A QUALITATIVE STUDY TO EXPLORE HEALTHCARE PROFESSIONALS' EXPERIENCES OF DISGUST WORKING WITHIN A PALLIATIVE CARE SETTING

By

Joshua Thomas Bailey Muggleton

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Introduction

On coming to this course, I set myself three personal learning objectives, with the overall aim improving my suitability for clinical work and research. First, to broaden my research interests, second to gain clinical experience in NHS settings with non-autistic populations, and third to become confident in qualitative research methods.

Prior to this course, I had extensive professional and personal experience with Autism and Autistic Spectrum Disorders. As a result, much of my previous research experience, and all my publications had been on autism, leaving me with a highly restricted field of study for a newly graduated psychologist. While Autism will always be of special interest to me, I felt it was important to develop parallel research interests outside this area, in order to grow as a well-rounded scientist, and ensure I explore alternative research options before becoming too specialised. Because of this, I set myself a goal of conducting the entirety of this research masters on subjects other than autism.

Just as my research interests before this masters had been largely restricted to autism, so had my clinical experience. During my summer holidays as an undergraduate I had managed to secure part-time work as an assistant psychologist. This was in a small private practice, and focused exclusively on autism. While this was excellent, in-depth clinical experience, I felt it was important for me to gain experience in the NHS. This was not only where I hoped to train and work as a clinical psychologist, but would also give me experience with a wider variety of clients, and in working with other professions. On a personal level, I also wanted to

prove to myself that I was able to transfer the clinical skills I had learned working with people with autism to other settings, and other clinical populations.

My final objective was born out of the lack of any teaching or research using qualitative methods in my undergraduate psychology department. Indeed, during the entirety of my undergraduate career, I did not read a single qualitative paper. I hoped by conducting a research masters focusing exclusively in qualitative methods, I would not only learn new skill set, but become familiar with another side to psychological research, and understand how I could apply these methods to my own research interests.

My first placement required me to use template analysis to understand the experience of parents of children with precocious puberty or premature adrenarche. As I elaborate in chapter one, I felt template analysis provided me with a gentle introduction to qualitative research methods. While this in itself was not enough to fulfill my third objective, it did give me the confidence to attempt my research project; a more in-depth, challenging, and much larger piece of qualitative analysis. However, while it was an interesting and enjoyable placement, I was not drawn to it in a way that encouraged me to develop it into a parallel research interest. Equally, while it did give me experience working with people without autism, this was not in a clinical setting.

My second placement was piloting a computerised cognitive remediation therapy programme for people with psychosis. While this study did not use either qualitative or quantitative research methods, it did give me my first experience of applied

research. It also accomplished my second objective; giving me experience working with a clinical population without autism in an NHS setting. More over, I found the multidisciplinary approach, diverse patient base, and the range of conditions made this setting more exciting, challenging and rewarding than private practice, and has enthused me to return to public sector after completing my masters.

My final research project was particularly daunting. Not only was this a large piece of research using an analytic procedure new to me, but unlike other available projects, it did not come with ethical approval. Having never applied for ethical approval from the NHS before, this was an extra, unplanned challenge that had to be accomplished under considerable time pressure. However, in addition to learning how to successfully apply for ethical approval, I feel by going through the process, my ability to cope with time pressure and uncertainty has dramatically improved. Through this, I have developed a more flexible, relaxed way of working, and I feel better prepared for undertaking larger research studies.

The final project accomplished my two remaining objectives. Firstly, by completing a significant piece of IPA analysis and receiving detailed feedback, I am now confident in my ability to use this methodology successfully and effectively. Equally, I have a greater understanding of other qualitative methodologies, giving me confidence in critically appraising and conducting qualitative research. Secondly, I feel I have discovered a parallel research interest. The study of emotions; how they are felt, how they effect our actions, and how they are perceived by others has been a particularly fascinating theme throughout the final project, and is one I am keen to explore

further. To that end, I am continuing to work with my supervisors to disseminate my findings and explore their implications.

Having completed my three objectives, I feel better placed to undertake clinical practice and research. As an undergraduate, despite an excellent education in research methods and statistics, my dissertation was, in part, dictated by the methodologies I knew. However, having completed this masters, not only do I feel confident that I can effectively draw upon and apply a wider range of research methods, but also that I can quickly learn and successfully apply completely new methods. As a result, I feel significantly more confident in myself in a scientist, and in my ability to answer more challenging research questions in a timely and professional manner.

CHAPTER 1:

A QUALITATIVE ANALYSIS OF PARENTAL EXPERIENCES OF CARING FOR DAUGHERS WITH CENTRAL PRECOCIOUS PUBERTY OR PREMATURE ADRENARCHE

Introduction

Puberty is a period of growth in height and weight. Primary sexual organs and secondary sexual characteristics also develop, and by the end of puberty, an individual is able to reproduce (Kakarla & Bradshaw, 2003; Partsch & Sippell, 2001). This development is caused by two distinct but parallel processes: adrenarche and gonadarche (Dahl, 2004).

Adrenarche is characterized by pubic and axillary hair growth (Pubarche), as well as body odor (Auchus & Rainey, 2004). This is a long-term process, and not usually visible before age eight in girls, or nine in boys. (Ibanez, Dimartino-Nardi, Potau & Saenger, 2000). Approximately one year after the start of Adrenarche, there is a release of gonadotropins; the start of gonadarche . These leads to the development of the gonads, releasing large amounts of estrogen in females (causing breast development and redistribution of fat), and testosterone in males (causing penile growth, development of muscles, and a deepening voice; Dahl, 2004). These endocrine processes are summarized in figure 1.1.

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Figure 1.1: Endocrine mechanisms in the onset of puberty. From Dahl, 2004, p11

Puberty

Hypothalamus   Pituitary

GnRH → pulses → FH/LSH → gonadarche
(release of inhibition)

[testosterone] → secondary sexual characteristics
[estrogens]

(?) → ACTH (?) → adrenarche
AASH
Other? → [adrenal androgens]

GRH → GH → growth spurt

Legend: gonadotropin releasing hormone (GnRH); growth hormone releasing hormone (GRH); follicle stimulating hormone (FH); luteinzing hormone (LSH), adrenocorticotropic hormone (ACTH); adrenal androgen-stimulating hormone (AASH), and growth hormone (GH)

Approximately 0.2% of females and <0.05% of males (Teilmann *et al*, 2005) will have some pubertal development before age eight in girls, or nine in boys (Colaco, 1997; Ibanez, Dimartino-Nardi, Potau & Saenger, 2000). When this development is limited to adrenarche, a diagnosis of Premature Adrenarche (PA) is given (Ibanez, Dimartino-Nardi, Potau & Saenger, 2000), however when both adrenarche and gonadarche occur, a diagnosis of Central Precocious Puberty (CPP) is made (Colaco, 1997). While an identifiable cause for CPP or PA (e.g neurofibromatosis) is common for males, the condition tends to be idiopathic in females (Pinyerd & Zipf, 2005; Soriano-Guillen *et al*, 2010).

Puberty is a challenging time for most children, but when the hormonal changes associated with it happen early, such in CCP and AP, they can present unique

problems. Girls with CCP often worry about comments from their peers regarding their physical differences, such as their breast development or pubic hair (Xhrouet-Henricks *et al*, 1992). This often leads to feeling of embarrassment and loneliness (Xhrouet-Henricks *et al*, 1992). These children are often withdrawn, tearful, and tended to show more symptoms of anxiety, depression (Xhrouet-Henricks *et al*, 1992), and a negative self-image (Solyom *et al*, 1980). Compared to their peers, children with PA are also more likely to show negative self-image (Solyom *et al*, 1980), and have more anxious and depressive symptoms (Dorn, Hitt & Rotenstien, 1999, Dorn *et al*, 2008). However, unlike CPP, behavioral problems, such as aggression are well documented in PA (Dorn *et al*, 2003; Dorn, Susman & Ponirakis, 2003).

Parents of children with CPP or PA may also experience "alarm, distress, distaste, guilt and confusion" (Kirk, Bandhakavi & Simon, 2008, p786), when coming to terms with their child's accelerated growth. In addition, the parenting of a child with CPP or AP is likely to be a very different experience. A child with CPP may look a lot older than their chronological and mental age due to their accelerated growth, leading to the perception of age inappropriate behavior. Children with AP may also exhibit moods of an intensity usually associated with teenagers, as well as face social challenges from their peer group.

To our knowledge, only one study to date has considered the effects of CPP and AP on parents. Solyom and colleagues (1980) interviewed 16 parents of children with premature adrenarche (n=4), premature thelarche (early breast development; n=6) and precocious puberty (n=6). These primarily focused on "the earliest thoughts,

fantasies and feelings"(p.387) parents had about the early signs of breast or hair development, and about the child's reactions to medical examination.

Solyom *et al.* (1980) reported that the primary concerns parents of children with PA relate to sexual "acting out" (p.391), as well as embarrassment about their child's condition, and denial of their sexual development. Parents of children with CPP's first worry is often that cancer may be causing their condition. However, once this is allayed, their worries mirror that of parents of children with PA. Interestingly, while most parents reported worries about their child engaging in sexual activity, at the same time they denied their child was developing sexually. This dichotomy could potentially have been a source of stress for parents.

Solyom *et al*'s (1980) study was focused purely on parents' reaction to the symptoms and diagnosis, and did not consider either the long-term experiences of parents, or changes in day to day living as a result of the condition. Therefore, this study aimed to understand the long-term phenomenological experiences of parents with a child CPP or AP in order to establish a more holistic representation of issues faced by these parents.

Methods

Ethics

Ethical approval was granted by the NHS Research Ethics Committee (West Midlands), as part of a larger study (appendix 1H)

Participants

Participants were recruited through a larger study investigating the psychological effects of CPP and PA on children with the condition. A purposive sampling method was used to select six girls with CPP or AP whose parents were comfortable talking about their child's condition. All parents gave informed consent. One parent asked to be removed from the study before interview. Information on child diagnosis, demographics and interview participants is displayed in **Table 1.1**.

Table 1.1
Participant demographic Data

Interview	Interviewees	Ethnicity	Siblings	Childs Diagnosis	Cause	Child age at diagnosis	Child age at interview
1	Mother	Asian-Indian	None	CPP	Idiopathic	8y 5m	9y 2m
2	Mother and Father	White British	1 older brother	PA	Idiopathic	6y 6m	8y 7m
3	Grandmother*	Afro-Caribbean	None	CPP	Triggered by cerebral shunt	9y 1m	10y 4m
4	Mother and Father	White British	1 older brother	CPP	Triggered by infantile arthritis	Unknown	9y 6m
5	Mother	White British	1 younger sister	PA	Idiopathic	5y 11m	9y 0m

* Grandmother was the primary carer and special guardian of the child

Procedure

Willing parents were contacted by a researcher to arrange an interview in their home. Interviews followed a semi-structured format, lasting approximately one hour. The interview schedule was devised collaboratively between the researchers and two supervisors specializing in qualitative research and puberty disorders (Appendix 1A). Follow up questions were used to investigate topics and issues that appeared to be of concern for parents, and focused on the emotional impact for parents, and elaboration of incidents the participants found challenging. Interviews were recorded using a dictaphone and transcribed within 48 hours.

Template analysis (TA; King 1999) was used to analyze the parent's accounts. This involves "the development of a coding "template", which summarizes themes identified by the researcher(s) as important in a data set, and organizes them in a meaningful and useful manner" (King, 2012). After interviewing, an *a priori* template was created, based on impressions from interviews, and Solyom *et al*'s (1980) findings (Appendix 1B). When applied to the first interview, new themes immerged, and the template was expanded and restructured (Appendix 1C). This was applied to the remaining four interviews, with minor additions being made where needed. After applying the template to all transcripts, the data within each theme was re-analyzed to ensure reliability. Lastly, the template was re-structured to better account for interconnections between themes, resulting in the final template.

To maximize validity, interviews were conducted in parents' homes, and regular supervision was used to reflect upon interviews, emerging themes, and the structure of the template. An audit trail was kept, as recommended for Template Analysis (King, 1999).

Analysis

Summary of Template

The Template diverged into two main themes. First, a narrative moving parents from acceptance to action (see Figure 1.2 and 1.3 for structure, and appendix 1D for example quotes). Second, an exploration of the parent-child relationship, and how this is changed to support the child (see Figure 1.4 for structure, and appendix 1E for example quotes).

Figure 1.2. Structure of the theme "Acceptance to action" part 1.

This figure shows the relationships between different subthemes for the first half of the theme "Acceptance to action". This covers from parents realizing something is different about their child ("what could it be?") to taking responsibility for their child's condition ("Parent's responsibility") for the condition

Figure 1.3. Structure of the theme "Acceptance to action" part 2.

This figure shows the relationships between different subthemes for the second half of the theme "Acceptance to action". This covers the different ways in which parents protective drive manifests, and the thoughts, worries and consequences they experience

Figure 1.4. Structure of the theme "The parent-child relationship".

This figure shows the relationships between different subthemes, with the child-side of the relationship at the top, the parent-side at the bottom, and the change in the relationship in the middle

Summary: Acceptance to action

Diagnosis allowed parents to move from worry over their daughter's symptoms to acceptance, and finally responsibility. During this time, worries emerged over their daughter's mood and future development. Parents' feelings of responsibility led to an increased desire to protect their child, motivated by a need for their child to be seen as "normal". As a result, parents would go to great lengths to control others' perception of their daughter. A more detailed summary can be found in appendix 1F.

Summary: The Parent-Child Relationship

Children were affected by greater than expected mood swings, in addition to having to deal with issues normally affecting teenagers, all at a very young age. While parents felt their child was mature and coped well, this was still a source of difficulty. Parents responded with greater communication, empathy, and patience. In doing so, parents were supported in part by family and friends, but felt significant support came from their child's doctor. A more detailed summary can be found in appendix 1G

Analysis of subthemes

Two subthemes were chosen for in-depth analysis on the basis of the author's impression of their importance to parents.

Analysis: Parent-child communication

Parents felt they had to change their communication styles with their children. Notably, they felt a need for honest communication with their child about the condition.

"Honesty is the key thing. I don't want to tell her […] a load of lies, because the reality is, it's gonna happen, and she's […] got to be taught the right way, you know, there's only one way to tell her, and that's to be honest and tell the truth, […]. You know, I've lied to her all these years about Father Christmas and the Tooth Fairy, I can't lie to her about this." [4:601]

This mother makes the comparison between the disorder and childhood myths. She says she cannot lie to her daughter about the disorder as she did about the myths. This comparison highlights the distinction between an adult and a childish topic, and seems to imply that she is talking to her child as if she was an adult. She emphasizes that she "can't lie to her about this", suggesting that the lies are told to protect children are not possible in this situation. This is too important to lie about, and that she does not feel there is any other course of action possible, other than to tell her daughter: "there is only one way to tell her, and that's to be honest". The fact that it is important again hints at the maturity of the conversation – that this is not childish things but serious in nature.

The hardest thing was explaining when she bleed […] I didn't really know how to explain to her what periods were, and thankfully it stopped, so I haven't really explained to her about periods, though, which I know is bad, but probably I will when she, she just understands (2:193)

While parents felt they need to be honest with their child, their level of openness in the information they give is moderated by their ability to explain the information. Menstruation in particular was challenging for mothers to explain. Here, one mother

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recalls how she did not know how to explain menstrual bleeding to her daughter. Further she seems relieved when the bleeding stopped, suggesting that not being able to talk to her daughter about the bleed was a source of anxiety for her. Additionally, her suggestion that her not telling is "bad" suggests she feels guilt that she has not explained this to her daughter, suggesting a belief that honesty is the only course of action.

> *"We're very open, we can talk about anything, erm, so at least she can talk to me. So I think that probably helps, […] its just hard sometimes" (5:47)*

In response to their openness, parents want the child to be open with them about their experiences. This mother highlights how important it is for her that her child is able to talk to her about anything. In particular, her phrasing "at least she can talk to me", suggests that she does not believe there is much that can be done to help her daughter sometimes, other than listening to her. For example, she cannot stop her daughters mood swings, however through having an open relationship, she can provide some support to her daughter.

Parents experienced both increased communication, and more honest communication. The drive behind this stems from a belief that this is something that the child has a right to know and understand, and a hope that in return for the parents openness, the child will feel able to talk about their problems with them, allowing parents to help further. The result is that communication between mother and daughter becomes more mature, perhaps adding to parents perception of both increased child maturity, and their child as both a child and a teenager.

The key motivator behind parents' protective actions was for the desire for their daughter to appear normal, and hide any indications of CPP or PA.

"Yeah, very anxious, yeah. I just. I don't want her to be seen as different, because she doesn't look different normally, and she isn't different than any other little girl, so, I don't want them to know the difference. (2:180)

While this mother insists that her daughter "isn't different than any other little girl", she also acknowledges that her daughter is different. If she believes that her daughter is different from the group norm, and fears ostracization, she may then want her daughter to be seen as "normal", and present a view she knows not to be true in order to conform to the group norm, in this case, insisting her daughter is normal. While conformity can result in attitude change (Hardy, 1957), because her daughter's differences are highly salient and regularly observed, the mother's personal attitude cannot change, explaining the two opposing statements.

You don't want your kids to be singled out in any way. If a child is slightly different, it's amazing how quickly other children pick up on it. I mean, they are, they're so clever at singling just certain things out, erm, and kids can be really mean, as well. I mean, I'm still, I went through a little bit of bullying when I was at school (5:223)

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Supporting this theory, this mothers' statement suggests that she is motivated to hide her daughters' differences for fear of bullying, or more generally, social rejection. Fear of rejection has also been found to lead to greater conformity (Hardy, 1957), and seems a likely explanation for how strongly mothers insist their child is "normal", when their personal views are otherwise.

All mothers experienced a strong drive to try and ensure that their daughters appeared normal. This appears to be motivated by fears their daughter may experience ostracization or bullying and from their social group, and is a significant cause of anxiety for parents. It is possible that reducing parents' fear of their child's differences being observed may reduce their anxiety. However, doing so would also reduce their protective behavior, and leave their child vulnerable. Given that individuals have been found to form groups over even minimal differences, leading to group bias (Tajfel *et al*, 1971), it is possible children would experience some social rejection.

Discussion

This study sought to understand the phenomenological experience of parents of children with CPP or PA. Parents appeared go through a process from acceptance to action, and experience significant changes to the parent-child relationship. In addition, worries, anxiety, and (in many cases) guilt were common contributors to the makeup of themes.

All parents felt a strong drive to protect their child, fearing they may be ostracized for their difference. Parents went to great lengths to ensure that they were not seen as

different from their peers, which was the cause of most the changes in their behavior. However, Solyom *et al* (1980) reported only two out of ten parents were "over protective", and only four of ten reported worries of social rejection. One explanation for this inconsistency is that Solyom and colleages focused on feelings and fantasies before and during diagnosis, where as this study took a long-term view. Therefore, parents may not have had time to consider the possible reactions from their daughters' peers on learning of her condition, or may not have experienced any negative reactions from their daughters peers as a result of the diagnosis. Such events might, according to our template, result in protective behavior.

We also observed that parents insisted their child was normal while simultaneously acknowledging their child was different, and theorized this was due to wanting to conform to the perceived social norm, for fear of ostracization. While a desire to be "normal" was not noted in Solyom *et al* (1980), they did find that parents worried about sexual acting out, while denying their daughter was developing sexually. Similarly, many mothers said their daughter "Isn't different than any other little girl' (2:180), yet still acknowledge their daughters development when discussing their worries and the difficulties they face.

Wanting to conform to a perceived social norm and denying any difference should not necessarily be limited to parents of children with PA or CPP. Factors affecting whether or not parents feel a need to conform, such as the visibility of the condition and the perceived social stigma need to be investigated to gain a better understanding of parents' experiences of conditions (enabling better support), and to improve social acceptance of medical conditions.

Parents worried about future growth, reproduction, and in the short term, their child's mood. In contrast, Solyom *et al* (1980) found nine out of ten parents worried about sexual acting out, an issue never mentioned by any parent in this study. Given that research on adult height of those with CPP started in the mid 1990s, (e.g Paul, Conte, Grumbach & Caplan, 1995), parents may have been unaware of the potential decrease in adult height in the 1980s, and are now better informed by doctors. However, recent research has also found that sexual development predicts sexual activity in females, regardless of age (Flannery, Rowe & Gulley, 1993), yet this worry has reduced. Given more sexualized popular culture (Coy, 2009), sexual acting out may be less of a concern for parents compared to height, reproductive and mood worries, and therefore not reported. Similarly, given parents were often reliant on doctors for informational support; changes to this information could directly affect parents' worries. This highlights the powerful position doctors have to affect the experiences of parents, and the need for doctors to think carefully about the medical, ethical and psychological ramifications of the information they give to parents, as well as ensure that their approach is consistent across the profession.

Because of the small sample size, it was not possible to separate the experiences of those with children with PA from those with CPP. However, it seems likely that those with CPP will have experiences, for example, relating to menstrual bleeding, that parents with PA would not. In addition, the inclusion of two cases of non-idiopathic CPP may have lead to less detail on worries related to possible causes, as this was only a relevant issue for three fifths of the sample. Future research should therefore

attempt to identify separate templates for CPP and PA, and where possible, identify differences while restricting their sample to idiopathic cases.

Additionally, although there is no minimum sample size for TA, it is recommended for "a middle range of sample sizes" (King, 2008). Therefore, the use of only five participants may mean that some themes (for example, fears over sexual acting out) may not have been discovered. Furthermore, because TA focuses on between participant differences, rather than the individual account (King, 2008), some of the context of parent experiences is lost, and subtler personal themes may have been missed.

Due to time constraints, it was decided to focus on parents with daughters, since these cases are more likely to be idiopathic. This means that our template is female centric, and may not be applicable to parents of boys with the condition. Given this research has highlighted feelings of anxiety and guilt among parents of girls with CCP or PA, research on parents of boys with these conditions is needed to build an accurate picture of their parents experiences, and the possible support they may need.

In conclusion, parents face significant difficulties caring for a child with CPP or PA. Parents experienced significant concerns over their child's growth, reproduction and mood, and an fear of their child being perceived as different. Thought therefore needs to be given on how to best support parents of children with these conditions.

Reflection

Before my placement, I had no knowledge of CCP or PA. Therefore, my first challenge was to quickly familiarize myself with existing literature in this area. Reviewing existing literature provided me with a good knowledge base, but my understanding of this area was best developed through discussing research with my supervisor. In the past, I have lacked the confidence in my own knowledge and opinions to do this. However, by attempting it, I feel my confidence in my ability to critically discuss a topic with my supervisor has grown, and I hope to maintain this in my future placements.

Since I had little interviewing experience, I spent time reading about how to conduct interviews for qualitative research, and conducted a practice interview. Additionally, I completed the NIHR Good Clinical Practice basic training, and familiarized myself with the NHS lone worker policy for my own safety, and to ensure my research was going to be conducted ethically and to the best, possible standard. While I felt nervous before each interview, my confidence grew, and by my final interview, I felt secure in my ability to pick up on important themes and to get the most out of each participant.

Before I started my analysis, I familiarized myself with Template Analysis through online resources provided by King (2012). However, while these provided me with a knowledge base, it was through the application of the technique that I came to a clear understanding of it.

My diagnosis of Aspergers Syndrome means that understanding others' perspectives is harder for me to do. By using TA, a less in-depth technique than IPA, I have been given a gentler introduction to qualitative analysis, and time to develop skills to overcome difficulties caused by my diagnosis. This has significantly increased my confidence in my abilities to apply IPA effectively in my summer project.

I often felt lost during my write up. The way in which qualitative research is written felt very different to anything I had previously done, and it took time for me to learn this new format. This difficulty was compounded by a very tight word limit for a word-heavy analytical technique. However by choosing to write a full report, I have become more confident and experienced in the style, rules and language for writing qualitative research, which I felt I needed in order to attempt my summer project.

In retrospect, I would have preferred to focus on only CCP, as while many issues parents with daughters with PA are the same; I felt there were some subtle differences that my template could not capture. Equally, because the two non-idiopathic cases may have also have provided confounds, but had to be used due to time constraints. I have learned that for my future research, I need to be more careful with my recruitment of participants to attempt to avoid possible confounds, such as those in this placement. I significant part in achieving this is going to be preparation, and allowing myself more time to recruit the best possible participants.

During the placement, I put significant pressure on myself by setting tight deadlines, which resulted in my transcriptions feeling rushed. Errors such as "their" vs "there", spell check errors, and the general presentation lead to me feeling the work was not

my best. During transcription, I felt that such problems did not matter, as they would only play a minor role in the finished piece. However, because I am feeding into a larger piece of work, I should have spent more time on this, and as a result, I am now spending time improving my transcriptions.

Finally, the research conducted during this placement is feeding into my supervisor's PhD work. In particular, themes relating to parents perception of their child's interaction with others is going to provide a comparison with the child's own perceptions, in the hope of establishing a detailed qualitative and quantitative picture of children's experiences of having CPP or PA.

CHAPTER 2:

DELIVERING A COGNITIVE REMEDIATION THERAPY (CRT) WITHIN AN EARLY INTERVENTIONS SERVICE

Introduction

Delivering a Cognitive Remediation Therapy (CRT) for Psychosis in an Early Intervention Service

Joshua Muggleton

For my second placement, I was working within an Early Interventions (EI) Service, piloting a computerized Cognitive Remediation Therapy (CRT) programme for people with psychosis.

