve their emotional disturbance (Bell, Moorman & Delbanco, 2010). These psychological responses may be mediated by error outcome, subsequent patient and team response, and institutional reaction (Sirriyeh et al., 2010).

Application of stress appraisal frameworks has identified problem and emotion-focused coping strategies in studies of second victims, informed by the transactional model of stress (Lazarus & Folkman, 1984). Coping methods reported include seeking social support, accepting responsibility, distancing, ‘planful problem solving’, and disclosing to others, although this latter strategy may be difficult without organisational facilitation (May & Plews-Ogan, 2012; Newman, 1996; Seys et al., 2012; Waterman et al., 2007).

The experience of error as highly aversive may be particularly problematic during a clinician’s training. Exploration of the impact of clinician error at this time thus seems particularly important, given this is a seminal time in development of knowledge, skills and behaviour both technical and cultural. Prospective longitudinal data examining staff in training revealed self-perceived medical errors predicted adverse impact on quality of life and burnout measures, as well as increasing likelihood of depressive response (West et al., 2006). Furthermore, these US trainees showed an increase in self-perceived errors in the following three months. It has been argued impact of error, and coping strategies to manage error, persist well beyond training and may be distinct from perceptions of error in more mature clinicians (White et al., 2008). Focused examination of impact on clinicians in training may help to understand their responses, and underpin efforts to ensure future clinicians are equipped to deliver best, safe care.
1.2 Why systematic review, why metasynthesis?

Examination of clinician response to error has been undertaken in few reviews (Schwappach & Boluarte, 2008; Seys et al., 2012; Sirriyeh et al., 2010; White et al., 2008); which have offered a broad understanding of the emotional impact of error and the need for appropriate organisational response. However the reviews share a number of limitations, notably an over inclusive remit, collating data using differing methods, from mixed professional groups, and at different stages of training. Whilst all reviews have advocated a need for specific support more closely tailored to the second victim, this has been founded on very general findings, and offers little scope to develop specific approaches. This includes offering limited scope of a nuanced account of impact during training.

Whilst previous quantitative studies have highlighted diverse impacts of being a second victim (determined by assumed and measurable responses), they are limited in capturing the richness of detail associated with emotional, social and psychological effects of error. By contrast, analysis of qualitative research can help to develop a ‘thick’ understanding (Geertz, 1973) of the experience of medical error for those in training, as well as offering culturally sensitive and practice based evidence (Sandelowski, 2004).

There has been recent growth in the utilisation of methods to synthesise qualitative research (metasyntheses), which offer an evidence-based practice approach to incorporating qualitative findings (Thorne, 2009), particularly to support healthcare policy and practice (Barnett-Page & Thomas, 2009; Mays, Pope & Popay, 2005). Meta-ethnography, an approach to metasynthesis, attempts integration of qualitative findings which are themselves interpretive syntheses of data; taking an inclusive approach to accommodate findings from a range of studies to be fashioned into a new interpretation. Thus meta-ethnography does not represent a unit of secondary research but is a primary analysis of the studies included to develop a new understanding, beyond a simple aggregation (Noblit & Hare, 1988).
This review aims to synthesise the existing evidence on how those in medical training experience clinical error to enhance understanding of impact and responses for those at a critical stage of professional development. For the purposes of this review those in a stage of training will be considered as medical students, postgraduates or trainees, and speciality/ general practice (GP) training, hereafter referred to as trainees. In the UK this would encompass those completing an undergraduate medical degree, foundation years 1 & 2, and speciality training (British Medical Association, 2014).
2 Method

In the interests of rigour and transparency, a structured approach to reviewing literature may minimise the influence of bias and error (Mulrow et al., 1997). Therefore in order to guide the literature review the Preferred Reporting of Items for Systematic Reviews and Meta-Analyses (PRISMA, Moher et al., 2009) was followed. A review protocol was generated based on a template provided by Booth et al. (2012) (Appendix B).

2.1 Journal articles selection

2.1.1 Selection criteria

Inclusion criteria used for selecting papers for the metasynthesis were as follows:

i) Used qualitative methods, of both data collection and analysis, to investigate the impact and experience of medical error. Where mixed methods were used studies were included only when possible to identify the data and concepts drawn from qualitative sources

ii) The participants for the study were in the process of medical training (from undergraduate through to completion of speciality training and thus defined as a training grade)

iii) Written in English

iv) Published in peer-reviewed journals

Studies were excluded if:

i) They included other healthcare professions

ii) Were intervention studies, reviews, discussion papers or book chapters

2.1.2 Information Sources

After an initial scoping search, a full search was carried out of four electronic databases (Scopus, searchable years 1966-2015; Medline, 1946-2015; PsycINFO, 1967-2015; Web of Science 1955-2015) using the combination of terms outlined in Appendix C. Searches took place in October 2014, updated in March 2015.

A number of other sources of information were also targeted, notably the Agency for Healthcare Research and Quality’s (AHRQ) Patient Safety Network online patient safety
resource (www.psnet.ahrq.gov). Experts in the field of patient safety and second victims were also consulted and contact was made with some of the most cited authors, and a request sent for suggestions of relevant publications to the National Patient Safety Forum’s (NPSF) listserv (online email forum). Reference and citation lists for studies included in the review were also checked for additional studies.

An initial total of 670 journal articles generated (614 from database searches, 76 from additional sources), following the removal of duplicates this left 446 journal articles for potential selection.

2.1.3 Study Selection

Titles were then screened to exclude those studies not relevant to the area of the review, and abstracts of the remaining articles were reviewed before finally examining the full texts. A diagram of this process can be found in the Figure 1.
Figure 1 Flow chart of study selection

- Studies identified through database searching (n=614)
- Studies identified through other sources (n=76)

Total after duplicates removed (n=446)

- Abstracts Screened (n=43)
  - Studies excluded based on relevance (n=27)

Full text articles assessed for eligibility (n=16)

- Studies excluded based on eligibility criteria (n=9)

Studies included for metasynthesis (n=7)
2.2 Data extraction

Data extraction was informed by the purpose of the review – to understand the impact medical errors on trainees. A standardised approach to data extraction was undertaken to offer transparency and evidence systematic approach taken, guided by Noyes and Lewin’s (2011) advice for qualitative systematic reviews for the Cochrane group (Appendix D). This involved reading and rereading of each article identifying key findings, until all studies were accounted for and no new findings emerged.

The data extracted from the selected studies comprised researcher findings including what is concluded, inferred, or interpreted from the data collected in the study, termed metaphors by Noblit and Hare (1988), considered to be an empirical/analytical stance on conceptions of data and findings (Sandelowski & Barroso, 2007). In this sense it is the researchers’ interpretations which form the primary data for this metasynthesis, and are considered to be identifiable and separable from the original data themselves. Thus first order constructs are considered to be the participants’ ‘common sense’ interpretations, and second order constructs are the researcher’s interpretations of the first order constructs. In meta-ethnography the second order constructs/findings/metaphors are the focus of further abstraction and interpretation to develop third order constructs. However, it is acknowledged that in practice the distinction between first and second order constructs is not always clear, as any first order representation is likely to include to some extent the researchers’ interpretations.

2.3 Quality Appraisal

Studies may lack transparency in their reporting of the chosen methodology, but still offer rich and useful concepts grounded in the data which would be an argument against their exclusion (Dixon-Woods et al., 2004). For this reason it was decided no studies were to be excluded based on grounds of quality appraisal, but quality was to be considered in the reporting of the synthesis as one of the characteristics of the studies included.

Quality appraisal embraced several iterations, initially undertaken in conjunction with data extraction using a standardised approach – the qualitative Critical Appraisal Skills Programme tool (the CASP – CASP, 2006). This standardised tool was chosen due to its
relative ease of use, endorsement by Noyes and Lewin (2011) as part of the Cochrane Collaboration Qualitative Methods Group and offered focus on the technical aspects of the studies and so could be carried out concurrently with data extraction.

There were concerns in applying the CASP with regard to issues of reflexivity and ethics, which were felt not only important in terms of rigour and moral acumen, but also of relevance for the findings each study offered. Similar issues have been noted elsewhere and as such additional efforts were made to examine the quality of the included studies in ways relevant to the current review (Toye et al., 2013).

The typology of findings (Appendix E, Sandelowski & Barroso, 2003, 2007) was used to support judgement of the degree of interpretation in the included studies, and also to help support appraisal of the quality of research available. A conceptual approach to quality appraisal for meta-ethnography (Appendix F, Toye et al., 2014) was applied to assess conceptual clarity and inductive integrity (the degree to which interpretations can be trusted).

2.4 Metasynthesis Process

Meta-ethnography, like metasynthesis as a whole, has developed with different approaches and schools of thought (Thorne et al., 2004). The approach used in this review is based on that of Sandelowski & Barroso (2003, 2007), which favours an interpretive integration of qualitative findings based on findings drawn from the body of studies reviewed as a whole, and is argued to be more amenable to healthcare policy and practice (Thorne et al., 2004).

This process involved the following stages: (a) thorough reading of each paper; (b) extraction of findings related to the experience of error; (c) mapping of key findings; (d) clustering and translation of findings from one study into another; (e) re-reading of each paper using constant comparison of findings into themes identified, and; (f) producing the final description of themes. Findings were further abstracted into third order constructs, and synthesised using a ‘Lines-of-argument’ (LOA) approach which seeks to say something about the whole, based on selective studies of the parts (Noblit & Hare, 1988, p.62). This process is in line with the interpretive and inductive approach favoured by Sandelowski & Barroso (2007), and was therefore felt appropriate means to express
an understanding of medical trainees’ experiences of error. This process was supported through discussions with the trainee’s research supervisor; including both the resolution of alternative readings of the included articles, and also to challenge and refine the third order interpretations.
3 Results

3.1 Characteristics of included studies

Seven papers met the criteria for review, and reported data collected from a total of 578 medical trainees. The papers included in the review encompass a variety of countries with varied cultures and healthcare systems, and over a long time span (1984-2014). This could have created a problem in terms of heterogeneity of the sample, whereby the papers are too diverse to pool in a systematic review. That is, the findings extracted from each paper had the potential to reflect aspects of the particular culture or moment in time, rather than reflecting how doctors in training experience errors in different ways. However, the findings were surprisingly congruent despite the diversity in the papers, suggesting that the inclusive criteria were not a problem in this case, and the findings appear to capture some robust aspects of this experience that are persistent across the time span and different contexts. The characteristics of included studies can be found in Table 1.

3.2 Quality Appraisal

Quality appraisal was undertaken in several phases following initial dissatisfaction with the rigour of only the CASP process. The results of the CASP can be found in Appendix G. A conceptual approach to quality appraisal for meta-ethnography was carried out with key features detailed in Table 1 (Toye et al., 2013), in addition to a typology of findings (Appendix H; Sandelowski and Barroso, 2003, 2007).

3.3 Presentation of results and prioritisation of novel findings

The results of the synthesis are first presented in theme groupings used to display the data for the synthesis, keeping closely to the language of the original studies incorporating both first and second order quotes to support the explanation and naming of themes. The findings were interpreted into a lines-of-argument (LOA) synthesis in which three third order constructs were developed and used to interweave the findings: i) Intense and co-constructed emotional response; ii) In error trainees revealed as being
betwixt and between and; iii) Professional assimilation at a cost. Table 2 details the presence of each study within the particular themes and concepts.
Table 1. Summary Information for studies included in review

<table>
<thead>
<tr>
<th>Study</th>
<th>Engel et al., 2006, USA</th>
<th>Fischer et al., 2006, USA</th>
<th>Kroll et al., 2008, UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aim</td>
<td>To explore the medical error experiences and responses of residents across different specialities. This study focuses on subset of questions regarding emotional and coping responses from a larger interview on 'medical mishaps'.</td>
<td>To identify factors that affect learning from medical errors</td>
<td>To examine the experiences and perceptions of error among junior doctors through capturing rich data.</td>
</tr>
<tr>
<td>Recruitment</td>
<td>Convenience choosing of teaching hospital, randomly sampled residents to reflect total population</td>
<td>Recruited from all students at UMMS Medical school, $25 gift certificate offered for completion – 30 randomly selected from 72 initial respondents</td>
<td>Part of larger study into professional development of young doctors. 40 participants randomly selected from stratified pool of 317 eligible who had graduated from one medical school in 2000 or 2001 and who had worked between 6 and 12 months as pre-registration house officers (PRHOs)</td>
</tr>
<tr>
<td>Participants</td>
<td>26 residents; including 5 surgery, 17 medicine, 4 obstetrics/gynaecology. 11 in first postgraduate year (PGY), 5 in second, 7 in third, 2 in fourth, 1 in fifth.</td>
<td>59 in total, including 30 medical students, and; 29 residents; 21 internal medicine(PGY 1-3), 8 surgery (PGY 1-4)</td>
<td>38 junior doctors, working across 10 hospitals</td>
</tr>
<tr>
<td>Design/Methodology</td>
<td>Semi structured interview; transcribed, not specified if in person/telephone. Protocol designed to draw out descriptions of 3 errors and one near miss.</td>
<td>Semi structure telephone interview focused on attitudes and response to error; audiotaped &amp; transcribed. Hypothetical case offered for those who could not recall one</td>
<td>Semi-structured interviews; audio-recorded and transcribed; field notes also made</td>
</tr>
<tr>
<td>Analysis</td>
<td>Not specified; described as being iterative &quot;with the goal of drawing out categories and themes of discussion&quot; (p.88)</td>
<td>Iterative process using content analysis</td>
<td>Grounded approach using open, axial and selective coding. Specified attention to deviant cases and constant comparison</td>
</tr>
<tr>
<td>Findings</td>
<td>Findings in two broad areas of emotional response and mechanisms for coping.</td>
<td>Main findings in 4 areas influencing learning from medical errors (a) awareness of errors; (b) factors influencing trainee response; (c) types of response reported; (d) formal teaching</td>
<td>Four main themes reported, (a) a norm of selective disclosure; (b) the effects of the team; (c) individualised blame and responsibility; (d) the learning moment</td>
</tr>
<tr>
<td>Quality</td>
<td>Limited number of concepts provided in the form of explanations, is largely descriptive – there was the urge to abstract further. Context described for recruitment but little mention of participant-researcher relationship. Limited description of analysis and also concerns that selecting only this part of a larger interview may have removed some of the context.</td>
<td>Initially descriptive elements in results section but developed into clearer concepts in discussion. Clear details of recruitment, no mention of researcher-participant relationship. Limited supporting quotes. Disconfirming cases provided. Recognition of limitations; bias in qualitative research and use of hypothetical case for many.</td>
<td>Clarity in reporting of aims of study, chosen methodology, and concepts developed. Could benefit from more concept-indicator links. Contradictory cases presented, themes appear to represent general sense. Analysis involved 3 researchers, 2 of whom were from non-medical backgrounds which was reported as a strength.</td>
</tr>
<tr>
<td>Study</td>
<td>Mankaka et al., 2014, Switzerland</td>
<td>Martinez &amp; Lo, 2008, USA</td>
<td>Mizrahi, 1984, USA</td>
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<tr>
<td><strong>Aim</strong></td>
<td>To qualitatively explore the experience and coping mechanisms of female residents with respect to medical errors.</td>
<td>To examine medical students’ experiences with medical errors</td>
<td>To examine how house officers acquire their perceptions and definitions of error and how they defend them when they are made</td>
</tr>
<tr>
<td><strong>Recruitment</strong></td>
<td>Purposeful sampling; emails sent to target population of 57 female residents of a Swiss University Hospital, 8 recruited to interview</td>
<td>Secondary analysis of data collected as part of written assignment for medical ethics course at a major medical school</td>
<td>Part of a larger 3 year longitudinal study of internists’ socialization to the doctor-patient relationship, carried out at a major medical centre</td>
</tr>
<tr>
<td><strong>Participants</strong></td>
<td>8 female internal medicine residents, aged 28-33, 2nd to 6th PGY</td>
<td>147 essays were analysed from fourth-year medical students</td>
<td>290 internal medicine house officers</td>
</tr>
<tr>
<td><strong>Design/methodology</strong></td>
<td>Semi-structured interviews; audiotaped and transcribed</td>
<td>Anonymous essays; “On one page, prepare a description of an important mistake you have made or observed during medical school.” (p.734)</td>
<td>Ethnographic, longitudinal and cross sectional approach utilizing observation, interviews (N=83) &amp; self-administered questionnaires (N=207)</td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
<td>Phenomenological framework; inductive thematic analysis, although deductive component as structure given by interview schedule; comparative method applied</td>
<td>Essays were inductively coded for themes and frequency counts, using NVIVO software. Used a combined approach of a priori and inductive coding</td>
<td>Not explicitly stated; although highly interpretive - grouping into themes various individual and social responses to medical error</td>
</tr>
<tr>
<td><strong>Findings</strong></td>
<td>Seven main themes reported, (a)insufficient culture of safety; (b) perceived causes of errors; (c) negative feelings in response to errors; (d) variable attitudes of the hierarchy; (e) talking as key coping method; (f) defensive and constructive attitudes to errors; (g) gender specific experiences</td>
<td>Results focused on the reporting of (a) description of errors; (b) trainee responses to errors; (c) senior doctors’ responses to errors; (e) disclosure</td>
<td>Main findings focus on the use of 3 defensive responses to manage stressful situations; denial, discounting, and distancing. Also includes findings of insular and self-protective subculture, and increasing toleration of errors throughout training.</td>
</tr>
<tr>
<td><strong>Quality</strong></td>
<td>Clear concepts indicated. Detailed description of aims, methods, rationale and context of research. Reflexive in considering location of interview, interviewer-participant relationship, description of researcher backgrounds/ aims for research. Although primarily inductive, recognition of deductive elements.</td>
<td>Concepts not explicit, although greater shift from description to explanation in discussion. Lots of quotes used to support descriptions. Contradictions reported. Limitations of using data retrieved from an academic assignment acknowledged.</td>
<td>Clear concepts presented with high degree of abstraction and explanations. Limited detail on analysis and rationale for methodology. Interpretations provided with clear grounding in the data. It is unclear how interpretations may have been challenged.</td>
</tr>
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</table>
Table 2. Meta-ethnography 3rd Order constructs and themes from included studies

<table>
<thead>
<tr>
<th>3rd Order Constructs</th>
<th>(Experiencing and managing an intense and co-constructed emotional response)</th>
<th>In error trainees revealed as being betwixt and between</th>
<th>Professional assimilation at a cost</th>
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<td></td>
<td>Emotional Impact</td>
<td>A paradox of learning</td>
<td>Unpredictable responses to trainee errors</td>
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<tr>
<td></td>
<td>Talking as a means of coping</td>
<td>Being in a training position – excluded and confused</td>
<td>Acculturation with an insular and self-protective subculture</td>
</tr>
<tr>
<td></td>
<td>Constructive &amp; defensive attitudes to errors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd Order themes of findings from included studies</td>
<td></td>
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The presentation of the results from this synthesis have prioritised those findings which are felt to be novel additions to extant literature. As such those findings which have replicated other reviews noting the intensity of emotion and the coping methods employed are not included here, and relate to the third order construct “intense and co-constructed emotional response”. The results and discussion will therefore emphasise how this emotional impact is a distinctive experience for trainees given the context of learning and developmental needs, coupled with an emerging identification with, and membership of, the medical profession. For reference, the replicated findings for themes excluded from this write-up can be found in Appendix I.

For clarity, presentation of results will firstly consist of a description of the second order constructs drawn from the seven included studies included for review which have been grouped into themes. Further interpretation of these constructs into third order constructs is then offered, and these are synthesised using a lines of argument (LOA) approach.

3.4 Description of Second Order constructs from reviewed studies

3.4.1 A paradox of learning

“If it has a poor outcome it’s more likely to stick in my head because you feel, obviously, horrible for causing harm to the patient and causing a poor outcome, versus if there’s no poor outcome, then you may be less likely to keep it in your mind.” Fischer et al., 2006, p.420

Trainees described learning most effectively from errors for which they felt personally responsible and which conferred more risk to patients, but these errors caused the most intense emotional reaction, “many felt that these internal responses influenced their learning” (Fischer et al., 2006, p.421). “I think you feel worse about a mishap when you did something to a patient and something bad happened” (Engel et al., 2006, p.89). Thus more emotionally distressing errors tended to invoke a response of taking responsibility and reflection.
Trainees revealed insight and an impetus to reflect on the error and its context, appearing aware that a defensive attitude may inhibit the learning “If you’re sort of defending a mistake you made . . . it takes away from your learning from it” (Fischer et al., p.421). There was the indication in the studies that trainees were more likely to accept responsibility in situations where outcomes were less severe or could be fixed compared to more serious outcomes (Kroll et al., 2008). This presents a learning paradox whereby those errors from which trainees were most likely to learn were those for which they were least likely to take responsibility.