Today

- Aims:
  - Provide an introduction to the rationale and evidence for CRT
  - Provide insight, based on my experiences, into how a computerized CRT program can be delivered in an Early Interventions Service
    - Problems and potential solutions
  - Reflect on the experience

During the next 20 minutes, I hope to provide you with an introduction to the rationale and evidence behind CRT, and my experiences piloting a computerized CRT programme within an EI Service. I will also discuss the problems (and potential solutions) we encountered using this protocol, before reflecting on my experiences working within the EI Service, and what I have gained form the placement

Back to Basics

- **Psychosis (in ICD-10, 1994) can include:**
  - Hallucinations
  - Delusions
  - Psychomotor retardation
  - Catatonia
- **Apparent more recently**
  - Cognitive deficits

The ICD-10 (1994) defines psychosis as a constellation of symptoms including hallucinations, delusions, psychomotor retardation and catatonia. However, more recently, cognitive deficits have started to be regarded as a "central feature" (p.531) of psychosis (Bowie & Harvey, 2006)

Cognition in Psychosis

▸ Timeline:
- ◦ Evident before first psychosis
- ◦ Moderate to severe impairment at first psychosis
- ◦ Several domains remain impaired in remission

(Bowie & Harvey, 2006; Wykes & Van der Gaag, 2001)

▸ Areas of impairment include
- ◦ Attention
- ◦ Working memory
- ◦ Visual and verbal memory
- ◦ Executive function

(Bowie & Harvey, 2006; Brewer *et al.* 2006; Barrett, Mulholland, Cooper & Rushe, 2009)

Cognitive deficits are evident from before the first episode of psychosis, and continue to decline during the first episode of psychosis. While some cognitive functions to improve in remission, many will remain impaired (Bowie & Harvey, 2006; Wykes & van der Gaag, 2001). Areas affected often include including working memory, attention, long-term memory and executive functioning (Barnett *et al*, 2005; Barrett, Mulholland, Cooper & Rushe, 2009; Brewer *et al*, 2006)

Cognitive Remediation Therapy

▸ "Significant association between neurocognition and functional outcome"

(p.133, Green *et al*, 2000)

- Psychosocial Skill Acquisition
  · Conversation skills, symptom management, basic life skills
- Social Problem-Solving ability
  · Identification of social problems and generation of solutions
- Community outcome
  · Occupational functioning, independent living, social relationships and support

(Green *et al*, 2000)

▸ CRT: Improve cognition → improve functional outcome?

There is evidence of a "significant association between neurocognition and functional outcome" (p.133, Green *et al*, 2000), which can be broke down into three areas:

- Psychosocial skills, such as conversation skills, managing symptoms and basic life skills

- Social Problem-Solving ability

- Community outcome: an individuals occupational functioning, independent living, and social support.

CRT therefore aims to improve cognition, in the hope that functional outcome for individuals with psychosis can be improved, leading to higher quality of life, and self esteem.

Cognitive Remediation Therapy

▸ "Brain training" tasks
  ◦ Tasks exercise different cognitive functions known to be impaired in psychosis.
  ◦ Emphasis on developing strategies
▸ Two key components to training:
  ◦ Verbalizing (i.e saying the strategy, task requirements, thoughts)
  ◦ Errorless learning (start easy, slowly increases difficulty)
    · Scaffolding (guiding by facilitator)

  (Wykes & van der Gaag, 2001)

 CRT presents clients with tasks similar to the "brain training" games commercially available to improve memory or cognitive performance. However, the tasks in CRT are targeted at areas of cognition known to be impaired in psychosis, and help the user develop strategies to make solving the tasks easier, thereby reducing cognitive load.

Wykes and van der Gaag (2001) identified two key components for effective CRT. First, that clients verbalize information. By saying the task requirements, strategy, and their thought process, clients are supporting their verbal memory by providing rehearsal, as well as maintaining their attention (Wykes and van der Gagg). Second, Errorless learning: this not only avoids de-motivation after past failures, but also in ensures that existing problems in memory do not lead to an incorrect response being remembered (Wilson *et al*, 1994). As part of this, scaffolding by therapists is used to

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improve motivation and recall, as well as to aid reflection on thought processes and

strategies.

Evidence for CRT

- Wykes *et al*, (2003)
  - Intensive OT vs CRT. 6 month follow up
    - Improvements in memory still apparent in CRT group
    - Improvements in social behavior and symptoms in CRT maintained
- Wykes *et al* (2007)
  - Small scale RCT
    - Significant improvements in cognitive flexibility
    - CRT had a moderating effect on the link between cognitive change and functional change
- See Wykes & Spaulding (2011) for review

While one research group has produced most of the recent literature around CRT, there is sufficient evidence to conclude that CRT does have a positive effect on functional outcome. However, it should be noted that improvement is not always across all cognitive domains

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Delivering a CRT programme

Placement Aim:
To deliver a new computerized CRT programme to outpatients with Psychosis and report on it's operation and efficacy

▸ Based at the Early Interventions service, Nuneaton
▸ 7 Individuals referred for CRT
  ◦ 1 completed
  ◦ 2 ongoing
  ◦ 4 discharged due to lack of attendance
▸ Sessions lasted approximately 90 mins
▸ Ran Tuesday – Friday for 9 weeks
▸ Each therapist worked 1:1 or 1:2 with clients
▸ CIRCuiTS

The aim of this placement was to deliver an new computerized CRT programme for outpatients with psychosis, and report on it's operation and efficacy. Based at the EI Service in Nuneaton, seven individuals were referred for CRT, of which one completed training and two are still receiving training. The remaining four were discharged after failing to attend more than two sessions, due to lack of motivation, an issue discussed later. CRT sessions lasted approximately 90 minutes, and were conducted four days per week for nine weeks. During sessions, therapists would work 1:1 or 1:2 with clients, guiding them through the CRT program: CIRCuiTS.

CIRCuiTS is a computerized CRT program, providing 31 tasks designed to improve cognition. Each task is repeated up to 14 times over the course of training, each time increasing in difficulty. The example shown here is rotations. This is the screen clients first see when starting a task, and contains both a general description of the task requirements, and the opportunity to view a demonstration of how to complete this type of task.

Before starting, clients were asked to reflect on their past performance and strategies by rating how difficult they predicted the task would be, and how long it would take. Often clients would rush through this stage, and therapists were required to slow clients down to ensure meaningful answers were given.

Clients were then asked to select one or more strategies to employ during the task. Strategies fell into two types. The first type required the client to do something, for example, rehearsing the instructions out loud, or visualizing the task requirements. The second type provided the client with tools for completing the task

For example, in this task, the client has to identify which of the four smaller images is different from the first. However, the strategy selected makes the computer force the client to respond yes or no to each of the four smaller images in order, thereby ensuring they consider each of the four possibilities.

Most tasks have two or more parts to it, and some of which would ask slightly different questions. For example, here, the client is required to identify which shape is different....

 …where as here, they are required to identify which one is the same. These changes were often subtle, and regularly overlooked by both the client and therapist, leading to errorful learning. This did, however, encourage both clients and therapists to re-read the question after every stage of a task

On completing a task, clients were given their score, and were required to reflect on how difficult they found the task, and the usefulness of their strategies. Again, clients often rushed this, requiring therapists to ask questions in order to ensure meaningful responses and reflection.

Discussion

Problem

▸ Motivation
- Requires large amount of effort to travel
  - Up to 2 hours travel time each way
  - Anxiety provoking
- Regular attendance required (4 times per week for 9 weeks)
- No immediate benefit
- Tasks tiring, not fun

There were some problems in implementing the therapy, the most severe of which was motivation. The EI Service at Nuneton covered a large area, meaning clients spent up to four hours a day on public transport to come to the service to attend therapy. Additionally, many clients experienced heightened anxiety when leaving home, or suffered from depression, both of which negatively impacted their motivation. Given that clients did not experience any immediate or tangible benefit from training, it is unsurprising that many felt unwilling to commit to traveling to the clinic regularly.

Solution

- ▸ Portable
  - ◦ Can take to clients
  - ◦ No travel issues – higher completion rates
  - ◦ Can be done online
- ▸ Little training of therapists needed
  - ◦ Could be done by most Mental Health Care Professionals with minimal extra training
  - ◦ Personal relationship may make training easier

However, one of the strengths of this programme is its portability. Since the program can be run from a laptop, or from any computer with an Internet connection, there is potential for taking the programme into clients' homes, thereby overcoming a significant motivational barrier. Equally, therapists required little training in order to facilitate the therapy, which may allow Healthcare Professionals already seeing clients on a regular basis to deliver this therapy as part of their existing work with clients. Furthermore, the existing rapport with clients would likely improve motivation, and transference of strategies developed during therapy into everyday life.

Problems and solutions

▸ Tasks start "too easy"
  ◦ Leads to rushing → errorfull learning
  ◦ Leads to boredom → lower motivation, poorer attention
  ◦ Balance needed between boredom and errorless learning
▸ Solution: Skip tasks?
▸ Solution: Adaptive program

Another problem was that many clients complained that the tasks were "too easy". This often led to them rushing through tasks, not reading instructions, and utilizing strategies. Additionally, many clients became bored with the task, attending less, and not working unless prompted.

The program is, however, adaptable, allowing therapists to enter the program and skip specific tasks for the client; for example, if a client was unable to complete a specific type of task. However, therapists were reluctant to skip tasks 'because they were too easy' as they were not confident that participants performance was sufficient for them to be able to move directly onto harder tasks without making errors, compromising both learning, and motivation.

Instead, we suggest the development of an adaptive program. This could use a client's previous scores, time taken to complete tasks, and similarities between task requirements, to create a predictive program that delivers the most difficult tasks a client should be able to solve without making errors. While this may not be infallible, with appropriate scaffolding, this may be able to deliver a more engaging experience for clients

Problems and solutions

▸ **Subtle change in task requirements leading to unintentional errors**
  ◦ Solution: Highlight changes in easier tasks, reduce highlighting with experience
▸ **Too short**
  ◦ Traditional CRT typically 40, 1 hour sessions
  ◦ One participant completed in 10, 90 min sessions.
  ◦ Not enough material to do sessions regularly
    · Regularity needed for long term effects
    · Solution: more material. Set time/task limits.

As stated earlier, often the task requirements would change during the task. While this may improve cognitive flexibility and inhibition, this does require clients (and therapists) to notice the change. We therefore suggest that highlighting changes to task requirements when they change may improve scores. This could also be reduced over time, to encourage participants to take control over regularly checking instructions

Finally, one participant completed all tasks within 10 90-minute sessions. This is significantly shorter than the 40 1 hour sessions traditionally delivered (Wykes & Reeder, 2005). Given that the length of training is likely to impact success, we suggest that more material needs to be created. At the same time, enforcing specific time limits, or limits on the number of tasks completed in any one sitting may also help pace clients.

Reflections on placement

Reflections on placement

▸ **Private sector vs NHS**
  · Underestimated the amount of documentation required of staff
  · Long-term view
  · Diversity and number of clients
▸ **Introduction to Psychosis**
  ◦ Little knowledge of the condition beforehand
  · Unsure what to expect when I met clients
  · Had preconceptions based on media and psychological theory
  · Upon meeting, quickly developed a richer and more diverse view

In addition to delivering CRT, this placement provided me with a chance to experience working in the NHS. Previously, my clinical experience was in private practice, therefore working within the NHS provided a very different culture and working environment. In particular, I was surprised at the extent of documentation that was required by staff. Moreover, the system and regulations for inputting this information was often impractical, and requiring considerable more time than was taken in my earlier experiences

My work in private practice often meant client contact was limited either by insurance, or the length of the course of work being conducted. However, working in the NHS, I was able to see how clients and their condition progressed over the three years they were assigned to EI services, and how the support from the NHS changed over that

time. This longitudinal view was something I had yet to experience, and has provided me with a richer understanding of mental health over the long-term. At the same time, the diversity and volume of clients seen was markedly greater than my earlier experiences, and has given me an appreciation for the practical and cultural problems that can affect psychological therapy

This placement was also my introduction to psychosis, and I was unsure what to expect when I met clients. I was, however, very aware of preconceptions I had formed about people with psychosis, based on both academic knowledge, and its portrayal in the media. I feel it is hard not to have preconceptions about a condition without meeting people with that condition and speaking to them about it. These preconceptions can be a barrier to understanding and support, and so meeting clients learning about their experiences, and dispelling those preconceptions helped me feel more confident with these clients, and has better prepared me to work with clients with similar problems in the future.

Reflections on placement

- Introduction to psychosis
  - Struck by intensity of experiences
    - Often anxiety, depression and frustration in ASD
    - Fear and very intense anxiety (both linked to hallucinations and delusions) in psychosis
- Confidence
  - Working with non ASD populations
    - Previous experience was with ASD and comorbidities (anxiety and depression)
    - First experience working outside this area
    - Can transfer skills and experiences

Most of my previous work was with clients with Autistic Spectrum Disorders (ASDs), where depression and anxiety are common. However, when reading case histories and attending review sessions, the level of fear and anxiety in individuals with psychosis was beyond anything I had previously encountered. This is something I could not have learned academically, and it has broadened the range and intensity of emotions I know can occur in mental illness that I will come across in my career.

Working with people with psychosis helped me gain confidence in my ability to work with different client groups. Before this placement, my experience was mostly with people with ASDs, and treating comorbid conditions. Therefore, there was a fear that my abilities in this area would not transfer. However, working with a new disorder increased my confidence working with different populations, not just those with

psychosis, and helped me see learn how I can apply my previous skills and experience to different client groups

Reflections on placement

▸ **What have I learned?**
  ◦ Further developed my delivery of WAIS
  ◦ Learned how to deliver the D–KEFS
  ◦ Honed my psychometric report writing
  ◦ Familiarized myself with literature on psychosis, cognition in psychosis, and CRT
  ◦ Became aware of the diversity of psychosis, and its effects on individuals
  ◦ Learned about the obstacles to setting up new programmes within the NHS
  ◦ Learned about the operation of NHS trusts

So, what have I learned from this placement? In addition to my delivery of the WAIS improving, and learning to deliver the D-KEFS, I have developed my skills in psychometric report writing. I have also become familiar with the literature on psychosis, cognition in psychosis and CRT, which is complemented by the personal stories of clients with psychosis. Finally, I have become more aware of how the NHS operates, and the barriers this can present when trying to deliver new (or existing) therapies.

Any Questions?

CHAPTER 3:

A QUALITATIVE STUDY TO EXPLORE HEALTHCARE PROFESSIONALS' EXPERIENCES OF DISGUST WORKING WITHIN A PALLIATIVE CARE SETTING

Abstract

Background:

Although disgusting symptoms are common in healthcare settings, previous research identified that healthcare professionals systematically avoid contact with patients with disgusting symptoms (Kray, 2004; Lawton, 1998), potentially compromising patient care. Equally, as showing disgust is thought to be unprofessional (Holmes, Perron and O'Byrne, 2006), healthcare professionals may feel unable to express or process disgust in their work, leading to long-term emotional difficulties.

Aim:

To investigate how palliative healthcare professionals' experience and cope with disgust, and how they are supported in doing so.

Methods:

Six palliative healthcare professionals were interviewed. Their transcripts were analysed using Interpretive Phenomenological Analysis (Smith, 1996)

Analysis:

Fifteen themes in how palliative healthcare professionals experience and handle disgust were identified and explored.

Conclusions:

Three key findings emerged. Firstly, participants were uncomfortable talking about disgust at work, and were unable to access support for disgust. Secondly, in focusing on their patients' needs, participants often neglected their own emotional needs.

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Finally, participants were at risk of reducing vital socio-emotional support for patients with disgusting symptoms. We suggest that some of these adverse effects may be counteracted by providing managers with training and resources to encourage their staff to talk openly about disgust and other emotions, and by providing psycho-education for staff on the effects of disgust.

Introduction

Disgust

The definition of disgust (and emotion more broadly) is subject to considerable debate (c.f. Ekman, Sorenson and Friesen, 1969; Ekman, 1992; Ortony and Turner, 1990; Barrett and Wager, 2006). For brevity, we shall avoid these theoretical and existential arguments and define disgust by its phenomenology: disgust is an intense, negative reaction to stimuli, which urges us to withdraw (c.f. Darwin, 1898; Barett & Wager, 2006; Rozin, Haidt & McCauley, 2000). Indeed, failure to withdraw (or sometimes merely the memory of the stimuli) is enough to elicit a strong visceral reaction.

Rozin, Lowery, and Ebert (1994) broadly divide disgust into two categories. Firstly, 'core' disgust. This is rooted in the Darwinian definition of disgust as a reaction to something "offensive to the taste" (Darwin, 1898, p257), and defines disgust as caused by the ingestion of food that is sour, burning, used, decayed, or smells bad. The second, 'elaborated disgust' includes "body boundary violations [including mutilation, deformity, and gore], inappropriate sex, poor hygiene, and death"(Rozin, Lowery and Ebert, 1994, p.870). Here, it is the meanings and associations of what someone sees that causes disgust.

Disgust in healthcare settings

Body boundary violations, death, offensive smells and (potentially) poor hygiene, are likely to be common in healthcare settings. Therefore, healthcare professionals need to be able to effectively deal with experiencing disgust on a regular basis. Accordingly, disgust sensitivity is a predictor of whether students pursue careers with high (i.e medicine and nursing) or low (i.e pharmacology) exposure to disgust (Consedine, Yu & Windsor, 2013).

A natural reaction to disgust is to avoid disgusting stimuli; indeed, evolutionary theories of disgust are based on avoiding objects that may cause us to be ill (Rozin, Haidt & McCauley, 2000). It is therefore unsurprising that both Kray (2004) and Lawton (1998) found healthcare professionals (nursing students and hospice staff respectively) systematically avoided contact with patients with symptoms they found to be disgusting. This has a direct impact on the quality of patient care, potentially resulting in negligence or death.

Effects of disgust on healthcare professionals

Disgust can also affect healthcare professionals personally. There is an expectation that those working in healthcare cannot show disgust – to do so would seem unprofessional (Holmes, Perron & O'Byrne, 2006). However, suppressing these emotions to maintain professionalism could have adverse effects.

Physiologically, emotional suppression is associated with activation of the sympathetic nervous system (SNS). Over time, regular activation of the SNS is

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thought to cause cardiovascular damage, and increase risk of cardiovascular disease (Damaree *et al*, 2006). Similarly, SNS activation has been linked with suppression of the immune system (Besedovsky *et al*, 1979), potentially resulting in staff illness.

Psychologically, emotional suppression reduces the behavioral expressions of emotion, but prolongs the feeling of emotion (Gross, 2002, Richards & Gross, 1999, Olafsson *et al*, 2013). Additionally, as suppression is an active process, it uses cognitive resources, potentially reducing cognitive performance in other tasks (Gross & Levenson, 1997), such as memory (Richards & Gross, 1999; Gross, 2002; Richards & Gross 2006). Such reductions in cognitive ability are likely to be detrimental to patient care, and increase the risk of medical mistakes.

Emotional suppression also has an adverse effect on a person's emotional functioning. Gross and Oliver (2003) found, compared to controls, those who suppressed emotions experienced more negative emotion, were less likely to share any emotions, and as a result, had poorer social support to help them cope. They also found those who used suppression were "less satisfied with themselves and their relationships, more pessimistic about their future, and more prone to depression" (p.360).

Coping with disgust in healthcare settings

To our knowledge, only one study has investigated how healthcare professionals cope with disgust in their work. Krey (2004) interviewed nursing students about how they experienced disgust, how they coped, and how training could be improved. However, because this sample had only been in nursing for a short time, it seems

likely that their strategies for coping with disgust were still forming. Equally, Krey's analysis highlighted the need for emotional endurance. If some participants lacked this endurance and later dropped out, then their ways of coping with disgust may have been qualitatively different, skewing the findings. Therefore, further investigation using participants experienced in dealing with disgust on a regular basis is required.

Disgust in Palliative care

In the UK, there are approximately 5,500 healthcare workers specialising in palliative care, in addition to thousands more who deliver elements of palliative care within a broader healthcare setting (NAO, 2008).

Amongst healthcare professionals, those working in palliative care are particularly likely to experience distressing, unsightly, or foul smelling symptoms (MacLeod, 2011). These may include fungating tumours, tumours that burst through the skin, fistulas, uncontrolled vomiting, fecal vomiting, and fecal and urinary incontinence, all of which are likely to elicit a disgust reaction.

The ubiquity and intensity of disgust-eliciting symptoms in palliative care suggests that those working in palliative care are likely to have established coping strategies, and an insight into how disgust is viewed in healthcare settings. Therefore, this study aimed to understand the experience of disgust in palliative healthcare professionals, how they could be best supported in their work, and the strategies and psychological processes employed when dealing with disgust.

In order to understand the perspective and experiences of palliative healthcare professionals, Interpretive Phenomenological Analysis (IPA; Smith, 1996) was used.

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IPA is a qualitative approach that combines phenomenology (the study of subjective experience), hermeneutics (the use of interpretation to gain understanding) and idiography (the focus on the particular) to understand the detail the 'lived experience' of individuals (Smith, Flowers and Larkin, 2009). Unlike other strategies, IPA aims to do this "in a way which, as far as possible, enables that experience to be expressed in [the participant's] terms, rather than according to predefined category systems" (ibid, p32). IPA has been increasingly used in studies addressing resilience and challenges in healthcare professionals (Ablett & Jones, 2007; Nobel, Marie & Finlay, 2008), and was therefore seen as a suitable methodology.

Method

Ethical approval

As part of this MRes project, I completed all applications for ethical approval to the University of Birmingham Ethics Committee (Appendix 3D), and the NHS Research and Development Service for Walsall (Appendix 3E and 3F), both of which were granted before starting participant recruitment (Appendix 3G and 3H). The project was sponsored by the University of Birmingham (Appendix 3I and 3J). To protect patient and participant confidentiality, interview transcripts are not provided in this thesis.

Participants

Participants were recruited from a palliative care centre in the West Midlands. The centre provides a wide range of end of life services, including day and overnight hospice care, chemotherapy, as well as psychological, occupational and complementary therapies. Following an open invitation to staff to take part in the

study, six staff members volunteered. Participant information sheets and consent forms can be found in appendices 3A and 3B. Below is a brief description of participants, using their assigned pseudonyms.

"Alex" is a doctor with 16 years experience in palliative care in a number of hospitals and hospices. For the last 11 years she has been a palliative care consultant. In her current post she primarily sees patients on wards at the palliative care centre, and at a large local hospital.

"Briony" is an occupational therapist qualified for 20 years. For the last 15 years, she has been working in palliative care, although she had some palliative cases even before that. She usually sees patients in their home, or at the day hospice.

"Caroline" is a nurse and the manager of the palliative care centre day hospice, catering for people with moderate to complex palliative care needs. She has worked in palliative care for thirteen years, both in hospitals and hospices.

"Deborah" is a lymphodema nurse specialist, with 27 years experience in nursing, the last four and a half of which have been in palliative care. She primarily sees patients in their homes, or at the palliative care centre. While many of her patients are terminally ill, she also sees patients whose lymphodema is caused by a non-terminal illness.

"Elizabeth" is lead nurse for the lymphodema service, with 28 years experience nursing in the community, the last eight of which have been spent in palliative care.

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She primarily sees patients in the community, or at the palliative care centre. Like Deborah, while many of her patients are terminally ill, she also sees patients with non-terminal causes of lymphodema.

"Fiona" is a senior nurse at the day hospice, working with clients with moderate to complex palliative care needs. She has 21 years experience in nursing, all of which has either been in palliative care or with a significant number of palliative patients.

Procedure

Following guidelines set by Smith, Flowers and Larkin (2009), participants attended a semi-structured interview at the Palliative Care Centre, lasting approximately 50 minutes. An interview schedule (Appendix 3C) was used to guide the interview, and focused on five key areas:

- An exploration of participants' past experiences with a patient with disgusting symptoms
- Participants' thoughts and feelings around disgust
- How participants approach a patient with disgusting symptoms
- What support participants use when dealing with disgust
- The institutional understanding of disgust

Both before and after each interview I noted down thoughts, feelings and impressions of the interview or participant in a reflective diary. The interviews were audio recorded and transcribed verbatim by myself within two weeks. Information that could be used to identify a patient or staff member was excluded from transcription.

Transcripts were analysed based on the procedure set out by Smith, Flowers and Larkin (2009). In the first stage of the analysis (summarised in figure 3.1), each participant's transcript was examined separately. For each transcript, I revisited my notes of thoughts feelings and impressions of each interview, before listening to the recording of the interview while reading the transcript. Preliminary thoughts on data during this time were recorded separately. Next, a detailed line-by-line analysis explored and noted the participant's descriptions and understanding of their experiences, and what it meant for them. These notes were summarised and formalised into shorter codes – a description of how the segment of text relates to the research questions. These were then grouped into subthemes in a way that organised the data while retaining the complexity of the relationships within it (appendices 3K, 3M, 3O, 3Q, 3S, and 3U). These subthemes were then converted from a collection of codes into a summary description of each participant's subthemes (appendices 3L, 3N, 3P, 3R 3T, and 3V). This process was repeated for each interview. After the analysis of the first, second and third interviews, the analyses were reviewed by two supervisors and myself to ensure that the interpretations drawn from transcripts appeared valid. This was done using summary descriptions of subthemes and passages from the transcripts.

Figure 3.1: Flowchart of stage one of the analytic procedure

The first stage of the analysis yielded 149 subthemes from six participants. In the second stage of the analysis, the descriptions of subthemes in the "summary of participant subthemes" documents (appendices 3L, 3N, 3P, 3R 3T, and 3V) were

used to collate these 'individual subthemes' into a collective analysis. The aim was to create a collective analysis that describes the themes present across all interviews, and uses individual differences and similarities between interviews to create a rich, detailed description of how participants experienced disgust in palliative care. Fifteen collective subthemes emerged (Appendix 3W). Each collective subtheme was explored to ensure that its contribution was meaningful. Equally, each individual subtheme was checked to ensure it contributed to all collective subthemes relevant to it. Collective subthemes were then grouped into collective themes to add structure and clarity. The summary of the collective subthemes (appendix 3X) was used for triangulation by two supervisors and myself.

Researcher's experience and influences

To understand the context in which participants worked, I spent two months working as an honorary assistant psychologist at the palliative care centre before conducting the interviews. During this time, I shadowed staff members working in a variety of healthcare professions, both in the palliative care centre, and in the community. Some of these staff members later volunteered to take part in this study, giving me a pre-existing familiarity with some participants, which may have altered my interview technique, or the depth of questioning. Equally, while shadowing staff, I was struck by the compassion and selflessness of those working in palliative care, and I developed an appreciation and admiration for the work they undertook. Because of this, I may have tended to see participants as selfless victims, as opposed to people unwilling to admit to the emotional impact of their work on themselves, or to adopt measures to combat it.

Early in my analysis I realised that staff felt unable to talk about their feelings. This issue felt particularly important to me, as in my past work as an assistant psychologist and campaigner on mental health issues, I have seen many people who have felt unable to express their emotions, and the detrimental effects that had on their mental health. It is possible that this may have biased my analysis to over-interpret ambiguous information about the discussion of emotions at work, and assume the detrimental effects of doing so.