Trainees did not express need for more formal teaching on errors, preferring more “open discussion” of errors, facilitated by experienced medical professionals with focus on “real errors” (Fischer et al., 2006; Venus et al., 2012). “And then you talk to people, especially people who you think you respect and you feel that you’ve learned a lot from and you find out that they’ve had similar experiences” (Engel et al., 2006, p. 90)). This was further supported by the finding that “most learning seems to have occurred where the situation was discussed and feedback was constructive and supportive” (Kroll et al., 2008, p.986). However, across reviewed studies utility of formal discussions was more contested, depending on traditions of sub-specialties (e.g. surgery, obstetrics and gynaecology) (Engel et al., 2006).

3.4.2 Being a in a training position – excluded and confused

“I really had this problem which is that the only people who you can talk to about these things ... are the same people who are grading you” (Fischer et al., 2006, p.421)

Respondents revealed challenges faced by being in a training position, both managing demands of learning and evaluation, navigating personal and professional changes in identity. Trainees often found themselves in new and difficult to understand situations, during which dilemmas arose as they appraised situations from both a lay and medical perspective, yet seemed to not fully belong to either group.
Learning about error seemed to involve making sense of a frenzied environment where clarity and order was at times scant. “My mind was swimming with the dynamics of the situation... I was baffled that as a medical team we had no further discussion of the patient... And if we were to address it, is it even true that a medical error did occur?” (Martinez & Lo, 2008, p.737). The same study also noted that as a student they were “not privy to the conversations that occurred with the family” following an error (Martinez & Lo, 2008, p.738). In this sense the trainees were not only acting differently to their medical colleagues, they were also at times treated differently.

Being in a training position and thus developing a new professional identity could create a tension between how participants may have wanted to respond to an error versus what was expected of them. “I think it’s important to talk to patients [about errors] ... but the problem is ... I feel like we’re almost not supposed to” (Fischer et al., 2006, p.421). This sense of needing to conform to expected norms in order to feel professionally included extended to the capacity trainees perceived they had to admit error and seek support. Trainees were “too often uncomfortable to speak of their errors within their work environment, for fear of being either blamed or stigmatized as weak” (Mankaka et al., 2014, p.4).

It was apparent that being unable to obtain support from senior colleagues was not only personally distressing but also posed a danger to patients. “And I think as soon as that happened, as soon as I got snapped at by my seniors, I just said forget it, its game over and I left it. I think that tragically, probably people would have lost their lives because I was so shocked with them that I couldn’t even go to them and say I’ve got this problem. They were just not interested” (Kroll et al., 2008, p.985).

Whilst trainees noted how they may have felt at odds with their medical colleagues in some instances, they also felt differently to their friends and family, who without medical training could not fully understand or relate to their experience – “I don’t talk to my family because they don’t understand. They’re not in medicine” (Engel et al., 2006, p.90).
3.4.3 Unpredictable response to trainee errors

“Many potentially valuable learning opportunities were missed, either because the senior’s response was inappropriate, or because juniors did not access help” (Kroll et al., 2008)

Numerous responses revealed how opportunities to learn from mistakes were influenced by interaction with colleagues; opportunities to talk through errors in a constructive and sensitive manner contrasted with an approach which blamed and criticised the trainee. Responses appearing punitive, tended to be those in which the degree of either blame or reassurance directed towards the trainee was perceived as excessive. Whilst polarised, both responses seemed to have similar impact, reducing the opportunity to learn and develop favourable attitudes to error.

Analysis of error, although emotionally challenging, was felt by some to aid their learning (Venus et al., 2012). A positive experience by one participant described a discussion with a senior colleague following an error indicated a constructive and open-minded response in which “he reacted very well, he listened to me and we talked together...” (Mankaka et al., 2014, p.5). Conversely, a sense that trainees were blamed, or held responsible without analysis of the situation were found to be unhelpful. “You got everything completely wrong, you’ve got to learn how to examine a patient”, “that women with abdominal pain you saw the other day ... she nearly died and it’s all your fault” (Venus et al., 2012, p.284).

Potential exposure to blame seemed to generate development of a veneer of competence precluding help-seeking and development (Kroll et al., 2008). “I think I would be sort of embarrassed to talk to the people on the team that I was working with” (Fischer et al., 2006, p.421). Indeed trainees were described as “too often uncomfortable to speak of their errors within their work environment, fear of being either blamed or stigmatized as weak” (Mankaka et al., 2014, p.4). However, feedback which offered exculpation, minimizing errors as ‘not the junior’s fault’, normalising them, was not necessarily helpful, and whilst reducing intense emotions, did not necessarily convince the trainee that their practice was adequate. An example is seen below:
“Um and I’d like to feel if, if they felt there was a major problem they
would have sat me aside and said, you know, “That was a bad one, you
need to sort that out, you know you can’t do that.” ‘But on the whole it’s
been supportive. You know, “Don’t worry about it, it’s not your fault,”
which I think is hopefully true...’” (p.987) (Kroll et al., 2006).

Furthermore, unpredictable responses of those around them regarding errors leaves
trainees recognising there is a learning need, but this is thwarte by the fear of being
disregarded or derided.

3.4.4 Acculturation with an insular and self-protective subculture

“There are no black and white, just all greys-so what somebody might consider gross
mismanagement someone else might call an understandable error. It depends on what
your perspective is and it changes each year. I think you become more lenient to some
extent, particularly when you see someone doing something that you’ve done once that
didn’t work...” (Mizrahi, 1984, p.141)

Respondents’ experiences across studies reflected a “dissonance between professional
expectation and the normative culture of medical training” (Kroll et al., p.987). As one
participant noted “In my mind I know what I think is the right thing to do, but sometimes
it’s a little different than the culture dictates” (Fischer et al., 2006, p.420). This seemed
to be a key part of the trainee experience and over time “most learners felt that the
influence of this ‘adopted’ medical culture superseded their individual ethic” (Fischer et
al., 2006, p420). Thus these novel practices and attributions were incorporated into
their own behavioural and attitudinal repertoire as they adapt to exist in the medical
world.

With increasing exposure to a medical culture of high autonomy (Mizrahi, 1984) trainees
articulated feelings that only peers or colleagues are able to reduce any feelings of guilt
and isolation. The “norm of selective disclosure” (Kroll et al., 2008, p.984) suggesting
doctors themselves to be arbiters of accountability, confers “a strong sense of
professional ‘loyalty’. Within this doctors, despite discomfort, kept quiet over others’
Trainees disclosed that as they become more familiar with likelihood and experience of error this risk was accepted as integral to being a doctor, inevitable” and “part of the practice of medicine” (Fischer et al., 2006, p.420) and appeared linked to a change in their own attitude to error. This imported concept of hidden curriculum refers to the unwritten, unofficial or unintended aspects of medical training (Hafferty & Franks, 1994). For trainees there was a sense “whatever their personal tendencies, they quickly assumed the ‘perspective of medicine’ as they began training” (Fischer et al., 2006, p.421).

The role models and practices trainees were exposed to appeared to benefit learning, and participants reporting being “impressed” by those colleagues who demonstrated integrity, honest and compassion which inspired them (Martinez & Lo, 2008). This study also suggested repeated exposure to negative exemplars might lead the trainees to accept this practice.

Throughout their training, trainees “are continuously shaping their perspective on their own and others’ errors and redefining levels of culpability” (Mizrahi, 1984, p.141) as they move from a lay position and become embedded in the medical profession. “The more I get into the medical profession the more I kind of want to defend doctors in making mistakes” (Fischer et al., 2006, p.420).

3.5 Interpretation of findings - Synthesis of results into a Lines Of Argument

In taking the body of the studies as a whole, three third order constructs of the trainee experience of medical errors were identified with increasing levels of abstraction seeking greater explanation and synthesis of the identified themes. These were: intense and co-constructed emotional response, in error trainees revealed as being betwixt and between, and professional assimilation at a cost. The development of these themes are interpretative and thus a subjective account, albeit derived through systematic process. These interpretations are informed by the reviewer’s own position and experiences, of reference here are experiences as a trainee clinical psychologist working in physical
health settings, and theoretical predilections towards psychodynamic theories of individuals and groups.

3.5.1 Experiencing and managing an intense and co-constructed emotional response

The emotional reaction following an error is experienced by trainees can be intense and aversive for a number of reasons; the horror at what has happened to a patient, the trainee experience of violating the very standards and aspirations they set themselves in helping others, and the perceived and actual response from peers and colleagues. These can also be understood as internal conflicts and anxieties. The emotional response by trainees requires ways to manage this emotional pain in the form of constructive or defensive attitudes, the latter in some way a solution to limiting emotional pain by titrating the emotional impact associated with error, before a more constructive attitude can develop in order to learn from the mistake.

However, the defences deployed by trainees reflect their own response but also, are often required, supplied and encouraged by the culture in which the trainee is immersed. In this way the responses to error may be considered as part of a social defence system (Menzies-Lyth, 1960). The varying responses to disclosure of errors, the excessive reassurance or blame of the error maker, and the shared defences serve to inhibit the raw sense of guilt and horror trainees disclose in experiencing errors. This social defence system can affect trainees in two ways, firstly to ensure their own feelings remain unconscious, and secondly to distort their behaviours and interaction to maintain the defences themselves.

3.5.2 In error trainees revealed as being betwixt and between

Incorporating a social defence into their own personal repertoire is to some degree functional for trainees in that it helps them to survive in their new role and new culture in the face of extremely demanding emotional situations. However prior to this internalisation of cultural defences the trainee may have few means of navigating the new world they find themselves in. This is both revealing to understand how the culture of medicine is perceived by a relative ‘outsider’ but also indicates why medical errors are experienced differently by trainees.
This can be further contextualised by the use of an imported concept – the rite of passage. Developed by Van Gennep (1960) as a means of understanding the way individuals move between two positions to achieve new status, with three notable phases - separation, transition or limen, and incorporation, it argues that trainees experience this same process of separating from the lay world moving towards incorporating themselves within the medical world. Turner (1967) further elaborates on this concept to give greater emphasis to the period of liminality as being ‘betwixt and between’ the two positions, that is in this case not-a-lay-person-not-a-doctor. The liminal person is in many ways invisible socially, is without structure, lacks rights and reflect about their cultural world to be able to return to it with new responsibility and powers (Beech, 2011). Incidentally, it is this liminal position which offers a window into this world as the trainee exists not quite as an accepted member but is more than a lay observer.

This sense of limbo between two worlds is reflected in trainees’ disclosure that they do not feel friends and family can offer the validation and constructive feedback needed, but that professional channels, in offering either censure or exoneration cannot contain the emotional intensity experienced. It is only through the resolution of this position by in which trainees are able to then function; how this conflict is managed may have lasting implications for how the trainee will in the future experience and respond to errors.

3.5.3 Professional assimilation at a cost

In what is the most abstracted construct, trainees are considered to have passed through the liminal phase and have undergone a process of acculturation whereby they have incorporated any available coping methods and defensive practices in order to deal with error. The studies identified a number of findings as to how trainees may learn through the hidden curriculum, which by its definition is not codified, and so this potentially capricious process may define the practice acquired by trainees.

It is desirable that trainees will experience errors in a supportive environment which allows the space and containment of the extreme emotional response, validation of professional competency and potential, alongside constructive feedback. However,
within the included studies such experiences do not represent the dominant narrative, rather a defensive culture regarding error is subsumed by the trainee in order to remove the emotional intensity of experiencing error. As such future practice is likely to continue with this absence of emotion and continued defensive attitudes, a potentially maladaptive means of coping and may have considerable costs for the trainee, colleagues and staff.

3.6 Lines of Argument Synthesis

Synthesising the three interpretive constructs to provide an integrated account of trainee experience of medical error can be considered using LOA approach. The trainee experiences error with a great emotional intensity as error conflicts with the healing identity aspired to; the subsequent response seeks to alleviate the psychological pain and distress caused. However, this individual process does not take place in isolation; the trainee exists in an environment in which they are neither fully incorporated nor fully competent in navigating, and they internalize the available responses to error offered both implicitly and explicitly by culture in which they exist. The trainees’ incorporation of cultural responses to error via the hidden curriculum is a process which ultimately leads to a consolidation of these values and attitudes as their own. The implication of this process is that trainees’ formative experience will in essence give rise to an internalised way of functioning based on their training experience. There is indication from the included studies that this may include both positive and negative experiences, and thus adaptive and maladaptive ways of responding to error. Key to this is recognition and respect given to the emotional response.
4 Discussions

This review represents the first of its kind to synthesise the existing qualitative research literature pertaining to the experience of medical error by trainee doctors. Complementing previous reviews, this too highlights the intensity of emotion experienced in the wake of an error and reported coping strategies (Schwappach & Boluarte, 2008; Seys et al., 2012; Sirriyeh et al., 2010; White et al., 2008). New interpretation is offered by the explanation that trainees undergo a process of internalisation of the available means of managing emotional intensity whilst assimilating to a professional culture which shapes the individual trainee response to error and learning. These latter nuanced findings and implications for trainees will form the focus of this discussion.

4.1 Contextualising this review with other literature

This review has highlighted how the experience and coping with a medical error by trainees is a product of both personal and culturally available means. In considering the six-stage trajectory model of second victims there is a considerable emphasis on managing both the interpersonal and professional implications involved (Scott et al., 2009; see Appendix J for full model), which it is argued will potentially be experienced in changed or intensified format by trainees. The lack of professional experience and identity may inhibit the trainee ability to navigate this process successfully in terms of drawing on resources and support networks which may be less developed than with more experienced colleagues, such as those from which the six-stage model was developed (n=31, with a mean of 13.5 years’ experience). This is supported by other findings which indicate individual personality may be the most influential factors in determining the likelihood to both seek and obtain support following an error (Schwappach & Boularte, 2008).

This review has identified how experiences of emotion in relation to practice error may be excised with potential implications for trainee doctors, which relates to similar findings whereby medical students’ narratives around patient safety incidents have the emotion “squeezed out”(p.1728) through systems for reporting errors (Waring, 2009). A recent critical synthesis has highlighted the importance of emotion in the learning and
transfer of clinical skills and knowledge, advocating the significance of affect to avoid a simplistic, rational and mechanistic approach to medical education (McConnell & Eva, 2012). This review endorses similar proponents of an approach to medical education which seeks to “work with” rather than eradicate or quash emotional experience (Shapiro, 2011).

4.2 Implications

The findings of this review highlight the implications of the role of the culture and environment trainees are placed into may have significant bearing on their experience and learning. Given the identified unpredictable nature of seeking support it is suggested that more formal measures are required in order to influence and shape the experience of trainee doctors. The role of compassion, or the concern for the suffering of others, in healthcare has been of increased focus in the UK in recent years with particular reference to the role of culture and individualised blame in which the patient was not always put first (Francis, 2013). However, whilst identification of such problems is not necessarily original, critics have argued efforts have fallen short of offering a psychological perspective which may better inform current practice (Garner, 2014).

This review endorses the potential role of psychology in offering well designed assessments and interventions in supporting NHS culture, and there are notable examples of this. Anxiety in work settings has been identified as eliciting two responses - ‘creating defences’ or ‘creating meaning’ which can occur at the individual and organisational level, as also has been identified in this review (Wren, 2014). Psychology can play a key role in helping to more consciously manage the challenges posed which may give rise to defences in order to give them validation, meaning and understanding.

Originally developed with GPs, psychodynamically informed Balint (1964) groups have been shown to prevent burnout and increase satisfaction whilst being seen as a place of safety where emotional demands of the work can be considered (Kjeldman & Holmstrom, 2008). Currently, Balint groups tend to only be commonplace in psychiatry training (Yakeley et al., 2011); however their inclusion in wider medical education may serve a particular benefit regarding the experience of medical error. More recently the development of ‘Schwartz Center Rounds’ (www.theschwartzcenter.org) originating
from the USA provide a similar regular space for healthcare professionals to explore
psychological, emotional and social challenges of the work with the aim to promote
compassionate care. Pilots of this approach in the UK have shown outcomes including
better teamwork and reduced stress, but also notably a less hierarchical environment
and more open culture in the workplace where it is “safe to speak” (Goodrich, 2012,
p.120). Such approaches which will provide a supportive and open context for doctors
in training to explore the emotional and psychological implications of experiencing
errors, amongst other aspects of the work are a recommendation of this review.

The population for this review naturally focuses the attention on learning from errors
which it hoped would follow from an emotionally and psychologically safe environment
to make sense of errors. It is therefore interesting to note within the literature reviewed
there was a limited exploration or detailing of the depth of learning from errors. It is
hoped that greater cultural acceptance and support for those involved in errors will
facilitate a more open and thorough examination of the technical aspects of learning in
such situations.

4.3 Critique of literature

In taking the literature reviewed for this study as a whole, studies published to date have
focused on a largely negative accounts of the experience of medical errors by trainees,
similar findings have been noted elsewhere (Sirriyeh et al., 2010). Furthermore, the
widely used term ‘second victim’ may be damaging to such efforts to foster a
developmental model implying potential for growth and development, in both research
and practice. A more affect inclusive means of understanding and supporting those who
experience medical errors is offered through the notion of post traumatic growth (PTG;
Tedeschi & Calhoun, 1996). PTG conceptualisations of medical error have recently been
identified as a means of helping clinicians to go through the processes of acceptance,
taking responsibility, and incorporating events into their identity and new narratives of
their experience (May & Plews-Ogan, 2012; Plews-Ogan et al., 2013). Such approach
avenues for future research and practice within a defined framework.

All of the studies included in this review with the exception of two (Kroll et al., 2008;
Mankaka et al., 2014) reported what was considered to be less than satisfactory account
of the relationships between researchers and participants, and/or acknowledgement of the potential impact on the data and findings due to the position and power dynamics of trainees being studied by more senior medical colleagues. The findings of this review indicate trainees alter their behaviour in light of the perceived responses of those senior to them, something which future research will need to consider. This may be achieved through research design, although this may face practical difficulties based on resources, however a more reflexive approach would be favoured and/or for this to be clearly identified in the research report.

4.4 Limitations

This review has taken an interpretative approach to synthesising studies and it is recognised that findings offer only one possible reading of the data, and are constructions of the reviewer and will be influenced accordingly. Through the process of supervision and reflection efforts have been made during the process of completing this review to ensure these are identified and accounted for. It is noted that of the seven included studies four of these took a more descriptive approach as the others were exploratory in their nature. As such the degree of abstraction applied to each finding may vary between studies in those cases where a concept has merely been described rather offering an explanation, although validity of findings is maintained through findings being grounded in multiple studies.
5 References


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Abstract

Cancer Patients Experience of Perceived Diagnostic Error: An Interpretative Phenomenological Analysis

Diagnostic error is defined as one which is missed, delayed or incorrect. Research focused on diagnostic error is an emerging domain of the wider patient safety field. Whilst such research has sought to mitigate and minimise error, the harms caused by diagnostic error have not been privileged in their own right, instead only considered alongside other adverse events.

This research sought to develop knowledge of the patient experience of diagnostic error, using cancer as an exemplar. An Interpretative Phenomenological Analysis (IPA) approach was undertaken and six participants (aged 59 to 79 years) including four females were interviewed. Transcripts were analysed following an IPA approach which sought to develop themes initially from individual accounts before considering patterns across all cases.

Three superordinate themes were identified; i) diagnostic error as invalidating; ii) shifting appraisals of diagnostic error during the cancer journey; and, iii) seeking reconstruction of the self. Individual quotes are provided to support both the superordinate themes but also represent the individual experience of perceived diagnostic error.

The present study offered findings related to the deep personal nature of perceiving diagnostic error and the implications for the sense of self. This study also highlighted how perceptions of diagnostic error may prevail as part of a means of coping with the enormity of a cancer diagnosis. The lack of opportunities for redress may leave those experiencing perceived diagnostic error perpetually burdened by it. Considerations for clinical practice and future research are discussed.
1 Introduction

Diagnostic error can be considered as one which is missed, incorrect, or delayed (Graber, 2005), or essentially as a missed opportunity in diagnosis (Singh, 2014). Estimating the incidence of diagnostic error is problematic. Identifying if, when and how an error has occurred is much more difficult than other adverse events given the complex nature of diagnosis over time and given numerous potential information sources (Wachter, 2010). Such complexity has led some to consider diagnostic error to currently be both the ‘Achilles heel’ (Scarpello, 2011) and “the next frontier” (Newman-Toker & Pronovost, 2009) in patient safety.

Eight different approaches have been used in published research to assess the extent of the problem each presenting with varied strengths and limitations. These include autopsies, patient and provider surveys, simulated or standardised patients, secondary reviews, audits, malpractice claims, case reviews and voluntary reporting systems (see Graber, 2013 for narrative review). Such differing approaches have yielded diverse results although consensus has settled on an estimate of 10% and this is supported by autopsy studies (e.g. Shojania, et al., 2003) which are regarded as the “gold standard” for identifying diagnostic error (Graber, 2013, p.21). Whilst UK data are more scarce, a US review of medical malpractice claims from the last 25 years found diagnostic error to be the leading cause for a claim, constituting the highest proportion of pay-outs and more frequently resulting in death (Saber Tehrani et al., 2013).