Analysis

For brevity, of the fifteen subthemes generated, only five are discussed here; *the importance of being an empathic professional*, *disgust damages relationships with patients*, *the phenomenology of disgust*, *distraction*, and *talking about difficulties, not disgust*). These were felt to be the five most important themes, and chosen collaboratively between two supervisors and myself. The remaining ten themes are discussed in appendices 3Y to 3AI.

<u>The importance of being an empathic professional</u>

"Because of the job that we do, we, we're doing nursing because we're caring, you know? We care; we want to do the best for our patients" [D153]

For participants, wanting to be a "caring" professional is vital to them, and a key motivator for staff. As Deborah explains, they are doing nursing *because* they care; both personally and professionally, they want to do the best for their patients. This is not limited to medical care, and includes looking after the socio-emotional needs of

their patients. This manifests in two ways; a desire to gain a holistic understanding of the patients' problems and concerns, and providing socio-emotional support.

"So I think you're conscious of your patients, and how they feel, erm. And often they will discus – erm, discuss and describe how they feel, because of what's going on with them. […] I'm trying to, you know, understand what's important to someone, and whether that is about doing something for themselves, or getting out, or seeing people again, or in some context, I need to understand what they're, how they're feeling about that, or what's restricting that" [B121]

Participants wanted to gain a holistic understanding of their patients' problems and concerns, as they believed this would facilitate the delivery of best possible care. As Briony explains, it is not just her patients' medical needs that concern her, but also their social and emotional needs. She is "conscious of how [her] patients feel", and she tries to "understand what is important to someone". Doing so involves being an empathic professional; putting herself in her patient's shoes, considering what their life is like, and using her professional expertise to overcome the issues they face.

"I don't want to be seen as if I'm failing that patient, and I'm doing my whole holistic assessment, you know. So I'm looking at everything, erm, because that's what I like to do when I'm seeing a patient. You know, it might be something completely irrelevant to what I've gone in to see, erm, and then end up talking to me about something else, so I'm looking at the whole person" [D155]

As Briony is an occupational therapist, she is perhaps more likely to be particularly concerned with how a patient's symptoms impact their social and emotional functioning. However, we see the same concern in other participants. Deborah is a Lymphoedema nurse, and therefore might be expected to be less concerned with a patient's wider functioning. However, like Briony, she sees completing a holistic assessment as a vital part of her work. Indeed, this is so important to Deborah that she sees not doing so as "failing" the patient.

"… there is something about being calm with whatever is given to you as a doctor that can be very helpful in palliative care, so then, whatever horrors they [patients] go through, you're not losing it. You might show a bit of empathic distress, but not, erm, you're different from the person in the street who won't look at them, or that charity workers who go there, you're able to hold it, so I wouldn't want to think that I wasn't able to do that. […] They [patients] all disintegrate, because, you know, telling someone they're going to die, they do, often, not always. So you're sort of sitting there in the middle of this, sort of holding it." [A279]

The second part of being an empathic professional is providing socio-emotional support. Alex describes how she needs to be a source of calm and emotional support for patients. She draws on this skill when patients are emotionally "disintegrating" on learning of their prognosis, and long-term, when she is supporting them through whatever "horrors" they might face. In doing so, she feels "empathic distress", but has to "hold it", in order to remain calm and support her patients. On a personal level, it

was particularly moving that even when she feels upset, she is being empathic; putting her emotions aside in order to be what her patient needs her to be.

Disgust damages relationships with patients

"With any doctor-patient [consultation], if you are trying to communicate well, you should be looking in a bit, and thinking 'what is actually going on here', erm, and some people talk about having the third person in the room looking in, and helping you to make sense of it. And I think the problem with, when there is a physical symptom that you find revolting, you end up with your own revulsion…overwhelming that view, so then you're having to work even harder. Am I making… I'm talking very metaphorically? You're having to work even harder to hear what the person is really saying to you, because you, you're trying to deal with all the other stuff as well"

Interviewer: yeah, it's sort of clouding?"

"Clouding! yeah, yeah. It's clouding your ability" [A101]

The feeling of disgust in relation to patients' symptoms interfered with participants' ability to do be empathic professionals, which affected their ability to gain a holistic understanding of a patient's needs, and provide socio-emotional support. Here, Alex describes how she has to be an empathic professional; thinking about "what is actually going on here", and trying to understand "what the person is really saying to you". However, when confronted by symptoms she finds "revolting" she finds her ability to empathise is "clouded" – she can't "hear" the patient in the same way she usually can, and has to "work even harder to hear what the person is really saying to

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you" to compensate for this lost connection. This suggests disgust is having an impact on professionals' empathic ability.

One explanation for the effect of disgust on professionals' empathic ability is that disgust takes attention away from the patient. Supporting this, participants felt shock when they first saw a patient's disgusting symptom (see *phenomenology of disgust*, below). Equally professionals could find it harder to empathise with someone with disgusting symptoms, as the urge to withdraw generated by disgust is directly contradictory to the approach and compassion needed for empathy.

Alex also mentions she is "trying to deal with all the other stuff as well", suggesting a high pre-existing cognitive load from delivering medical care to her patient. This load is added to when attempting to overcome the sudden loss of empathic connection. This increase in load could be explained both by trying to direct attention back to the patient, or by trying to create an empathic connection, despite the urge to withdraw.

> *"… once you've done the assessment with them, it might reduce any social interaction you might have with that patient. […] it's a stepped approach. The first step has got to be about the symptom management. The second step in conversation is almost a social type bit, and although that's very important, because these people have enough stigma that they get landed with, a lot of them of their own doing anyway, once I've done the symptom management, the bit that I'm really there to do, anything else that I can give thereafter is a bonus. So if the bonus on that day is only a small bonus, then that's the way it's got to be"* [F432]

The effect of disgust on empathy also reduced participants' ability to provide socio-emotional support. While providing socio-emotional support is "very important" to her work, Fiona recognises disgust "might reduce the time that you want to spend with the patient". Consequently, sometimes her desire to stay longer to provide emotional support is not sufficient to overcome her feelings of disgust, leading her to withdraw from the patient early, a feeling mirrored in other participants.

There are marked differences in the effect of disgust on participants' ability to provide socio-emotional support and holistic understanding. When trying to gain a holistic understanding, Alex feels she *has* to do this. As a result, disgust is either distracting, or damaging to her ability to empathise. However, Fiona sees providing socio-emotional support as a "bonus", and she has to decide how much of this "bonus" to give to patients. Here disgust is not affecting her *ability* to use empathy in her job, but is influencing her *decision* over how much support to give. Disgust is not necessarily affecting Fiona's empathic ability, but is in direct opposition to it; if her feelings of disgust are too great, the desire to withdraw will outweigh her empathic drive to help the patient, and cause her to leave earlier.

The Phenomenology of disgust

By defining disgust by its phenomenology (see introduction) we were able to ensure that, regardless of how participants' labeled their experiences, the phenomenon we were examining was consistent across interviews. It is therefore unsurprising that participants commonly reported feeling two of our pre-defined characteristics of disgust: feelings of nausea, and a desire to withdraw from disgusting symptoms.

Participants also reported two additional aspects to disgust that we had previously not considered; shock and sadness.

"You can't help but, because you do recoil and your face does give you away" *[F81]*

"Its such a... reflex response to do that [screws her face up in disgust]". It's not something you control [A40]

"Generally, once I've steadied myself, I can deal with it" [F116]

Participants felt shock when first confronted with something disgusting. Here, Fiona and Alex explain their reaction was something they couldn't control – an automatic "reflex" or "recoil". The accompanying automatic facial expression of disgust was a particular worry to participants, as showing disgust would violate their professional standards (Appendix 3Y) and damage their relationship with patients (see *disgust damages relationships with patients*, above). However, as Fiona describes, once staff were able to steady themselves, they were able continue their work while suppressing disgust.

The recoiling on seeing a disgusting symptom was the first point at which participants would feel the withdrawal component to disgust. Depending on the severity of the symptoms, personal sensitivities, and whether or not participants had to approach or touch a symptom, nausea would often follow shortly after.

The second unexpected element to disgust was a feeling of sadness or upset at patients' symptoms. A discrete model of emotions would suggest emotions should be thought of as separate emotions (c.f Ekman, 1992) and therefore sadness should be disregarded from an analysis of disgust. However, disgust and sadness were closely linked for participants:

"[I] was just trying to focus on the fact that he was, he was here with us and he needed our help. But try taking your, taking your eyes off this dreadful wound he'd got, it was awful. […] I felt, erm, upset, really upset for him". [C82/88]

Describing this incident, Caroline assumes two different positions. First, she describes her own position as a healthcare professional – her difficulty taking her eyes of the symptom, and her desire to help him. However, Caroline also assumes the patient's perspective; she tries to focus on the patient, that he needed their help, and crucially this made her feel 'upset for him'. These two perspectives lead to two separate emotions. As a professional, the symptom is evaluated egocentrically, as something disgusting for her to look at and work with, and is the root of her feeling of disgust. However, when assuming the patient's perspective, the symptoms have a profound impact on her patient's life, both medically and socially, for which she feels upset. Her descriptions of the wound as 'dreadful' and 'awful' can therefore be read very differently depending on which perspective is taken; as a professional, they imply disgust, but as a patient, they imply sadness.

"I know I tried to deal with it the best I could, and erm. … but […] it was the smell and the appearance, and it was, it was that almost… dis-, disgust I think

is a strong word, but it, I think I, 'oh my goodness' you know? [mhm] How do you, can you survive like… that's how I felt, how can you live day to day like this? You know?" [D67]

Other participants have the same duality of perspectives. Here, Deborah explains how she felt disgusted by the symptom, but also sad for the patient, putting herself in their position and feeling how it must be for them. This duality is mirrored in that participants talked about feeling disgust, but also place significant importance on being an empathic professional (above).

Finally, participants did not *know* how their patients felt about their symptoms. Instead they assumed unquestioningly that their patients must feel sad about their symptoms, and adopted that sadness themselves. Therefore, participants may have projected their own feelings of sadness onto the patient.

Distraction

"It's probably afterwards that you might think about [disgust] a bit more, because at the time, you probably erm, use some sort of techniques to bypass it don't you? So you're not, its almost you know it's there, but you don't think about it. So you focus on something else. So probably focus more on concentrating with her writing down how she was feeling, or what sort of things, or me explaining to her what I can do to perhaps help a little bit with symptoms that she'd got" [E234]

Participants' primary way of coping with disgust was distraction. This involved two related processes: *disengaging attention* and *refocusing attention*.

First, participants disengaged their attention from disgust. Elizabeth describes how "you know it's there, but you don't think about it", suggesting that although disgust is felt, she is able to stop herself from actively thinking about disgust. Since participants reported that thinking of disgust made their feelings of disgust worse (appendix 3Z), this denial of feelings may prevent a feedback loop between thoughts and feelings of disgust forming (Figure 3.2). Such a loop would both capture their attention, and make their feelings of disgust more salient.

By disengaging their attention from disgust, participants were able to refocus their attention on the patient. However, this does not just aid participants in doing their job; Elizabeth describes how focusing on the patient is one of her "techniques to bypass" disgust. This suggests that focusing her attention on the patient serves a protective function against disgust. For example, by refocusing her attention on the patient, she could minimise the amount of attention she can give to disgust, thereby preventing the feedback loop from reestablishing.

> *"I, erm, distract by usually hurting myself. Not massively [laugh] don't give me any masochistic tendencies here, but I will er, most likely put my thumb in the center of my palm, [to] provide myself a certain amount of distraction" [B51]*

Some participants had difficulty disengaging attention, perhaps because of the cognitive demands of doing so. Here Briony explains how she causes herself pain to

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redirect her attention away from disgust. As pain "interrupts and demands attention" (Eccleston & Crombez, 1999, p356), it would be highly effective at breaking the feedback loop between feeling and thinking about disgust.

"I think I'm just thinking of it a bit more as a task, than a…. it doesn't sit comfortable with me when I'm saying it, but its almost like 'right, I've got to do', you know 'Mrs X's manual lymphatic drainage today […] but, I'm just seeing the actual area, not the whole person. That's my way of trying to deal with it. […] And that's, that does sit really uncomfortable with me, erm…. So I think it is about… detaching myself, and just seeing it, seeing the lady as an object, and something I've just got to get on and do it." [D120]

Figure 3.2 : The disgust feedback loop

This figure summarises the feedback loop that exists between thoughts and feelings about disgust (red), and two interventions employed by staff (green). Here, the feeling of disgust (the smell being overwhelming) is elaborated on, leading to thoughts of vomiting on the patient. This makes the feeling of disgust more salient. This loop is stopped either by preventing elaboration (by disengaging attention), or by using the feeling of pain to override disgust

Some participants used a different cognitive strategy; "detaching". Here, Deborah is clearly aware of her surroundings and what she needs to do, however, by 'seeing the lady as an object' she is detaching her empathic response, and therefore not

attributing emotions. This is not a permanent detachment, indeed detaching her empathy for any amount of time does 'sit really uncomfortable' with her as an empathic professional. However, by detaching her empathy she is able to minimise her feelings of disgust.

While an empathic connection from healthcare professionals might provide motivation to overcome disgust (see *the importance of being an empathic professional*, above), it is not immediately clear why disgust should require empathy. Assuming Deborah's disgust is elaborative (Rozin, Lowery and Ebert, 1994), one explanation would be that by detaching empathy, the context of the situation (i.e. this is a person, this is something they live with every day), may become less salient. This would reduce the material that can be elaborated on to cause disgust.

Talking about difficulties, not disgust

>*"I think we don't allow ourselves to talk about disgust. I think it's sort of a closed door, […] I think if you went in, and said something 'right, what symptoms do you find difficult', they wouldn't use the word disgust" [C408]*

For participants, the word 'disgust' was taboo (appendix 3AC). As a result, participants "don't allow ourselves to talk about disgust", preferring to use the word "difficult".

>*"If we talk about it as a team, I think we talk about it [interventions] not in the fact we found whatever is going on disgusting, but more how sad and how hard it must be [for the patient] to cope with that. […] So we talk about it in*

terms of empathizing with our patients. We don't talk about it in terms of 'oh my god, did you see that, that's awful isn't it?' and you know, I think, I think that's, you know, there's a real distinction in there, and we're very clear about that." [B407]

Briony explained how staff discussed interventions by focusing explicitly on the patient, and how the patient feels about the symptom. This is mirrored in her example of how staff would not talk about disgust. The phrase "did you see that, that's awful isn't it?" is focused on the professional's own experience, not that of the patient. The "real distinction" Briony alludes to is between the empathic and egocentric ways of talking about disgust. This is supported by *the importance of being an empathic professional* (above), and focusing on the patient, rather than themselves (appendix 3AA).

Briony's comments also encourage staff to project their own feelings of disgust onto patients. By taking a patient-centered view and not being allowed to talk about their own feelings, staff may be more liable to project their own feelings onto their patients. This view is supported by Briony's later comments:

"I know someone's come to me and said 'oh I know you've seen so and so' or you know 'oh that's hard isn't it', and I say 'yeah it is hard, I don't know how she copes with it', and they might say, you know 'oh its difficult', and I'll say 'oh I know'." [B419]

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When a colleague talks about how hard it was *for them* to see their last patient, Briony immediately reframes the conversation in terms of the patient by saying "I don't know how she copes with it". Her colleague's response of "oh it's difficult" now implies it is difficult *for the patient*, rather than for themselves. This is an acceptable response for Briony, who now agrees with her colleague. While some projection of feelings appears to be going on, it is unclear whether staff are aware of this and talking about their own difficulties as the patient's in order to get support, or whether they are unaware of their projection.

> *I might say 'I found myself pinching my hand' or something, so you might share strategies in that respect with one and other, but you're certainly not, so I think you share strategies, and you discuss how hard it is for the patient. [B423]*

Although participants appeared to project their emotions onto their patients, and avoid using the word "disgust", the subtext and language staff used did allow participants to recognise when colleagues found something "hard". Despite talking about how hard something was for a patient, Briony was able to recognise that her colleague struggled with disgust. This allowed her to share her strategies for dealing with disgust, and provide support.

Finally, it was not only participants who used the term "difficult" in favor of "disgust". When reviewing transcripts, I found I had often inadvertently used the word "difficult" as it felt a more sensitive way to describe disgust. Equally, when coding, I would sometimes write "difficult" in place of disgust. While this may have influenced the

wording of some responses, it is also indicative of how strong the urge to avoid using the word disgust is in that setting.

Discussion

From the analysis, three key findings immerged. First, while participants experienced disgust in the course of their work in palliative care, they saw it as unprofessional. Second, participants were highly focused on their patients' medical, social and emotional needs, but may have neglected their own needs. Third, the feeling of disgust in participants never impacted the medical care offered to patients, but reduced the socio-emotional support participants were able to offer to patients.

Disgust is unprofessional within palliative care

As predicted by Holmes, Perron and O'Byrne (2006), participants saw disgust as unprofessional (appendix 3Y). This had two effects. Firstly, participants developed strategies to avoid showing patients disgust, and were distressed at the prospect of a patient realising their disgust (appendix 3Y). Secondly, although participants felt they worked in a supportive team, they were afraid of being judged by their colleagues for expressing feelings of disgust. (appendix 3AC).

Participants avoided showing disgust around patients by suppressing their emotions. According to previous research (Damaree *et al*, 2006; Besedovsky *et al*, 197) this may make them vulnerable to long-term cardiovascular damage, and immune system suppression, potentially increasing the likelihood of them taking sick leave. Further, Gross and Oliver (2003) suggested that those using emotional suppression were "less satisfied with themselves and their relationships, more pessimistic about their

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future, and more prone to depression"(p.360). While these issues were beyond the scope of the current interviews, the emotional suppression used by participants suggests that they may be susceptible to a "troubled sense of wellbeing"(p360). In addition, suppression of feelings of disgust appeared to draw on participants' cognitive resources, supporting previous research (Gross and Levenson, 1997). This may have reduced the attention participants paid to their patients' care (*Distraction* and *disgust damages relationships with patients*, above).

The belief that disgust was unprofessional caused it to become taboo within the workplace (Appendix 3Y and 3AC). Therefore participants felt restricted to talking about difficulties their *patient* experienced, or in delivering treatment to the patient, rather than their own difficulties in dealing with disgust (*talking about difficulties, not disgust*, above). As a result, staff support often dealt with disgust implicitly, without directly acknowledging the thoughts and feelings participants experienced (appendix 3AF).

In a review, Pennebaker, Zech and Rimé (2001) concluded that although talking about the emotional content of past experiences did not reduce the impact of these experiences, people often wanted to talk about them. Doing so improved individuals' sense of wellbeing, compared to talking about the factual details of the experience, and resulted in significant health improvements. Similarly, Finkenauer and Rimé (1998) found that not sharing emotional experiences resulted in a greater search for meaning, suggesting that talking about emotional experiences "contributes to the processing of the emotional information and to the completion of the cognitive needs which were elicited by the emotional event" (Pennebaker, Zech and Rimé, 2001,

p14). Therefore, while talking about disgust may not reduce the emotional impact of an experience, participants may experience subjective improvements in their emotional wellbeing, feel a sense of closure over the event, and objective improvements in their physical health.

Participants focused on patients medical, social and emotional needs, neglecting their own

Disgusting symptoms would often trigger emotions secondary to disgust, which would require processing (*The phenomenology of disgust*, above). However, although participants were highly focused on the medical, social and emotional needs of their patients (appendix 3AA, and *the importance of being an empathic professional*, above), in doing so, they tended to minimise or neglect their own emotional needs (appendix 3AA). Compounding this, participants felt they were unable to talk about their emotions, particularly disgust, within palliative care, as those outside palliative care wouldn't understand (see *talking about difficulties, not disgust*, above, and appendix 3AD). As a result, participants appeared to project some of their own emotions onto their patients (see *the phenomenology of disgust* and *talking about difficulties, not disgust*, above).

While projecting their emotions onto patients may provide participants with a professionally acceptable outlet for their emotions, it also carries considerable psychological costs. By projecting their feelings, participants' emotional wellbeing may become linked to the emotional or physical wellbeing of their patients. They may feel that in healing their patient, they are healing themselves. Supporting this, several staff members went beyond what would normally be expected of them in order to

ensure that *they* treated the patient. Equally, participants sometimes personalised their patients, linking their emotional wellbeing to their patient's wellbeing (appendix 3AA). Therefore, it is important that palliative healthcare professionals are given an outlet for their emotions to avoid projecting their feelings onto their patients, particularly given the often deteriorating condition of patients in palliative care. Despite this, NICE quality standards (2011) only specify that healthcare professionals in palliative care require support in dealing with loss, grief and bereavement, not in disgust, or the ongoing suffering of their patients.

<u>*Disgust reduced patients' socio-emotional support*</u>

Finally, disgust reduced participants' socio-emotional support for their patients, mirroring findings from Lawton (1998) and Krey (2004) (*disgust damages relationships with patients*, above). However, participants went to great lengths to ensure that the quality of their patients' medical care remained uncompromised; putting aside their own feelings to ensure the job was done properly (*Distraction*, above, appendix 3AA). Although they were reluctant to do so, in extreme cases where they felt unable to deliver best medical care, participants were able to use an informal mechanism created by staff whereby they could pass on patients to other staff members (appendix 3AG). While regular changes to staff could adversely affect continuity of care, and potentially increase patients' stigma, the rarity with which this was done means that it is unlikely that patients' medical care will have been compromised by the disgusting nature of their symptoms.

In a study of 79 cancer patients, healthcare professionals were identified as an important source of emotional support (Dunkel-Schetter, 1984). More recently, Slevin

et al, (1996) found that healthcare professionals were three of the five top sources of support for cancer patients. Therefore, participants' reduced ability to provide socio-emotional support may have a significant impact on how supported patients feel.

Lack of socio-emotional support has significant effects on patients' wellbeing. Dunkel-Schetter (1984) found that 87% of cancer patients reported trying to cope by keeping their thoughts to themselves, often because they felt uncertain about how others would react. Palliative healthcare professionals are likely to be one of the few people patients would feel able to talk to about their diagnosis, particularly if they involve embarrassing or intimate problems caused by their symptoms, or worries about how their condition will progress. Equally, Sleven *et al* (1996) reported that patients who felt dissatisfaction at the support they received scored significantly higher on the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983). Finally, it was important to participants (and NICE quality standards; NICE, 2011) that they provide a holistic assessment of the patients' needs (including their socio-emotional wellbeing), as it enabled them to better care for their patients (*Importance of being an empathic professional*, above). It therefore seems likely that a reduction in access to socio-emotional support will have a direct impact on patients' emotional wellbeing, which in turn is likely to affect their physical wellbeing (Kim *et al*, 2000; Gripp *et al*, 2007).

Recommendations

The key findings identified that participants suppressed their emotions when around patients, felt unable to talk about their own emotional difficulties, projected their

unexpressed emotions onto patients, and reduced their socio-emotional support for patients. Based on the analysis, possible solutions to these problems were identified.

While participants may need to suppress their emotions around patients in order to remain professional, the effects of this may be exacerbated by their inability to discuss disgust at work, requiring participants to 'hold it together' (appendix 3AB). By breaking the taboo around disgust, participants may be able to access support, minimising the effects of suppressing and 'holding together' their emotions.

Participants described how, on occasion, they were able to break the taboo of disgust, although this required significant self-confidence in order to overcome the fear of being judged. Participants were, however, able to talk about disgust when someone else, such as their manager, brought it up (Appendix 3AC). When managers did bring up disgust, they felt able to do so because of their position of authority, removing some of their fear of being judged (Appendix 3AC). Therefore, a top-down approach, focusing on training and encouraging managers to break the taboo and provide support for disgust may be particularly effective.

Training for managers on disgust is likely to require four elements. Firstly, although participants reported feeling disgust, they often did not recognise it as disgust before taking part in the study. Therefore, providing psycho-education on the phenomenology of disgust may help managers identify disgust in themselves and others, and know when to provide support. Secondly, a group discussion of past experiences of disgust at work, how they felt and how they dealt with it may help participants recognise the ubiquity of disgust, and break the taboo. Thirdly, by

providing training on how to approach disgust with their team, they may feel more confident in their ability to provide support for disgust, both in clinical supervision, and 'checking in' support. Finally, managers may benefit from additional training on emotions elicited alongside disgust, helping them to identify and support these emotions in their staff. By providing an outlet for these emotions, staff may be less likely to project their feelings onto their patients.

Participants' primary concern was always to provide the best care possible for their patients, making this an excellent motivator for change in staff practices. Although they were sometimes willing to pass on patients due to disgust (appendix 3AG), this was rarely used when it threatened patient's socio-emotional care. By educating staff on the unavoidable effects of disgust, and the value of socio-emotional support, they may feel better able to use this system for patients who they are able to treat, but whose symptoms they find particularly disgusting, and are at risk of reducing their socio-emotional support for.

Implications of findings

The analysis detailed the experience of six palliative healthcare professionals working with disgust. However, by taking an idiographic, rather than nomothetic approach, these results are not directly generalisable to other palliative or non-palliative healthcare professionals. Despite this, where these findings resonate with healthcare professionals, they do provide a framework by which to understand the likely experiences of those working with disgusting symptoms, and suggestions for developing support structures. However, the results highlight the possible implications of disgusting symptoms on patients' and professionals' physical and

mental health. It is therefore vital that frontline healthcare services, working with patients with potentially disgusting symptoms, consider whether their staff members are adequately supported to cope with, express and understand disgust.

These findings also add to the literature emotions. By taking a qualitative approach in a palliative care setting, they provide a detailed phenomenological account of how regular exposure to disgusting stimuli can be felt and understood in an ecologically valid setting. Equally, the findings inform the theoretical debate on the nature of emotions. While there is considerable argument as to whether emotions are discrete or dimensional, much of emotion research has focused on how a single emotion is triggered and experienced. This research highlights how multiple emotions can be triggered by the same stimulus and how they interact, providing researchers with a detailed account of how this is experienced, and a starting point for future investigation.