Research into causes of diagnostic error has argued that it arises from an interplay of multiple factors related to cognition and systems (Graber et al., 2005), notably the “anchoring bias” whereby an initially suspected diagnosis pervades despite indications to the contrary. Various initiatives have been developed to mitigate error such as or clinician checklists (Croskerry, 2003). Similarly a number of system-wide interventions have targeted personnel, and clinical technique, such as, introducing additional clinicians to a diagnostic process or using computer systems to mine electronic data to identify potential cases of missed diagnosis. Yet a recent systematic review found there to be just two studies exploring the role of systems approaches targeted at patients (McDonald, Matesic et al., 2013). For further research targeted at reducing diagnostic
errors please see recent narrative reviews for the cognitive (Graber et al., 2012) and system-related (Singh et al., 2012) interventions.

Whilst there has been a growing number of published studies examining diagnostic error over the last decade, there has been little focus on the perspective of the patient within this research. This has been a trend previously identified in other areas of patient safety research (Vincent & Coulter, 2002). When considering the research into diagnostic error it is useful to note the separation of the process that caused the error from outcome or impact of the error (Newman-Toker & Provonost, 2009). It is argued that developing knowledge of the patient perspective of diagnostic error can help to inform efforts at a clinical level for those who may be living with the impact of this experience.

1.1  Current research on the impact of diagnostic error from a patient perspective

Only one published study has examined the patient experience of diagnostic error in its own right has been identified (Belsh & Schiffman, 1996), using a cross sectional, and forced choice questionnaire survey. Whilst it provides circumscribed insight regarding the objective impact of diagnostic error (such as delays in treatment or unnecessary surgical procedures) it offers little on the patient’s own constructions and appraisals of the experience.

All other studies examining the patient experience of diagnostic error have done so alongside other adverse events, (Elder et al., 2005; Entwistle et al., 2010; Kistler et al., 2010; Kuzel et al., 2004; Mazor et al., 2012; Mazor et al., 2013; Molassiotis et al., 2009; Ocloo, 2010) within which nuanced description of personal experience appears lost. Grouping adverse events together it is not possible to ascertain to what degree such studies can be generalised to diagnostic error.

A number of patient advocacy groups have anecdotally highlighted patient experience of adverse events including diagnostic error (see for example www.patientstories.org.uk), yet with no systematic analysis of this to better inform research and practice. Detailed analysis may provide new concepts and ways of understanding diagnostic error to enable a more patient-centred approach to this problem both in research and practice. One study has identified the impact of delayed
diagnosis and how it may be of great significance for how patients and their families might adapt and react to a child’s diagnosis of cancer (Dixon-Woods et al., 2001).

Developing knowledge of the patient experience of diagnostic error is the main aim of this research. It is recognised that this may also help to inform the process in which diagnostic errors are made. Schiff (2008) has argued that patients can be considered as ‘co-producers’ in diagnosis and in cases of error can help to provide a source of feedback that is often lacking for diagnosis. More recently it has been identified that engaging patients to facilitate voluntary or prompted reports of error could be a means of measuring incidence of diagnostic error (Graber, 2013). Patient involvement in diagnostic safety has been identified as a key partnership to support both research and practice, notably in developing theory to guide diagnostic error prevention and understanding factors which inhibit and encourage patient involvement (McDonald, Bryce et al., 2013).

1.2 Understanding Diagnostic Error through the exemplar of cancer

In order to develop insight regarding patient experience of diagnostic error this research will use the exemplar of cancer, a regular practice within the published patient safety literature (Porter et al., 2010). Cancer is the leading cause of death worldwide and projections are for this to continue to rise (WHO, 2013), with most recent incidence data for all types of cancer in the UK revealing approximately 270,000 new diagnoses each year (National Audit Office, 2010). Within the context of cancer, recent research has considered the role of ‘missed opportunities’ in diagnosis which can be considered as post-hoc judgements suggestive that alternate actions may have given a more timely diagnosis (Singh, 2014). Such missed opportunities are considered to typically occur in three main phases; initial diagnostic assessment, diagnostic testing and interpretation, an, diagnostic follow-up and co-ordination (Lyratzopoulos, Vedsted & Singh, 2015).

Over 1,500 reports of diagnostic error relating to cancer have been reported in one year (June 2007 to May 2008), representing a small but significant percentage of those annually diagnosed (National Patient Safety Agency, NPSA, 2010). However, this data is elicited from a voluntary reporting system. Given there are particularly low levels of reporting for patient safety incidents in primary care settings (approximately 1 in 200 of
all reports) this important phenomenon is likely to affect many more people than represented by these statistics. A recent study using ‘trigger tools’ to retrospectively identify potential cases of diagnostic error from medical records found cancers as accounting for 5% of all missed diagnoses in a primary care sample (Singh et al., 2013). In 2006 European ratings of UK cancer care placed the UK as 9th and 22nd for male and female mortality rates respectively in comparison to 27 other European countries (EUROCARE-4, 2009). Experts have suggested late diagnosis may well be responsible for poorer comparative performance in cancer care in the UK and that if improved the UK would have survival rates comparable to the European average (Coleman, 2008).

Reduced diagnostic delays in cancer may improve prognosis and reduce psychological distress (Risberg et al., 1996). Whilst diagnostic delays have been studied within cancer these have largely focused on delays on the part of patients (e.g. Walter et al., 2012). There are no known studies involving cancer patients’ experience of perceived diagnostic errors which offer a detailed insight. A study into cancer patients’ perceptions of ‘problematic events’, of which diagnostic error was an area identified amongst other clinical and communication problems, identified physical and emotional harm caused by such errors, but provided a descriptive rather than interpretative account to make sense of this experience (Mazor et al., 2012; Mazor et al., 2013). These studies also highlighted the need for further research relating to actual experiences of error rather than hypothetical cases.

Research focused on diagnostic error is an emerging domain of a wider patient safety movement but is gaining momentum in both research and clinical settings with growing acknowledgement of its importance. Whilst various interventions seek to mitigate and minimise error, and harms caused by diagnostic error in cancer have been examined alongside other adverse events, these have never been privileged in their own right. This research sought to develop knowledge of the cancer patients’ experience of diagnostic error, and the subsequent sense making of this process. The aim of this study was to gain greater insight as to what the impact of perceived diagnostic error may be and did not involve any predetermined hypotheses.
1.3 Aims and Objectives

1. To understand patients’ experience of perceiving a diagnostic error.
2. To understand the impact of this experience on living with cancer, including treatment and living in illness remission.
3. To add to the research literature regarding the understanding of the diagnostic error from a patient centred psychological and emotional perspective.
3 Method

3.1 Design

A qualitative design was adopted to allow for in-depth exploration of the previously unstudied experience of persons experiencing perceived diagnostic error prior to a diagnosis of cancer. This idiographic approach was taken in order to develop rich data in a manner which would allow flexibility for participants to express areas of importance to them and for the researcher to probe in response to participant accounts.

Interpretative Phenomenological Analysis (IPA) is particularly concerned with lived experience and its personal meaning, with a development and history of use in health psychology and the experience of illness (Smith, 1996, 2011). IPA is often applied when “concerned with complexity, process or novelty” (Smith & Osborn, 2008, p.55), has been successfully used to understand experiences in cancer study (Hvidt, Iversen & Hansen, 2013; Reynolds & Lim, 2007), and was considered well suited for this.

IPA has three main underpinnings; phenomenology, hermeneutics, and idiography. Phenomenology is the philosophical study of seeking to understand human experience; in this study the experience of perceived diagnostic error from the patient perspective. Hermeneutics, as a theory of interpretation, requires the researcher to examine how a phenomenon appears and is presented by the participant, the researcher must then analyse the participant’s account to be able to offer a perspective or interpretation. In this way establishing an objective truth of reality is not sought, but rather proximity to the participant’s constructions of reality. The researcher must be cognizant of their own preconceptions and bias which may influence the interpretation and attempt to account for these (Shaw, 2010). This is recognised as the double hermeneutic - the researcher’s interpretation of the participant’s interpretations of their experience (Smith & Osborn, 2008). In order to account for the researcher’s own preconceptions a continuous reflexive approach is encouraged, known as the hermeneutic cycle (Smith et al., 2009). The idiographic element highlights the unique encounter and perspective that give rise to individual meanings of experience, without imposing any specific assumptions.
3.2 Epistemological position

This research was undertaken from an epistemological position of critical realist social constructionism (Appendix K). As such the findings of this research study are considered to be subjective and an interpretation of the researcher.

3.3 Ethical Considerations

The research protocol was initially peer reviewed within the Clinical Psychology Department at the University of Leicester, and full ethical approval obtained from Local Research Ethics Committee (LREC - Appendix L).

The nature of the research required an approach sensitive to the experiences of the target population. As such several steps were taken account for this. All participants were provided with information advance of interview and given opportunity to discuss any concerns through telephone/ email contact to ensure consent given was fully informed. This process also allowed for the development of a degree of trust and rapport with participants. Participants were also given the option of providing their GP details to be used by the researcher in the event that concerns were raised during the course of the interview process for which the participant may wish to gain further support, although this was not needed during the course of the study. During the interview participants were informed of their right to withdraw their consent at any time, and also to request comfort breaks in the interview, as the researcher also remained sensitive to participant distress during the interview. Participants were also provided with a debrief sheet following interview.

3.4 Participants

3.4.1 Sample

The idiographic element of IPA seeks to offer “detailed, nuanced analyses of particular instances of lived experience” (Smith et al., 2009, p.37) which is allied to the aims of the proposed research. This approach typically uses small samples in order to ensure a thorough, systematic analysis with depth which would not be possible with large samples. IPA does not seek generalizability but instead to offer theoretical
transferability by focusing on a particular phenomenon (Smith & Osborn, 2008). A sample size of three to six participants is considered appropriate for a research study at this level and is considered large enough to allow general themes to be considered between participants whilst allowing for detailed analysis and consideration to be given to the individual experience (Smith et al., 2009).

3.4.2 Inclusion Criteria

The inclusion criteria were participants who: (i) have a diagnosis of cancer; (ii) believe they experienced a diagnostic error prior to their diagnosis of cancer; (iii) are willing to discuss these two parts of their life and the subsequent meaning for them; (iv) are aged 18 or over; and (v) can speak English to a level that permits participation in a semi-structured interview.

3.4.3 Exclusion Criteria

Participants were excluded if their experience was not one of diagnostic error. The definition of diagnostic error was considered to be one which is missed, incorrect or delayed and this definition was described in discussing the research with prospective participants. Those persons who wished to take part in the study were asked to briefly describe their experience and this was discussed with the researcher to ensure their experience was one of diagnostic error. The purpose of this was to exclude those patients who may confuse diagnostic error with other issues, most notably quality of care (e.g. Agoritsas et al., 2005). During the recruitment phase 2 persons were excluded for this reason.

3.4.4 Final Sample

Six participants were recruited to the study, including four females. Participants were aged between 59 and 79. Interviews focused on errors perceived to have taken place up to eight years prior to interview. The errors reported included something more benign being diagnosed for symptoms the participant later believed were due to a diagnosed cancer such as the explanation for a particular lump or blood in stools; delays in the reporting of medical test results to participants; misinterpretation of test results; and most notably the delay in receiving what was considered to be a definitive diagnostic test such as a scan. Participants believed the error in their diagnosis caused a delay of
approximately 3, 3, 5, 6, 36 and 96 months respectively. All participants with the exception of one who was retired were in work during the time of the perceived error; at the time of interview all participants had retired from work. Following their treatment for cancer participants described a range of side effects which they continued to live with including physical and cognitive impairments, such as the loss of ability to eat solid foods or to walk unaided, in addition to other difficulties such as that caused by pain or facial disfigurement. Demographic information is limited in order to maintain anonymity.

3.5 Procedure

3.5.1 Materials

Research materials are presented in Appendices M – P including a participant information sheet (PIS), GP information sheet (optional), consent form, participant debrief, and interview guide.

3.5.2 Recruitment

It was felt appropriate to recruit for this study from non-NHS settings in order to allow participants to be able to feel comfortable in expressing fully their experiences and perspectives without placing them in a position of potential conflict with their healthcare. A purposive approach was taken to recruit a homogeneous sample with a shared experience of diagnostic error. Participants were recruited from cancer support groups in the community, and interviews took place in neutral venues. A flowchart of the research process can be found in Appendix Q.

3.5.3 Interviews

Interviews were set up with the participant to be a ‘one sided conversation’ in which the emphasis was on entering the participant’s world as closely as possible, adopting a naïve but curious stance, beginning with more descriptive and narrative rhythm of the interview moving towards an affective and specific account (Smith et al., 2009). An interview topic guide (Appendix R) was produced based on readings of the literature, however this was not to be used dogmatically, but rather was produced in advance to
aid the researcher to consider possible areas for interest and prompts which may be useful to explore particular themes.

Interviews were audio recorded and transcribed by a professional transcription service under a confidentiality agreement. It is recognised this may have reduced the initial immersion in the data, however the researcher subsequently spent time checking through each transcript and anonymising all data, adopting pseudonyms and changing identifiable information to generic terms.

3.6 Analysis

The approach to data analysis followed that described by Smith and colleagues (2009). Although it is noted that there is no singular analytic method to IPA, this approach was followed as it offered a structured suitable for a researcher using IPA for the first time. This involved:

1. Becoming familiar with the data through multiple readings with initial comments and thoughts noted.
2. Exploratory coding encompassing; descriptive comments staying close to what the participant has said; linguistic comments to make note observing how the account was presented; and, conceptual comments to begin to abstract a sense of meaning for the contextual and overarching concerns of the participant.
3. Developing emergent themes based on the exploratory coding from step 2 clustering of themes seeking to identify convergent and divergent patterns.
4. Ordering and refining of themes from across the transcript to produce a structure which points to the most interesting and important aspects relevant to the research question.
5. Once all transcripts had been analysed, patterns across cases were identified.
6. A written narrative was then constructed giving a balanced account of the data - the experience of persons with cancer perceiving diagnostic error, but also interweaving interpretative commentary.

Examples from the analytic process can be found in Appendix S.
3.7 Quality issues

In the interests of ensuring validity, a notoriously difficult challenge for qualitative research, the framework identified by Yardley (2000) of core principles for demonstrating validity of qualitative research were adhered to. These are sensitivity to context; commitment and rigour; coherence and transparency; and, impact and importance. This is in addition to drawing upon the quality criteria in IPA put forward by Smith (2011) of ensuring the written thesis clearly prescribes to the theoretical underpinnings of IPA, is transparent and provides a coherent and plausible analysis.

3.7.1 Sensitivity to context

Previous research had identified the lack of patient inclusion in patient safety research and similarly the dilemmas faced by patients involved in such research (Vincent & Coulter, 2002). Support groups from which participants were recruited were approached in a sensitive manner by contacting gate keepers. Similarly, presentations to the groups were made as a collective, within the groups’ usual settings, and with prior notice in order to ensure the researcher’s presence was non-threatening.

In analysing the data efforts were made to ensure the interpretations were sensitive to and grounded in the accounts, fully aware of issues surrounding interpretative violence and adopting a centre ground between suspicious and empathic hermeneutics in keeping with IPA principles (Ricoeur, 1970; Smith et al., 2009; Willig, 2012).

3.7.2 Commitment and rigour

Commitment was demonstrated by numerous efforts, including the original design of the research project itself, attending IPA training, logistical arrangement of interviews in neutral venues, and the attendance to a peer IPA group. Rigour as an indication of thoroughness was indicated by the efforts to ensure a suitable sample was obtained, the in depth interviews carried out, and the systematic approach to analysis of research interviews. Supervision with an experienced clinician and researcher was also used to help support the analysis. In writing up the narrative aspect of the analysis steps were taken to ensure quotes and descriptions were drawn from the range of participants.
3.7.3 **Transparency and coherence**

The clarity of writing in this research report seeks transparency to offer a logical description of the process. The researcher set out to present coherent arguments and descriptions which are in keeping with the principles of IPA, most notable demonstrating phenomenological awareness and hermeneutic sensibility which are balanced with interpretative insights offered.

3.7.4 **Impact and importance**

Ultimately the test of the validity of IPA research lies in whether or not the report offers something of interest and utility to practitioners and researchers alike, as such efforts were made to highlight the key implications of the findings.

A chronology of the research process can be found in Appendix T.
4 Results

The data obtained from interviews with the six participants detailed their experiences of perceived diagnostic error. These were constructed by all participants as a loosely temporal sequence, from initial concerns regarding ill-health and medical consultations, through living with diagnostic uncertainty to an eventual cancer diagnosis, treatment and recovery. In this sense, narratives tended to follow their “cancer journey” within which diagnostic error was a feature, although in places this was less prominent, particularly during the treatment phase. There was some difference in the individual experience of diagnostic error, notably with four participants who experienced active, troubling symptoms and concerns that reassurance or benign diagnoses were insufficient (Andrew, Tina, Susan & Mary), in contrast to those (Audrey & Mike) who experienced no initial concerns.

Three superordinate themes were identified as detailed in Table 1

Table 1. Summary of themes

<table>
<thead>
<tr>
<th>Superordinate theme</th>
<th>Subordinate theme</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnostic error as invalidating</strong></td>
<td>Dr knows best</td>
</tr>
<tr>
<td></td>
<td>Being on the conveyor belt</td>
</tr>
<tr>
<td></td>
<td>Struggling alone</td>
</tr>
<tr>
<td><strong>Shifting appraisals of diagnostic error during the cancer journey</strong></td>
<td>Being suspicious but trusting</td>
</tr>
<tr>
<td></td>
<td>Not wanting to hear the ‘Big C’</td>
</tr>
<tr>
<td><strong>Seeking reconstruction of the self</strong></td>
<td>Surviving in the moment through detachment</td>
</tr>
<tr>
<td></td>
<td>Diagnostic error as more damaging than cancer</td>
</tr>
<tr>
<td></td>
<td>Redress as elusive</td>
</tr>
<tr>
<td></td>
<td>Finding personal agency</td>
</tr>
</tbody>
</table>

4.1 Diagnostic error as invalidating

The participants’ detailed consultations with doctors (either GP or consultant) consequent on perceived changes in their health which they believe resulted in diagnostic error, a conclusion drawn either at the time or in retrospect. These experiences and sense of invalidation for their subjective experience not only seemed
to impact on sense of self, but also had further implications for the lack of diagnosis as an objective statement of suffering.

4.1.1  Dr knows best

Accounts included both single incidents of perceived error (i.e. one particular consultation with one doctor) and those occurring over a period of time with repeated consultations. Such consultations were perceived as impersonal and undermining of personhood, and appeared to reflect a power imbalance in which ultimate authority was the preserve of the medical professionals.

*One doctor in, they were very, very nice in, you know, really um, but there was one lady doctor who was actually horrendous to me. She treated me like I was a hypochondriac. And, um, oh what, you know, what are you doing here again and making a big fuss and being kind of paranoid and all of this she goes, you’ve got constipation. So I got the impression, ‘so what?’*

Susan (later diagnosed with bowel cancer)

Such questioning of legitimacy is considered to be a challenge to the sense of self. Such feelings of invalidation are still accessible - Susan describes how this experience is still with her to this day.

*And I still have that letter actually and it really, really hurt me because she put into words what I felt happened in that short interview with her at the hospital where she, you know, thought I was being paranoid and she’d put that kind of to that effect [...]*

*But it was on file and she’d said that about me. And I felt that in the interview, the very short interview that I had with her, I’m being dismissed again you see really, sent home packing really.*

Susan

---

4 [...] denotes unrelated text removed
Susan notes that her invalidation is ‘on file’, with official status and temporal permanence, imposed unfairly and psychologically endures for her as ‘I’m being dismissed’ switches to a present tense account. The sense of being reduced to something less than the person was a feature of participants’ accounts of consultations in which they felt their concerns had not been heard. Mary notes how these were felt in part to be due to both her age and sex.

*His manner was so ghastly, so patronising, you know, “there, there dear, don’t you worry your silly little head.” And I think as a middle aged female you haven’t got any street cred in any sphere*

Mary (later diagnosed with a recurrence of a brain tumour)

Her apparent shaming within the process of diagnostic error appears to have longstanding implications. Mary describes how she felt humiliated and isolated by what she felt was the doctor “playing god.”

*Well to me it’s totally insulting to be told that, um, doctor knows best. Um, and that you haven’t got a contribution to make to your own diagnosis. It invalidates your experience of being a patient. [...] It’s so humiliating. It’s so humiliating.*

Mary

The loss of role as a patient is felt to be deeply undermining as a person and being without contribution. Being without influence is an overriding memory of diagnostic error for Audrey.

*The things I’ve learned along the way like, it’s like being without a voice. Without a literal voice.*

Audrey (diagnosed with mouth cancer after three years)
4.1.2 Being on the conveyor belt

Being diminished within individual medical consultations was echoed within the wider healthcare system, perceived to be impersonal, and at times dehumanizing. For those living with perceived diagnostic error, engagement with professionals and the healthcare system is described as feeling impersonal and mechanistic. Clinical content of care may be adequate but respondents described a lack of connection and acknowledgement of suffering, creating a sense of invalidation. Andrew highlights how once he had been referred by his GP to the hospital he was now part of a new process.

\[
\text{But I could see, from their position at the surgery they’d done the next step and they’d done it quick. So credit to them. Then I was on the hospital’s conveyor belt.}
\]

Andrew (later diagnosed with cancerous growth in a lymph node)

Andrew’s account gives a sense of the need to be processed quickly and mechanistically, as one of many on a production line, his unique distress being lost as he becomes an object. The lack of personal connection is experienced as a lack of acknowledgement of distress. Audrey describes how she attended a check-up following the removal of a tumour, but the emphasis was placed on her body, and not her.

\[
\text{He said to the student look at this beautiful piece of work. He said isn’t that wonderful? How is that neat? And the student said oh, yeah. [...] I decided really that he wasn’t interested, it confirmed a bit of a belief that I’d got that about surgeons anyway in that they do see people as a lump of meat. They don’t actually, um, see them as a human being. They just see it as a lump of meat, you know, chop out the bad bit and make it heal.}
\]

Audrey

Audrey conveys affront construing the doctor talking about her as a ‘lump of meat’. Audrey’s comments describe an impersonal almost brutal interaction, yet at the heart of this account she described how the ‘bad bit’ is removed in order to allow her to ‘heal’,
which it may be argued is the ultimate objective, but is perceived as lack of interest in personal suffering.

4.1.3 Struggling alone

Being alone with the suspected condition or symptoms and unable to access support, because subjective illness experience was denied credence through diagnosis was a source of struggle for participants. Susan notes how the lack of a diagnosis denied her connection with her family, through having no shared means of understanding afforded by diagnosis, creating a void.

*But they [Susan’s children] wouldn’t have known where I was coming from, they’d not, you know, they’re fit and health athletes. And, uh, you know, they knew that, you know, I’d got problems but, you know, I hadn’t had a diagnosis to say that it was something serious. You know, I was just in this limbo really and, I mean, what do you say to people?*

Susan

Lacking the validation of a diagnosed serious illness could not only inhibit the potential for social support and understanding but can exacerbate tensions. Tina identified strain within her marriage for prioritizing her pain over other areas of her life.

*And it did cause a rift in the family because, um, my husband was like “oh what’s wrong with you, you’re just being lazy, get up.”*

Tina (later diagnosed with cancer of the tonsil)

The impact on broader personal relationships was also experienced during this “limbo” phase notably with work colleagues. Andrew described how the “golf ball” on his neck which he felt was gravely serious was ascribed a different meaning by others, and in turn his suffering.

*People go on about oh yeah, got an infection, got swollen glands but this was a bloody golf ball sticking out of me neck. And part of it, or two thirds was inside. It was like an iceberg, you know, it was large*
but a lot of it was buried [...] I was irritated because I got the impression from school, was they knew I'd had a few days of tonsillitis before the Easter break and for two weeks had basically been ill at home, and then was having another week off.

Andrew

Andrew’s use of the iceberg metaphor is illuminating as this gives a sense that the real danger, of the iceberg is hidden, and the reaction of others only based on a surface level understanding, positioning him as though a malingerer.

4.2 Shifting appraisals of diagnostic error during the cancer journey

This theme seeks to capture the sense of a change in response to possible diagnostic error at different stages of illness, but also to note how the notion of diagnostic error may have also had a psychological function at times during this journey. Diagnosis not taking place in a timely manner gave rise to a sense of fear, uncertainty and desire for information and knowledge, coupled with an experience of suspicion, of the self, the body and others. Such suspicion seemed to initially be overridden by a trust in the medical profession and a deference to their knowledge. Whilst suspicions regarding one’s own health were apparent, these were not verbalised, and for some served to keep the potential enormity of a cancer diagnosis at bay. However, when cancer was realised in diagnosis, there was a sense of detachment and inability to make sense of the experience of error at the time of diagnosis and treatment. The subthemes presented represent a loose temporal process.

4.2.1 Being suspicious but trusting

Following the experience of symptomatic ill health without a diagnosis to validate this, participants reported questioning the process, themselves and others. Susan identifies a comparison of her own sense of working hard to manage her health problem which at the time was not diagnosed as cancer.

Because it felt as if they weren’t dealing with it to me and I felt there was something really seriously wrong. Cos I felt ill and I was working
full-time and I was thinking, well, what’s, what’s, what’s not being
done here really?

Susan

Susan suggests an available option was in some way being withheld. As ‘working full-time’ intimates she is doing all that she can, but perhaps others are not so competent. A questioning stance towards professionals in their care was a feature of some of the participants’ accounts, in that more could always have been done to aid them. Yet trust in doctors and their expertise was apparent as participants’ own perceptions demurred to professional status. As Tina notes despite being unsure of a doctor’s diagnosis she trusts their professional capacity, beyond her own and her dentist’s expertise.

It was just like, he’s [the doctor] the expert, let’s do what he said and
the dentist said okay. What else can we do? You know, that’s what’s
what he said, so that’s what we’ll go with. So had the tooth taken
out, the dentist said I’m still not convinced it’s that.

Tina

Whilst absence of diagnosis appeared incongruent with persisting subjective feelings of ill health, the powerful effect of trusting in a diagnosis was also seen in participants without intrusive symptoms. Respondents deferred to the expertise of doctors being from a “generation that places total trust in doctors” (Mike).

To hear a doctor say to me, as he did, as he looked at it, to say, that is
an ordinary cyst, and nothing to worry about. I immediately felt that
I’d largely wasted time, there was some relief, didn’t know what else
it might be, uh, got up and simply got on with my life.

Mike (later diagnosed with skin cancer)

The relief Mike felt at this diagnosis of nothing of concern was linked to a belief he was in some way incorrect to have presented with this concern, and implies a sense of guilt in doing so. Noting that he was able to ‘get up’ and ‘got on’ suggests the doctor’s words
were in some way transformative for him, and he moved from limbo to resume active living on the basis of the doctor’s words.

4.2.2 Not wanting to hear the ‘Big C’

In order to avoid, at least for a short time, participants may to some extent sustain diagnostic uncertainty because this provides less existential threat. Simultaneous constructing responsibility for diagnosis on the doctors involved may serve to further avoid the diagnosis in the midst of the private belief their illness is indeed cancer.

As Audrey notes she was not believing of the explanation provided that a lump in her mouth was caused by her biting her mouth in her sleep but suggests a sense of naivety in her sense making at the time.

**Audrey:** No, I was sure I’d know. I know you do a lot of things subconsciously but, um, something like that, it hurt and you’d have blood in your mouth and, you know, because you’d bite through it all wouldn’t you (?)? But I’m a lot wiser now than I was then.

**Researcher:** So what was different? So you’re wiser now, what was different then?

**Audrey:** I really wasn’t aware that people had mouth cancer. And, um, no-one had actually mentioned cancer along the way.

Audrey describes how she felt suspicious, and had reasoned this to herself with the lack of blood or evidence to support this explanation. Audrey goes on to note how cancer had not formed any part of previous consultations. Participant accounts were suggestive of construing a sense of importance to maintain a distance from the possibility of a diagnosis of cancer through preferring a lesser, albeit inaccurate diagnosis. Mike explains following his experience of diagnostic error he is angry at himself for trusting the doctor’s initial comments that he had nothing to worry about, which might indeed reflect his own hope or delusion.
We’re all ultimately responsible for ourselves. Um, I am angry at myself because I did not actually question it. I simply took it on trust, um, and that’s the reason for my anger [...] Perhaps it was just really what I wanted to hear anyway.

Mike

There is anger and regret that information available to Mike at the time was not considered differently. Susan demonstrates more explicitly this internal battle against the idea she may have cancer.

I thought I’d got this big heavy cloud hanging over me but there was something really serious and I felt inside that there was something and I, of course I thought it was the big C. Uh but, you know, I kept asking people am I paranoid? Perhaps it isn’t, perhaps it’s something else, it could be something else.

Susan

The idiomatic term, ‘the big C’, gives the sense that cancer is unspeakable, too threatening to be fully spoken. Susan seems to be wrestling with the idea that the cause of her pain and suffering is in fact cancer, reasoning with herself the possibility of there being another cause for her ill health. In this way, the lack of timely diagnosis may serve to support the hope illness symptoms are not indeed cancer. Andrew notes his sense of waiting for procedures was ‘delaying the inevitable’.

I was delaying the inevitable and I was in limbo but I knew it was delaying the inevitable. And the inevitable was a diagnosis of which I was not going to be happy. But no-one had mentioned the C word.

Andrew

There is a sense that because cancer had not been mentioned, it was not given formal status and so did not exist, until given, as though created, by a medical professional. In this sense cancer becomes construed as something imposed externally through
language, and not from within the body. Andrew captures a sense that amidst the confusion the conveyor belt is now taking him closer to death.

And I felt then that I was on a conveyor belt to death anyway. Uh, and so obviously after seeing the MRI results I was in quite quickly. The biopsy was booked, I was having a biopsy the following week. I don’t think the C word was still mentioned.

Andrew

Cancer never being mentioned is key to how he recalls his experience, yet there are times when this assertion becomes more fragile.

I knew the exact timetable of my events, sequence of events and I’d never had the cancer word mentioned. I’d had things like ‘Oh well all the blood tests show it can’t be any of these cancers Andrew.’ But no-one had said the fact to me that it might be a squamous cell carcinoma.

Andrew

Andrew provides contradiction as to whether or not suggestion of cancer had featured in his diagnostic journey, offering a sense of how error is positioned within the confusion and uncertainty of his journey. Error may be seen to serve a purpose in providing an identifiable place for his anger and frustration to be targeted, a place which Andrew did not feel responsible for and seems keen to identify.

4.2.3 Surviving in the moment through detachment

The existential threat presented by a cancer diagnosis, when it finally came, had an immense psychological and emotional impact. Despite any previous concerns of diagnosis not taking place in a timely manner, there was an imperative to focus on treatment and in this sense diagnostic error remained unspoken. Andrew describes being a ‘zombie’ throughout his treatment.
It was, you’re in a state of detachment but you’re not detached because you’re involved. But you feel very much like a zombie. [..] I was in zombie land and just doing what I was told.

Andrew

Andrew invokes being in ‘detachment’ at this time, to cope, and ‘a zombie’, operating as a passive empty shell as the enormity of his diagnosis becomes inescapable. The overwhelming sense of threat and need to survive cancer and treatment took precedence over thinking of diagnostic error. Susan remarks how the experience of diagnostic error is like a trauma.

I think when people in a trauma, it’s only if you survive a trauma that you can cope with it really, you know.

Susan

Susan gives a sense that the experience of diagnostic error is only something which can be survived at the time, and it is later it must be coped with, and perhaps made sense of. Mary too describes an inability to process and makes sense of events following the diagnosis of cancer recurrence.

I don’t think with all these stresses that I was particularly rational about things or logically following things.

Mary

The sense that diagnostic error, or indeed anything but the possibility of death being given attention to think of and make sense of indicates that such processes will thus take place post-hoc, and as such it is possible that any sense making of the experience will ultimately be couched in that context of survivorship. Given the confusion taking place at the time and the multitude of events to make sense of in survivorship there is a sense of many similarities and connections between the cancer and diagnostic error, which may be a reflection of the events being so closely related, but may also point to how both are made sense of. Susan goes on to relate the two as ‘traumas’.
You know, it’s very deep, it’s very deep the hurt and, you know, the trauma that people go through. Not just about misdiagnosis but being told, going through all these illnesses.

Susan

Susan’s words offer multiple readings, first that the experience of cancer and diagnostic error are both very similar in their nature of causing deep hurt, which is undoubtedly true. But also there is a possible reading that cancer, and diagnostic error are both facets of the same thing and in some way in separable.

4.3 Seeking reconstruction of the self

Only after treatment and entering a period of remission or survivorship, did issues of diagnostic error become prominent as the process of adjustment took place. Audrey describes succinctly the loss of the self in the experience of cancer, and how this experience was expedited as she felt due to error she went from being well to unwell almost instantly when finally diagnosed.

I think you lose your identity as well, with it coming as such a shock. Because you’re there one minute and then you’ve gone the next. It’s how it feels, that you’re taken away. And whether you ever get that person back, or whether you want that person back I don’t know.

Audrey

In survival, narratives of profound alteration and a desire to make sense of the experience were apparent. This is not novel in adjustment following serious illness, however for some its intertwining with appraisals of diagnostic error seemed to detract from efforts to feel restored or valid in survivorship.
4.3.1 Diagnostic error more damaging than cancer

All participants felt perceived diagnostic error led to an increased severity of their cancer, thus requiring more severe and aggressive treatment, greater side effects and resultant suffering and disability. Within accounts, the role of diagnostic error was constructed as cause of their suffering, and not cancer, perhaps affording explanation for suffering rather than the randomness of disease.

A key theme of Mary’s account is her belief that the cognitive and physical impairments she suffers would not have been caused if there were no delay in discovering her brain tumour.

*I feel I would have been alright if, you know, the new tumour hadn’t...*  
*It was very big, and sort of exacerbated any damage*  

Mary

She goes on to say how with the exception of her brain tumour and the side effects of treatment causing physical and cognitive disability she has no health concerns.

*Well I’m perfectly fit really.*  

Mary

Mary’s assertion that she is perfectly fit seems juxtaposed to the challenges she has described related to her physical and cognitive difficulties, but emphasises the perceived damage of diagnostic error. The importance of culpability in illness was an important feature for some. For example, Mary draws a favourable comparison to a brain tumour over Multiple Sclerosis (MS).

*MS you think this is a sort of something, you know, genetically that you could be culpable for. Whereas I feel totally innocent as a victim of a brain tumour.*  

Mary

Mary’s choice of language as feeling ‘totally innocent’ and a ‘victim’ of a brain tumour gives a sense of the psychological search for something to blame, a role which may be
ascribed to diagnostic error. Tina describes how being left unable to eat is constructed in her mind as being due to diagnostic error.

_The treatment wouldn’t have been so aggressive and it maybe not have left me how I’ve been left now, which is unable to eat. You know, I think maybe I think whether it would or not, I don’t know, we’ll never know. But I just have that thing that, you know, it wasn’t for the want of trying to find out what was wrong with me._

_Tina_

Tina’s account also demonstrates a sense of uncertainty within her but the notion that diagnostic error has exacerbated her experience of illness seems to be a preferred narrative.

4.3.2 Redress as elusive

All participants discussed a need to find redress in the wake of diagnostic error, in the form of a complaint or apology. However this was not something most participants felt was easily available to them in ways which would restore the sense of self. Susan notes a sense of fear in seeking to make a complaint about the experience of diagnostic error.

_Um, lots of things go wrong for people in the NHS and, um, scary things, really scary things at awful time. I mean I heard all those kind of stories and be too ill to deal with it and they’re frightened to deal with it because of comeback as well._

_Susan_

Threat of ‘comeback’ may silence persons experiencing error for fear of retribution being enacted in their care. Restriction in the ability to seek redress was also considered to be unattainable due to the vulnerable position of being a patient. Audrey notes a sense that the power imbalance could be evoked by the doctor she felt was responsible for a diagnostic error.
I don’t have any faith asking him about it and could just say oh it’s how it goes, I would be shrugged off by him. And then he supposedly has superior knowledge on such things, um.

Audrey

The sense of challenging the system in this way seemed to stack the odds firmly against participants and so making a complaint was considered not worthwhile. Participants gave a sense of begrudging acceptance of their experience of diagnostic error, and as a painful experience to reengage with this in survivorship would be unhelpful. Tina thus sees the idea of making a complaint as pointless.

Um, to be honest I don’t know. I suppose because I was so poorly, um, and then after I did start to get better you just think (sighs) what’s the point? You know, it’s not, it’s not worth dragging it all up and going through it again. I might as well just get on with it, you know, um.

Tina

For others, the notion of a complaint seemed to not offer the redress they would want. Mike is clear that to make a complaint regarding his care was not something he would consider even if he could prove it.

Where’s the evidence? How can I prove negligence? I don’t see it that way. Um, and if I had succeeded, who would pay? Everyone on their insurance policies. To me it seemed quite pointless. I think, and this is why I’d like to meet that doctor, uh, I, yes, there are things to, to learn that can be put right and avoided in the future.

Mike

Mike desire is more of a personal redress in making contact with doctor who he felt had made the original error. This would be an opportunity to have a voice and find revalidation from the experience. Perceiving such inopportunity for redress presented a sense that in diagnostic error participants were left with something which was
incomprehensible but ultimately not possible to discharge. Audrey describes a type of emotional trap she is left in with feeling unable to speak up formally of her experience.

*I could get angry if I wanted but there’s not a lot of point because there’s nowhere to throw it, you know. I would just be, um, rattling around in anger. So I think that’s why I’ve got these peculiar words of bewilderment and strange and peculiar.*

Audrey

4.3.3 Finding agency

The experience of diagnostic error was detailed as being one of compliance with the medical system based on trust and deference to the perceptions of greater knowledge with a lack of agency. Participants described a sense of taking control in different domains which seemed both restorative and preventative of future harm.

In diagnosis Susan became more active, finding peer support groups, changing her diet and taking more exercise. Most strikingly Susan’s sense of autonomy saw her stop chemotherapy after one week.

*I didn’t think I would survive it at all, you know. I just couldn’t cope at all with it. So they thought, they were a bit astonished by that, and I said well that’s how I feel, but you know, if I change my mind I’ll, I’ll let you know, I’ll let you know.*

Susan

Placed into a broader context of the 8 years Susan felt powerless and without validation for her illness, this decision seems to embody a sense of taking control for the first time in this process. Planning to take a more assertive approach to future healthcare consultations was a feature of all participant accounts. As Mary notes, she will now only seek care from the best and most experienced clinicians she can find.

*Well going to the top, insisting on, um, not being fobbed off.*

Mary
There was a sense within the participant accounts that such actions inferred a reduced or even minimal chance of further health complications. Andrew identifies how he is using his own personal finances to help safeguard against further errors in his care should his cancer recur.

*To speed things up. In fact, I’ve saved money cos in the future if it ever comes back, to have treatment privately cos I don’t trust the health service any more.*

Andrew

Such efforts indicate a continued sense that the diagnostic error was more harmful to patients than the cancer, and that such errors can be avoided through consultation with the best and most experienced clinicians money can buy. This may suggest that the associated subtheme of diagnostic error being the cause of greater suffering in illness, then makes this an avoidable entity which may offer psychological comfort as there are means of taking control and agency.

Whilst for some speaking out and making a complaint regarding their experience was unattainable, the opportunity to do so did offer a sense of agency for those able to do so. Susan noted that whilst no formal action was taken the experience was still worthwhile.

*Why was it useful? Um, it, it, gave me a bit of control back in a way. And I don’t mean power, far from that, um, I just thought I’d got an opportunity to say something.*

Susan

Susan also identified how the professor involved in her care “took it on board” and she had in some way “jostled” the medics. These terms gives a sense that for Susan, in making a complaint she was given a voice and sense of agency in making a complaint, and it was this which brought satisfaction. In this way it was finding agency against diagnostic error itself which was somehow important – it gave a focus of something to control and act against.
The sense of finding personal agency in the wake of diagnostic error for participants seemed an important aspect of coping, however there was also a suggestion for one participant that there were no available means of making sense of their experience that would provide agency. Mary describes how although the challenges of diagnostic error and cancer have left her stronger, this strength is not desired.

And some people say, you know, adversity has made them a better person and I can't get my head around that at all. I think it’s, um, it’s positive thinking to the extreme of being ridiculous. I’m a good enough person as it is, so I don’t feel I need any adversity to try and prove I can be a better person. You know, I can’t, um, this is just a disaster for me.

Mary

Mary describes a lack of wishing to conform to the notion of being stronger in adversity to be validated, feeling this is in some way rejecting of the person she already is. The use of present tense ‘is’, rather than ‘was’ which may describe her prior to adversity gives a sense that Mary is caught trying to find a sense of herself in the present which matches the reality of her disability. Perceptions of diagnostic error being tied so closely to the lasting physical disability seemed to make finding personal agency challenging as ultimately neither are perceived to be rectifiable.

I think it will always be anger and be humiliation as the overriding emotions. [...] It means people don’t believe me. Think I’m making a fuss or I’m being a victim unnecessarily. And, you know, being physically disabled is humiliating, falling over is humiliating. Um, and not being a sort of bone fide human being anymore, not participating in the wider world.

Mary

Perceptions of diagnostic error are ultimately perpetuated and the injustice and invalidation initially experienced continues, as means to access the wider world once more are perceived as unavailable.
5 Discussion

This research sought to explore the experiences of persons diagnosed with cancer who perceived they had experienced a diagnostic error prior to their correct diagnosis. The specific emphasis was to understand the psychological and emotional aspects of this experience. An IPA approach was used to explore the experience of six participants. Three superordinate themes were identified as a means of seeking to explain this process; diagnostic error as invalidating; shifting appraisals of diagnostic error during the cancer journey; and, seeking reconstruction of the self.