Study limitations

Although the sample was purposive, by extending an open invitation to palliative healthcare professionals in a business unit, it relied on participants volunteering to take part. Therefore, participants may have volunteered because disgust was an issue they had little support for, and wanted to talk about, skewing our sample. However, it is equally possible that most staff felt disgust was an issue too sensitive to discuss in an interview. Therefore, those who volunteered to participate may have been unusual in feeling able to talk about disgust.

Interviews also relied on self-report of events. While some events were recent, others were several years old, and may have been subject to confabulation. Supporting this, detailed reading of participants' transcripts revealed several minor factual inconsistencies. However, while minor details changed, the underlying schemas (likely to be responsible for confabulation) remained unchanged throughout the interviews. Therefore, although transcripts may be subject to factual errors, this is unlikely to have affected the phenomenology of working with disgust in a palliative care environment.

Conclusion

Healthcare professionals experiencing disgust in the course of their work are at risk of compromising both their emotional health, and patient care. This is a particular at danger in environments where disgust is thought to be unprofessional, which leading staff to suppress, deny, and possibly project their feelings. These effects have not been previously identified or researched in healthcare professionals. While further nomothetic research is required to define the extent of these effects across settings, healthcare providers should consider what support their staff receive, and whether their work culture allows them to utilize that support for disgust.

APPENDICES TO CHAPTER 1

Appendix 1A:

Interview schedule

Tell me a bit about your daughter

Has your perception of your daughter changed?

Tell me about when you first noticed any changes and the process of getting a diagnosis.

What does your daughter understand about their diagnosis?

How do you think the disorder has affected your daughter?

How do you think your daughter has been affected at school?

How did you explain your daughter's diagnosis to their teachers?

How has your relationship been with your daughter's school and their teachers?

How has the disorder affected you as parents?

Are there any experiences you have had regarding your daughter's diagnosis, which you feel were particularly difficult?

How has information from doctors changed your view of your daughter?

When you found out about your daughter's condition, what did you think would happen?

How do you think it has affected the relationship between you and your daughter?

How would life be different for you if your daughter did not have the condition?

How do you think it has affected other family members if at all?

How do you think others would understand your daughter's diagnosis?

How do you think the way other people behave towards your child has changed, if at all?

What do you think other adults notice about your daughter?

How do you think other children perceive your daughter?

Are there any situations you find particularly difficult?

What are your hopes for the future?

Is there anything else you would like to add?

Appendix 1B:

a priori template

- Trying to hide the condition

    o Embarrassment

        - Denial of sexual development

        - Sexual acting out

    o Protection of child

- Stress

    o Due to child's…

        - Emotional problems

        - Behaviors

        - Sexual acting out

    o Due to other people

        - School provision

        - Peoples reactions

- Worries

    o Pre/during diagnosis

        - Cancer

    o Post diagnosis

        - Short term

        - Too much weight

        - Long term

        - Height

        - Fertility

Appendix 1C:

Interim template

- Acceptance

    o Value of a diagnosis

    o Need to attribute cause/blame

        ▪ Parents, Food, God, Shunt

    o Getting on with it

        ▪ Parents responsibility

        ▪ Doctors responsibility

    o Condition ends soon

- Friends and family

    o Negative comments/not understanding

        ▪ Family – Grandparents

        ▪ Friends

        ▪ Public perception not as bad as expected

    o Support from close friends

    o Support from family members

    o Support from doctor

- Parent-Child relationship

    o Growing up too fast

    o Child maturity

    o Improved communication

        ▪ Child understanding

    o Emotional problems

        ▪ Patience

- Empathy

- Dad having a different relationship

- Protection Vs Independence

  - Wanting to appear normal

  - Protective drive

  - Protective actions

    - Lying

    - Telling school

      - Trust

      - Support

- Worries

  - Growth/bone development

  - Reproduction

  - Weight

  - Mood

    - Expecting worse

Subtheme	Quotes
What could it be?	*"I didn't know what was happening. I didn't think it could ever happen. I don't know why it was happening. I thought she's a little girl, why is her body doing this? I duno, I was confused. That's probably… yeah, I really didn't understand it." (2:467)* *"Initially a bit worried because they said, erm, we had the MRI scan to check for, er, you know, a tumor, and luckily that was clear" (5:98)*
The value of a diagnosis	*"knowing what the problem was and knowing that, there was an answer, it wasn't a problem" (3:82)* *"Once it's been diagnosed, you sort of feel, more secure, more confident, because you know that other people that, sort of, trod that path, and they know, they know what might happen" (2:375)*
Worries	*"The moods was the only thing I was scared about, but she just proved me wrong" (1:289)* *"we just, the only thing, if at all, the only thing we worry about is her weight" (1:219)* *Will she stop having her period, you know? A woman only produces so many eggs. Will she be thirty, but, you know. But she might go through the change early. I do, I know I shouldn't run away with it, but there are times when I think "could she, could it all come to an end at such a young age, as well", because she's starting at a young age." (4:512)*
Need to attribute cause/blame	*"Why her? you know, why, what why should it be…. What have we ever done?" (4:107)* *"Everybody keeps saying that, you know, children are getting much earlier than they should, because of the preservatives and all that" (1:81)* *"hopefully its not our fault". (5:808)*
Acceptance	*"I found it hard to accept she was going through… I think for me, and I know this is going to sound really stupid, but when, when… when the doctor or consultant, professor or whatever says to you when your daughter's eight "they can have a baby", it kinda puts a different perspective. Now, naive as I was, 'don't be stupid, she can't have a baby, she hasn't had her period', but medically, her body is capable of producing a*

bay, but of course, I'm there like 'don't be so bloody stupid, she can't get pregnant without a period'. I know, I know, I know, but she's my baby." (4:454)

Getting on with it	*"For some children this happens, so we just have to take it. It's come to us now, we have to deal with it, whatever it is. And then I told her that this is how it's going to be for the next two years." (1:84)*
Doctors responsibility	*"I don't think we could have gone through it without them, not without knowing we've got these six month checks to now, and they measure her, and they take her height and they weigh her, and they do a physical examination and its just really reassuring to know you've got someone so high up medically looking after her, and that's a big thing, that's, that's very reassuring" (2:381)*
Parental responsibility	*"we tried to do everything, again, making her dance even more. Swimming, and everything, walking. I used to, I used to take her walking to the university because there, that's where she goes swimming. We used to [laugh] oh my, I used to walk with her and come back walking after swimming lessons, so it was like, and, you know, my legs were just killing me [laughs], sometimes. It was just like we were trying to do everything." (1:261)*
Protective Drive	*"You're thinking about that, and whether she's going to get teased, or, you know, what's going to happen, but, you know, we'll deal with it at the time. So, I don't, I won't let it happen basically. You know, I've already said I'm not going to let her get bullied in any way shape or form for being different, so wi'll just have to deal with it" (5:216)*
Worries about public perception	*"I've always been very protective, and now it's made me even more protective. I don't want anybody to see her in that position again" (2:228)*
Negative social impact of diagnosis	*"People think she is somebody at high school. Erm, but then if she's messing about and being silly, and to be fair, she doesn't, but you know, if she did, and outsiders looking in thinking 'oh, she's a bit silly for a twelve year old', but in actual fact, she's not a twelve year old, she's a nine year old, and what she's doing is actually right for her age" (4:625)*

"She's a big girl. Erm, I mean, my dad, even my dad's made a couple of comments occasionally about her size. Not – only joking, but I have a look at him, and you know, give him that look to say 'no, don't' because I'm here when she's trying to get dressed to go to school somewhere and says she's fat." (5:575) |

Grandparents acceptance and understanding	A: In the end, I think they've both accepted it now, and they treat her normally really B: But my mum won't bath her A: yeah C: she's had to bath herself because mums a bit funny about seeing her, the changes (2:65)
Perception not as bad as expected	"She looked a bit sad about that, but at other times she was just sort of like…. Feeling like, you know, the queen around them. So, in some areas she was put on the spot and didn't feel comfortable, but in other areas she sort of felt like, 'I'm the lady now', so they had a good laugh about it, dress up and what have you. Bras went wandering around" (3:127)
Importance of appearing "normal"	"She's really normal, she's such a normal little girl, and she's had this thing on us too early, and its…. A strong thing, and its, probably…. Its… its just she's so normal, she really is" (2:686)
Condition ends soon	"they're all getting older, and there all going to start developing, so its not just M" (2:248)
Protective Actions	"I have always been very careful, and like I say, when she dances, everything comes off and they get their outfits on, and I've always made sure that if I wasn't there that someone who knew me was there to cover her up when she got changed" (2:233)
Perception and independence vs protection	"I have asked K if she wants me to go into school and ask if she can get changed on her own. Erm, but then, you worry about if you segregate her, they're going to start asking questions, 'why is K being' you know, so that could cause a problem" (5:174) "I try not to, I don't want to make a big thing of it, because if I do, then obviously it will make a big thing of it for her, so erm. That's why, like the question about asking her if she wants to get changed separately. Its not a deep and meaningful conversation, it's a, you know 'do you want me to go into school and see if you can get changed on your own'" (5:611)
Lying to people to protect their child	"all her moods are just in the house. Outside she's as good as gold. No one ever complains of her behavior, so far. So I was like, why would I need to tell them, so I haven't"
Telling people to protect their child	A: We have informed the school, and we've informed her dance school

B: and brownies
A: and brownies, so wherever she stays over, or if she's got to be changed with her class, its sort of, the teachers are aware
B: she's at risk of an early period as well, so people are aware, they're not to panic. (2:153)

Support

"There's nothing there really for where she can put a sanitary bag, or needs to go to the toilet or stomach ache. Where can she get the medicine from, you know? So this teacher, I mean, she's good, she goes "C, if you need, I've got my own in the cupboard, if you run out, I've got some in there, if I run out, I know you've got some in your bag', so they've got a really good relationship. She's absolutely brilliant. She's a really nice teacher." (4:410)

Trust

"No, I haven't told them. I was debating about it, and then my husband and I, we just sat and we… I was like, its… you can talk to the headmistress, ok fine, but she will be changing in like two years, and she will be changing two different classes. There'll be a class teacher and a classroom assistant. I don't want everybody knowing about her, you know? I mean, it might be, they might keep it, I trust them to keep it confidential, but…. There are rumors here and there. I, I, I don't want anything affecting her. (1:172)

Example quotes from the theme "The parent-child relationship"

Theme	Subtheme	Quotes
Child Differences	Child and teenager at the same time	*"but at nine, she should be allowed to be running around the house naked if she wants to" (4:37)*
	Emotional problems	*"That's one of the things that I think has shocked us both, is that, you know, she will just get emotional" (2:30)*
Child Attributes	Child maturity and coping	*"I think it was a hell of a lot for a little girl of her age to go through, but credit to her, she's, you know, found a slot for everything" (3:182)*
	Problems in understanding	*"yeah, the worst bit is, not being, she not being able to understand. Being young, she doesn't understand what you're trying to tell her. There's a, she can't take it in, not now. When she's older" (4:88)*
Differences in Parent-Child communication	Greater communication	*"But me and C have got a …. Yeah, a good relationship like that. Honesty is the key thing. I don't want to tell her, you know, a load of lies, because the reality is, its gonna happen, and she's, she's, she's got to be taught the right way, you know, there's only one way to tell her, and that's to be honest and tell her the truth, innit really? You know. I've lied to her all these years about father Christmas and the tooth fairy, I can't lie to her about this. " (4:601)*
	Empathy	*"Emotionally she has had a lot to deal with, which is pan – which hurts, it hurts me as a mum." (4:135)*
	Patience	*"We've been aware of it [the diagnosis], so we've made allowances sometimes when she has got very stressed and very emotional.*
	Dad less involved	*"B: its probably that you and C are a bit more closer as you have something a bit more in common, or something extra in common A: Yeah…. Yeah we do talk"*
Parental Support	Friends and Family	*"They [mums friends] have just accepted her really. I mean, its been here for the last three years, so. They were with me with it was diagnosed, and you know, M goes to the*

hospital, and they're very supportive really."
(2:582)

Doctor   *"They were really good. And the consultant was just, really really good. I, and he was so helpful, god bless him, and he just, erm, said… it was quite a shock, and he just said, if you, you know, if you, you, it to stop, you know, it the sudden, if you need to, if it were my daughter, I would start all the treatment straight away and then there was no looking back."*
(1:57)

Detailed summary of the theme "Acceptance to action"

Parents experienced worry and confusion over their daughter's symptoms, and the possible alternative diagnoses, such as cancer. When a diagnosis was given, parent's feelings of confusion were resolved. However, diagnosis also leads to a new set of worries. In the short term, parents worried about possible mood swings, although many were later surprised at how mild mood swings were. Long-term worries focused on fertility and to a lesser extent, height. Parents also found idiopathic nature of the diagnosis hard to accept, and felt they needed to attribute blame or a cause. While a pre-existing medical condition was sometimes blamed, often parents blamed either food or themselves.

When a diagnosis is given, some parents went though a period when they found it hard to accept. Once this was achieved, parents felt they could tackle the condition and move on with life. Parents appeared to feel doctors took the responsibility of dealing with the medial aspects of the condition away from them, and often expressed worries over that responsibility being handed back to them when they were signed off. However, parents felt significant personal responsibility in needing to protect their child. This was explicitly linked to the disorder, and is not simply parental protectiveness.

This need to protect their child was driven by a fear of the public's perception. All parents were able to recall numerous incidents when the disorder had had a negative social impact. Indeed, parents often kept the diagnosis from their own parents, for

fear of their reactions. When grandparents were told, it often had an undesirable effect on their relationship with their granddaughter. It was rare for the condition to be associated with a positive social situation. At the heart of parents concerns over the public's perception was a desire for their daughter to be seen as "normal" at all costs, regularly emphasizing how normal their child was during the interview, despite the diagnosis. Additionally, there was a feeling that the condition would end when other children developed, and their daughter would "normal" again, despite their long-term worries about growth and reproduction.

While parents felt they had not control over the biological aspects of the condition, they went great lengths to control others perception of their daughter. This was moderated only by their desire for their child to be independent, and not wanting their child exposed to the extra attention over protection would cause.

Central to the issue of protection was whether or not they inform people about the diagnosis. Informing, for example, school, often lead to extra support, but it also involved people learning about their daughter's condition, something parents were keen to avoid. While one mother decided not to tell the school, most parents did inform people who have responsibility for their child for any length of time. However, parents often found it hard to trust people with this information, and doing so was driven solely by needing to support their child through the condition.

Appendix 1G:

Detailed summary of the theme "The parent-child relationship"

Both the child's mood swings, and a view that the child is dealing issues they should not yet be facing emerged as sub-themes affecting the child. While parents often felt that their child had exhibited maturity and coped well with the condition, often problems in the child's understanding of the condition was a source of difficulty.

Parents responded with greater communications and honesty between mother and daughter, which often aided their child's coping and understanding of the condition. They were also more patient with their child, particularly in during mood swings. Although it was not clear whether this was more than they exhibited with their other children, there was a sense of empathetic duality, with parents often reporting that negative incidents hurt them, as well as the child. Finally, both fathers who took part in the study reported they were often less involved in helping with the condition, with the view that the child's mother was in a better position to help due to her own experience as a teenager.

Parents support came firstly through friends who were informed about the diagnosis were often a source of support, and family members (in particular spouses, but rarely grandparents). However, doctors also provided considerable reliable support, both by taking responsibility for the medical side of diagnosis (see previous theme), but also in their advice and empathetic response.

Appendix 1H

Research Ethics Committee Approval

Below is a scan of the ethical approval letter from the National Research Ethics Committee Ethics Committee for the West Midlands. Because this is a scan, the following pages do not have page numbers

APPENDICES TO CHAPTER 3

UNIVERSITY OF BIRMINGHAM

[NHS trust logo removed from publication]

Participant Information Leaflet

Study Title

A qualitative study to explore health care professionals' experience of disgust working within a palliative care setting

My name is Joshua Muggleton and I am studying for a Masters Degree in Clinical Psychology in the School of Psychology, University of Birmingham. I am being supervised by Dr Ruth Howard, Senior Academic Tutor, University of Birmingham, and Dr Helen Guy, Macmillan Clinical Psychologist. I am inviting you to take part in a study to look at health care professionals' experiences of disgust in a palliative care setting.
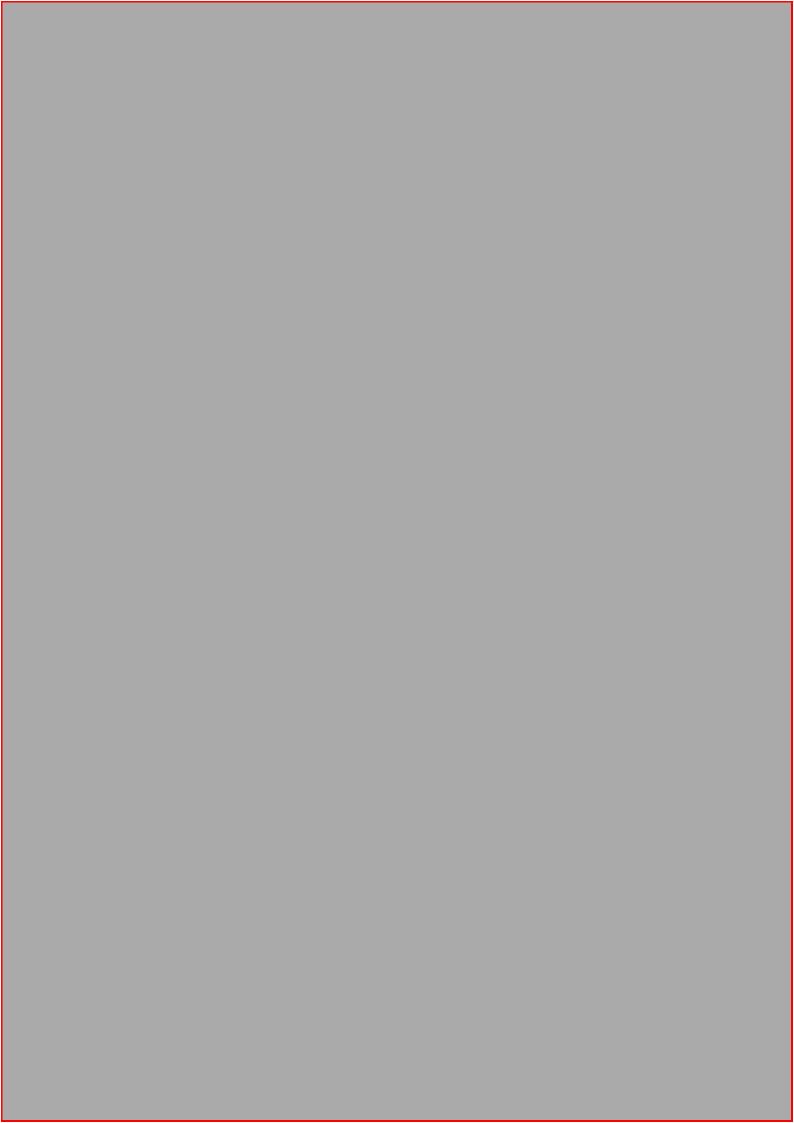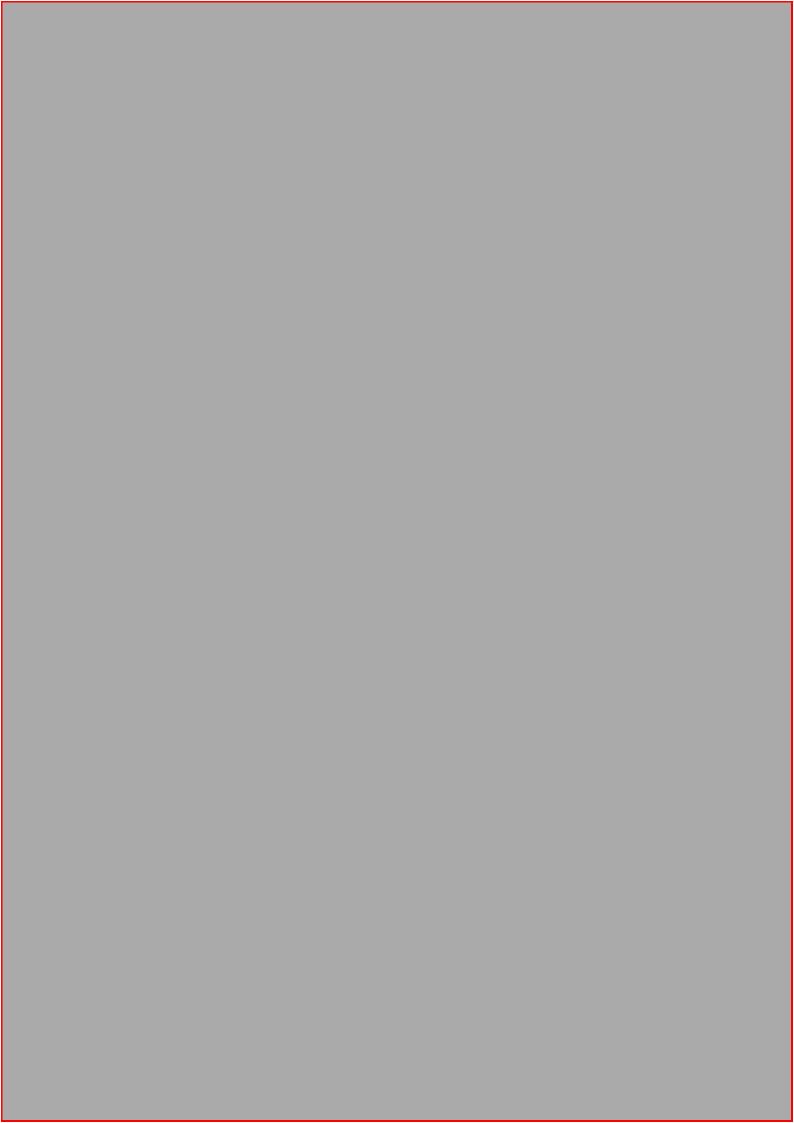
Study Summary

Health care professionals working in palliative care may have had to deliver care to patients with distressing, unsightly or foul smelling physical symptoms. These might include weeping wounds, incontinence of urine and faces, vomiting, faecal vomiting, fungating tumours, and tumours which burst through the skin. One common reaction to these symptoms is to feel disgusted, which can include physical and visceral reactions, such as nausea, or recoiling. Despite the strength of these feelings, health care professionals often try to disguise these feelings to maintain professional and ethical standards, and lessen distress for their patients.

This study aims to explore health care professionals' experiences of disgust, and how they make sense of, and manage these experiences. It is hoped that the findings from this study may result in a deeper understanding of the psychological and

emotional coping mechanisms health care professionals use to manage these experiences, and sustain themselves in the professional palliative care environment.

Invitation to participate

Given your experience in working in palliative care, and with dealing with patients whose symptoms can lead to feelings of disgust, I would like to invite you to participate in this study. This will involve an individual interview at the [location removed from this publication], lasting approximately one hour.

During the interview, you will be asked about your experiences of feeling disgust when working with patients. Your identity will be protected at all times during the study (see below), however, please note that <u>this interview will be digitally recorded, and anonymised quotes may be used in the publication of this study</u>. To help protect your identity and to respect patient confidentiality, we ask that you avoid using the names or identifying information of any patients you have cared for. You will be reminded about this during the interview by the researcher.

You will not be forced to disclose anything you do not wish to, however you may find the experience emotional. Time and space will be provided after the interview should you wish to reflect and gather yourself before leaving. Afterwards, if you feel you would like to talk to a professional about issues raised in the interview, you are invited to contact Dr Helen Guy, Clinical Psychologist (contact details below), who will be happy to talk to you further.

Participation in this study is voluntary, and you are free to withdraw from the study before or during the interview. After the interview, you may withdraw from the study up to two following the interview. However, as analysis will begin on the data you have provided after two weeks, it will be impossible to withdraw from the study after this time.

Validation

Once an initial analysis of the data has been conducted, we would like you to comment on the themes emerging from the data in order to aid meaningful

interpretation. To do this, we would like to send you an e-mail detailing the emerging themes that we feel were important to participants, and our interpretation of them. This information will not be specific to any one interview, and will not contain any quotes or identifiable information. You would then be asked to read these themes, and comment on them. On receipt, your responses will be transferred to a word document and anonymised and your original e-mail deleted. The anonymised response will then be subject to the same security procedures as the interview data

Reward

While we are unable to offer any monetary reward for taking part, we hope that as a result of this study, we will have a better understanding of how health care professionals experience and manage their feelings of disgust when working in palliative care.

Confidentiality, anonymity and data security.

Interviews will be recorded on a digital audio player and transcribed by the interviewer within two weeks, after which the audio recording will be destroyed. When transcribing the interviews, any information inadvertently identifying patients or interviewees will be removed. To identify your transcript we will use a code number, this will allow us to identify your data should you wish to withdraw from the study. All interview transcripts will be stored securely in a locked filing cabinet.

Results of the study

This study will be published as part of my thesis for my Masters in Clinical Research, and be made available via the University of Birmingham library. Additionally, it has been agreed that the results of this study will be shared with your NHS trust, either in print, or though presentations. Finally, the results of this study are likely to be of interest for those working in health care, particularly in palliative care, and therefore the results of this study may be shared with other NHS trusts, presented at conferences, or published in peer reviewed journals relevant to palliative and end of life care.

Funding

This study is being sponsored by the University of Birmingham.

Contact details

If you have any questions, concerns or comments, please feel free to contact either myself (Joshua Muggleton), my clinical supervisor Dr Helen Guy, or my academic supervisor Dr Ruth Howard:

Joshua Muggleton
Honorary Assistant Psychologist
[Contact details removed from publication]

Dr Helen Guy
Macmillan Clinical Psychologist
[Contact details removed from publication]

Dr Ruth Howard
Senior Academic Tutor & Consultant Clinical Psychologist (University of Birmingham)
[Contact details removed from publication]

Please retain this leaflet for future reference

   [NHS trust logo removed from publication]

Participant consent form

Study Title

A qualitative study to explore healthcare professionals' experience of disgust working within a palliative care setting

Information storage and handling

This information is being collected as part of a research project concerned with healthcare professionals' experiences of disgust by the School of Psychology in the University of Birmingham in collaboration with [trust name removed from this publication] NHS Trust. The information which you supply, and that which may be collected as part of the research project will be recorded on a digital audio player before being transcribed and stored in a password protected file. The digital recording will be destroyed two weeks after the interview. All printed copies of transcripts will be stored in a secure filing system, then destroyed after use (September 2013 at the latest). Only the researcher and his two supervisors (Helen Guy and Ruth Howard) will have access to your data. The data will be retained by the University of Birmingham and will only be used for the purpose of research, and statistical and audit purposes. By supplying this information you are consenting to the University storing your information for the purposes stated above. The information will be processed by the University of Birmingham in accordance with the provisions of the Data Protection Act 1998. No identifiable personal data will be published.