This study represents the first of its kind to explore in depth the experience of perceived diagnostic error for those later diagnosed with cancer. The findings indicate the intricate and fluctuating experiences of both the cancer journey and diagnostic error, whereby appraisals and subsequent responses take on different meanings and significance over the course of illness, treatment and recovery. The initial experience of diagnostic error may be perceived at the core of being on the part of patients whereby they are not simply suffering a mistake or misunderstanding, but rather a deep questioning of, and affront to, their personhood. Further to this, the context of perceiving an error as taking place within a life threatening illness distorts and challenges the ability to appraise and make sense of the error as an isolated entity. However, perceptions of diagnostic error may also have a functional role in managing the enormity of a potential cancer diagnosis. For example, maintaining a belief in an incorrect diagnosis despite concerns to the contrary to delay an inevitable diagnosis, or finding an identifiable source of anger through perceptions of diagnostic error may offer alternative means to manage the intensity of emotional turmoil when faced with such a diagnosis. As such diagnostic error may not only have implications for disease progression and treatment, but may also have an important role in how patients may make sense of the emotional and psychological aspects of their illness. Therefore perceptions of diagnostic error may serve a psychological function in illness regardless of whether or not opportunities have or have not been missed. Such functions may be considered as having both adaptive and maladaptive qualities when considered in the context of the cancer journey from diagnosis through treatment and into survivorship.
This study has found support for findings of previous studies which have examined patient safety incidents from the patient perspective. This included anger, mistrust and resignation (Elder et al., 2005; Molassiotis, et al., 2009); perceptions of not being taken seriously and concerns of the consequences of confronting error (Entwistle et al., 2010); damage to doctor-patient relationship (Mazor et al., 2012); the perceived dominant position of the medical profession in the social process of medical harm (Ocloo, 2010); and associated losses of time, discomfort, worry and financial implications as a result of the error (e.g. Belsh & Schiffman, 1996).

The final sample for this study were older people (mean age at time of interview 66.5 years), and whilst this idiographic and purposive sampling approach does not offer generalisability for the wider population, results do raise issues to be explored in further research. Notably, the sense of dismissal and invalidation spoken of by some participants may be a function of their generation and the expectations held regarding the medical profession. Similarly, these findings may also be indicative of particular responses and attitudes towards older people presenting with physical health problems. Whilst it is not possible to make firm conclusions these suggestions are noteworthy and may offer further avenues for extending this research, and similarly identify potential limitations of this study.

5.1 **Diagnostic error as invalidating**

Participants described how in various ways they experienced a sense of invalidation during their experience of perceived diagnostic error, ranging from the direct dismissal of concerns by healthcare professionals, to perceptions of being processed within a dehumanising system to being unable to access support for their suffering in the absence of a diagnosis of serious illness. These lived experiences seemed to leave participants with a sense of their suffering, and in turn they themselves were in some way less valid.

A validating response can be considered as one which does not necessarily seek to address or change the account provided, but rather meets with it a sense of understanding and acceptance, as opposed to one which may deny the subjective account (Linehan, 1997). The notion of invalidation and dehumanisation within health
settings has been identified (Haslam, 2006) and considered by some as a process of managing the emotional and psychological distress brought about by carrying out healthcare work (Menzies-Lyth, 1960). Whilst such perceptions and implications of diagnostic error may vary according to the setting and health concern, but within a cancer setting such experiences of invalidation may be particularly damaging. The experience of cancer may have profound repercussions across a patient’s life, yet at the heart a humane and trusting relationship with a doctor may be considered as most crucial as the challenges of treatment, survival or palliative care (Baile & Aaron, 2005). Such invalidation is also damaging to the notion of patients and doctors acting as ‘co-producers’ in finding the correct diagnosis, and thus can increase the likelihood of further diagnostic errors (Schiff, 2008).

The findings of this study highlighted a sense of being denied a social legitimacy for their suffering in diagnostic error. Furthermore, the lack of a clearly defined illness means there is at the time no recognised path for treatment and recovery to help make sense of their experience. Without this participants had a sense of isolation. In this way, participants described how in being without a diagnosis they did not have access to what Frank termed a ‘restitution narrative’ which would enable them to be restored to full health (2013). This narrative posits that whilst we may experience illness today, health is restorable and thus the story has a happy ending. Frank also notes the role of ‘narrative surrender’ in which the subjective experience of illness must be contextualised within medical terminology (2013). Similarly, the perception of diagnostic error may mean there is access to the world of illness but not of disease, whereby the former constitutes the perception and experience within a sociocultural context, but the latter captures the biomedical breakdown/disruption in functioning of the body (Kleinman et al., 1978).

Invalidation in cancer patients is not an area which has been extensively studied. However, within the literature other more ‘hidden’ illness experiences, such as those of rheumatic conditions have revealed more about the experience of invalidation and its significance for loneliness and lack of social support (Kool & Geenen, 2012). Invalidation has been shown to have a negative correlation with symptom severity and quality of life in a sample of persons with fibromyalgia (Ghavidel-Parsa et al., 2014), most markedly
when invalidation came from spouses or close friends, when compared with healthcare professionals. However, the findings of the present study indicate invalidation in the form of lack of diagnosis may have repercussions for and damage the validation available from friends and family.

Social support can be considered as both a positive contributor to health and also as a potential ‘buffer’ to stressors (Cohen & Wills, 1985). Participants described how they were not only unable to access social support to help alleviate stress, but also experienced some social elements as being stressors in themselves as participants were considered as lazy or malingering instead of being unwell. Such negative social interactions have been shown to have a negative impact on well-being, and may even surpass the positive effects of more supportive networks (Lincoln, 2000). Studies of social support in cancer have identified those who are socially isolated may have an increased risk of mortality in breast cancer (Kroenke et al., 2006), whilst those with greater levels of social support reported higher levels of quality of life and less anxiety and depression (Parker et al., 2003). In addition to the sense of invalidation in diagnostic error, those experiencing it may also find reduced levels of social support and the associated health benefits.

5.2 Shifting appraisals of diagnostic error during the cancer journey

In the absence of a diagnosis for their suffering, participants described a number of experiences as they sought to make sense of both diagnostic error and cancer together. This included a distrust of the self and professionals involved in their care, reframing or ‘wishful thinking’ in which diagnostic error was considered more prominently than cancer, and an emotional and psychological detachment from the experience of illness.

Participants described a sense of distrust in what health care professionals involved in their care were saying or doing. The role of trust in cancer care can be particularly important and has been considered a ‘need’ of patients given severe and life threatening nature of the illness and was largely based on the interpersonal skills of the clinicians involved (Hillen et al., 2011).
A finding of the present study was the suggestion of cognitive reframing of events surrounding the diagnostic process in which information was selectively attended to. The term ‘denial’ has been considered as a cognitive strategy applied to aid coping with a stressful situation and has been identified as a coping method which may be deployed in the experience of cancer (Kreitler, 1999). The degree to which denial can be considered as an adaptive or maladaptive approach in cancer is debated however both cognitive and psychoanalytic standpoints acknowledge denial as an appropriate and transient response to a stressful and threatening situation (Vos & de Haes, 2007). Denial has been studied as a means of protecting the individual from aspects of the illness and their consequences in addition to possible culpability (Vos et al., 2008; Silberfarb et al., 1993). Longitudinal studies in breast cancer have indicated denial in patients may decrease over the course of illness and time, yet this may increase during the terminal phase (Culver et al., 2002; Heim et al., 1993).

However use of the term denial may be considered as pejorative and potentially unhelpful to both patients and clinicians in the context of the present study of diagnostic error, and indeed elsewhere. Within the research design it is not possible to identify whether or not participants experienced a diagnostic delay. However, the current findings indicate perceptions of diagnostic error may be an indication of an error taking place, a construction of events to enable coping the stressful and emotional demanding possibility of a cancer diagnosis, or indeed both.

The term disavowal (Freud, 1926 as cited in Salander & Windahl, 1999) is considered to be an act whereby reality is not rejected as in denial, but rather the significance of external events (e.g. possible diagnosis of cancer) is in some way evaded by process of distortion, rationalization or misinterpretation. As such the meaning or significance for the individual is unheeded rather than outright reject (Salander & Windhal, 1999). A may preferred term may be to diagnostic error potentially serving as a cognitive manoeuvre or ‘cover story’ for the enormity of a cancer diagnosis, whereby attention is focused on something less painful and is a process of preconscious processing (Dorpat, 1987). In relation to the present findings such a cover story may have taken place during the journey to diagnosis, whereby the presence of a particular symptom such as a lump is rationalized as not being cancerous, and evidence is sought to support this notion, such
as the lack of diagnosis. This may serve to perpetuate both perceptions of and instances of diagnostic error.

5.3 **Seeking reconstruction of the self**

The perceived experience of diagnostic error was identified as being invalidating for patients and involved an ‘attack’ of sorts on the self. Participants varied in the degree to which they were able to adjust to their experience of both cancer and diagnostic error. There was a sense that the experience of diagnostic error may provide a means of finding personal agency following treatment which may be in some way restorative. However, there was also the indication that through being unable to find agency or redress, they were left with this as part of their experience and themselves in a manner which was psychologically and emotionally burdensome.

Finding meaning and purpose for a traumatic experience can be considered as a facet of post traumatic growth (PTG). PTG is typically considered to be the positive psychological adjustment following a traumatic or significant event identified through increased appreciation for life, relationships and the self (Tedeschi & Calhoun, 1996). In this present study some of the participants’ constructions of diagnostic error and the means available to them to find redress or control enabled them to find a sense of adjustment and satisfaction, such as making a formal complaint (e.g. Susan). Such action orientated problem focused coping has been identified as a predictor of PTG after cancer (Stanton *et al.*, 2007). However, for the majority of participants in the present study such problem focused means of coping were not perceived as being available to them. As such within diagnostic error whilst the notion of the error may indeed serve as an adaptive means of coping with the emotional enormity of a possible cancer diagnosis, such beliefs may be more problematic for longer term adjustment.

Dominant constructions of cancer in published discourse relating to what it means to have and live with cancer have been identified as the imperative to think positively, cancer as war and cancer as a moral concern (Willig, 2011, 2012). Willig argues that to be diagnosed within the context of such discourses which place emphasis on the individual to do all they can to ‘fight’, be positive and take control over events with the burden of responsibility resting on them. As such, to show suffering may be difficult
when faced with a cancer diagnosis, or indeed when making sense of the experience and reconstructing identity in illness remission. Such difficulties in expressing the pain and emotion associated with cancer may therefore be more easily located in the identification of diagnostic error. However, such identity construction may prove both empowering and restrictive, as indicated by the varying degrees of agency and control found by participants.

5.4 Clinical implications

Whilst more timely diagnosis would clearly be beneficial, in the absence of a medical explanation for suffering, clinicians may serve patients well to help acknowledge and manage the suffering they are presented with. Strategies may include showing commitment to the patient and accepting the patient is suffering and taking responsibility for care, tolerating and making explicit the uncertainty, emphasising a focus on coping rather than curing in the short term, and helping them to find a validation for suffering in the absence of a diagnosis. Such strategies may decrease distress whilst a diagnosis is reached, and have been identified as having use when working with patients presenting with medically unexplained symptoms (Stone, 2013).

The use of patient narratives of diagnostic error in raising awareness for patient safety with doctors in training could be further explored (Jha et al., 2014; Stang & Wong, 2015). Such approaches are designed to help doctor’s appreciate the patient experience in a way which engages on an emotional level to aid identification with the patient and learning (Kumagai, 2008).

The role of clinical psychologists in working with patients perceiving diagnostic error may be to enable them to have voice and agency to speak of their concerns. This may serve to either highlight cases of error, but also to allow fears of perceived error to be allayed if this is the case. Clinical practice should also acknowledge the potential for such concerns to be useful as coping strategies whilst being mindful of what they are aiding the patient to cope with and considering the timing of interventions. Furthermore, there may be benefit in aiding colleagues to understand the delicate nature of the cognitive manoeuvre which may be taking place as an act of emotion focused coping (Lazarus, 1993). This may mean preventing efforts unnecessarily seeking to accentuate the
threats and danger the patient may be seeking distance from, if misperceived as a conscious avoidance of reality which may compromise health.

The longer term implications of perceptions of diagnostic error in survivorship may need to be considered in light of the degree of control and meaning provided to the individual. However, where this may prove to be challenging and distressing for patients, the role of narrative psychology approaches (e.g. Freedman & Combs, 1996) to aid the development of new stories about the self and sense of identity may prove beneficial given an experience in which the construction of such preferred realities may have been limited.

5.5 **Strengths and Limitations**

This study offers a number of new findings. The deep sense of invalidation experienced in diagnostic error may be particular to diagnostic error over other adverse events as it is so closely allied to questioning the subjective experience. The role of diagnostic error as a possible means of coping with the threat and fear of cancer during different stages of the cancer journey may be both adaptive and maladaptive. The implications for experiencing diagnostic error are not only limited to appraisals of the error itself but may be intertwined with the broader cancer journey, and illness remission.

This study has a number of potential limitations. Firstly, participant accounts and perceptions of error were not independently corroborated, as such the experiences detailed may not represent a confirmed experience of diagnostic error. However, the idiographic approach undertaken has emphasised the phenomenological experience of diagnostic error to participants who believed this to be ‘true’, as such the sense making aspects of this experience are argued to be the same regardless of how objectively ‘true’ the claim is. Furthermore, the exploration of diagnostic error as a possible device to help limit the impact and threat of cancer may thus apply in such cases where error may not have taken place.

Participants were also a self-selecting sample and as such were motivated to discuss the present topics which may have had some impact upon the data. Given the retrospective recall nature of the research, it is not possible to suggest whether or not such constructions of cognition were taking place during the experience, or are a
reconstruction of events in which diagnostic error now serves as a useful device to keep the historic and possible future threat of cancer at a distance.

This study set out to explore the experience of diagnostic error using cancer as an exemplar. However, within this study the experience of cancer and diagnostic error have been shown to be intertwined and having a bi-directional impact on one another in how participants made sense of each of them at differing points of the cancer trajectory.

5.6 Recommendations for future research

This study has taken an idiographic approach and does not offer directly transferable findings, although may offer theoretical generalisability (Smith et al., 2009), as such future research may benefit from quantitative study to seek to understand prevalence of the findings reported here. In this way the findings from this study may act as hypotheses for future study. For example, in considering the finding of invalidation experienced in diagnostic error, adaptation of the Illness Invalidation Inventory (Kool et al., 2010) to measure discounting and lack of understanding in social relationships may offer further illumination of this finding. Such approaches may also help to shape future interventions and their evaluation.
6 References


Critical Appraisal

This section of the thesis is devoted to a critique and reflexive account of the research process. This appraisal draws upon notes made in a reflective diary which were more formal attempts to be mindful of my experiences throughout the course of the research, but also based on more spontaneous reflexions often made through scribbled notes, text messages or emails sent to myself, or ideas written on a white-board in my home. In this way I feel my journey through the research process and the learning I have gained from it has not necessarily only occurred in formal reflection, but is based upon the experience of reflexivity as events, decisions and challenges of the research process were made sense of in my own mind beyond an academic exercise (Shaw, 2010). In this way, the research process has influenced me both professionally and personally.

7.1 Research Topic Selection

Coming to clinical training I had personal experience of navigating healthcare systems for serious concerns regarding my own health and that of my family. In particular I was interested in the experience of waiting in the system, for appointments, test results and treatment. This was coupled with work experience supporting individuals who may be attempting to navigate such systems whilst wondering what the implications were of this waiting, and how others experienced this. Moreover, how did people try to navigate this process? From a clinical perspective, I was interested in the possibility of what intervention could be offered during some of these waiting periods, such as to the utility of self-help or educational information that could be provided as an adjunct to waiting.

Being placed in a Medical Psychology setting for my first placement I became aware of a regular theme of some clients of the service who identified the experience of ‘the NHS’ itself as being a challenge alongside their physical ill-health. This experience further directed my thinking and reading towards medical errors and their implications for patients. I was particularly interested in diagnostic errors as this seemed to involve a more interactional element between doctor and patient than other types of error. I was interested to know more about what people would do when faced with a potential diagnostic error, and more so as to what the psychological and emotional consequences
of this would be. I felt passionate about this topic as there was a sense of tragedy in the accounts of diagnostic error I came across which seemed so needless, something I believed would keep me motivated through what was going to be a demanding research process.

7.2 Designing the research

Initially I had an interest in diagnostic error and this was free from any particular illness or condition which would serve as an exemplar. I initially chose an exemplar which was an illness which was very personal to me, based on the fact that I would already have a wealth of knowledge and resources to draw upon. However, in beginning the process of developing my research proposal and tentatively making links with regards to support and recruitment for the study, I became increasingly aware that I was making decisions being mindful of my own personal situation rather than the needs of the research. This experience has taught me that whilst the inherent motivation provided by researching a topic with personal meaning may be advantageous, judgement is required to consider how ‘close’ the topic is to the researcher.

Choosing a methodology for the research I was naïve at best in the early ideas I had to explore the experience of diagnostic error. Inspired by reading particular studies regarding the breakdown of relationships between GPs and patients (Stokes et al., 2003) I was particularly interested in a study of dyads and to utilise a grounded theory method to develop a model to understand diagnostic error. However, as I considered the practicalities of such research, and became aware of the fact the research I had been inspired by was based on a PhD study, I recognised the need to reduce my expectations of what I could achieve and to be realistic in my aims.

I was drawn to Interpretative Phenomenological Analysis (IPA) as an approach which would allow me to focus on a specific aspect of diagnostic error – the patient experience, but to do so with rich detail. I had previously come across the approach and had been inspired by the way a narrative could be produced which offered both individual and nuanced understanding couple with a psychological perspective which may contribute to understanding of that experience. I felt energised by the opportunity to place my own interpretations within the research and the challenge this presented. In choosing this
approach I was conscious this was new to me and following recommendations from within the literature I chose to attend a weekend workshop on IPA (Hefferon & Gil-Rodriguez, 2011; Smith, 2011a). I have found the learning from this weekend invaluable and have consulted the resources I gained many times through this process. Attending further, dedicated research methods training is something I will endeavour to do when undertaking future research, or indeed clinical approaches as the experiential nature of the learning seemed so valuable.

7.3 Ethical considerations

I was initially faced with several ethical considerations with regard to my research project. The first being the concern about what the research may uncover and how any specific allegations of negligence or harm which may arise from participant accounts were to be addressed. I was pleased to have the support of the Operational Lead for Research and Development at the Trust who I was able to discuss my proposed study with. In these discussions it was felt there was the need to put in place a mechanism with the local trust who were likely to have responsibility for any physical health provision which participants may have been discussing, in the event there was the need to raise any concerns with them. Whilst this would act as a safeguard in the study, this also was felt to be good practice in terms of ensuring relevant departments/services who may be impacted by the research were made aware of it taking place. I was surprised when I was later informed that there was no need for such a mechanism to be in place as I was not recruiting via the Trust.

7.4 Participant Recruitment

I had chosen to recruit participants from non-NHS sources as I felt this would allow participants to speak freely of their experience, without fear of possible recrimination. This was based on the sense that if I recruited through NHS services, participants may feel that even with assurances of confidentiality they may in some way still be visible as taking part in a research study regarding patient safety which may in turn impact upon their care. Whilst it is hoped this would not happen, comments revealed within the research confirm there may be a fear of speaking out about patient safety problems in case of “comeback” (Susan).
On reflection, I have wondered if with a carefully designed research study I may have been able to recruit through NHS services. Although, given my initial difficulty in finding advocates for my study I am unsure how easy this would have been. Nevertheless, I feel in some ways there may have been a missed opportunity in carrying out this research to serve in itself as an opportunity to raise the profile of the experience of diagnostic error by having knowledge of the study present within services where it is theorised such events may occur.

I chose to recruit participants through support groups and organisations, which are typically peer led. Having had previous experience working with such groups, I felt these would represent a recognised site at which potential participants may be found. Furthermore, through the official structure of such groups and organisations I felt there was the opportunity to engage with gatekeepers easily, but also to allow a distance to be kept from difficult individual personal experiences at the first instance. I chose to initially contact groups and provide them with information about the study and to request the opportunity to attend in person to discuss/recruit for the study. I felt this approach would give groups the control and ability to respond to what I envisaged may be a difficult topic for some.

I found the recruitment process to be challenging and at times not straightforward. I found myself needing to rely on the good intentions of members of the public as opposed to persons doing a professional role where more may be expected in terms of making arrangements for attending groups or conducting interviews. At times this created a challenging dynamic whereby my reliance on participants to collect data was prioritised above all else. For example, one participant cancelled two arranged interviews at short notice resulting in loss of research time and also room booking fees for a community venue. I found this to be a frustrating experience at the time as I felt the pressure to obtain data, but recognise this as a likely factor of conducting such research.

In recruiting for the research I typically would attend a group and speak for a short while about my research, field any questions then ask any potentially interested parties to speak with me afterwards or to contact me via telephone or email. In this process I felt I faced a number of challenges. Firstly I found myself to be a target for some hostility by
individuals who felt they had experienced a poor standard of care, as I became an embodiment of the NHS. Similarly, I also encountered a lady who had suffered due to a medication error in her care who expressed a strong desire to be part of the study as she wanted the opportunity to tell her story. Unfortunately as she did not meet the criteria I was not able to recruit her. Whilst such experiences are not necessarily new with regard to clinical experiences of a similar nature, I found being positioned as a researcher rather than clinician initially a difficult adjustment. However, being able to interact with people who may have experienced what they perceive to have been patient safety incidents in this way was a humbling experience but also gave further inspiration that the research I was undertaking had merit.

7.5 **Data collection**

I found the process of data collection to be something I looked forward to in the research process as although I had read and studied around the topic for some time, the opportunity to witness the lived experience was exciting. At the same time, I was anxious that what was my research data was a very difficult life experience for the participants. I was particularly careful to try to make participants as comfortable as possible throughout the process, ensuring interviews were arranged around their schedule, ensuring all expenses were paid, checking the rooms hired in advance for suitability and providing drinks and tissues within the interview itself. I feel my thinking had been inspired by my training placement at the time within a Dynamic Psychotherapy Service where thinking about ‘the frame’ for therapy, how this is created and its purpose. Whilst it is not possible to mirror this in research I was certainly inspired by these ideas. This also included time in advance of the interview and indeed on the day to emphasise the idea of the process being like a ‘one sided conversation’ and that my approach will be more naïve and curious, and may feel in some ways ‘artificial’ (Smith *et al.*, 2009). I was also conscious that whilst efforts to develop rapport with participants is considered an important aspect of qualitative research (Kvale, 2003), this felt at times difficult to do within a single research interview and did reflect upon what data may have been collected had this taken place over a number of meetings.
In the interviews themselves I found the initial tension between therapeutic and research modes of functioning difficult. Having practised this during an IPA training weekend I had some foresight as to how this would be but still found this to be a challenge in the moment. For example, the desire in a therapeutic context may be to identify links, relationships and patterns based on a client’s presentation, both verbal and non-verbal, yet such interpretations were to take place post hoc. Whilst this was to some extent frustrating as it may have facilitated a deeper understanding, I recognised the limitations and expectations of the research interview, noting participants had not contracted for therapy. I found the reflective diary useful in these instances to allow me to note my ‘wonderings’ within and after interviews, particularly to be able to come back to these during the analysis.

I had developed an interview schedule initially as part of the research proposal stage, and then developed this over time. I was aware of the mixed appraisals of using interview schedules and how they may serve to both shape and inhibit the data but also to how they can aid clarity and make best use of interview opportunities. As such I decided not to work rigidly with the interview schedule but to aim to let the conversation flow and be led by the participant, bearing in mind however, particular topics and ways of opening these up as detailed in the schedule. However, on reflection I am uncertain of this approach. Firstly, when seeking an inductive approach to this study, such questions and preconceived means of accessing particular experiences may have imposed something on the data. Similarly, my own questions were loosely in a temporal sequence and the interviews themselves followed this. Whilst I feel this is perhaps more of a reflection of ‘cancer journey’ I cannot be completely sure of my influence in this process. On reflection, I feel the use of the schedule was in part offering me a sense of reassurance within the interview, and as a novice researcher I feel now more able to consider alternative approaches. In writing up my research and noting how intertwined cancer and diagnostic error seemed to be in the data I would be interested to know how the data may have looked had I used a single question (such as “Can you tell me about the experience of diagnostic error?”) to start the interview and then be led by the participant.
7.6 Analysis

I chose to have the research interviews professionally transcribed due to practical reasons. Whilst these reasons are still valid I am conscious that in taking this option I denied myself the opportunity to fully engage with the data through the transcription process. Upon receipt of the transcripts I took time to ensure they were anonymised and personal identifiers were removed which did give me the opportunity to become more familiar with the data. However, on reflection and in particular the difficulty I found in the analytic process with being able to consider participant narratives and the themes encompassed, I am left to wonder how being able to undertake the transcription myself may have impacted upon this.

I found the analysis process to be particularly demanding for a number of reasons. Firstly, I was keen to ensure I attempted to carry out good quality research and commit time to the analysis. However, I found in practice this was more challenging, as although I had taken ‘blocks’ of research leave to enable me to become engrossed with the data in analysis and also to fit with training placement demands, this meant analysis had become a concentrated process. In contrast to my experience of completing the literature review, which was in itself a form of primary research (meta-ethnography), where I had taken time to analyse and reflect upon the data, this was more difficult with the research project and the demands on time. My learning from this process going forward to future research and indeed similar clinical tasks would be to ensure such analysis, where possible, is spread over time. Furthermore, I feel the amount of data I collected was perhaps too large given the time constraints of completing a DClinPsy. With six interviews with an average length of 1 hour 40 minutes there was a lot of data to engage with. In light of this I have reflected on the reasons for this and my learning. As this was an average length it may in some way be representative of the nature of the topic I was researching that longer interviews would be required, and as suggested by the findings, the experience of diagnostic error was so tightly connected to the experience of cancer which is in itself a major life event. This was something I may have initially been naïve with regards to and could have better informed my research design, however, in designing the research I was keen to ensure the study of diagnostic error was within a context which would give it significance and salience.
I have also reflected on how my analysis may have been aided had I narrowed my focus within the data from the broad scope of examining the experience of diagnostic error to focusing on the particular, such as one of the three superordinate themes which emerged, or a particular point in what seemed to be a collective trajectory account. In this way, the construction of future research projects and questions will be better informed by this learning which I feel can only be experiential.

Although there were a number of challenges during the analysis of this research study I found the opportunity to engage with the data in an interpretative way to be an invigorating and insightful process. I was also made more cognisant of the power and responsibility involved with interpretation. Most notably the idea of ‘interpretative violence’ and the potentially damaging impact of interpretations which may impose something harmful and ill-thought on the data, and in turn the participants and groups studied (Willig, 2012). I found this particularly challenging as I came to consider the role of diagnostic error as a means of coping with the pain and distress of cancer by identifying an external cause for such suffering. Whilst I feel such an assertion is grounded in the data, I felt I was in some way further invalidating the experience of participants and that the use of terms such as ‘denial’ and ‘disavowal’ could be considered pejorative and hurtful without context. This was something I found especially challenging, as the experience of participants itself was one of invalidation and I was concerned my own interpretations may be perceived in such a way. However, I found with discussions with my supervisor and further reading able to make better sense of this and identify this as being a feature of such research to search for such ‘secret gems’ which participants themselves may not be aware they reveal (Smith, 2011b). In particular I was able to make better sense of the need to balance representation with interpretation (Larkin et al., 2006). I also found particular solace in the following quote “Partial, temporary and tentative, we have a responsibility to position ourselves in relation to our data, and our position will not necessarily be the same as our informants (have no illusions they will not agree with each other either)” (Kidder and Fine, 1998, p.49; as cited in Larkin et al., 2006).
7.7 Writing the research report & Dissemination

I found the write up of the whole thesis to be both demanding but also enjoyable and engaging as I had the opportunity to give voice to my research experience and to offer something to the existing research in this area. This at times was difficult to capture in what was initially a daunting word count but later seemed a restriction as judicious pruning was often required to help distil and succinctly capture elements of the research. Whilst frustrating in some ways, I have been able to recognise this as a valuable skill, one which I will continue to nurture in both future research and clinical opportunities.

In addition to submission of the thesis for academic purposes I hope to put both parts forward for publication as I believe they offer a new contribution to the existing literature. To have parts of this work published would present a great personal achievement and sense of completion for the DClinPsy process.

7.8 Reflections on the process

The research experience has also influenced my approach to clinical work. Firstly, I have found great pleasure and interest in exploring interpretation as a concept within both research and clinical practice, to consider the power and different purposes they can serve (Willig, 2012; Ricoeur, 1970). This is something I will continue to be mindful of and pursue in my learning. A finding of this study was to recognise the role of diagnosis and indeed its transformative power and the meaning it creates of subjective experience which is accessible to others. Throughout training I have found myself to be sceptical of the merits of diagnostic labels of emotional and psychological distress, yet the experience of this research study has enabled me to become more understanding of the benefits that having ‘official’ recognition from health professionals of suffering can offer.

Finally, the two overriding personal learning points I have from this experience are to recognise the worth of working towards ‘good enough’ and ensuring enough attention is paid to self-care. Both of which I am sure will be valuable in my future career as a Clinical Psychologist.
8 References:


Appendices

Appendix A – Author guidelines for target journal

Medical Education

Author Guidelines

*Medical Education* is an international, peer-reviewed, journal with distribution to readers in more than 80 countries. The journal seeks to enhance its position as the pre-eminent journal in the field of education for health care professionals and aims to publish material of the highest quality reflecting world wide or provocative issues and perspectives. The contents will be of interest to learners, teachers and researchers. It aims to have a significant impact on scholarship in medical education and, ultimately, on the quality of health care by prioritising papers that offer a fundamental advance in understanding of educationally relevant issues. The journal welcomes papers on any aspect of health professional education.

1. The journal’s mission in education and research
Manuscripts and reviews submitted to *Medical Education* may be used by the editorial team for teaching and research purposes with potential authors and reviewers. Authors and reviewers may be asked from time to time to take part in surveys. Every effort will be made to protect confidentiality. Names will not be passed to third parties.

2. Ethical issues
Manuscripts should be prepared in accordance with the *ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals* (see [http://www.icmje.org/](http://www.icmje.org/)). All manuscripts are considered on the understanding that they have not been published previously in print or electronic format and that they are not under consideration by another publication or medium. *Medical Education* is committed to the Committee on Publication Ethics (COPE) Code of Conduct ([http://publicationethics.org/](http://publicationethics.org/)). Authors should familiarise themselves with issues of publication ethics noted by COPE including duplicate publication, duplicate submission and ‘salami slicing’ as these behaviours will not be accepted. By submitting your manuscript to *Medical Education* you accept that your manuscript may be screened for plagiarism against previously published works.

3. Submission of manuscripts
Manuscripts should be submitted online at [http://mc.manuscriptcentral.com/medicaleducation](http://mc.manuscriptcentral.com/medicaleducation). Full instructions and support are available on the site. Papers not correctly formatted will be returned to the authors for correction and resubmission. It is recommended that, where possible, figures are embedded at the end of the manuscript in a single document. Identifying details (see section 8) are requested during the submission process rather than in a separate document. If you cannot submit online, please contact the Editorial Office (*Medical Education*, Plymouth Science Park, Davy Road, Plymouth PL6 8BX, UK. E-mail: med@mededuc.com).

4. Criteria for manuscripts
All manuscripts should meet the following criteria: the writing is clear and the information important and likely to be of interest to an international audience. For
research papers, the study methods should be appropriate and the data valid; and for both discussion papers and research papers, the conclusions should be reasonable, should be supported by evidence with proper citation, and should offer a compelling argument for how publication of the work would advance understanding for the field. Consonant with this latter criterion, we do not generally publish curriculum descriptions or quality evaluations primarily of relevance to specific locations. Papers are selected for peer review and publication based on these criteria. We publish roughly 10% of research manuscripts received each year. We welcome contributions from authors whose first language is not English, although it is recommended that the manuscript be reviewed and edited by a colleague or commercial editor who is fluent in written English prior to submission. All authors are encouraged to review the Guidelines for Reviewers (see Med Educ 2009; 43:2-4 and click ‘read’ at www.mededuc.com) prior to submitting their manuscripts.

5. Editorial and peer review process
All submitted manuscripts are read initially by the editor. One or more associate editors may also be involved in early decision making. Papers with insufficient priority for publication are rejected at this stage. Other manuscripts are sent to experts in the field for peer review. Author identity is not disclosed to reviewers, but reviewers are encouraged to sign their reviews in the interest of providing responsible feedback (see Med Educ 2012; 46:924-5). Guidelines for reviewers are available from www.mededuc.com click ‘read’. Average time to initial decision is less than one month and nearly all manuscripts receive such a decision within 12 weeks. All accepted manuscripts are edited according to the journal’s style and returned to the author as page proofs for approval. Authors are responsible for all statements made in their work.

6. Categories of manuscript
Medical Education publishes original research papers, review articles, special feature pieces, and short reports of research in progress or of educational innovation, commentaries, and letters to the editor. Specific guidelines are shown below:

**Original Research:** Generally less than 3,000 words, but longer papers will be accepted if the context warrants the inclusion of more text (see Med Educ 2010; 44:432). An abstract, structured under subheadings, of no more than 300 words must be included and the paper should contain a maximum of five tables or figures with references included in the Vancouver style. The paper will usually be organised using the Introduction, Methods, Results, and Discussion (IMRAD) structure. The introduction should include a strong conceptual framework that indicates how publication of the paper can be expected to fill a gap in knowledge that is important for the field to fill. The context of the work and your choice of methods must be made clear. Qualitative and quantitative research approaches are equally welcome. All papers must also clearly articulate how the findings should be interpreted and how they advance understanding of the issue under study. See Med Educ 2009; 43:294-6.

**Review articles:** Generally less than 3,000 words, plus a structured abstract of no more than 300 words. References must be in Vancouver style and up to 2 tables or figures are permissible. Systematic or critical reviews are welcome, but again, both types of reviews will be held to the criterion of needing to advance understanding beyond the current. See Med Educ 2008; 42:852-3.

**The Cross-Cutting Edge:** Generally less than 4000 words plus a structured abstract of no more than 300 words. References must be in Vancouver style and up to 2 tables or figures are permissible. Authors are warned that Cross-cutting edge papers are aimed at a very particular niche, which is to make cutting edge research (empirical findings and theory) that is relevant to but generally published outside of health professions education journals (i.e., cross-cutting) accessible to the readership of Medical Education. See Med Educ 42(10):950-1 for an overview and please send...
inquiries to med@mededuc.com if you are uncertain about whether or not your planned article fits this section. Ideas for topics/authors to recruit are also welcomed.

**Really Good Stuff: Lessons learned through innovation in medical education**

Short structured report of no more than 500 words with no figures or tables and one allowable reference. These articles should have a maximum of four authors and the report should be organised into three sections: What problem was addressed? What was tried? What lessons were learned? Detailed guidelines for this section are available online at www.mededuc.com click ‘read’ or from ‘Instructions and forms’ on the online submission site http://mc.manuscriptcentral.com/medicaleducation. Authors are advised to also see Med Educ 2011; 45 (5) 434-5.

**Commentaries:** Brief discussion articles focused on a particularly timely issue in health professional education, these papers are up to 1,000 words in length and should include no more than 10 references. 5 short ‘pull-out’ quotations (extracted verbatim from the commentary, each of which is approximately 18 words long) should be supplied to highlight the main messages the author would like readers to take away from their commentary. An abstract is not required.

**When I say…:** Generally less than 500 words plus 5 references. These brief articles are aimed at clarifying important terminology within the field in a meaningful and entertaining way. Interested authors should consult Med Educ 2013; 47:856-7 for details regarding the specific focus of this series. As well, they should review the “When I say…” virtual issue (accessible by clicking ‘read’ at www.mededuc.com) along with more recent issues of the journal to ensure that the topic of interest has not already been covered.

**Letters to the Editor:** Up to 400 words plus 6 references in Vancouver style. Brief descriptions of research results or educational innovations are not accepted as letters because such documents belong in one of the sections describe above.

7. **Preparation of manuscripts**

A checklist to assist in the preparation of the manuscript for submission and the guidelines for authors are available by clicking ‘instructions and forms’ on http://mc.manuscriptcentral.com/medicaleducation

**The anonymous manuscript**

A full version of the manuscript as well as a fully anonymised version should be submitted. In the anonymised version authors should NOT identify themselves or their institution. This includes ensuring that neither the filename nor the footer/header contains the authors' names or initials.

**Front matter:** Authors should restrict titles to 15 words or fewer (90 characters including spaces), and the editor reserves the right to edit titles. Most manuscripts should also include a structured (i.e., sub-titled) abstract of up to 300 words.

**Main text:** We encourage the use of the active voice, short sentences and clear sub-headings throughout the text. The manuscript should be double-spaced with a wide margin (at least 3 cm) on either side. All pages should be numbered. Do not use abbreviations without first defining the abbreviation in full. All scientific units should be expressed in SI units. Both numbers and percentages should be given (not percentages alone) when relevant. Where statistical methods are used in analysis their use should be explained in the setting of the study and an appendix given if the method is particularly unusual or complex. For all research-oriented manuscripts a consideration of the strengths and weaknesses of the approach used should be included. To ensure that your paper is as impactful as it can be, authors are encouraged to consider tips for optimising the likelihood that their work will be identified through an internet search (see http://exchanges.wiley.com/authors/writing-for-seo_334.html).

**End-matter:** Where figures, tables or illustrations from other publications have been used, appropriate permissions should be obtained prior to submission.
Referencing should be double spaced using the Vancouver style. Authors are advised to consult the BioMedical Editor (http://www.biomedicaleditor.com/vancouver-style.html) for details of the Vancouver reference style. Additional illustrations/appendices can be published on-line as supplementary material.

Keep a copy of the original manuscript for reference. An e-mail acknowledgement of receipt will be sent by the journal. Any material sent to the Editorial Office will not be returned.

We reserve the right to copy edit papers to house style before final publication, but substantive changes will be the responsibility of the authors.

8. The identifying information The corresponding author should ensure that the following information is provided for each author during the submission process:
a) The full address, institution and contact details. It is the corresponding author’s responsibility to ensure that each author holds a user account on the submission system and that the details held are current.
b) The individual contributions made by each author to the work described in the paper. All authors must meet all of the ICMJE criteria for authorship, which include:
   • Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
   • Drafting the work or revising it critically for important intellectual content; AND
   • Final approval of the version to be published; AND
   • Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.
c) Details of any funding
d) Details of any acknowledgements
e) A statement indicating whether ethical approval was sought and received for the research described. All work involving research on human subjects must comply with the Declaration of Helsinki (http://www.wma.net/e/policy/b3.htm) and authors must confirm, where appropriate, that informed consent was given. We expect ethical approval to have been sought from an appropriate body, such as an Institutional Review Board (IRB) or Independent Ethics Committee (IEC), where such bodies exist to review educational research. Both the manuscript itself and the online submission form should indicate the outcome of the application, even when the decision was that no ethical approval was required. Where no formal framework for ethical approval is currently available, please provide a statement confirming if ethical considerations were made by a qualified person outside the group directly involved in work reported in this paper. There should also be a statement confirming the following points: That the work was carried out in accordance with the Declaration of Helsinki, including, but not limited to the anonymity of participants being guaranteed and the informed consent of participants being obtained. See Med Educ 2009; 43:194-5.
f) Details of any potential conflict of interest. A conflict of interest exists when professional judgement concerning a primary interest (such as patients’ welfare or the validity of research) may be influenced by secondary interests (personal matters such as financial gain, personal relationships or professional rivalry).

9. Copyright/licences
Following acceptance of an article for publication the corresponding author will receive an email from Wiley's Author Services system that asks the author to log in to their online site where they will be presented with an appropriate licence for completion. Authors should ensure that they respond to this email promptly. Authors who wish to make their article open access and available to all on Wiley Online Library,
including those who don’t subscribe to the journal can do so by paying (or having their institution pay) for OnlineOpen. See http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1365-2923/homepage/FundedAccess.html for details about OnlineOpen as well as Wiley-Blackwell’s policy on compliance with funder mandates.

10. Proofs Proofs will be sent to the corresponding author via e-mail as an Acrobat PDF file. Your e-mail server must be able to accept attachments up to 4MB in size. Acrobat reader is required to read these proofs. It can be downloaded free of charge from www.adobe.com/. Authors are required to provide corrections promptly; if you are going to be out of e-mail contact for an extended period, please supply us with the contact details of someone who can attend to the proofs in your absence.

11. Fast tracking A fast tracking system is in place for selected manuscripts. Papers of particular importance or topicality will receive priority when being scheduled for publication. Accepted and published papers may be used for publicity and public relations purposes.
Appendix B - Review Protocol Template (from Booth et al., 2012, p59)

Background

The is a growing body of research which examines to phenomena of second victims – those healthcare professionals who are involved in medical error, to consider the impact of this experience and how best to support the individuals involved for both personal and professional outcomes. A recent review (Sirriyeh et al., 2010) highlighted methodological and measurement limitations to being able to generalise across all existing studies. In particular this has meant differing groups have been sampled by differing studies based on profession, setting, speciality, stage of training etc, and some of the data collection methods may not have captured the emotional intensity of the experience.

Objectives

This literature review seeks to focus on the emotional and psychological experience of medical error for medical doctors during a stage of training. Focusing the review on a particular group is aimed at increasing the ability to draw generalisations and conclusions about this group. Furthermore, this review will only examine qualitative studies in order to increase the capacity for the richness of the emotional experience to be best represented.