Statements of consent

Please tick to confirm each statement:

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☐ I confirm that I have read and understand the participant information leaflet for this study. I have had the opportunity to ask questions if necessary and have had these questions answered satisfactorily.

☐ I understand that my participation is voluntary and that I am free to withdraw myself and my data at any time for up to two weeks after my interview, without giving any reason. If I withdraw my data, it will be removed from the study and will be destroyed.

☐ I understand that the interview will be audio recorded and transcribed and I agree to this.

☐ I agree to the use of direct quotations provided that anonymity is preserved.

☐ I understand that my personal data will be processed for the purposes detailed above, in accordance with the Data Protection Act 1998.

☐ Based on the above, I agree to take part in this study.

I do/do not (delete as appropriate) agree to be part of the validation process, and to being contacted on the following e-mail address:

………………………………………………………………………………………………

Participant Signature:………………………………………… Date: /   /

Participant Name:…………………………………………………..

Researcher Signature:………………………………………… Date: /   /

Name of Researcher: Joshua Muggleton

Appendix 3C:

Interview Schedule

Example past experiences

Have you been in any situations where you have experienced something disgusting in one of your patients? (such as…….)

What is your first reaction when you see or smell something disgusting at work?
- How do you feel?
- What do you think?
- What do you do?

How do you approach something you find disgusting at work?
- Physically
- Mentally

Is there a situation that stands out in your mind when you had to approach something that you felt was disgusting?
- Can you tell me about that situation? (remind the participant to try not to use names etc.)
- How did you do it? How did you manage your feelings? How did you work with that patient? Was there anything you did afterwards to cope with your feelings?

Thoughts and feelings around disgust

Does feeling disgusted by your patient's symptoms affect how you think of or interact with that patient?

Do you think patients and colleagues can tell when you find something disgusting?

How do you feel about patients knowing you find something about them disgusting?

Do you talk to colleagues about your feelings of disgust?
- If yes, how do you feel when you share those feelings?
- If no, why is that? What stops you?

How do you feel about your reactions with patients with symptoms you find disgusting?

Approach

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How do you feel after you have had to approach something you find disgusting?

- Is there anything in particular you do when you have been working with a patient whose symptoms you find disgusting? (take a shower, go for a walk, talk to someone….etc.)

Have you ever been unable to approach a patient because of a symptom you found too disgusting?

       What were your thoughts at that time?

       How did that make you feel at the time?

       How do you feel about it now?

Support

What support do you get/seek when or after dealing with disgusting symptoms?

- Supervision?
- Colleagues?
- Family/friends?

Have you found this support helpful?

Are you able to talk about things you have found disgusting at work?

Have there been any times when you needed support but were unable to access it?

- What happened?
- How did you feel?

Institutional understanding and support

Would you like to see a better understanding of disgust?

In general, do you think there should be more support for people when they feel disgust in a palliative care setting?

Appendix 3D
University of Birmingham application for ethical review

UNIVERSITY OF BIRMINGHAM APPLICATION FOR ETHICAL REVIEW	*OFFICE USE ONLY:* Application No: Date Received:

1. TITLE OF PROJECT

A qualitative study to explore healthcare professionals' experience of disgust working within a palliative care setting

2. THIS PROJECT IS:

University of Birmingham Staff Research project ☐

University of Birmingham Postgraduate Research (PGR) Student project ☒

Other ☐ (Please specify):

3. INVESTIGATORS

a) **PLEASE GIVE DETAILS OF THE PRINCIPAL INVESTIGATORS OR SUPERVISORS (FOR PGR STUDENT PROJECTS)**

Name: Title / first name / Highest qualification & position School/Department Telephone: Email address:	Dr Helen Guy Doctorate in Clinical Psychology, Clinical Clinical Health Psychology, [NHS trust [Removed from this publication] [Removed from this publication]

Name: Title / first name / Highest qualification & position School/Department Telephone: Email address:	Dr Ruth Howard ClinPsyD, Senior Academic Tutor ClinPsyD Course, School of Psychology [Removed from this publication] [Removed from this publication]

b) **PLEASE GIVE DETAILS OF ANY CO-INVESTIGATORS OR CO-SUPERVISORS (FOR PGR STUDENT PROJECTS)**

Name: Title / first name / Highest qualification & position School/Department Telephone: Email address:	Mr Joshua Muggleton BSc (Hons) Psychology, Honorary School of Psychology [Removed from this publication] [Removed from this publication]

c) **In the case of PGR student projects, please give details of the student**

Name of Course of study: Principal	Mr Joshua Muggleton MRes Clinical Dr Ruth Howard	Student No: Email	[Removed] [Removed]

Name of student: Course of study:		Student No: Email	

Principal	

4. ESTIMATED START   Date: <u>April 2013</u>   **OF PROJECT**

     ESTIMATED END   Date: <u>September</u>   **OF PROJECT**

5. FUNDING

List the funding sources (including internal sources) and give the status of each source.

Funding Body	Approved/Pending /To be submitted
Not Applicable	

If applicable, please identify date within which the funding body requires acceptance of award:

Date: [ ]

If the funding body requires ethical review of the research proposal at application for funding please provide date of deadline for funding application:

Date: [ ]

6. SUMMARY OF PROJECT

Describe the purpose, background rationale for the proposed project, as well as the hypotheses/research questions to be examined and expected outcomes. This description should be in everyday language that is free from jargon. Please explain any technical terms or discipline-specific phrases.

Healthcare professionals working in palliative care often provide care for patients who may have distressing, unsightly and foul smelling physical symptoms (Macleod, 2011). Examples may include, weeping wounds, incontinence of urine and faeces, uncontrolled vomiting, faecal vomiting, production of sputum, ulcerated and necrotic skin, and tumours which burst through the skin. Automatic responses to these symptoms may include feelings of disgust and recoil. Healthcare professionals may try to disguise feelings of disgust in order to maintain professional and ethical standards (Holmes, Perron & O'Byrne, 2006) and lessen any distress for the patient and their carers. Furthermore, they may not feel that they can talk about their feelings and responses with other members of staff as acknowledging such experiences may result in feelings of guilt and shame. One empirical study with nursing students found that repressing such negative feelings may result in inner conflicts which can impact upon patient care, such as avoiding patient contact (Krey, 2004).

There is a paucity of empirical studies exploring this sensitive area. In this qualitative study healthcare professionals will be interviewed to explore their experiences of disgust, and how they make sense of, and manage these. It is hoped that the findings from this study can result in a deeper understanding of the psychological and emotional coping mechanisms healthcare professionals use to manage these experiences and sustain themselves in the professional, palliative care environment.

7. **CONDUCT OF PROJECT**

Please give a description of the research methodology that will be used

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This is a qualitative study. Data will be collected through the use of semi-structured interviews. All participants will be healthcare professionals working in a specialist palliative care setting within Walsall Healthcare NHS Trust.

Dr Helen Guy (Macmillan Clinical Psychologist) will informally approach potential participants who meet the inclusion criteria, to provide them with information about the research study (Participant Information Sheet). The Participant Information sheet will provide details about the study to enable informed consent. It will include the interviewer's contact details (Mr Joshua Muggleton). Participants who would like to take part in the research study and be interviewed, will be invited to provide their telephone contact details to Dr Helen Guy. These contact details will be passed to the interviewer, who will then telephone the potential participant to arrange a convenient time to discuss and gain informed consent and to carry out the interview.

Participants will be invited to attend an interview at [location removed from this publication]. Before the interview formally starts, they will have an opportunity to ask any questions and be informed they have the right to withdraw from the study at any time two weeks after the interview (prior to data analysis). Potential participants will then be asked to provide written consent to participate in the study. Interviews will be conducted by JM, following a semi-structured format, asking questions relating to their experiences of working with disgust (see interview schedule attached). Each interview will be recorded on a digital audio recorder, and will last approximately one hour.

During the interview, should any participant become distressed, they will be given the opportunity to pause or stop the interview. After the interview, participants will be given the opportunity to sit privately in the room to collect themselves before returning to work. Additionally, as part of the de-brief, they will be reminded that if they would like to talk to a professional about any of the issues raised in the interview, Dr Helen Guy (Macmillan Clinical Psychologist, clinical supervisor for this research project), will be happy to talk to them further. Contact details for Dr Helen Guy are on the participant information sheet, but will also be provided at the end of interviews.

Interview recordings will be transcribed verbatim within two weeks, after which the audio recording will be destroyed. The remaining transcriptions will be anonymised with numbers two weeks after the interview. An interpretive Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) will be used to identify themes and their meaning for the participants. Following this, participants who agreed to be part of the 'validation process' will be sent details of the emerging themes by email in order to gain feedback which will aid the interpretation of the data as part of the triangulation process.

8. DOES THE PROJECT INVOLVE PARTICIPATION OF PEOPLE OTHER THAN THE RESEARCHERS AND SUPERVISORS?

Yes ⊠ No ☐

Note: "Participation" includes both active participation (such as when participants take part in an interview) and cases where participants take part in the study without their knowledge and consent at the time (for example, in crowd behaviour research).

If you have answered NO please go to Section 18 . If you have answered YES to this question please complete all the following sections.

9. **PARTICIPANTS AS THE SUBJECTS OF THE RESEARCH**

   Describe the number of participants and important characteristics (such as age, gender, location, affiliation, level of fitness, intellectual ability etc.). Specify any inclusion/exclusion criteria to be used.

Three to six participants will be recruited. All participants will be healthcare professionals working in palliative care in [Name removed from this publication] NHS Trust, and will have regular direct patient contact. They may work in different job roles and at different professional levels within the palliative care setting. Ideally, participants will be recruited from a range of professional roles, e.g. in-patient nurses, community nurses, doctors, healthcare assistants, etc.

Inclusion criteria:
Healthcare professionals will be included in the study if they are:

   • Currently working as a palliative care healthcare professional in [Name removed from this publication] NHS Trust.
   • Willing to talk about and reflect upon experiences of disgust within their palliative care role.

Exclusion criteria:
   • Has been working in palliative care for six months or less

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10. **RECRUITMENT**

   Please state clearly how the participants will be identified, approached and recruited. Include any relationship between the investigator(s) and participant(s) (e.g. instructor-student).

   Note: Attach a copy of any poster(s), advertisement(s) or letter(s) to be used for recruitment.

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A purposive sampling method will be used to recruit participants. Dr Helen Guy (clinical supervisor for this research project and Macmillan Clinical Psychologist working in [name removed from this publication] NHS Trust) will informally approach potential participants who meet the inclusion criteria, to provide them with information about the research study (Participant Information Sheet). The Participant Information sheet will provide details about the study to enable informed consent. It will include contact details for the interviewer (Mr Joshua Muggleton, MRes student). Participants who would like to take part in the research study and be interviewed, will be invited to provide their telephone contact details to Dr Helen Guy. These contact details will be passed to the interviewer (JM), who will then telephone the potential participant to arrange a convenient time to meet to go through the consent process and carry out the interview.

11. **CONSENT**
   a) Describe the process that the investigator(s) will be using to obtain valid consent. If consent is not to be obtained explain why**.** If the participants are minors or for other reasons are not competent to consent, describe the proposed alternate source of consent, including any permission / information letter to be provided to the person(s) providing the consent.

Participants will be provided with a copy of the participant information leaflet to read. If they are interested in taking part in the study, they will pass on their telephone contact details to Dr Helen Guy, who will pass these to the interviewer (Mr Joshua Muggleton). Before the interview formally starts, they will have an opportunity to ask any questions and be informed they have the right to withdraw from the study at any time up to two weeks after the interview (i.e. prior to data analysis). Potential participants will be then be asked to provide written consent for the study. They will also be given the opportunity to provide written consent to being contacted during the period of analysis with a summary of the emerging themes and invited to give feedback on this to aid interpretation – the 'validation process'.

Note: Attach a copy of the Participant Information Sheet (if applicable), the Consent Form (if applicable), the content of any telephone script (if applicable) and any other material that will be used in the consent process.

   b) Will the participants be deceived in any way about the purpose of the study? **Yes** ☐   **No** ☒

If yes, please describe the nature and extent of the deception involved. Include how and when the deception will be revealed, and who will administer this feedback.

N/A

12. PARTICIPANT FEEDBACK

Explain what feedback/ information will be provided to the participants after participation in the research. (For example, a more complete description of the purpose of the research, or access to the results of the research).

Participants who expressed an interest in being part of the validation process will be contacted during data analysis via e-mail with a summary of emerging themes and their interpretations. They will be invited to offer feedback on the themes generated by the researchers via email and the researchers will give participants an appropriate timescale in which to provide this feedback. After the study has been completed, a written summary of the study will be made available to [Name removed from publication] NHS Trust, and a presentation on the findings will be given to participants, members of staff in palliative care within the Trust and other interested members of staff, including the Health Psychology Service.

13. PARTICIPANT WITHDRAWAL

a) Describe how the participants will be informed of their right to withdraw from the project.

Participants will be informed of their right to withdraw in the information leaflet, and will sign to say they have understood that they have a right to withdraw from the study, without giving a reason. They will be informed they are allowed to withdraw up to two weeks after their interview date. After this point their data will be included in the analysis, making it impossible to remove.

b) Explain any consequences for the participant of withdrawing from the study and indicate what will be done with the participant's data if they withdraw.

Should a participant ask to withdraw from the study, they will be allowed to do so, up to two weeks after their interview. They will be asked if they would like to give a reason, so that we can ensure the quality of the research experience is as high as possible for participants, but reminded that they are under no obligation to do so. Should they withdraw during or after the interview, their audio recording will be deleted. If this has already been transcribed, the transcription will be deleted and any paper copies destroyed. If it is more than two weeks after their interview, their data may already be in the process of being analysed, making withdrawal exceedingly difficult. Where possible, data will be withdrawn from the analysis. However, if this is not possible, participants will be informed that they can no longer withdraw their data.

14. COMPENSATION

Will participants receive compensation for participation?

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i) Financial
Yes ☐   **No** ☒
ii) Non-financial
Yes ☐   **No** ☒
If **Yes** to **either** i) or ii) above, please provide details.

N/A

If participants choose to withdraw, how will you deal with compensation?

N/A

15. CONFIDENTIALITY

a)   Will all participants be anonymous?
Yes ☐   **No** ☒
b)   Will all data be treated as confidential?
Yes ☒   **No** ☐

Note: Participants' identity/data will be confidential if an assigned ID code or number is used, but it will not be anonymous. Anonymous data cannot be traced back to an individual participant.

Describe the procedures to be used to ensure anonymity of participants and/or confidentiality of data both during the conduct of the research and in the release of its findings.

Participants will be asked to avoid any identifying details of themselves or their patients in their interviews. This will be made clear in the participant information sheet, and participants will be reminded of this during the interview. If any identifying information is included, for example, a first name, this will be replaced in the transcript with a letter (i.e "A").   Participants will have a code number attached to the transcript to allow them to withdraw should they wish. Only the interviewer (JM) will know which number corresponds to which participant.

If participant anonymity or confidentiality is not appropriate to this research project, explain, providing details of how all participants will be advised of the fact that data will not be anonymous or confidential.

N/A

16. STORAGE, ACCESS AND DISPOSAL OF DATA
Describe what research data will be stored, where, for what period of time, the measures that will be put in place to ensure security of the data, who will have access to the data, and the method and timing of disposal of the data.

Data will be stored in three main ways:

1. Digital audio recorder: The digital recorder will be stored in a locked room, and recordings deleted two weeks after the interview.

2. Hard copy print-outs: Paper copies of transcripts used during the analysis stage will be stored in a folder in a locked room. All hard copies will be shredded after the analysis and writing-up of the project has taken place.

3. Digital Audio Recording: During analysis, data will be stored in an encrypted folder on a password-protected computer. Post analysis, data will be stored by Dr Ruth Howard, Academic Supervisor on a password protected university computer account for 10 years.

Only JM, HG and RH will have access to the data.

17. OTHER APPROVALS REQUIRED? e.g. Criminal Records Bureau (CRB) checks

☒ YES   ☐ NO   ☐ NOT APPLICABLE

If yes, please specify.

The person carrying out the interviews and analysis (Joshua Muggleton) has enhanced CRB clearance as part of his work as an MRes student. In addition, Joshua Muggleton will have an honorary contract with Walsall Healthcare NHS Trust

18. SIGNIFICANCE/BENEFITS

Outline the potential significance and/or benefits of the research

There is a paucity of empirical studies exploring the area of disgust in palliative care. By understanding how healthcare professionals experience and cope with disgust, we hope to raise awareness of this issue, as well as to improve training, personal development, and support for healthcare professionals experiencing disgust. More broadly, we hope to minimise the impact of disgust on patient care, which has already been identified as a potential barrier to patient contact Krey (2004).

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19. RISKS

a) Outline any potential risks to **INDIVIDUALS**, including <u>research staff, research participants, other individuals not involved in the research</u> and the measures that will be taken to <u>minimise</u> any risks and the procedures to be adopted in the event of mishap

> The interviews may be emotive for participants, given the sensitive and emotional nature of disgust. Equally, it may be that participants experience feelings of shame or guilt over their reactions to patients' symptoms.
>
> Interviews will be conducted with great sensitivity, and it will be made clear to participants that they can choose not to talk about something, pause the interview, or stop the interview completely at any point. After the interview, they will be given the option of at least 15 minutes alone in the room (or with the interviewer if desired) to reflect and collect themselves before returning to work. The interviewer (JM) will also ensure they have the contact details for HG, Macmillan Clinical Psychologist working at the [location removed from this publication], and that participants are aware that they can talk to her about any of the issues raised in the interview.
>
> In addition to the risks already outlined, the researcher conducting the interviews (Joshua Muggleton) may feel distress or disgust at the content being discussed. Therefore, after each interview, the researcher will contact either Helen Guy or Ruth Howard (both clinical psychologists) for a de-briefing. Additionally, interviews will only take place when Helen Guy is in the building to ensure her availability, should the researcher or participant require support during or after the interview. Should Helen Guy not be immediately available, then the researcher will contact Ruth Howard for support, if required.

b) Outline any potential risks to **THE ENVIRONMENT and/or SOCIETY** and the measures that will be taken to <u>minimise</u> any risks and the procedures to be adopted in the event of mishap.

> There are no foreseeable risks to the environment or society

20. ARE THERE ANY OTHER ETHICAL ISSUES RAISED BY THE RESEARCH?

Yes ☒ No ☐

If yes, please specify

There is a minor risk that participants may inadvertently reveal confidential details about patients during the interview. Participants will be reminded during the interview that they should try not to reveal any identifying information about the patients they are talking about. Any such lapses will be removed from the interview transcript by JM.

21. **CHECKLIST**

Please mark if the study involves any of the following:

- Vulnerable groups, such as children and young people aged under 18 years, those with learning disability, or cognitive impairments ☐

- Research that induces or results in or causes anxiety, stress, pain or physical discomfort, or poses a risk of harm to participants (which is more than is expected from everyday life)   ☒

- Risk to the personal safety of the researcher   ☐

- Deception or research that is conducted without full and informed consent of the participants at time study is carried out   ☐

- Administration of a chemical agent or vaccines or other substances (including vitamins or food substances) to human participants.   ☐

- Production and/or use of genetically modified plants or microbes   ☐

- Results that may have an adverse impact on the environment or food safety ☐

- Results that may be used to develop chemical or biological weapons   ☐

Please check that the following documents are attached to your application.

	ATTACHED	NOT APPLICABLE
Recruitment advertisement	☐	☒
Participant information sheet	☒	☐
Consent form	☒	☐
Questionnaire	☐	☒
Interview Schedule	☒	☐

22. **DECLARATION BY APPLICANTS**

I submit this application on the basis that the information it contains is confidential and will be used by the University of Birmingham for the purposes of ethical review

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and monitoring of the research project described herein, and to satisfy reporting requirements to regulatory bodies. The information will not be used for any other purpose without my prior consent.

I declare that:
- The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it.

ther relevant professional bodies' codes of conduct and/or ethical guidelines.
- I will report any changes affecting the ethical aspects of the project to the University of Birmingham Research Ethics Officer.
- I will report any adverse or unforeseen events which occur to the relevant Ethics Committee via the University of Birmingham Research Ethics Officer.

Name of Principal investigator/project	**Dr Ruth Howard**
Date:	27 March 2013

Please now save your completed form, print a copy for your records, and then email a copy to the Research Ethics Officer,   As noted above, please do not submit a paper copy.

Appendix 3E
NHS Research and development application

The PDF generated from the IRAS website is presented on the following 29 pages.

Because the PDF cannot be edited, the following pages do not have page numbers.

Appendix 3F
NHS Site specific information form

The PDF generated from the IRAS website is presented on the following 10 pages.

Because the PDF cannot be edited, the following pages do not have page numbers.

Appendix 3H:
NHS approval

The PDF scan of the original NHS approval letter is presented on the following two

pages. Because the scan cannot be edited, the following pages do not have page

numbers.

Application for the University of Birmingham to Act as Sponsor under the Department of Health' s Research Governance Framework for a <u>research study</u> – <u>PF1</u>

The University is requested to agree to act as Sponsor for <u>staff led research</u> or <u>supervised-postgraduate student research study</u> falling under the Research Governance Framework for Health and Social Care with respect to the following project:

PLEASE CONSULT THE NOTES FOR APPLICANTS BEFORE USING THIS FORM

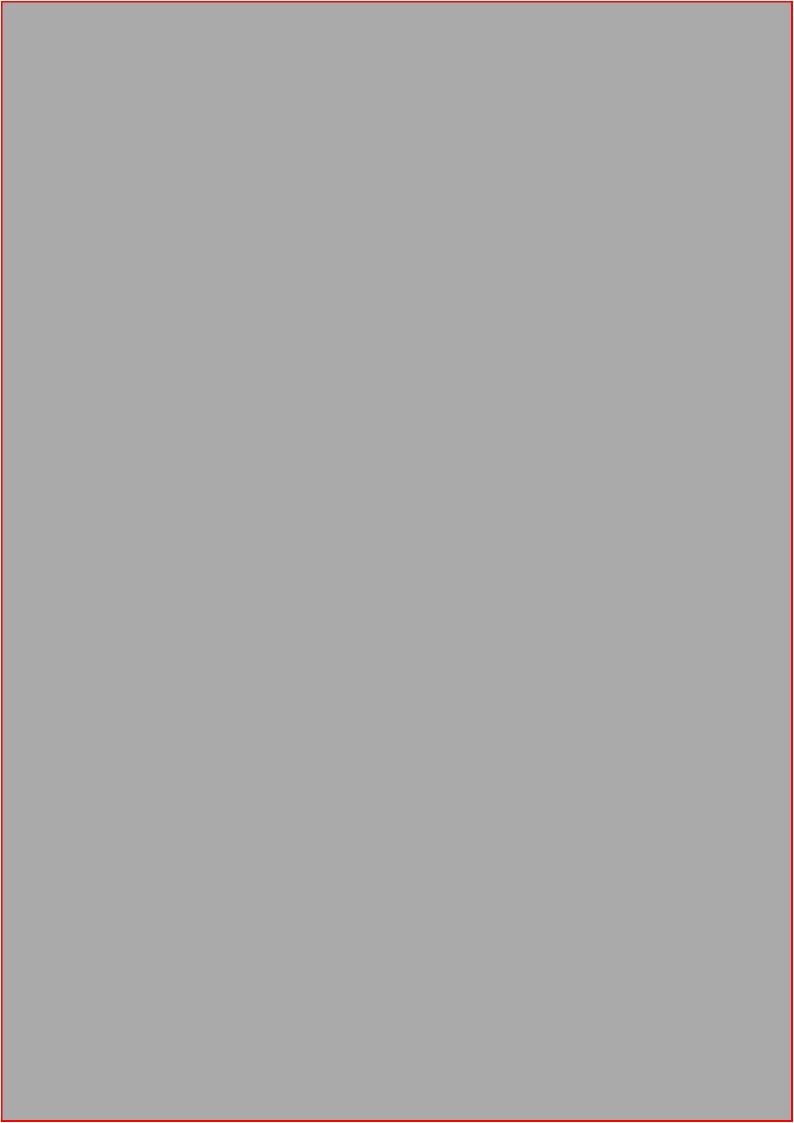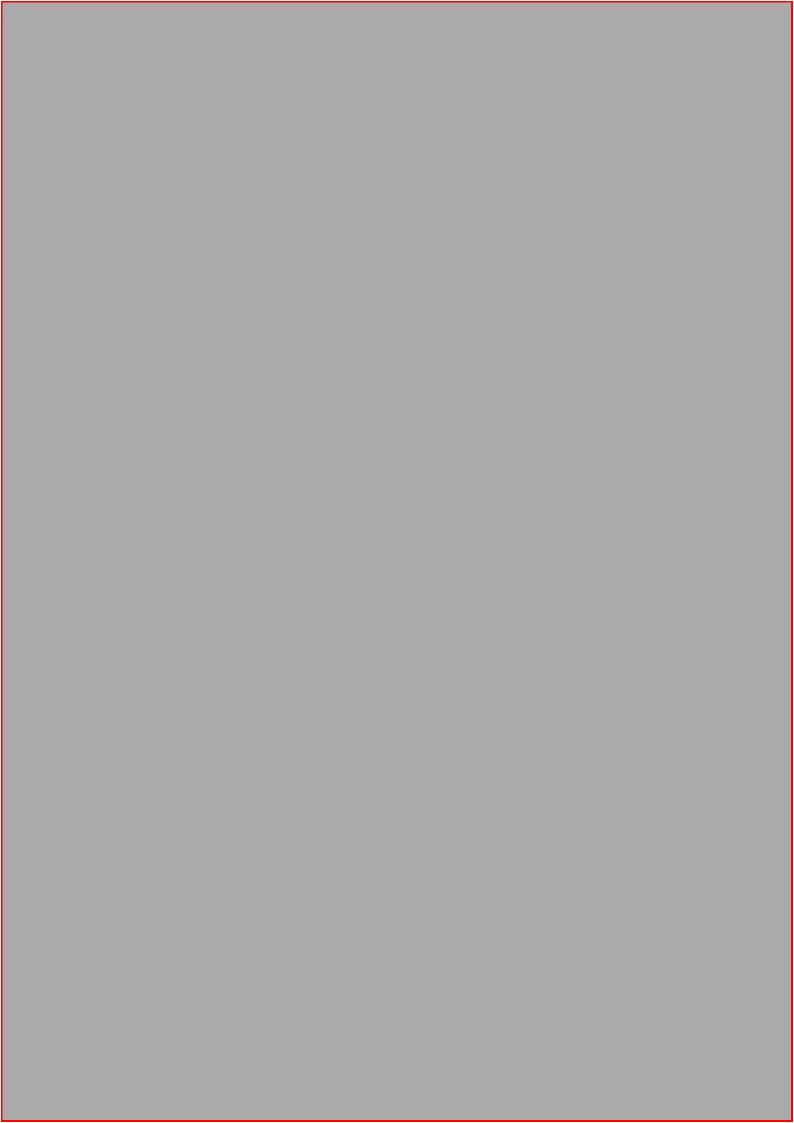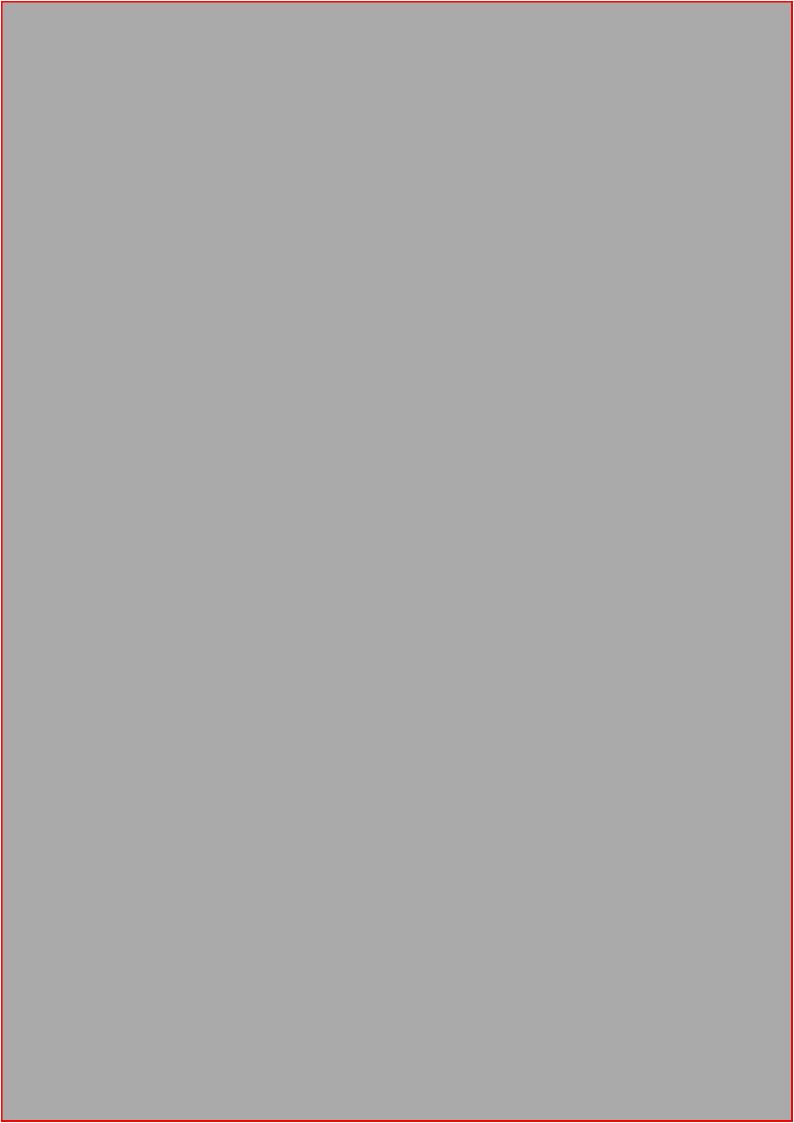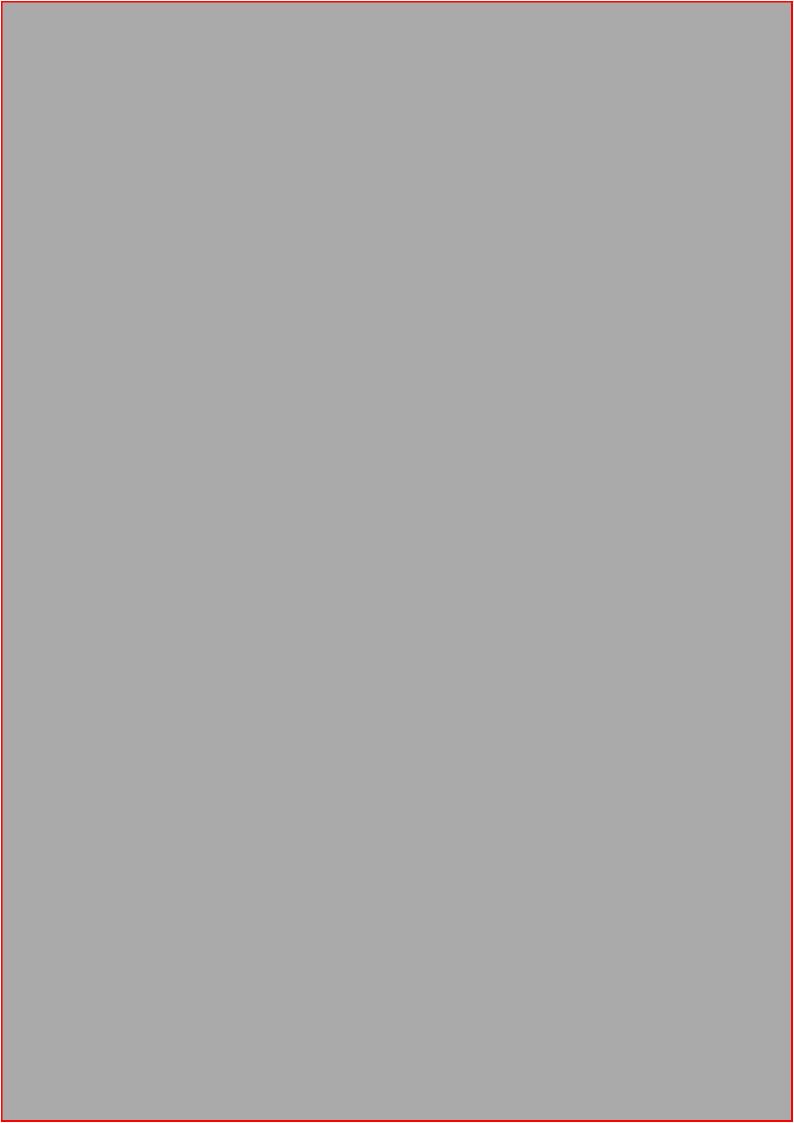| Project Overview			
Full Project Title	A qualitative study to explore healthcare professionals' experience of disgust working within a palliative care setting		
Chief Investigator (CI)	Dr Ruth Howard		
CI Employer	University of Birmingham		
UoB Lead if not CI			
UoB Lead e-mail	[Removed from this publication]	UoB Lead Phone	[Removed from this publication]
School	Psychology	College	
Protocol/Research plan author	Dr Ruth Howard, Dr Helen Guy, Mr Joshua Muggleton		
Study Details - Research Project			
Please Identify Project Type			
Research Project - Clinical			Yes
Research Project - Health Care			Yes
Research Project - Social Care			
Is Research Project Staff led or Student Project?		Student project	
Lay Summary of Research Project			

Healthcare professionals working in palliative care often provide care for patients who may have distressing, unsightly and foul smelling physical symptoms (Macleod, 2011). Examples may include, weeping wounds, incontinence of urine and faeces, uncontrolled vomiting, faecal vomiting, production of sputum, ulcerated and necrotic skin, and tumours which burst through the skin. Automatic responses to these symptoms may include feelings of disgust and recoil. Healthcare professionals may try to disguise feelings of disgust in order to maintain professional and ethical standards (Holmes, Perron & O'Byrne, 2006) and lessen any distress for the patient and their carers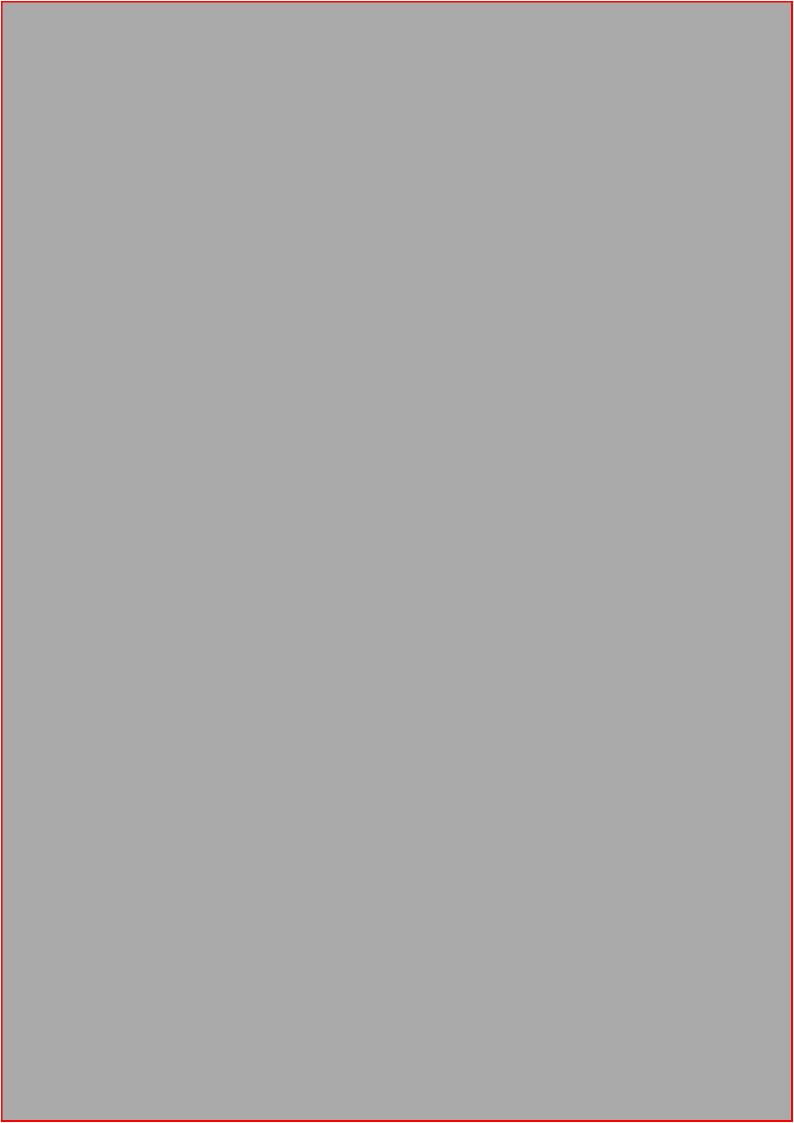. Furthermore, they may not feel that they can talk about their feelings and responses with other members of staff as acknowledging such experiences may result in feelings of guilt and shame. One empirical study with nursing students found that repressing such negative feelings may result

in inner conflicts which can impact upon patient care, such as avoiding patient contact (Krey, 2004).

There is a paucity of empirical studies exploring this sensitive area. In this qualitative study healthcare professionals will be interviewed to explore their experiences of disgust, and how they make sense of, and manage these. It is hoped that the findings from this study can result in a deeper understanding of the psychological and emotional coping mechanisms healthcare professionals use to manage these experiences and sustain themselves in the professional, palliative care environment.

If Student Project please indicate					
Doctoral Project		Masters Project	Yes	Undergraduate	
Student Name			Joshua Muggleton		
Academic Supervisor (if Not UoB Lead above)					
Clinical Supervisor (if appropriate)			Dr Helen Guy		
Will the Project require access to the following? (Tick all which apply)					
NHS Patients		NHS Patient Data		Human Tissue	
NHS Staff	Yes	NHS Facilities	Yes		
Healthy Volunteers		Non-NHS Patients		Social Care Clients	
Other Facilities or Participant Groups (please specify)					
Does the Project involve ONLY work using Tissue (Data) from a UK Registered Tissue (Data) Bank? If yes, please insert Tissue (Data) Bank information below. If No, please continue to "Project Details"					
Name of Bank					
Will the Tissue (Data) be passed to third party collaborators					
Project Details					
Planned Start Date	April 2013		Planned End Date	September 2013	
No of Research Sites in UK	1		No of non-UK Research Sites		
Study Funding Status					
Has Funding been confirmed for this Study (Y/N)?					No
If Yes, list Funders and amounts					
Is confirmed funding adequate to complete Study					Yes
If funding not confirmed, list sources applied to					
Is projected funding adequate to complete Study					
When do you expect to obtain confirmation of funding?					
Ethical Approval					
Has a University Ethics Self Assessment been submitted for this Study?					Yes

Is this Study classed by NRES as "service evaluation"?	Yes
Is there an existing NRES Ethical approval covering this study?	
If yes, please state REC and REC reference	
If yes, has a Substantial Amendment been submitted covering this study?	

Please complete the declarations below and return the **<u>original</u>** completed, signed form to:

Ms Jane Barclay
Research Governance Administrator
Research Support Group
Aston Webb Building
Edgbaston
Birmingham B15 2TT

DECLARATIONS

Declaration by Principal/Chief Investigator/Academic Supervisor (*)

I, (**Name**)…Dr Ruth Howard…….as Academic Supervisor (*delete as appropriate) for
Project Title: …… A qualitative study to explore healthcare professionals' experience of disgust working within a palliative care setting ……confirm that:

1. The information in this form is accurate to the best of my knowledge and belief.

2. I understand the duties required of the Investigators, the Funders and the Sponsor by the Research Governance Framework and I am appropriately trained and qualified to undertake the duties of Principal or Chief Investigator.

3. I undertake to comply with the University's policies and procedures and the principles of the Department of Health's Research Governance Framework for Health and Social Care, the principles of Good Clinical Practice, the Data Protection Act 1988, the Human Tissue Act 2004, and where applicable, the Medicines for Human Use (Clinical Trials) Regulations 2004 (and any subsequent Amendments thereto).

4. To the best of my knowledge my research team and the School are properly equipped to take on the duties of Sponsor delegated to it.

5. I take responsibility for completing a research proposal, discussing it with the Sponsor's representative and obtaining an appropriate independent scientific critique of this proposal.

6. I take full responsibility for the conduct and delivery of the research as proposed after obtaining favourable NRES REC ethics review and any appropriate NHS Research & Development permissions, and, where applicable, authorisation from the Medicines and Healthcare products Regulatory Agency.

7. I take responsibility for ensuring that all staff and students involved in this research are familiar and abide with the Research Governance Framework and the University's relevant policies and guidelines and, if applicable, the Medicines for Human Use (Clinical Trials) Regulations 2004.

8. I understand and agree that the study files, records data and documents may be subject to inspection for auditing and monitoring purposes. I shall assist with audits of the conduct of the Study whether undertaken by the Sponsor or a regulatory body.

9. I understand that information relating to this research, and about me as a researcher, will be held by the Research Governance Officer and on the Research Governance Database. This information will be managed according to the principles established in the Data Protection Act 1988.

Signed ....

Name: Dr Ruth Howard   ....   Date   11/4/13

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Declaration by Head of School

I, (**Name**)……………………………………………………………….……., in my capacity
as (Title) …………………………………………………………….confirm that:

1. I have read and understood the roles of the Investigators, Funders and Sponsors as set out in the Department of Heath's Research Governance Framework ofr Health and Social Care, 2nd Edition 2005.

2. The Chief/Principal Investigator and his/her team are appropriately trained and qualified to conduct the Study described above.

3. The research team and the School are properly equipped to carry out the duties of Sponsor delegated to it, including monitoring the project as appropriate.

I hereby recommend that the University accepts the role of Sponsor for the above project and shall ensure that the research team and the School carry out those duties of Sponsor delegated to them.

Signed ....

Name   ....   Date ....

For Postgraduate Research Student Projects:

Declaration by the Research Student acting as Principal Investigator

I,   **Name**:…………………………………………………………….., as the postgraduate
research student conducting the research for the above project confirm that:

1. The information in this form is accurate and to the best of my knowledge and belief
    and I take full responsibility for my role in this research project.

2. I understand the duties required of the Investigators, the Funders and the Sponsor by
    the Research Governance Framework and undertake the duties of Principal or Chief
    Investigator.

3. I undertake to comply with the University's policies and procedures and the principles of the
    Department of Health's Research Governance Framework for Health and Social Care, the
    principles of Good Clinical Practice, the Data Protection Act 1988, and the Human Tissue Act
    2004, and where applicable, the Medicines for Human Use (Clinical Trials) Regulations 2004
    (and any subsequent Amendments thereto).

4. I take full responsibility for the conduct and delivery of the research as proposed after
    obtaining favourable NRES REC ethics review and any appropriate NHS Research &
    Development permissions, and, where applicable, authorisation from the Medicines and
    Healthcare products Regulatory Agency.

5. I understand and agree that the study files, records data and documents may be
    subjected to inspection for auditing and monitoring purposes. I shall assist with audits
    of the conduct of the Study whether undertaken by the Sponsor or a regulatory body.

6. I understand that information relating to this research, and about me as a researcher,
    will be held by the Research Governance Officer and on the Research Governance
    Database. This information will be managed according to the principles established
    in the Data Protection Act 1988.

Signed   ……………………………….

Name   …………………………….   Date   ……………………………
E-mail address   …………………………………………………………….................

Appendix 3J:
Sponsorship approval from the University of Birmingham

The PDF scan of the original University of Birmingham sponsorship approval letter is presented on the following two pages. Because the scan cannot be edited, the following pages do not have page numbers.

Below is a list of codes from Alex's transcript. Each code is followed by a line number in brackets referencing the location in the transcript from where the code originated. Codes are grouped into subthemes (_italicized and underlined_), which themselves are grouped into themes (in **Bold**). Descriptions of all themes and subthemes can be found in Appendix 3L.

Her professional identity
Professionals Don't Show Disgust
not wanting the patient to see her disgust (39)
Does not want to seem insensitive, hence does not show disgust (48)
Professionals don't show disgust (55)
Need to 'behave professionally' (55)
Does not talk about what she finds disgusting with colleagues (87)
Professionals are not allowed to show disgust (157)
Important that when she tells people, they don't think it affects how she works (238)
Tries to underplay the difficulties she has with disgust (248)
Disgust is more (professionally?) difficult to show than distress (259)
Worried that patients will think she is disgusted at them (266)
It is rare for her to find something disgusting (293)
This is more difficult than psychological distress – there she can react, here she can't (392)
She finds the question 'do you feel disgust' threatening – she shouldn't feel it as a doctor (424)
Feels disgust challenges her view of herself as a doctor (490)
She has to find a reasonable excuse when she leaves (520)

The Empathic Professional
Does not want patients to feel judged (130)
Hopes patients don't think she has found their symptoms disgusting (255)
Is ok with showing some mild distress if they are distressed, but not ok if they picked up disgust (257)
Worried that by showing disgust, patients will think she is being judgmental (264)
She needs to be seen as an island of calm – to hold it, unlike anyone on the street (269)
Part of her role is supporting the patient through whatever happens to them (276)
She needs to be able to handle anything (278)
Her patients 'disintegrate', but she holds them together (282)
Empathy drives you to hide disgust (498)

Fear of compromising patient care
Does not want to compromise patient care by leaving early (48)
Fear of running out of the room (57)
Fear of finding excuses to leave early (58)
Responsibility to not let this person down, ether through reaction or leaving (63)
Going back later when you finish early (72)
She has only left early once or twice (72)

Emphasizes it's rarity → Feeling guilty over leaving (80)
Rarely has to leave early (94)
Very unprofessional to allow disgust to affect your work (158)
If you can't see a patient because they make you feel ill, you can't do the job (174)
She would never refuse to see a patient – need to be professional (202)
Keen to make it clear she will see any patient – anxious she is seen to fill her role (227)
Rare…. Again (256)
Walking out of a conversation is rare (344)
Does not leave abruptly, leaves earlier (344)
Tries to minimize the impact smell has on her leaving early (346)
She feels uneasy going into situations that are going to be disgusting, as she is worried about leaving early/not give best patient care (361)
Worries are about doing the job the best she can, giving the right amount of time with the patient is the yardstick (364)
Again – rare (514)

Challenging job
Communication is an important part of the job (101)
Having an inner supervisor to analyze a situation (102)
She is communicating complex information (117)
There is a lot she has to deal with when seeing a patient – it is difficult (121)
She likes to be challenged, but disgust is uncomfortably challenging (372)

Professional persona as a tool/shield
Different sort of challenge to angry patients – this is a more personal, rather than professional challenge (46)
Can put on a professional persona and put personality differences/etc to one side. (140)
Not liking a person isn't a problem – professional persona takes care of that (145)
She only has to 'keep it together' for a short time (471)

Disgust labels
Disgust as a judgment on someone
Disgust is not about judging patients, purely their symptoms (133)
Implied judgment, and therefore guilt over disgust (140)
She acknowledges disgust when someone else is feeling it, but talks about challenging/difficult when she feels it (349)
Disgusting as a judgmental word (438)

Professionally acceptable words for disgust
revulsion rather than disgust (37)
Revolting rather than disgust (54)
Using revulsion rather than disgust (108)
Revulsion, rather than disgust (131)
Dealing with disgust is a burden (348)
She describes feelings using un-emotive, work related words (356)

Disgust isn't explicitly talked about in palliative care. Instead, its challenging/difficult (399)
Symptoms are difficult, challenging, sometimes revolting – not disgusting (437)
People use other words for disgust (460)

Cannot use 'disgust' in palliative care
She is talking about overcoming her own disgust, but not about the emotion (365) – unprofessional to talk about these emotions?
She never uses the word disgust or disgusting in palliative care (421)
Disgust as a childish word (422)
Disgust is taboo (430)
Staff don't talk about how a symptom makes them feel (432)
Nobody says they were disgusted by a symptom (437)
Disgust is taboo (443)

Her personal identity
Personal disgust profile
Difficulty with smells and distorted faces (16)
Can deal with incontinence (23)
Dislikes but can deal with vomit (23)
Pregnancy making nausea worse (29)
Smell (from nasty cancers) makes her feel nauseous (31)
The size of the cancer on the face is important (34)
Smell can "overwhelm" and cause her to leave (71)
Smell as the main reason for leaving (84)
Finding facial cancer disgusting is personal to her (89)
Smell as overwhelming (91)
Smell is cloying – stays with her (92)
Could not do a job that was just head and neck cancer (181)
Sight was bad, but not as nauseating as smell (165)
She couldn't do a head and neck specialty job (336)

Disgust as a personal challenge
If they cause disgust, it impacts on her personally, and therefore professionally (148)
Disgust challenges her personally – it is a bodily response, not a professional challenge (372)

Using a mask to hide disgust
compose her face (36)
prepare herself physically (44)
Bracing herself (53)
Mask says on during patient contact (69)
Disgust cannot be stopped, so has to be disguised (160)
Her preparations are mostly physical – suppressing the disgust reaction reflex (351)
She has to put on a physical mask to hide her reactions (387)
The physical mask is only for smell, not for visual symptoms (388)
Focus is not showing disgust, rather than preparing herself emotionally for it (390)

"brace yourself" to cope with the smell (36)
Self talk (53)
Anticipation/fear is worse than being there (68)
Preparing to see a patient, she has to acknowledge it is going to be difficult, and prepare for it (127)
Psychs herself up with self talk to prepare (128)
Self talk – ordering herself to stay (163)

Disgust and its difficulties
Disgust is a reflex
Disgust response as a reflex – lack of control (40)
Can't control disgust response, so put on another layer/mask (41)
Revulsion (disgust) as being overwhelming/uncontrollable (107)
Can't get rid of disgust, so has to push them away – suppression (130)
She can't control disgust (132)
It is hard to put disgust to one side (136)
Disgust is difficult to put to one side (144)
The physical sensation of disgust is hard to put to one side (150)
Disgust is a physical reaction, making it hard to disguise (159)
Very cognitive, deliberate behavior to appear undisgusted (390)
Disgust is hard to stop (501)

Disgust makes her want to withdraw
Finds excuses to leave early (85)
Able to get away early if there are cognitive problems (95)
One time she was unable to ender a room because of the smell (164)
She needs to excuse why she couldn't see a patient with hyperemisis – can't just be that she couldn't see a patient (175)
Smell makes her want to run away (506)

Disgust uses cognitive resources
Trying to hear and hide disgust and work "gets a bit too much" – using cognitive resources (92)
Disgust clouds her inner supervisor (107)
She needs to think a lot harder about what is going on (117)
She has to put the emotion aside AND stay there – she is doing two cognitively demanding tasks at the same time (514)

Disgusting symptoms as 'things'
Cancer as a nasty 'thing' (19)
Disgust is 'a big thing' in the room, but isn't out of the room (333)
Disgust as another 'thing' in the room (333)

Disgust makes it harder to hear
Cancer making it harder for patients to communicate (59)
Having to get closer to people with worse cancers (62)
Cancer gets in the way of seeing a person as a person, making com harder (73)

Cancer causing physical communication problems (76)
Difficulty hearing a person through disgust (92)
What a person is really saying gets lost due to disgust (110)
Have to work hard to hear someone through disgust (110)

Sharing hard cases
Giving best patient care
Working in a team means playing to strengths and weaknesses – different people find different things difficult (195)
Passing on patients can mean better patient care (196)
Passing on patients to someone better able to care is professional (213)
Main role of passing on patients is giving them the best service (223)

Passing on as a coping mechanism
Disgust is avoided /got round (187)
Passing on patients also provides some self-protection (224)
Her way of dealing with disgust was to share with colleagues (348)

Anxiety over passing on patients
Feels guilt over passing patients on to colleagues (187)
Very uncomfortable admitting she passes on patients – guilt/challenge to professional persona (192)
Passing on patients does not fit with her professional persona (208)
Anxiety over people knowing she is passing on patients (209)
Makes it clear how rare it is to pass on patients (210)
Passing on patients does not cause anxiety (only telling people does) (213)
Very anxious I know she is not avoiding patients – violation of professional persona / she can do the job(218)
Talking about passing on patients clashing with dr persona causing anxiety(232)
Worries about it being seen as dodging work (477)

Negotiating who takes who
Pointing patients to other colleagues is passive (179)
Passing on patients is done covertly (201)
Agrees best person to treat with colleagues (216)
When negotiating who takes a patient, she doesn't talk about disgust (403)

Talking about disgust with colleagues
Talking about difficulties is important
Feels people need to know she finds some patients difficult so they ill tell her (245)
Telling people you find something difficult helps you find ways through it (250)

Discussing difficulties to improve patient care
Acknowledging difficulties is part of best practice (243)
Acknowledging difficulties helps improve patient care (243)
Sharing experiences allowed for discussion of how to improve patient care (300)
Primary concern is how the disgust affects patient/loved ones (301)
Discussion about disgusting symptoms is very medical/intellectual (432)

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Talking about difficulties easy
Able to talk what she is thinking, in the context of 'difficult' (238)
Telling people she finds disgust difficult is not hard for her (238)
She would be very open about telling people about her feelings (305)

Informal support only
She would share difficult experiences with colleagues (296)
She never needed more formal support (298)
She doesn't need anything more than informal support from colleagues for dealing with disgust (309)
Informal support is recognition that something was difficult (324)
Informal support does not discuss emotional reactions (324)
She can and has accessed stronger support, but never about disgust (326)

Camaraderie between palliative care professionals
Camaraderie with nurses (234)
She used to be part of a close knit teem, with a long term bond that she could talk about anything with (294)
Home provides indirect support (314)
She keeps home and work life very separate (316)
Not something her husband could meaningfully react to (318)
She needs to talk to someone who knows what she is talking about (319)

Appendix 3L:
Summary of Alex's subthemes

Her Professional Identity
These subthemes relate to her view of herself as a doctor, and the role she plays as a doctor.