Criteria for Inclusion/ Exclusion

Types of studies

- Studies with a qualitative collection, reporting and analysis of results. This may include mixed methods where it is explicitly clear that results and analysis are drawn from qualitative accounts

Types of populations

- Medical doctors in training – to include students, trainee doctors, residents, internists, house officers
- Any speciality to be included as the homogeneity being sought is those that are still explicitly at a stage of learning

Types of Interventions or exposure/ Types of Outcome measures

- Studies examining the impact of medical error
- Article where results and analysis are based upon qualitative approaches which explicitly indicate concepts as being drawn from the data

Setting/ context (where applicable)

- Any medical setting in any country

Search Strategy

- Electronic databases to be used – PsycINFO, Medline, Scopus
- Additional databases - Agency for Healthcare Research and Quality Patient Safety Network (http://psnet.ahrq.gov/)
• Other methods – given criticism of the lack of consistent terms being used in the literature an approach which favoured sensitivity over specificity was taken
• Hand searching reference and citation lists of relevant articles
• Contacting leading experts in the field and authors of studies included, patient safety listserv

**Study Selection**

**Method of Review**

• Follow a typical Title>Abstract>Full text reading approach
• All to be carried out by TS

**Assessment of methodological quality**

• Use of the Critical Appraisal Skills Programme (CASP)
• Conceptual approach to quality appraisal for meta-ethnography

**Data extraction**

• Data extraction table developed

**Data synthesis**

• A metasynthesis approach will be taken to collate and analyse the qualitative data, based on Sandelowski and Barroso’s (2007) inductive and interpretative approach to Noblit and Hare’s (1988) meta-ethnographic approach to metasynthesis.
Appendix C - Search terms used for literature review

## Appendix D - Literature Review Data Extraction table

### Eligibility

<table>
<thead>
<tr>
<th>Does the study use qualitative methods?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does this study focus on the impact of medical errors?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Does the study use doctors ‘in training’ as the participants?</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

### Data Extraction

<table>
<thead>
<tr>
<th>Citation</th>
<th>Research question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epistemology</td>
<td>Theoretical framework</td>
</tr>
<tr>
<td>Were ethical considerations discussed, if so how were these addressed?</td>
<td></td>
</tr>
<tr>
<td>Author discipline</td>
<td></td>
</tr>
</tbody>
</table>

### Context and participants

<table>
<thead>
<tr>
<th>Context and participants</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Setting</td>
<td></td>
</tr>
<tr>
<td>Participants</td>
<td></td>
</tr>
<tr>
<td>Population</td>
<td></td>
</tr>
<tr>
<td>Stage of training</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
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<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Speciality</td>
<td></td>
</tr>
<tr>
<td>Type of error</td>
<td></td>
</tr>
</tbody>
</table>

### Study design and methods used

<table>
<thead>
<tr>
<th>Study design and methods used</th>
<th>Data collection method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theoretical model</td>
<td></td>
</tr>
<tr>
<td>Analysis method</td>
<td></td>
</tr>
</tbody>
</table>

### Findings

<table>
<thead>
<tr>
<th>Findings</th>
<th>How presented?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key Theme/ Concept 1</td>
<td></td>
</tr>
<tr>
<td>Key Theme/ Concept 2</td>
<td></td>
</tr>
<tr>
<td>Key Theme/ Concept 3</td>
<td></td>
</tr>
<tr>
<td>Key Theme/ Concept 4</td>
<td></td>
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<tr>
<td>Key Theme/ Concept 5</td>
<td></td>
</tr>
<tr>
<td>Key Theme/ Concept 6</td>
<td></td>
</tr>
<tr>
<td>Key Theme/ Concept 7</td>
<td></td>
</tr>
<tr>
<td>Author recommendations</td>
<td></td>
</tr>
<tr>
<td>Author identified limitations</td>
<td></td>
</tr>
<tr>
<td>Author conclusions</td>
<td></td>
</tr>
</tbody>
</table>

### Reviewer comments
Appendix E - Types of qualitative research findings by integration method

Figure 1 – Types of qualitative research findings by integration method, taken from Sandelowski & Barroso, 2007

<table>
<thead>
<tr>
<th>Closest to data</th>
<th>Farthest from data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>No finding</strong></td>
<td><strong>Topical survey</strong></td>
</tr>
<tr>
<td>Exploratory</td>
<td>Descriptive</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Not research</strong></th>
<th><strong>Equivocal as qualitative research</strong></th>
<th>Qualitative Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exclude</td>
<td>Qualitative metasummary</td>
<td>Qualitative metasynthesis</td>
</tr>
</tbody>
</table>

*Categories are not considered to be discrete and some studies may be borderline*
Appendix F - Conceptual approach to quality appraisal in meta-ethnography

Conceptual approach to quality appraisal in meta-ethnography based on Toye et al., 2013

<table>
<thead>
<tr>
<th>Is there a clear concept?</th>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Think about</strong></td>
<td></td>
</tr>
<tr>
<td>• Are there clear translatable concepts?</td>
<td></td>
</tr>
<tr>
<td>• Can you, as a reader, see ‘the woods from the trees’? i.e. move from the descriptive to conceptual or explanatory</td>
<td></td>
</tr>
<tr>
<td>• Is there a clear concept or do you find yourself recoding and abstracting further?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Does the study demonstrate interpretive rigour?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Trying to judge the quality of interpretation based on three areas that are essentially around reflexivity and a sense of self-questioning.</strong></td>
<td></td>
</tr>
<tr>
<td>1. <strong>What is the CONTEXT of the interpretation?</strong></td>
<td></td>
</tr>
<tr>
<td>• Is there a clear rationale and aim?</td>
<td></td>
</tr>
<tr>
<td>• A reflexive statement to position the research?</td>
<td></td>
</tr>
<tr>
<td>• Is the intended and actual sample identified?</td>
<td></td>
</tr>
<tr>
<td>• Who is the researcher?</td>
<td></td>
</tr>
<tr>
<td>• Do we know the ethical context of the study?</td>
<td></td>
</tr>
<tr>
<td>2. <strong>How INDUCTIVE is the interpretation?</strong></td>
<td></td>
</tr>
<tr>
<td>• How grounded in the data are the interpretations?</td>
<td></td>
</tr>
<tr>
<td>• Do they describe contradictory data?</td>
<td></td>
</tr>
<tr>
<td>• If not; why isn’t this there?</td>
<td></td>
</tr>
<tr>
<td>• Are the concept-indicator links clear?</td>
<td></td>
</tr>
<tr>
<td>3. <strong>Has the researcher CHALLENGED THEIR INTERPRETATION?</strong></td>
<td></td>
</tr>
<tr>
<td>• Have the interpretations been challenged in anyway? Eg use of constant comparison, theoretical sampling, co-coding, member checking</td>
<td></td>
</tr>
<tr>
<td>• Remember, key is not to necessarily confirm/ refute interpretations but to give greater insight to concepts</td>
<td></td>
</tr>
<tr>
<td>• Could there be an alternative interpretation of findings?</td>
<td></td>
</tr>
</tbody>
</table>
Conceptual approach to quality appraisal in meta-ethnography (Toye et al., 2013)
**Appendix G - Quality Appraisal of included studies using the CASP tool**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Engel <em>et al.</em>, 2006</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Can’t tell/ No</td>
<td>Yes</td>
<td>Can’t tell/ No</td>
<td>Yes/ Can’t tell</td>
<td>Yes</td>
</tr>
<tr>
<td>Fischer <em>et al.</em>, 2006</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Can’t tell/ Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Kroll <em>et al.</em>, 2008</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Can’t tell/ Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Mankaka <em>et al.</em>, 2014</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes/ Can’t tell</td>
<td>Yes/ Can’t tell</td>
<td>Yes</td>
</tr>
<tr>
<td>Martinez &amp; Lo, 2008</td>
<td>Yes</td>
<td>Can’t tell</td>
<td>Yes/ Can’t tell</td>
<td>Yes</td>
<td>Yes</td>
<td>Can’t tell</td>
<td>Yes</td>
<td>Can’t tell</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Mizrahi, 1998</td>
<td>Yes</td>
<td>Yes</td>
<td>Can’t tell</td>
<td>Can’t tell</td>
<td>No</td>
<td>No</td>
<td>Can’t tell</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Venus <em>et al.</em>, 2012</td>
<td>Yes</td>
<td>Can’t tell</td>
<td>Yes</td>
<td>Can’t tell</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Can’t tell</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Borderline cases were reported as boundarying two categories, e.g. ‘Yes/ Can’t tell’, with the former being noted as the category which appeared most suitable, but with a leaning towards the second.
## Appendix H - Typology of findings in included studies based on Sandelowski & Barroso (2003) model

<table>
<thead>
<tr>
<th>Closest to data</th>
<th>Farthest from data</th>
</tr>
</thead>
<tbody>
<tr>
<td>No finding</td>
<td>Topical survey</td>
</tr>
<tr>
<td></td>
<td>Exploratory</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Engel <em>et al.</em>, 2006</th>
<th>Conceptual description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fischer <em>et al.</em>, 2006</td>
<td>Conceptual description / Interpretive explanation</td>
</tr>
<tr>
<td>Kroll <em>et al.</em>, 2008</td>
<td>Interpretive explanation/ Conceptual description</td>
</tr>
<tr>
<td>Mankaka <em>et al.</em>, 2014</td>
<td>Interpretive explanation</td>
</tr>
<tr>
<td>Martinez &amp; Lo, 2008</td>
<td>Conceptual description / Interpretive explanation</td>
</tr>
<tr>
<td>Mizrahi, 1984</td>
<td>Interpretive explanation</td>
</tr>
<tr>
<td>Venus <em>et al.</em>, 2012</td>
<td>Conceptual description</td>
</tr>
</tbody>
</table>
Appendix I – Literature review findings related to ‘experiencing and managing an intense and co-constructed emotional response to error’

Findings related to third order construct ‘experiencing and managing an intense and co-constructed emotional response to error’ which replicate findings of previous reviews.

Emotional Impact

“Overwhelming guilt and shame and the first gut realisation that my lack of attention could cause real harm” (Martinez & Lo, 2008, p.737)

All participants spoke of an intense emotional experience following a medical error. The perceived source and focus of these emotions were reported were the trainee themselves, their medical colleagues, and the patient involved.

Trainee experience encompassed “wide variety of feelings” (Venus et al., 2012: p.281) notably fear, guilt, embarrassment, devastation, shame, self-doubt and anger described as “extraordinarily awful” (Fischer et al., 2006). This level of distress was so intense it could impair functioning, and was experienced both through active involvement in errors, but also as witnesses of others errors and distress (Martinez & Lo, 2008). Intensity of emotional responses emotional responses appeared influenced by the error impact on a patient, the implications for the trainee, and by any ensuing interactions with peers and colleagues. “More intense reactions were reported for mishaps associated with poor patient outcomes and higher levels of personal responsibility” (Engel et al., 2006, p.92).

Trainee emotion could be so intense that it engendered feelings of professional incompetence and self-doubt; “Then, I had to go on and see new patients. It was hard… I was so frightened to see new patients” (Mankaka et al., 2014). Leading some to question their chosen career path, with participants noting “I was going to resign” (Mankaka et al. 2014, p.5), or “I thought I should just give up, change career and open up a B&B” (Venus et al., 2012, p.281). Emotional responses expressed also appeared related to a violation of altruistic reasons for entering the medical profession by hurting rather than helping someone. “… an ultimate measure of their competence is their perceived ability to keep people alive, and conversely, not killing anyone” (Mizrahi, 1984, p.137). Fear of legal and professional implications was also prominent “I think everyone kind of worries about making that large error that’s really going to cause injury or harm to a patient that may result in legal action” (Fischer et al., 2006, p.421). For some, there was an indication that resolution of the emotional disturbance was difficult, enduring for a lengthy period of time during which rumination was common as the trainees “replayed the scenario in their minds” (Venus et al., 2012, p.283).

Talking as a means of coping

One intern said in his interview that he would have liked “just to sit around a coffee and for someone to ask me ‘so, how are you feeling?’” (Venus et al., 2012, p.283)
For participants who experienced medical error a central coping mechanism involved talking and receiving social support. The process of talking appeared to be nuanced and professionally contextualised, functioning both to address the emotional needs of the trainees, but also to help them learn from the errors.

Talking seemed to provide trainees a means of connection, “validation and reassurance” (Engel et al., 2006, p. 92) and reduce the isolation and horror experienced after an error. This helped to stabilise their sense of self as a person capable of helping others and appeared more valued and legitimate when provided by trainee peers or medical colleagues given “concerns those without medical training could not fully understand or relate to their experience,” but could still be useful as a means of “venting” (Engel et al., 2006, p.90).

**Constructive and defensive attitudes to errors**

> “Today, I feel better, but I think I will never forget [this error], and I don’t want to forget because I don’t want that to happen again.”  (Constructive attitude to avoid repeating the error)

Same resident also said

> “In fact, it is the whole situation that created the problem, and it is not only me and my intervention that made the patient die. This error should be shared [among all the care providers], but they let me carry the can.” (Defensive attitude to reduce emotional intensity)

(Mankaka et al., 2014, p. 6)

Trainees articulated a number of cognitive and behavioural strategies as they made sense of their experience of error and which allowed them to continue rather than abandon training. Three of the studies reviewed (Engel et al., 2006; Fischer et al., 2006; Venus et al., 2012) explicitly utilised a previously developed and imported concept of constructive and defensive attitudes to medical errors (Wu et al., 1991). This concepts was also present in other studies but not named as such (Mankaka et al., 2014).

Constructive attitudes encapsulated an approach seeking to ensure errors were not repeated in the future, typically focused on learning and suggestive of a problem-focused approach seeking to alter the environment or the self (Mankaka et al., 2014, citing Lazarus & Folkman, 1984). “What is important, I think, is that after you do the mistake, and also when you do something good, revaluate what you did and changes you can make” (Fischer et al., 2006, p.421). Constructive changes were exemplified by carrying out additional checks during examination or producing prescriptions, checking details with patients and senior doctors, taking time to make decisions and seek advice, as well as seeking academic source material.

Defensive attitudes were exhibited by participants where efforts appeared to focus on cognitive reappraisal of error in order to reduce/remove perceived culpability, and accompanying emotional response (Mankaka et al., 2014). Such concepts are notably privileged in Mizrahi’s
(1984) ethnographic research with house officers, highlighting three types of defences; denial, discounting and, distancing.
### Appendix J - Scott et al. 2009 Trajectory for the recovery of second victims

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Chaos and accident response</th>
</tr>
</thead>
</table>
| Stage characteristics | Error realized/event recognized  
Tell someone – get help  
Stabilise/ treat patient  
May not be able to continue care of patient  
Distracted |
| Common questions | How did that happen?  
Why did that happen? |

<table>
<thead>
<tr>
<th>Stage 2</th>
<th>Intrusive reflections</th>
</tr>
</thead>
</table>
| Re-evaluate scenario | How did that happen?  
What did I miss? |
| Self-isolate | Could this have been prevented? |
| Haunted re-enactments of event | |
| Feelings of internal inadequacy | |

<table>
<thead>
<tr>
<th>Stage 3</th>
<th>Restoring personal integrity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance among work/ social structure</td>
<td>What will others think?</td>
</tr>
<tr>
<td>Managing gossip</td>
<td>Will I ever be trusted again?</td>
</tr>
<tr>
<td>Fear is prevalent</td>
<td>How much trouble am I in?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage 4</th>
<th>Enduring the inquisition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Realization of level of seriousness</td>
<td>What do I document?</td>
</tr>
<tr>
<td>Reiterate case scenario</td>
<td></td>
</tr>
<tr>
<td>Respond to multiple “why’s” about the event</td>
<td></td>
</tr>
<tr>
<td>Interact with many different event responders</td>
<td></td>
</tr>
<tr>
<td>Understanding event disclosure to patient/ family</td>
<td></td>
</tr>
<tr>
<td>Physical and psychosocial symptoms</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage 5</th>
<th>Obtaining emotional first aid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seek personal/professional support</td>
<td>Why did I respond in this manner?</td>
</tr>
<tr>
<td>Getting/receiving help/support</td>
<td>What is wrong with me?</td>
</tr>
<tr>
<td>Litigation concerns emerge</td>
<td>Do I need help?</td>
</tr>
<tr>
<td></td>
<td>Where can I turn for help?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage 6</th>
<th>Moving on (one of three possible trajectories)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dropping out</td>
<td>Is this the profession I should be in?</td>
</tr>
<tr>
<td>Transfer to a different unit or facility</td>
<td>Can I handle this kind of work?</td>
</tr>
<tr>
<td>Consider quitting</td>
<td></td>
</tr>
<tr>
<td>Feelings of inadequacy</td>
<td></td>
</tr>
<tr>
<td>Surviving</td>
<td></td>
</tr>
<tr>
<td>Coping but still have intrusive thoughts</td>
<td>How could I have prevented this from happening?</td>
</tr>
<tr>
<td>Persistent sadness, trying to learn from event</td>
<td>Why do I still feel so badly/guilty?</td>
</tr>
<tr>
<td>Thriving</td>
<td></td>
</tr>
<tr>
<td>Maintain life/work balance</td>
<td>What can I do to improve our patient safety?</td>
</tr>
<tr>
<td>Gain insight/ perspective</td>
<td>What can I learn from this?</td>
</tr>
<tr>
<td>Does not base practice/work on one event</td>
<td>What can I do to make it better?</td>
</tr>
<tr>
<td>Advocates for patient safety initiatives</td>
<td></td>
</tr>
</tbody>
</table>
Appendix K – Statement of Epistemological Position

This research was undertaken following an epistemological position of critical realist social constructionism.

The social constructionist approach is interested in the way in which knowledge is generated, typically through social processes, but acknowledge the role of social, historical and cultural context which will impact such processes (Gergen, 1985; Willig, 2013). Such approaches may typically be of a more relativist stance, in which there are many valid perspectives of the same phenomena and data are not considered to be directly mirroring reality. However, not all social constructionist researchers are relativists and may follow a critical realist approach (Harper 2012). Critical realism asserts that we can explore reality but that accounts do not directly mirror it, but note the role of other factors which may influence the account of it.

A critical realist social constructionism position gives merit to both the data (e.g. transcripts) in detail to give understanding, alongside further interpretation to make sense of the data within a “broader historical, cultural and social context” (Harper, 2012, p.93). Within the context of the present study this might include how individual accounts of diagnostic error may be shaped by broader notions of error and cancer beyond the individual experience.

The choice of such an approach is based on the researcher’s stance and is consonant with the epistemological flexibility of IPA (Larkin et al., 2006). Through its devotion to the idiographic and phenomenological aspects of the individual experience of participants the social constructionist elements are fulfilled in IPA. However, IPA’s commitment to go beyond the descriptive (Smith, 2011) and offer interpretation is recognised in this research study as being in line with a critical realist stance to consider the broader context of meaning to participant’s accounts, meanings which may not be apparent to them.

The process of the researcher making sense of the participant making sense of their experiences, known and the ‘double hermeneutic’ (Smith and Osborn, 2008) positions the researcher as part of the context of the meaning making of the study. As such, the intersubjective element of the research process must be acknowledged. The meeting of researcher and participant questions whether interpretations belong to or speak of the participant or the phenomenon under examination. Whilst an aim of using interpretative approaches is to help develop and emphasise a narrative drawn from the data which will be in some way illuminating and of utility, such an approach may also have unintended consequences. Negative impact of interpretations may take the form of distortions of accounts, the silencing of voices we seek to amplify in qualitative research, propositions of inferiority and possible infringements of the rights of participants and has been terms by some ‘interpretative violence’ (Willig, 2012).
Such risks highlight the need for researchers to adopt a reflective approach, in addition to being competent to approach interpretation responsibly, explicitly this was achieved through; ensuring the aims of the research were prioritised and clearly stated to participants; ensuring the participant voice is not lost; and, being open to alternative interpretations of the data (Willig, 2012).

Taking a reflexive approach allows for the researcher’s own preconceptions and foreunderstandings to be accounted for to remove or lessen challenges to interpretations (Shaw, 2010; Smith et al., 2009). The researcher came to this research study with previous clinical experience of working in a medical psychology setting, including work with individuals adjusting to experiences of cancer. The researcher also has experience of being both a patient and a primary relative of someone experiencing healthcare problems requiring prolonged engagement with healthcare professionals and treatment. Throughout the study a reflective diary was kept to aid the identification and tracking of the researcher’s stance which may have bearing on their interpretations of the data.

References:


Appendix L - Research Ethics Committee Correspondence

09 May 2014

Mr Tim Siggs
Trainee Clinical Psychologist
Leicestershire Partnership Trust
Clinical Psychology
104 Regent Road
Leicester
LE1 7LT

Dear Mr Siggs,

Study Title: Understanding the experience of perceived diagnostic error in individuals diagnosed with cancer: An Interpretative Phenomenological Analysis

REC reference: 14/EN/0147
IRAS project ID: 143711

The Research Ethics Committee reviewed the above application at the meeting held on 28 April 2014. Thank you for attending to discuss the application along with Dr Noelle Robertson; Academic Supervisor.