Subtheme	Description
Professionals don't show disgust	She believes that professionals should not show any disgust. Doing so is a direct challenge to her view of herself as a doctor, and causes her great anxiety, and she was keen to stress how rare it is. This stems from her view that disgust is a judgment on someone, and that as a doctor, she should not be judging someone because of their symptoms. Therefore, she cannot show any sort of emotional reaction to disgust.
The Empathic Professional	She believes that professionals should be empathic, both cognitively (ie how are they feeling), and emotionally (showing an emotional reaction). She is happy to show non-disgust emotions as part of her empathic professional role. However, she worries that by showing disgust, patients will feel she is judging them, although she has no evidence to support this. Part of that involves supporting the patient through whatever comes, and holding them together while they disintegrate emotionally.
Fear of compromising patient care	She believes that professionals need to give the highest possible standard of patient care. She is highly anxious of the possibility she might let that person down by leaving early due disgust. This could be by not giving them the full amount of time they deserve, or not being there to hold them together as much as she could. Either would compromise patient care. When disgust does compromise her patient care (leaving early), she ensures she goes back completes her work. She would never refuse to see a patient, and it is important for her that others don not think that disgust compromises her patient care. Again, throughout the interview, she was very defensive and anxious about this – even stating explicitly that she was anxious I would think she was skipping work.
Challenging job	Her job is challenging, due to both the medical complexities, but also the difficulty in communicating highly complex ideas in a simple way. However, she enjoys this challenge, and has developed strategies to help her analyze the situation
Professional persona as a tool/shield	She can use her professional persona as a defense against patients that she does not get on with, or are difficult to deal with (not in a disgust sense). She is there to do a job, and liking or disliking a patient does not need to be part of it. This does not work for disgust

Disgust Labels

These subthemes relate to her conception of the word 'disgust' and how it is used

Subtheme	Description
Disgust as a judgment on someone	She feels that the word disgust implies a judgment. For her, disgust has two components: The *feeling* of revulsion: the urge to withdraw The *implied* judgment of someone for doing, or being disgusting. E.g child defecates on the floor is "disgusting" and implies a judgment. It is important for her that her patients do not feel judged (see 'Professionals Don't Show Disgust' and 'The Empathic Professional'
Professionally Acceptable words for Disgust	She consistently used revulsion rather than disgust, and often referred to symptoms/cases as challenging/difficult. Revulsion has no implied judgment – it is something that is purely about an object, and does not have the social violation that disgust has come to have.
Cannot use 'disgust' in palliative care	She has never used, and never heard the word 'disgust' used in palliative care. It is taboo in a professional setting, and possibly seen as childish.

Her Personal identity
These subthemes relate to her as a person, and how she deals with disgust

Subtheme	Description
Personal Disgust Profile	This is what she personally finds disgusting. She has difficulty with smell, which makes her feel nauseous, 'overwhelms' her drives her to leave. Secondary to smell, she has problems with distorted faces, although this is not as nauseating, she still finds them difficult to approach. She would not be able to do a job where she had to deal exclusively with head and neck cancers. She is, however, able to deal with vomit, incontinence, and other wounds
Disgust as a personal challenge	Disgust is a physical, bodily response (See Disgust is a reflex). Unlike an angry or upset patient (which comes from outside, so she can protect herself using her professional persona) disgust comes from inside her. Because it affects her personally, it cannot be stopped by the professional persona, and indeed, is at risk of damaging that persona
Using a mask to hide disgust	Before going in to see a patient with disgusting symptoms, she takes time to prepare physically. This involves 'putting on a mask' – composing her face so that she does not show any disgust
Psyching herself up	She does some self-talk, acknowledging it will be difficult, but for the most part, telling herself that she is going to stay, and not compromise patient care. This is more like an instructor saying 'you are going to do this' rather than encouraging herself 'you can do this'. This is what she has to do in order to hold someone together

Disgust and its difficulties

These subthemes relate the nature of disgust, and the problems it causes her

Subtheme	Description
Disgust is a reflex	Disgust is uncontrollable, like a reflex. It is automatic, she cannot help it happening. Once she feels disgust, she has suppress the feelings inside her, as well as compose her face so as to disguise her disgust
Disgust makes her want to withdraw	The smell makes her want to run away. She tries to find excuses to leave early, for example, her hyperemisis. If the patient has cognitive problems, excuses may not be needed. On once occasion, she was unable to enter a room because of the smell
Disgust uses cognitive resources	Because of communication problems caused by disgust, she has to work harder to hear the patient. She also has to keep her emotion in check, putting on a physical mask, and fighting the urge to withdraw. Both of these up cognitive resources, and makes the job more cognitively demanding. Therefore, she has difficulty utilizing tools she uses to overcome disgust because of this. It can get 'a bit too much', and she has to 'just do it' – what is usually an internal discussion with herself turns into instructing herself
Disgusting symptoms as 'things'	She sees cancer and disgust as "things" entities in the room with them. They are very separate from the patient. Although she can professionally name it, personally, it is too powerful, too emotional to be named
Disgust makes it harder to hear	The emotion of disgust gets in the way of seeing the person as a person, and hearing what they are trying to say. This is in addition to the physical symptoms that cause disgust, which may also cause communication problems in themselves (ie tracheotomies').

Sharing hard cases
These subthemes relate to passing on hard cases to colleagues

Subtheme	Description
Giving best patient care	The main reason (or rationalization) for passing on patients is to ensure the best patient care – if someone's strengths are better suited to a particular case, then giving that person the case ensures the patient gets the best possible care.
Passing on as a coping mechanism	There was recognition that her way of dealing with disgust was to pass patients which she had extreme difficulty with onto colleagues, this way she can avoid disgust, and protect herself
Anxiety over passing on patients	She feels anxiety about how other people might see passing on patients to colleagues, (i.e that she is dodging work). Equally, while she says she is fine with passing on patients, there is evidence that there is some violation of per professional persona here, whish she dislikes
Negotiating who takes who	Deciding who takes on which patient is done covertly, if at all – sometimes it is more a case of 'letting' someone go into someone else's care. However, when there is a negotiation, disgust is not mentioned – it is more "this is more your thing".

Talking about disgust with colleagues

These subthemes relate to talking about difficulties (never disgust) with colleagues

Subtheme	Description
Talking about difficulties is important	She sees herself in a leadership role, and therefore feels that she needs to set an example by talking about what she finds difficult, so that others will feel able to do the same to her. This enables her to help others through their problems. However, she never talks about disgust.
Discussing difficulties can improve patient care	By sharing experiences, they can improve patient care by identifying problems, and sharing ideas for solutions. This is often in the context of a disgusting symptom, and how the patient or their loved ones might feel, and so how can they solve the problem for the patient and their family, rather than for staff to express their feelings
Talking about difficulties is easy	She feels able to easily talk to staff about what she is thinking and feeling. Oddly, she says she finds it easy to tell people she finds disgust difficult, but that staff do not talk about how a symptom makes them feel. Discussion of superficial difficulties is easy, and while she might like to say she can talk about her feelings generally, given what she has already said about disgust, she does not share her feelings around disgust
Informal support only	She has only ever wanted and needed informal support and has never needed to access anything more formal for anything disgust related. This informal support tends to be a quick debrief, with a recognition that something was 'difficult', but without any discussion of how it make her or others feel
Camaraderie between palliative care professionals	There is a sense of camaraderie with nurses, and her team – that they are people she can talk to, and who will meaningfully react to her because they know what it is like. While she might get indirect support from home, her husband is unlikely to be able to meaningfully react to what she says, as he would not have experienced anything like it.

Below is a list of codes from Briony's transcript. Each code is followed by a line number in brackets referencing the location in the transcript from where the code originated. Codes are grouped into subthemes (*italicized and underlined*), which themselves are grouped into themes (in **Bold**). Descriptions of all themes and subthemes can be found in Appendix 3N.

Delivering interventions in palliative care

Being an OT in palliative care
She is experienced as an OT (2)
She has worked with palliative patients for a long time (3)
Palliative patients have been a large part of her working life (6)
She has been working as an OT for 20 years (9)
Palliative care and OT work well together (13)
OT and PC allow her to focus on the person and their goals/needs (14)
PC is person centered (16)
Her role is different from other PC staff (19)
Her role is improving quality of life, rather than death (19)
PC allows her to be person centered (21)

Person centered working
She has worked in places that aren't as person centered – not as good (13)
Focuses on the patients priority – person centered (17)
Professionally, she wants to be person centered (21)
Some aspects of the job are less person centered, but overall good (24)
She enjoys her work, and the person centered nature of it (24)
Making a difference is a byproduct – focus is sorting peoples problems/goals (27)
Needs to be person centered (77)
The focus is the patient and their problems with their symptoms (137)
Does not label patients by their symptoms (139)
Focusing on how the symptom affects the patient (167)
Focus is on the patients and how they are affected by the symptom (168)
Patients are individuals (367)

An empathic, personal connection
The patient needs feel it is ok to be with her (118)
She is empathic in wanting to relate to her patients (120)
The patient must feel ok with her (121)
She is empathic in her role of needing to understand the patient and their problems (121)
A part of her job is talking about how they feel, and being empathic (122)
She is very aware of how her reactions affect her patients (124)
Her job is to understand what is important to someone (125)
This is a very empathic job (125)
She sees the symptoms medically, or in terms of how they are for the patient (135)

She needs to establish a connection with her patients (264)
She is asking very personal/emotional questions – she needs that rapport to do that (286)
She needs to be seen as someone who can understand and empathize with them (292)
She needs them to have confidence in her professionally (293)
she wants patients to be happy in her company (298)

Disgust destroys the personal connection
Does not want to react (52)
Tries to appear very relaxed (58)
Does not want patients to see her disgust (80)
Does not want disgust to interfere with her work (81)
Looking away could be seen as a sign of disgust (102)
She wants to look away but forces eye contact (102)
Concentration to seem 'normal' (102)
She doesn't want the patient to feel judged or labeled by their symptoms (120)
It is important the patient doesn't think she is upset by the symptoms (120)
She doesn't want to add to their problems my making them feel judged/labeled (124)
Overcompensating to seem 'relaxed; (161)
She wants the interaction to seem normal (162)
She overcompensates in assessments (191)
She tries to be normal in assessments (191)
She has to make sure she isn't showing any disgust (245)
She does not like using the word disgust (262)
She does not want to associate such a strong emotion with something about a patient – it damages the rapport (262)
She can't do best patient care without a connection with patients (265)
Disgust gets in the way of establishing a rapport with patients (265)
Disgust puts best patient care in jeopardy (265)
It is important to her to give best patient care (268)
She does not show any outward signs of discomfort (279)
She is worried patients will think she can't handle their symptoms (288)
She has to hide her disgust at sputum (640)

Working with disgust
Disgust is frustrating (42)
Disgust as challenging (51)
With head/neck/trachie – she has to get closer, making it worse (62)
Disgust is a difficulty - it makes it harder (66)
She doesn't want to focus on disgusting symptoms, but has to to do her job (77)
Being person centered means focusing on disgusting things (77)
Disgust as an 'issue' (79)
Problematic = disgust (88)
She has to discuss/actively process what she finds disgusting as part of her job (162)
She has to suggest strategies for dealing with what she finds disgusting – more active processing (162)
Her focus is what is important to the person, which means talking about the thing that disgusts her (165)

She has to do a LOT of processing of symptoms which she finds disgusting as part of her job (173)
She has to focus more on disgusting symptoms because of the patient (177)
Sometimes people are happy to live in a way she finds disgusting (179)
She cannot impose things to fix what she sees as disgusting (181)
What she finds disgusting can be the focus of her intervention (185)

Personal and professional mixing in palliative care
Her personality suits her job
A person centered approach is important for her (13)
She is naturally proactive and wants to get things sorted (28)
She finds PC a positive place to work as she can focus on peoples goals (29)
She feels she needs to be in control (235)
She loves her job and the patients (567)

The Empathic connection effects her
Disgust is upsetting (64)
Disgust is distressing (64)
Remembers cases that were bad *for the patient* (106)
The image and empathy she feels is what sticks with her, not the disgust (110)
Disgust = difficult (255)
Some patients stay with her more than others (367)
Patients stay with her because of disgust, or similarities to self (368)
Disgusting patients don't always stay with her (371)
Patients 'enter' her mind – she doesn't have control over which patients stay with her (372)
Patients that are similar to her are more likely to stay with her (375)
Some patients get closer than you expect (376)
Extreme symptoms stick with her because of how they must have been for the patient (395)
She is able to leave most patients and not carry them with her (397)
She does not tend to think about disgusting cases (398)
Awful = disgust (481)
She feels lucky to not be in her patients position (484)
She is human, it's a difficult job, it's going to be hard sometimes (486)
Patients remembered by their symptoms/disgust (650)
She has to manage work – she has to look after herself (629)

Work can't be allowed to touch home
she has to keep home and work separate (539)
She keeps everything different form home and work (540)
She steps into a 'work life' – uses clothes/etc as barrier (540)
She avoids talking about work at home – keep separate (543)
Life can't be perfectly compartmentalized (546)
Needs 'distance' (not just separate) between home and work (548)
Keeping distance protects her and what is important to her (549)
Understanding at home that they don't talk about her work (550)
She has had bad experiences of home/work crossing (556)
Need to live somewhere separate from where she works (557)

Outside work, patients see her as an OT, but she is herself – no professional persona to protect her (558)
She is vulnerable as herself, when not an OT (561)
Home is supportive through distance/relaxation (554)
Home gives her 'perspective' (567)

Personal disgust profile
She is fine (not disgusted) with most things (44)
Her problem is with sputum (45)
Sputum difficulties tend to be with Head and Neck/trachie (47)
Thickness of saliva/mucus makes a difference (50)
With head/neck/trachie – she has to get closer, making it worse (62)
Most cases that are disgusting are equally disgusting (86)
Trachies are always disgusting (88)
Trachies are worse with sputum/infected sputum (88)
Anyone handling sputum is a problem for her (90)
She makes a distinction between disgust and distress (94)
Fungating/open wounds are disgusting, but not disgust eliciting (133)
Disgust is as difficult as dealing with the way someone speaks to their partner/attitude/etc (150)
Disgust is caused by something 'not being right' (241)
Disgust is not limited to medical problems (260)
She has desensitized to it (313)
She has become 'desensitized' to sputum (643)
It takes time to desensitize to disgust (649)
The smell of drool made things worse (652)
Frequency is what affects desensitization (663)
Talking/thinking about disgust used to elicit a disgust reaction (664)
Talking/thinking about disgust used to elicit a disgust reaction (664)

Professional etiquette
Professionals don't show disgust
Devotes mental energy to not showing disgust (51)
She does not see disgust reactions in other professionals (65)
She thinks she hides disgust well (66)
Wanted to show it didn't disgust her (103)
Thinks she didn't react any differently (109)
She has to suppress her reaction to something disgusting (204)
She has never showed physical disgust in front of anyone (273)
She judges herself by how she is seen (295)
She thinks patients have not seen her disgust (304)
There is an expectation to how a healthcare professional should work (not show disgust) (315)
Don't see colleagues showing disgust (641)

Professionals don't talk about disgust, professionals talk about patients and symptoms
Being in a team allows her to share strategies (68)
Working in a team to develop strategies to avoid disgust impacting patient care (71)
Can use colleagues to deal with disgusting symptoms (73)

She sees the symptoms medically, or in terms of how they are for the patient (135)
She doesn't 'see or smell' patient symptoms – symptoms are often abstract, not personal (136)
She feels it is inappropriate to talk to other staff members about her feelings about a patient (211)
Will tell colleagues when 'they particularly need to know' (233)
Implicit acknowledgement of feelings, but not discussion of them (243)
She doesn't often talk about disgust (373)
Talking about disgusting experiences is rare (385)
She doesn't often talk about disgust (392)
She does not talk to colleagues about disgust (405)
Discussions are not about staff feelings about symptoms (408)
The focus is the patients struggling to deal with the symptom, not the symptom (411)
"We talk about it in terms of empathizing with our patients" (413)
Very clear distinction for her – completely unacceptable to talk about your disgust or gossip about patients, only talk about it medically/how it is for the patient (415)
Discussion focus is patients difficulties/coping, not their own (420)
Can share strategies to help cope with disgust (423)
Unlikely to talk about feelings (426)
Disgust isn't talked about (442)
Can talk about emotions about seeing a patient deteriorate quickly (444)
She does not expect to discuss staff struggling with symptoms (455)
Disgust isn't talked about (457)

Professionals don't gossip about patients
She feels that talking about patients symptoms/her feelings about then is gossiping (214)
She feels talking about her feelings about her patients 'sets them up' (217)
She doesn't want to establish any preconceptions about a client (219)
She is setting people up by talking about/labeling their symptoms (211)
She doesn't want to affect colleagues behavior by framing the patient (226)
She doesn't want the patient to be affected by staff preconceptions (266)
She didn't want to give the colleague any preconceptions about the patient (388)
Risking framing the patient outweighs preparing colleagues (391)
Discussions are about how a patient copes with their symptoms (409)
Does not gossip about patients symptoms (414)

Dealing with disgust
The feeling of disgust
She can prepare for disgusting situations if aware (74)
She knows a patients medial symptoms, but not if they are disgusting (133)
Going into a patient with disgusting symptoms is hard (140)
She can't predict whether she is going to be disgusted or not (145)
She can't prepare for disgust (145)
She can't prepare for disgust (157)
She instructs herself to go in to patients which have disgusting symptoms (141)
She wants to look away from the person (161)
She has no control offer the initial disgust reaction (203)
The feelings of disgust pass quickly after leaving (208)
She has an initial internal panic reaction to disgust (236)

Disgust is an uncontrollable reaction to a sight/smell (253)
Disgust is a such a strong emotion, it is difficult to say (264)
She used to gag on disgusting things, but has learned to suppress it (272)
Disgust is an automatic response – cant be stopped (640)
Disgust is something that can be managed – it cant be stopped, but it can be controlled (645)

Holding herself together
She is able to move from panic to pragmatic quickly (237)
She feels she has to hold in her initial disgust reaction (241)
She has to 'take a moment' to hold onto herself (243)
She has to actively suppress disgust and 'hold it together' (277)
After a visit, she has to take time to get herself back together – she had held herself together emotionally, now she can let go (359)

Pain is better than disgust
Uses pain to distract herself (pain getting cognitive priority) (56)
Easier to relax while in pain, than suppress disgust (57)
Pain is a distraction from disgust (61)
She can regulate the amount of pain/distraction – she can gain control over it (61)
She uses pain to distract herself (193)
Pain gives her control over disgust and lets her 'hold it together' (277)
She presents herself as relaxed, but is in fact in pain – easier to suppress than disgust (281)

Post event Distraction
After the event, she has a moment to cool down (206)
She uses humor to deal with disgust (311)
She rings someone, preferably someone close to her to distract herself (314)
She uses distraction after a hard visit, or after a disgusting visit (342)
She slips into her personal life for a few moments to distract herself after a visit (344)
She does something 'nice' in her personal life to distract herself (perspective?) after a visit (348)
Distraction to get past a disgusting visit (350)
Support also through distraction/jokes (526)
She would get distraction from non PC teams (618)
Distract or get support (627)

Post event checking in
'Checking in' – most support is regular informal debrief (517)
People are aware of others need to check in and support that (517)
Some people may not use checking in (523)
If people not in the office, no checking in (612)
Small team makes it hard to check in (615)
She is comfortable using check in support (519)
She would check in with other PC teams (621)
Location of office related to support availability (611)
Important to know you can talk to someone when you need to (622)

Relationships with other professionals

Other professionals find other things disgusting
She feels this is particular to her, she has some ownership over it (45)
Some recognition that other people have other difficulties (45)
 'My thing' – this is personal to her (53)
She is aware that different people find different things disgusting (212)
Sputum is 'her thing' – it is something personal to her (261)
She recognizes other people find different things hard (390)
Everyone has different disgust issues (437)

Palliative Care Professionals can handle anything
Disgust is something she experienced before palliative care (257)
Working in palliative care requires experience (305)
You should be able to deal with disgust in palliative care (306)
During/just after training you can show disgust (307)
She does not think she shows any disgust now (309)
She expects palliative care professionals to not show disgust (318)
Palliative care professionals should deliver best care under extreme disgust (320)
You have to desensitize to disgust to work in palliative care (314)
You've got to be able to deal with it in PC (480)
She has never needed to pass a case on (578)
She has never transferred cases because of disgust (593)
Disgust symptoms are more pronounced in PC (659)
They would transfer due to disgust, but disgust isn't an issue for staff (600)
The team wants to help patients, regardless of their condition – it has to be very severe for them not to do battle through (601)

Mutual support from people who know what it's like
'We understand this' – non PC profs wont get it (70)
Support from others working in the team (71)
Join responsibility/team work (96)
She feels she can share and support each other in the team (436)
There is a sense of camaraderie between staff (436)
She talks to people in PC generally, not just OTs (438)
She provides support for people on other cases (456)
PC teams help and support each other (472)
Those outside PC wouldn't be able to support her as well (472)
Being surrounded by people who know what it is like is supportive (473)
Team support is really important (475)
You don't get the support you need when working alone (475)
She needs somewhere where people understand what you are dealing with (477)
PC staff know the situation and won't judge her (478)
PC profs understand how difficult the job is (485)
PC profs understand, and know you are allowed to have problems (488)
She needs people to understand that she has problems and it's ok (488)
She can talk to anyone in PC and they know where she is coming from (489)
She feels able to give as good a support as she gets (495)
She needs the team support (495)
A sense of camaraderie with the team (496)

Palliative care teams are (and need to be) resilient – they have to support each other (498)
She feels she can go to anyone in PC (not OT) without any anxiety (514)
She can pass cases on if she needed to (578)
She has colleagues around her for support (579)
There is an 'understanding' in PC (579)
Help is for difficulties, not just disgust (580)
Outside PC people expect her to be 'superhuman' – PC understands you don't have to be (582)
PC understands that not everyone can deal with everything (582)
Referrals 'too close' to other people come to her (593)
Careful assigning, rather than transferring (593)
The team reacts to individual needs/difficulties (597)
The team would understand if someone had a disgust issue (600)
Very accepting of people finding things disgusting, but has never happened yet (602)
Has always been able to access support (609)
She had to find other ways of getting support (617)
You don't need to say anything to feel supportive/supportive environment (625)

Building supportive relationships in palliative care
When working on her own, she still needs to find that support (492)
She feels knows the team well, so can talk to them (509)
Element of trust/knowing a person needed to open up to them (509)
When new, may have fewer people to go to (512)
She needed to establish these supportive relationships herself, she couldn't go without them (519)
She can't just go to anyone – needs to know them a bit (521)
Getting informal supportive relationships a priority (525)
She builds those supportive relationships quickly (528)

Appendix 3N:
Summary of Briony's subthemes

Delivering interventions in palliative care
These subthemes relate to how she delivers her interventions in palliative care, and how disgust impacts upon that

Subtheme	Description
Being an OT in palliative care	She sees her role as different from other palliative care staff – she is more concerned with improving someone's quality of life, and retaining as much of what they did before diagnosis, rather than on ensuring they die comfortably. However, both OT and palliative care have a person-centered approach, complementing each other.
Person centered working	Her work, both as an OT, and as a palliative care professional HAS to be person centered. Her focus is on the person's goals, needs, and how their symptoms prevent that from happening. While this is a professional requirement, it is also important for her personally to work this way, and is a source of great job satisfaction for her
An empathic, personal connection	In order to have a person-centered approach she has to be very empathic, both to understand her patients' perspective, but also so that she can build a personal connection with patients. She needs them to feel comfortable with her, that she can handle anything, and that it is ok to talk to her about personal or potentially distressing things.
Disgust destroys the personal connection	Showing any disgust or discomfort at a patients symptoms may make them feel judged, that she can not handle their symptoms/problems, or does not enjoy being with them. This destroys that personal connection and person centered way of working, which is so important to her personally and professionally, and is vital in carrying out her work. She therefore tries to hide her disgust, and appear relaxed, but often overcompensates in doing so.
Working with disgust	In her work, she has to approach things that she finds particularly disgusting. This is either physically by getting closer, or by talking and thinking about disgusting symptoms in order to devise a solution for that person. This can make what she finds disgusting the focus of her intervention, making disgust harder to suppress

Personal and professional mixing in palliative care

These subthemes relate to how her personal traits and personal life interacts with her professional role

Subtheme	Description
Her personality suits her job	She is empathic, enjoys a having a person-centered approach, and is very goal orientated. When a problem has been identified she wants to solve it. This suits her job, which she enjoys
The empathic connection affects her	In having that empathic connection with patients, she becomes vulnerable. In particular, patients that she has a greater empathic connection with, either because of similarity to herself, or because of how hard their symptoms must have been for that person, making them more likely to be remembered and ruminated on. The vulnerability through this empathic connection makes her job difficult, which she has to 'manage' in order to look after herself
Work can't be allowed to touch home	She has to keep home and work separate. By having bags/money/etc separate, she is putting on protection that allows her to be empathic, but keep work things at work. When work has touched home, she has felt vulnerable, and after one bad incident, has gone to great lengths to keep them separate, including living in a different area. In contrast, home can be allowed to touch work, in order to give her perspective, and distraction.
Personal disgust profile	She finds sputum/mucus, particularly from tracheotomies to be disgusting, particularly when the sputum/mucus is thick, infected, or smells. These cases tend to be in head and neck cancers. However, over time, she has become desensitized to it, and while she still has to suppress a feeling of disgust, it is not as bad as it once was

Professional etiquette

These subthemes relate to how she feels professionals should act with disgust and disgust issues

Subtheme	Description
Professionals don't show disgust	She feels an expectation that healthcare professionals should not show disgust. She does not see disgust in her colleagues, and tries to suppress any disgust she feels herself. This is key to how she sees herself as a professional, and she judges her professional ability partly by whether or not she has shown disgust
Professionals don't talk about disgust, professionals talk about patients and their symptoms	She believes that it is inappropriate to talk to other members of staff about her feelings about a patient. While there may be an implicit acknowledgement that symptoms may be disgusting/distressing, both disgust, and distress more generally are not talked about. Instead, professionals talk about a patient's symptoms, either very medically, or in terms of how difficult it is for the patient. "we talk about it [disgust] in terms of empathizing with our patients". As part of this, they will share strategies for how they can best deliver patient care in these situations, but always in a way that is empathic to the patient
Professionals don't gossip about patients	She feels very strongly that talking about patients' symptoms in terms of disgust is gossiping, which is unprofessional. Gossiping not is not only talking about disgust (which is unprofessional), but that doing so 'frames' the patient for other professionals, which is both unemathetic, and could damage how that professional interacts with that patient

Dealing with disgust

These subthemes relate to how she feels and deals with disgust in her work

Subtheme	Description
The feeling of disgust	While she will know a patients medical symptoms, often disgust is something she can not prepare for. The hardest part for her was the initial 'moment' when you feel disgust. It is almost a panic reaction, which is uncontrollable and cannot be stopped. However, she is good at quickly getting over that, and grabbing a hold of herself bring things back under control.
Holding herself together	When seeing a patient, she has to 'hold herself together'. This starts when there is the first initial disgust reaction, where she has to take a moment to control that reaction. During the assessment, she is holding/controlling her emotions/disgust, and it is not until after the assessment that she can loosen her grip, and 'gather herself'.
Pain is better than disgust	She uses pain to distract herself. Pain overrides disgust (gets cognitive priority), but is also easier to hide than disgust. She can therefore use pain to regulate disgust, and she increases/decreases levels of pain to match her level of disgust. This is what let's her 'hold it together'.
Post event distraction	After an event, she needs a 'moment' to collect herself. This is followed by distracting herself by revisiting her personal life. By talking to her husband, or texting friends, she is leaving her professional persona, and visiting something that is untouched by work. She will also seek out distraction from colleagues when at work.
Post event checking in	Most of her support is through informal 'checking in'. This is a regular informal debrief that is sought out with other PC colleagues. This is a reciprocal arrangement, where you make time for each other when needed.