Documents reviewed

The documents reviewed at the meeting were:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advertisement</td>
<td>2</td>
<td>24 March 2014</td>
</tr>
<tr>
<td>Covering Letter</td>
<td></td>
<td>24 March 2014</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td>3</td>
<td>15 January 2014</td>
</tr>
<tr>
<td>Investigator CV</td>
<td></td>
<td>27 March 2014</td>
</tr>
<tr>
<td>Other: Summary CV for Supervisor</td>
<td></td>
<td>01 March 2014</td>
</tr>
<tr>
<td>Other: Non-NHS Site Specific Form</td>
<td>143711/586694/7/580/227028/295524</td>
<td>17 March 2014</td>
</tr>
<tr>
<td>Other: GP Details Form</td>
<td>2</td>
<td>24 March 2014</td>
</tr>
<tr>
<td>Other: Summary of SU Consultation</td>
<td></td>
<td>14 January 2014</td>
</tr>
<tr>
<td>Other: Participant Debrief Sheet</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Other: Evidence of Professional Registration | | 15 October 2012
Participant Consent Form | 2 | 24 March 2014
Participant Information Sheet | 2 | 24 March 2014
Protocol | 3.2 | 22 March 2014
REC application | 143711/586239/1/37 | 24 March 2014
Referees or other scientific critique report | | 20 November 2013
Summary/Synopsis | 1 | 27 March 2014

Provisional opinion

- The Chair asked how participants who became distressed during the interviews could be accommodated. The researchers responded that they will assess the situation on an individual basis and either pause the interview or alternatively ask the participant if they wish the interview to be terminated. Should participants still remain distressed at the end of the interview, this would be discussed and the impact it has had on the participant gauged by the researcher. Should the participant feel they need to speak to someone else, the researcher will contact a third party such as the participant's GP or Macmillan Cancer Nurses.

- The Chair asked for clarification on the GP's role in helping with this support. The researchers responded that they would write to the GP regarding concerns manifested at the interviews.

- The Chair pressed for how the researcher would deal with the situation should the participant's distress warrant immediate concern. The researchers responded they would contact the crisis team or alternatively the participant's GP.

- The Chair asked the researcher about the perceptions of patients in respect of system problems and individual problems in regard to diagnostic error and asked how they will 'tease out' the difference. The researchers responded that although a patient's perspective is often to identify individuals, evidence is that errors are usually due to the system. The researchers responded that they will be able to pick up on themes.

- The Chair asked about the rationale of asking for the GP's details if the GP is perceived to be the source of the problem. The researchers indicated that the details have been requested so that support could be obtained if the patient became distressed.

- The Chair asked about the location of the interviews. The researchers responded the interviews will take place on the university premises if convenient for participants or alternatively community buildings could be considered. There will be no interviews taking place in participants own homes.

- The Chair raised the concerns of the Committee regarding the stated information around storing data at home on a personal laptop or USB stick. The researchers agreed that it would be more appropriate to use the university server for storage of data and to access it remotely if needed.

- The Chair explained the Committee's discussion regarding the long statement in the
Participant Information Sheet regarding the purpose of the study. An alternative phrasing could be offered within the final opinion letter should the study be given approval with conditions. The researchers agreed to this.

The Committee is unable to give an ethical opinion on the basis of the information and documentation received so far. Before confirming its opinion, the Committee requests that you provide the further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

1. The section of the Participant Information Sheet entitled 'What is the purpose of the study' please re-word as follows: "The study aims to understand this experience from the patients' perspective and to consider what impact this experience has had on them. We hope this will raise awareness of the perspective of patients who have experienced such events and to consider the particular needs of such individuals." Many committee members found the original important sentence confusing.

2. In the section of the Participant Information Sheet headed 'What are the potential benefits of taking part?', the phrase "to reduce diagnostic errors" should be removed as this is not achievable with this study.

3. The Participant Information Sheet should include the following phrase: "This study will not be trying to identify individuals who might be blamed for any errors."

4. Please include a statement in the Participant Information Sheet which explains where the interviews will take place.

5. It needs to be clear what will happen to participants data should they choose to withdraw from the study. Please include either: "If you choose to withdraw from the study we would plan to use any information already giving during the interview but would ensure that your identity remains hidden" or "If you choose to withdraw from the study, we may not be able to remove any information already given as this has already been transcribed and made anonymous".

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact [REDACTED] REC Manager on [REDACTED]

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date
of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 08 June 2014.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

14/EM/0147 Please quote this number on all correspondence

Yours sincerely

[Blurred text]

Chair

Email: NRESCommittee.EastMidlands-Nottingham2@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to: Leicestershire Partnership NHS Trust
27 May 2014

Mr Tim Siggs
Trainee Clinical Psychologist
Leicestershire Partnership Trust
Clinical Psychology
104 Regent Road
Leicester
LE1 7LT

Dear Mr Siggs

<table>
<thead>
<tr>
<th>Study title:</th>
<th>Understanding the experience of perceived diagnostic error in individuals diagnosed with cancer: An Interpretative Phenomenological Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>REC reference:</td>
<td>14/EM/0147</td>
</tr>
<tr>
<td>IRAS project ID:</td>
<td>143711</td>
</tr>
</tbody>
</table>

Thank you for your letter of 24 March 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager [redacted] NRESCommittee.EastMidlands-Nottingham2@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the
study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact the HRA does not, however, expect exceptions to be made.

Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites
NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copies of advertisement materials for research participants</td>
<td>2</td>
<td>24 March 2014</td>
</tr>
<tr>
<td>Covering letter on headed paper</td>
<td></td>
<td>24 March 2014</td>
</tr>
<tr>
<td>Interview schedules or topic guides for participants</td>
<td>3</td>
<td>15 January 2014</td>
</tr>
<tr>
<td>Other [Participant Debrief Sheet ]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other [Evidence of Professional Registration ]</td>
<td></td>
<td>15 October 2012</td>
</tr>
<tr>
<td>Other [GP Details Form ]</td>
<td>2</td>
<td>24 March 2014</td>
</tr>
<tr>
<td>Other [Non-NHS Site Specific Form ]</td>
<td>14371/5866947/580/227028/255624</td>
<td>17 March 2014</td>
</tr>
<tr>
<td>Other [Summary CV for Supervisor ]</td>
<td></td>
<td>01 March 2014</td>
</tr>
<tr>
<td>Other [Summary of SU Consultation ]</td>
<td></td>
<td>14 January 2014</td>
</tr>
<tr>
<td>Participant consent form</td>
<td>2</td>
<td>24 March 2014</td>
</tr>
<tr>
<td>Participant information sheet (PIS)</td>
<td>3</td>
<td>19 May 2014</td>
</tr>
<tr>
<td>REC Application Form</td>
<td>14371/5862391/1/37</td>
<td>24 March 2014</td>
</tr>
<tr>
<td>Referee's report or other scientific critique report</td>
<td></td>
<td>20 November 2013</td>
</tr>
<tr>
<td>Research protocol or project proposal</td>
<td>3.3</td>
<td>19 May 2014</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td>Tim Siggs</td>
<td>24 March 2014</td>
</tr>
<tr>
<td>Summary CV for Chief Investigator (CI)</td>
<td></td>
<td>27 March 2014</td>
</tr>
<tr>
<td>Summary, synopsis or diagram (flowchart) of protocol in non technical language</td>
<td>1</td>
<td>27 March 2014</td>
</tr>
</tbody>
</table>

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed
guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

14/EM/0147 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

[Redacted]
Chair

Email:NRESCommittee.EastMidlands-Nottingham2@nhs.net

Enclosures: “After ethical review – guidance for researchers”

Copy to: [Redacted]
Appendix M - Participant Information Sheet (PIS)

University of Leicester

Clinical Psychology Department
104 Regent Road
Leicester
LE1 7LT
T: 0116 223 1639
F: 0116 223 1650

Participant Information Sheet
Cancer patients experience of diagnostic error

You are being invited to take part in a research study. Before deciding if you would like to take part or not, it is important that you understand why the study is taking place and what it will involve. Please read the following information carefully and take time to consider if you would like to take part. You may wish to discuss taking part in the study with a friend, relative or someone you trust. If you have any questions which are not answered here, please contact the Tim Siggs on the details listed at the end of this information sheet.

What is the purpose of the study?
The study aims to understand diagnostic error from the patients' perspective and to consider what impact this experience has had on them. We hope this will raise awareness of the perspective of patients who have experienced such events and to consider the particular needs of such individuals. This study will not be trying to identify individuals who might be blamed for any errors.

What will happen if I take part?
If you agree to take part the researcher will arrange to meet with you in order to complete an interview. The interview is likely to take no longer than ninety minutes, although it may be shorter than this. Breaks can be taken during the interview. The interview will focus on your experience of diagnostic error and what this has meant for you. The interview will be recorded and then transcribed. Once your interview has finished your part in the research is complete.

Where will the interviews take place?
The location of the interviews will be either a University of Leicester premises if convenient for participants or alternatively community venues will be considered where this is not possible.

What are the potential risks of taking part?
It is not envisaged that there will be any risks in taking part in this study. However, talking about your experiences might be something people can find upsetting or uncomfortable. The researcher will discuss with you at the end of the interview any aspects you may have found particularly distressing and will be able to signpost you to further sources of support if this is deemed necessary.
What are the potential benefits of taking part?

To participate in this study you may find it to be a positive experience and the chance to reflect on and vocalise thoughts and feelings regarding your experience. Participants will also be helping to contribute to research seeking to better support patients who have experienced diagnostic error.

Will my information be confidential?

All of the information you provide will be confidential and the interview you give will be anonymised and all personally identifiable bits of information will be removed. Interview data will be kept on encrypted computer hardware and be destroyed five years following the study.

The only exception to confidentiality would be if concerns were raised during the interview that there was a risk of significant harm to you or someone else, the researcher may be obliged to break confidentiality. Should this situation occur, the researcher will seek to discuss this with you and what steps may be involved, for example, contacting your GP to arrange for additional support.

What will happen if I choose to withdraw from the study once I have taken part in the interview?

You are free to withdraw from the study at any time. If you choose to withdraw from the study, we may not be able to remove any information already given as this may have already been transcribed and made anonymous.

What will happen to the findings of the study?

The results of the study will be available in 2015/16 and will form the researcher’s doctoral thesis and it is expected to be published in a peer-review journal. If you would like to receive a summary of the findings please let the researcher know at the time of interview.

Has the study been officially approved?

The study has been reviewed and given ethical approval by NHS Research Ethics Committee.

Who is carrying out the study?

The study is being conducted by Tim Siggs, Trainee Clinical Psychologist as part of his Doctorate in Clinical Psychology at the University of Leicester. This work is being supervised by Dr Noelle Robertson (nr6@le.ac.uk or 0116 223 1639), Consultant Clinical Psychologist & Research Director University of Leicester Clinical Psychology Department.

Further Information

If you require further information please contact Tim Siggs by emailing ts228@le.ac.uk or telephoning 07591981868.
Appendix N - GP Information Sheet

GP Information Sheet

Cancer patients experience of diagnostic error

The welfare of participants taking part in this study is of paramount importance. In addition to your right to withdraw from the study at any time and for unscheduled breaks during the interview, in order to ensure your needs are met all participants are asked to provide contact details for their General Practitioner (GP). Should there be sufficient concern raised by yourself or the researcher, your GP will be sent a letter detailing any concerns relevant to your welfare. In any such event, this will be discussed with you, and only information relevant to your welfare will be shared and not wider details of your interview. To clarify, your GP will only be contacted should the interview give rise to concerns for your welfare and this will be discussed with you, either during the interview or in a follow up telephone conversation.

If you have any questions regarding this, please speak to the researcher.

<table>
<thead>
<tr>
<th>Name of GP</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GP Practice Address</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

Alternatively, if you do not wish to provide your GPs contact details at this time, please tick here to confirm that you understand that by doing so this may make it more difficult for the researcher to contact your GP should any matters of concern arise during your participation in this study.

Please sign to confirm you have read the above information regarding how the details you have provided may be used.

Signature........................................................................................................................................

Date........................................

Name..............................................................................................................................
Appendix O – Consent form

Clinical Psychology Department
104 Regent Road
Leicester
LE1 7LT
T: 0116 223 1639
F: 0116 223 1650

Consent Form

Cancer patients experience of diagnostic error

I, _________________________________, the undersigned, hereby consent to participate as a volunteer in the above named research project and consent to the audio recording of any interviews completed as part of this research project.

Audio tapes are confidential, will be stored securely and will only be listened to by specified people involved in this research project.

All audio tapes will be stored in a secure locked environment during the course of the research project. Following completion of the research all tapes and data will be held in a locked room at the Clinical Psychology Base at the University of Leicester and will be destroyed after five years, in line with university regulations. There will be no identifying information on the tapes or transcripts of interviews being stored.

Consent Statements:

I. The nature of the research project has been fully explained to me and I am aware of what my participation will involve. I have been provided with a detailed participant information sheet and understand that I will be required to be interviewed by a researcher.

II. I have been given the opportunity to ask questions about the research and these questions have been satisfactorily answered.

III. I understand that my participation is voluntary and that I may withdraw from the research at any time, without giving reason.

IV. I understand that the risk in this study is that I may become upset or distressed through speaking about my experiences and that I can ask for a break in the interview or a complete termination at any time and without giving reason.

I am submitting myself for participation in this research project with the full knowledge and understanding of the nature of the research project and of what will be expected of me. I agree to all consent statements detailed above.

Participant Signature: __________________________________________

Name in Block Capitals: __________________________________________

Date: ________________________________________________________

Researcher Signature: __________________________________________

Name in Block Capitals: __________________________________________

Date: _________________________________________________________
Participant Debrief Sheet

Cancer patients experience of diagnostic error

Thank you for taking part in this study, it is hoped that you have found the experience a worthwhile one. If you have experienced any difficult feelings as a result of the nature of the research interview and feel you would like additional support, this sheet has been provided to give you some details which may be of use.

- You may want to contact your GP as a source of support, they may also able to refer you to additional sources of support in your area
- If you feel you would benefit from more immediate medical advice, you can contact NHS Direct on 0845 4647 or by visiting [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk). In an emergency you can always call 999
- If you have a query, concern, require information or wish to make a complaint about the services provided by University Hospitals of Leicester (including Leicester General, Glenfield and Royal Infirmary Hospitals) you can contact the Patient Information and Liaison Service (PILS) by calling free phone 08081 788337 (Monday to Friday, 10am-4pm), by writing to Patient Information and Liaison Service, The Firs, C/O Glenfield Hospital, Groby Road, Leicester, LE3 9QP, or by emailing [pils@uhl-tr.nhs.uk](mailto:pils@uhl-tr.nhs.uk)
- Macmillan cancer support offer a help line which you can contact to ask any questions, seek support or just to have a chat by calling the free phone number 08088 080000 (Monday to Friday, 9am to 8pm). You can also visit [www.macmillan.org.uk](http://www.macmillan.org.uk)
- You may wish to draw support from family and friends and others you consider to be part of your support network. This could include the group/ organisation from which you initially found out about this study.
- If you would like to contact the researcher for this study, Tim Siggs, to discuss any matters further you can do so by calling 07591 981868 or emailing [ts228@le.ac.uk](mailto:ts228@le.ac.uk)
Appendix Q - Flow chart of research procedure

**Recruitment Phase 1**
- Formal contact made through named contact of support group to request personal attendance, providing PIS and requesting opportunity to speak with group
- Attend group in person to present overview of study and answer any questions/offer clarification, provide further PIS
- Provided researcher contact details to all present and took those of interested parties

**Recruitment Phase 2**
- Follow-up contact made with interested parties in days following initial meeting to discuss possible recruitment/ask further questions
- Further conversations with interested parties to ensure research criteria was met
- Matters of consent and individual need (e.g. accessibility) discussed
- Research interviews scheduled

**Interview**
- Carried out in University of Leicester building or community venue
- Audio recorded
- Average time 1 hour 40 minutes
- Participant debrief following interview with debrief sheet provided with contact details of relevant support
- Interviews were transcribed by professional transcription service working under a confidentiality agreement

**Analysis**
- Interpretative Phenomenological Analysis applied
- Supported by ongoing discussions with supervisor and peer IPA group
Appendix R – Interview topic guide

1. Cancer – In your own words
   - Could you describe in your own words your cancer?
   - In your own words, what is it like for you living with cancer?
   - How have you made sense of having cancer?
   - How does it affect you?

2. Diagnostic Experience
   - What was your journey to diagnosis like?
   - When were you diagnosed?
   - What sense do you make of your diagnostic experience?
   - Why do you think your experience was this way?
   - Has your feeling regarding this changed over time?

3. Experiencing Error
   - What is it like to experience diagnostic error?
   - When did you become aware that error had taken place? How did this happen?
   - What causes error?
   - What can reduce error?
   - What has your experience or diagnostic error taught you?
   - What has it been like to make sense of experiencing diagnostic error?

4. Treatment
   - What was your experience of treatment for cancer?
   - Was this in any way affected by your experience of error?

5. Adjustment
   - How have you adjusted to having cancer?
   - What changes has it made to your life?
   - How do you manage your health since being diagnosed?
   - What influences how you manage your health?
   - What role, if any, has the diagnostic error played in this?

6. Clinician Interaction
   - What has been the impact of your experience on your interaction with clinicians?
   - Has your view of the medical profession changed? How do you make sense of this?

7. Overall Impact
   - Do you think your experience of diagnostic error has changed the way you might have managed your health had this not happened?
   - How do you view health professionals involved in your care?
Appendix S – Examples of analytic process

146 that says you have a disease, you know, what have you got this constellation
147 that you’re trying to deal with in turn, another thing.
148 Interviewer
149 What difference do you think it would have made had you had, you know, the
150 label, an illness, sort of something to put to it?
151 Respondent
152 Well something would have been done. You know, it would have been a, it
153 would have been a great weight lifted off, my shoulders, I think that
154 something, I thought I’d got this huge heavy thing hanging over me, but there
155 was something really serious and I feel isolated, there was something and I
156 of course I thought it was the big C. You know, I kept asking people am I
157 paranoid? Perhaps it isn’t, perhaps it’s something else, it could be something
158 else. And at one point after one interview with, um, a doctor, who was very
159 nice. He said it could, um, what could it have been an ovary that had, um, um,
160 shrivelled up or something and was causing me a problem, you know, and, uh,
161 something that hadn’t been, occurred to me that it had caused all these awful
162 things. I don’t know, you know, it was a hard thing to say, to me it was
163 anyway. Um, so I don’t know, it was just, I was overwhelmed with it really.
164 Because it was my life, dealing with old problems. Um, and trying to get
– Can you tell me about any recent visits to see a doctor?
– How do you view your role in managing your health?
– Has diagnostic error changed the way you think or feel about yourself?

8. What else would you like to tell me about your experience?

• Prompts to help go ‘deeper’
  – How?
  – Why?
  – Can you tell me more about that?
  – Tell me what you were thinking?
  – How did you feel?
# Appendix T – Chronology of research process

<table>
<thead>
<tr>
<th>September to December 2012</th>
<th>Initial contact with research supervisor and development of ideas</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>January to May 2013</strong></td>
<td>Draft research proposal developed</td>
</tr>
<tr>
<td><strong>May 2013</strong></td>
<td>Research proposal submitted to University of Leicester (UoL) peer review</td>
</tr>
<tr>
<td><strong>June 2013</strong></td>
<td>UoL peer review of research proposal</td>
</tr>
<tr>
<td><strong>June to December 2013</strong></td>
<td>Preparation for REC</td>
</tr>
<tr>
<td><strong>October 2013</strong></td>
<td>IPA training weekend</td>
</tr>
<tr>
<td><strong>January 2014</strong></td>
<td>Service user consultation</td>
</tr>
<tr>
<td><strong>March 2014</strong></td>
<td>Submission to REC</td>
</tr>
<tr>
<td><strong>April 2014</strong></td>
<td>REC meeting</td>
</tr>
<tr>
<td><strong>May 2014</strong></td>
<td>Amendments made to protocol</td>
</tr>
<tr>
<td><strong>June 2014 to January 2015</strong></td>
<td>Full REC approval received</td>
</tr>
<tr>
<td><strong>August 2014 to February 2015</strong></td>
<td>Recruitment &amp; interview of participants</td>
</tr>
<tr>
<td><strong>February to March 2015</strong></td>
<td>Literature Review</td>
</tr>
<tr>
<td><strong>March to April 2015</strong></td>
<td>Analysis</td>
</tr>
<tr>
<td><strong>May 2015</strong></td>
<td>Write up</td>
</tr>
<tr>
<td><strong>May to July 2015</strong></td>
<td>Submission of thesis to UoL</td>
</tr>
<tr>
<td><strong>July to September 2015</strong></td>
<td>Viva preparation</td>
</tr>
<tr>
<td></td>
<td>Dissemination of findings</td>
</tr>
<tr>
<td></td>
<td>Preparation for poster presentation and publication</td>
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