Relationships with other professionals

These subthemes relate to how she thinks of and is supported by other professionals in palliative care

Subtheme	Description
Other professionals find other things disgusting	There is a feeling that her disgust is particular to her. However, she acknowledges that other people find other things disgusting. She is aware that other palliative care professionals find things disgusting, and that she is not alone in this.
Palliative care professionals should be able to handle anything	There is a view that people in palliative care should be able to handle anything. While at times (see next subtheme) she acknowledges that people in palliative are not 'superhuman', and that it is a difficult job, she also believes that to work in palliative care, you have to be experienced, and desensitized to disgust. People in palliative care need to be able to deliver high quality care despite extremely disgusting symptoms. This is the standard to which she holds herself.
Mutual support from people who know what it's like	There is a strong sense of working as a team, and mutual support within that team. She provides 'check in' support for others, as they do for her, and feels that those outside of PC would not be able to provide this sort of support. She believes there is a feeling that people in palliative care are superhuman, but people will not judge her for finding things difficult – unlike anyone else, they understand what it is like. The team is reactive to peoples needs, and would be accepting of her if she had to transfer a client, but it has not happened yet.
Building supportive relationships in palliative care	Although she gives the impression she could talk to anyone in palliative care, the feels she needs to know the team/person well to talk to use them for support, and put great effort into forging these supportive relationships early on in her job. Indeed, there was a sense of urgency; that she could not go without these supportive relationships.

Below is a list of codes from Caroline's transcript. Each code is followed by a line number in brackets referencing the location in the transcript from where the code originated. Codes are grouped into subthemes (*italicized and underlined*), which themselves are grouped into themes (in **Bold**). Descriptions of all themes and subthemes can be found in Appendix 3P.

The surface professional
Working in palliative care
She is experienced in palliative care (3)
She has worked in different palliative care settings (6)
She has worked in different palliative care settings (6)
Has mostly worked in hospice settings (7)
Has mostly worked in hospice settings (7)
The finds the job challenging (9)
She had treated a lot of patients with disgusting symptoms (17)
She does a job with less disgust now (17)
Everyone comes across disgust in their work (395)

Responsibilities as a manager
She needed to be aware of her own feelings about the case (46)
She needed to be aware of others/how they would cope (46)
She was in a position of authority – felt she could bring up feelings (132)
She felt responsible for her colleagues wellbeing (175)
She feels she has to encourage team openness (243)

Being in a team
Talking focuses on practical/best patient care (94)
Shared strategies for dealing with feelings/the situation on a personal level (133)
A sense of being part of a team that supports each other (176)
Aware that different people find different things hard (177)
Support through feeling you are not alone in what you are feeling (184)
She feels she can talk to her team (243)
She knows what different people find difficult (245)
Using expertise (dressings, oils, etc) to minimize disgust (257)
Primary goal is improving patient QoL (262)
Make life better for other patients/staff second (263)
She asks team members to do things she finds disgusting (271)
Passing off patients is getting 'help' – no guilt (272)
Reciprocal support/passing of patients (273)
Empathy within the team – they understand it is hard (274)

Emotion and emotion processing in palliative care professionals
Approaching disgusting symptoms
Disgusting symptoms need to be approached and treated (24)
The disgust creates problems that have to be dealt with (76)
Disgusting symptoms have communication problems (80)
It isn't something that can be avoided (146)

Disgusting symptoms have to be seen/thought/interacted with (146)
She has always felt able to deal with anything (166)
No choice – she HAS to deal with it (557)
She can't ignore patients that need help – (560)
Sometimes nobody is there to support her (561)

Professionals feel disgust
Disgust is a weakness (280)
They feel disgust (376)
Worried about what colleagues might think if she said she felt disgusted (386)
Disgust is not talked about (392)
People feel it, but aren't allowed to label it disgust (418)
PC prof lie to themselves about disgust/deny it (424)
 'on many levels perhaps we can't' [deal with disgust] (556)

Feelings comorbid to disgust
She feels shock when she first sees disgust (73)
What she sees is very emotive – sad? (76)
Feel shock at the symptoms (88)
This isn't just disgust, this was horrific (93)
It is so horrific thoughts stop you thinking about it (109)
She is very sad for patients (110)
Cried over him – very sad, and personalized patients (111)
It was emotional seeing someone in that state (150)
Frightened that it could happen to someone (even her) (357)
She has personalized it – that it could happen to her (357)
There is more than disgust – there is shock, repelled, etc (384)
She is grieving over patients (473)
The disease and what it does is scary (519)

Not talking about emotions
Can talk to the team about distressing/disgusting patients (94)
No explicit talk about emotions (94)
No explicit talk about emotions (94)
They don't usually talk about feelings (123)
They don't usually talk about feelings (123)
Usually does not feel able to talk about feelings (132)
Nobody talks about disgust, so little support for it (413)
Can talk about disgust issues and its affects on staff, just not the word disgust (429)
Affected us – not much talk about feelings (430)

Emotions aren't processed
Not processed her experiences enough because she can't talk (360)
You take some of the emotions of work home (467)
Emotions stay with her for a long time (470)
She has to keep going, even with emotions building over time (470)
When she is relaxed, she lets go of all these emotions (471)
Emotions ferment and aren't acknowledged/dealt with (474)
She needs to feel safe and relaxed to let go of her emotions (475)
She needs to feel relaxed to let go of her emotions (483)

She has to work to hold in her emotions all the time (484)
Keeping hold of her emotions take effort/cognitive resources (484)
Family have witnessed her emotions breaking out (489)
She does not want to let out her emotions at work (503)
Sometimes emotions come out at work (503)

The feeling of disgust
Personal disgust profile
Loss of face particularly disgusting (20)
Smell made disgust worse (22)
Something dehumanizing about face being taken away – taking part of what makes the person human (142)
Disgust is a physical feeling (161)
Smell makes disgust worse (170)
She finds sputum disgusting (251)
She finds sputum/trachies disgusting (269)
Sputum being outside the body is wrong for her – disgusting (270)
Disgust makes her feel nauseous (275)
Sputum is hear weakness – other people have different ones (280)
The feeling of disgust passes quickly (301)
More problems with sputum than anything else (303)
She feels sick (308)
Touching/being contaminated by sputum makes it worse (309)
She wants to get away from the symptom (311)
Sputum where it shouldn't be/visual of it particular problem (311)
Disgust worse with food/coughing/phlegm (317)
Some things she would feel too ill to do (eating with bad trachie) (318)
She can deal with vomit / feces / most smells (326)
Sputum is an issue at home as well as work (328)
Sputum has always been an issue (328)
Smell doesn't bother her (433)
Disgust at the situation/world/context in which this was happening – bad things happen to good people (454)

How extreme some cases can be
She gets told medical information about patients (40)
Medical description does not prepare you for actually seeing the patients symptoms (44)
A sense of how extreme this case was, how it is wrong, and completely inconceivable (54)
She finds it hard to adequately describe how extreme what she has seen is (65)
Hard to believe such disgusting things happened (70)
She felt disbelief at the symptoms she was facing (83)
This was something people shouldn't see/know about (97)
This case was horrific – she was horrified by it (26)
Some things are too emotive to talk about – couldn't convey the experience thorough words (344)
Can become disillusioned at the world (457)
She has seen things that have made her question her view of the world (463)

Could not talk to them about this – they wouldn't be able to understand it (92)
She couldn't talk to family about this – they wouldn't understand (97)
"it's like being in a war zone sometimes. You keep these thoughts to yourself and you don't share it with anybody (113)
She doesn't feel she is allowed to share her thoughts with anybody – they wouldn't understand (114)
People felt they couldn't talk about it at home (125)
Can't believe it until you've seen it (536)
People who weren't there won't understand how bad it was (536)
Some things she feels she can't talk to anyone about (345)
It's a war zone – you needed to be there to understand what its like (348)

Disease and the person as separate entities
Cancer as a separate entity 'eating away' (19)
Disgust is aimed at what the disease was doing to the patient (21)
Nasty wound – cancer/wound as having a motive/being vindictive (28)
The wound was awful – not the person (45)
Disgust at the disease, not the person (56)
The disease happens to him – the patient is out of control and the victim (66)
The disease was doing this to the patient – disease separate (66)
Cancer and the person are separate entities (141)
Cancer is separate – it starts to take over/mask that person (142)
Cancer masking the person (145)
Separation of person and symptom (259)
Distinction between patient and symptom (279)
Tendency to think disgust is about the patient, rather than symptom/disease (397)
Disgust is only appropriate to feel to a symptom (400)

Empathy
Vocational empathy
Difficult for the patient to live like that – empathic (22)
Getting through disgust by focusing on the person – rehumanising (49)
Focus on horrible for the patient – empathizing (58)
Feeling for the patient being attacked – empathy (66)
Cruel to make patients go through some of what they go through – empathizing (68)
Uses empathy to approach symptoms (88)
Feeling a lot of empathy for that person (102)
Empathy for him (103)
Even when talking about their feelings, it comes back to the patient and empathizing with how it was for him (137)
Empathy for how the person has to deal with the condition (524)
Admiration of how patients cope with symptoms (524)
Every condition is awful for the patient – there are no degrees (537)
Worried about whether patients can cope with their symptoms (539)

Making it personal
Feels upset for him (88)
She takes that person on inside herself (102)
The case stayed with her – stayed inside? (103)

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Great sadness for him (103)
She puts herself in his position – taking him/the disease on herself (105)
She makes it personal – thinks about her own family (109)
She gets close to patients – empathy (505)
She imagines herself in their shoes – personal, empathy (518)
'what must it be like to live with that' – very personal (528)
Worried it could happen to her/her family (535)

Empathy from patients
She remembers patients that empathize with her / apologize (217)
She worries about how other patients deal with symptoms (322)
Parents took time to recognize staff's difficulty, despite their own problems – empathy? (445)
Parent feels they shouldn't have to deal with something so disgusting – apologizing, empathy? (445)
What is remembered is that mum recognized their difficulties (451)

Disgust is Taboo
Professionals can't talk about disgust
Can talk to the team about distressing/disgusting patients (94)
Staff don't have to talk about disgust – implicitly acknowledged and worked around (245)
Staff never use the word disgust (369)
Staff use disgusting/challenging/etc (370)
Staff feel disgust, but don't express it using that word (371)
Would never use disgust around a patient/symptoms (372)
The word disgust is unprofessional (376)
Disgust is untempered – too strong a word (377)
Other words are more professional, and less emotive (379)
She has never used disgust in relation to a patient's symptom (380)
Colleagues can talk about feelings, but disgust is too strong a word (386)
Talking about disgust is hard to do (397)
Disgust is too powerful to risk using about a symptom and have it misinterpreted (400)
Nobody talks about disgust, so little support for it (413)
Disgust is on a par with death – something around them that they don't talk about (422)
Can talk about disgust issues and its affects on staff, just not the word disgust (429)
Affected us – not much talk about feelings (430)
Using the word difficult for disgust (435)
Never used the label disgusting at work (592)

Professionals don't think about disgust
She does not think about disgust (570)
Thinking about disgust is avoided in palliative care (571)
She wouldn't label things as disgusting, but now sees they were (572)
She has felt disgust before, but didn't recognize/name it disgust (580)
Recognizing disgust make her re-think herself (580)
Disgust was felt but not recognized before this conversation (582)
Recognized disgust at home but not work (590)

Professionals can't show disgust
She can't show her team that she is disgusted (74)
Having a professional head on – she has to be professional, conform to that expectation (155)
There is an expectation that profs don't show disgust (156)
She keeps the professional exterior, but feels disgust inside (160)
She thinks she may have shown disgust in the past (203)
She feels she has to hide her feelings (203)
She feels she is bad at hiding her feelings (204)
Not too anxious patients pick up that the situation is disgusting, as long as she isn't showing it (206)
Patient and her know disgust is there – its who admits it first (207)
Common for patients to pick up that something is disgusting (213)
She feels a professional obligation to not be disgusted/reassure patient's it isn't an issue (222)
She has to fight the disgust reaction to keep it hidden (252)
She feels she shouldn't show any disgust (290)
She may show some disgust by accident (290)
Guarded because she is worried about giving away disgust (333)
She feels she can't be seen to be disgusted (334)
People working with people aren't meant to think/feel disgust (377)
Self imposed expectation that they can't talk about disgust (408)
Don't use the word disgust in front of patients (542)
She is expected to be able to deal with anything (511)
There is an 'unwritten rule' that you deal with disgust (512)

Fear of not living up to that expectation
'scared' of not meeting that professional standard re disgust (515)
Scared of letting patients know about disgust (516)
She feels she represents societies attitudes to their condition (550)
If she finds something disgusting, so will the rest of society (551)
If profs cant deal with it – friends and family cant (552)
People assume palliative care profs can deal with disgust (555)
She feels under pressure to meet high expectations (564)
She has been frightened at the idea of not meeting those expectations (564)

Breaking the taboo
Patients break the ice first – she can then acknowledge it (214)
She has become more confident in breaking that professional mould and allowing herself to admit disgust (223)
She admits to disgusting symptoms, but asks them how they affect the patient (226)
She feels it is better to acknowledge it than deny/lie (227)
She doesn't want to lie to her patients (230)
She wants a good working relationship with patients (230)
She feels confident to talk to patients about disgust in their symptoms FOR THEM (234)
Focus on admitting disgust is making it less disgusting for the patient – not themselves (236)

People wait for someone else to use the word before they fell they can use it (410)
Disgust is taboo, someone needs to break the ice first (418)
Once it is labeled, and people start to talk about it, others will feel they can (419)
Staff admit to feeling disgust, but only after they are prompted with the word (436)
Not confident talking about disgust with patients (544)

Dealing with disgust
Controlling emotions by focusing on the treatment
Trying to make the interaction normal – overcompensating (51)
Felt she failed to look at him as much as she should (52)
She has to keep her emotions under control (63)
Very practical – she focuses on doing what needs medically doing (75)
She hides her emotions in the room (166)
Physical preparation and talking herself up (275)
She is confronting her disgust (289)
She tries to keep the intervention 'normal' (291)
Conversation with the patient diverts her attention from what she is doing (294)
Tries to make eye contact to show not disgusted (295)
Physically distancing herself after the event (299)
She is tense during the event (300)
She is more guarded with patients with disgusting symptoms (333)

Post treatment de-stress
She lets her emotions out once she has left the room (167)
No time to process emotions at work (181)
Processing of emotions often happens at home (182)
Feelings are more complex than disgust – need significant processing (182)
She needs to get away from the symptom – out the room, fresh air (277)
She needs time to calm down after the event (300)
She can only release after the event (300)
She is confronting/ acknowledging how 'awful' the situation was (300)
Tries to distract herself after the incident (314)

Indirect support from family
She can talk to her family about good/bad day, some basic stuff about work (90)
She can talk to family about disgusting cases without judgment (340)
Her family see her disgust at sputum as a quirk (342)
Family support her and know what she is crying about (492)
Family give indirect support – don't know details (496)
She can't talk about details of why she is upset (496)

Checking in support
Did talk about feelings in a debrief after the event (121)
Support was informal (131)
Regular short informal debriefs (174)
Debrief part of daily routine (179)
She can access formal support, but never needed to for disgust (191)
Planning around disgust (261)
Support is informal, and always available – part of working in a team (365)
Could talk to people formally, but never sought it for this (356)

Appendix 3P:
Summary of Caroline's subthemes

The surface professional
These subthemes relate to the basics of working in palliative care, and how she sees her role

Subtheme	Description
Working in palliative care	She has worked in different palliative care settings for a number of years, but predominantly in hospice settings. Thought these, disgust has been a common factor in her work, although less so in her current position. She finds the job challenging but rewarding
Responsibilities as a manager	She feels a responsibility for the welfare of her own staff, and so is aware of not just her own feelings, but those of her staff, and how they might cope with different symptoms they are presented with. To that end she encourages team openness, and by being in a position of authority, feels empowered to talk to the team about feelings
Being part of a team	She feels part of a supportive team that she can talk to. There is an understanding that they do a hard job, and that it can be difficult, but that other people in the team know what it is like, and understand that. She feels able to draw on other team members for their expertise in either making symptoms less disgusting, or in asking colleagues to help patients she has difficulty with. Throughout all of this, the focus is always on improving the patients quality of life

Emotion and emotion processing in palliative care professionals

These subthemes are about how disgust, and other emotions are dealt with in palliative care

Subtheme	Description
Approaching disgusting symptoms	In the course of her work, she routinely has to approach symptoms that she finds disgusting. Sometimes, there is no choice in the matter, she HAS to deal with it – she cannot ignore patients who need her help, particularly when there is nobody else around to support her, or the patient
Professionals feel disgust	Professionals feel disgust, yet at the same time, they are not allowed to label it disgust. Sometimes, disgust is not even recognized, and there is a feeling that this is something very much denied by palliative care profs. As a result, disgust is often not dealt with
Feelings comorbid to disgust	When she first sees something disgusting, she will often feel shock, or horror at the symptoms. This is disappears over time, and is often replaced by a great sadness, even grieving for the patients, and the fact they are having to go through this. Finally, she feels scared by what the disease has done to the patient, and that that sort of thing could happen to someone, even herself.
Not talking about emotions	The team can talk about distressing or disgusting patients, but they almost never explicitly talk about emotions or feelings. As a result, there feels like there is little support for disgust
Emotions aren't processed	Because staff do not talk about emotions, they are not processed. Staff end up take emotions home with them. For her, these emotions can ferment for a days, weeks or months, and only come out when she is relaxed enough to let go of these emotions, which often involves crying. Until that time, she has to work to keep those emotions in, as she does not want (or feel able?) to let them out at work

The feeling of disgust

These subthemes relate to how disgust is felt

Subtheme	Description
Personal Disgust Profile	She has problems with sputum, particularly from infected tracheotomies, or where sputum is spread over someone's front. Getting closer to sputum is harder, and her disgust is particularly strong when she accidently touches it. She feels the need to get away from it, and when she does, the feeling soon passes. However, while she is in the vicinity, she feel sick. She also has difficulty with facial disfigurement, and its dehumanizing of patients She also finds certain situations disgusting, such as the tone someone takes with their partner
How extreme some cases can be	She gets told medical information about patients, and is sometimes warned of disgust, but that does not prepare her for when she actually sees something particularly disgusting. Some cases are particularly extreme, and she feels disbelief at what she is seeing. It can be too horrific, too emotional to convey through words, and can even make her question her view of the world
Couldn't understand it if you weren't there	She could not talk about what she has seen to people who were not there. Others, such as family, simply would not understand what it was like. *"it's like being in a war zone sometimes. You keep these thoughts to yourself and you don't share it with anybody"*
Disease and person as separate entities	She sees the disease and the patient as very separate entities. She often implies motive to the disease, or that the disease has some willful action of its own ('what the disease is doing to the patient'). Despite her very strong emotions around what she sees and has to deal with, she sees the person and the disease as separate entities, with the disgust only being directed at the disease, never the patient.

Empathy

These subthemes relate to her personal connection with patients

Subtheme	Description
Vocational empathy	She is very empathic towards her patients. She can understand how the patient must feel, worries about how patients will cope with their symptoms, and uses that empathy to help her approach and deal with the disgust she feels at the symptom itself. This is the empathy a person needs to have with a caring job to be able to understand and treat that person.
Making it personal	At times, she goes beyond being empathic for her clients, and makes their situation personal to her. She puts herself in their position, or considers what would happen if one of her family had the condition. She also gets more deeply emotionally involved with patients, and can feel upset or sad for them to a degree I would not expect of a healthcare professional
Empathy from patients	Patients also empathize with her – saying that 'she shouldn't have to deal with this'. This concern over her well being from her patients tends to stick with her

Disgust is Taboo

These subthemes relate to how professionals feel about disgust, and how it is thought of professionally

Subtheme	Description
Professionals can't talk about disgust	Professionals are not able to talk about disgust. The word itself is one they never use; it is too powerful, so they do not dare use it for fear someone might think they are talking about the patient, rather than the disease. Instead they use words such as challenging. Disgust itself is a taboo subject, on a par with death. It is implicitly acknowledged and worked around, but rarely addressed directly.
Professionals don't think about disgust	Disgust is something that palliative care profs avoid thinking about. They may feel disgust, but they often will not label it as such at work, although they can do so at home. Only though this study did she actually recognizes how often she felt disgust.
Professionals can't show disgust	Palliative care professionals can not show disgust. She has to hide her feelings from both her team and her patients, which she has to work hard to do. She feels she is not good at hiding her feelings, and it does change her interactions with patients: she tends to be more guarded, and has to force herself to make eye contact. Patients are, however, allowed to pick up that the *situation* is disgusting, and if they talk about it, she will feel able to talk about it. However, until that happens, it is taboo – there is a **self imposed** professional expectation that she should be able to deal with anything
Fear of not living up to that expectation	She feels a she has to live up to that expectation of not being disgusted/being able to handle anything. People assume palliative care profs can deal with anything, and so she puts herself under great pressure to meet these expectations. Indeed, she is scared of not meeting that standard, and letting patients see her disgust
Breaking the taboo	There have been occasions when she has been able to break the taboo around disgust. These have been either when she has felt in a position of authority, and therefore able to bring it up with her subordinates, or when patients have mentioned/asked if something is disgusting. With both, the focus is still on improving patient care, but when brought up with staff, there is some acknowledgement of feelings.

Dealing with disgust

These subthemes relate to how she deals with disgust on a day-to-day basis

Subtheme	Description
Controlling emotions by focusing on treatment	In addition to using her empathic connection to approach disgust, she tries to suppress the feelings by focusing on the treatment. She tries to think about what she has to do, or on talking with the patient to distract herself, while trying to keep the intervention as normal as possible. During this time she is very tense, and more guarded, but gets the intervention done
Post treatment moving on	Once the intervention is over, and she is outside the room or building, she can let out her immediate visceral emotions. She needs to get away from the symptom, release her hold over herself, and acknowledge the difficulty that the situation presented. However, deeper processing of emotion tends to happen at home, and is far more complex than just disgust.
Indirect support from family	She can talk to her family about whether she has had a good or bad day, but often not more than this. They will sometimes see her cry, and while they will not know exactly what it is about, they will know it is about a patient, and not to press for details. There is a sense that them 'being there' is supportive
Checking in support	She is often able to have a quick informal debrief. This does not tend to talk about feelings, although there is some talk about 'issues' and how things affect staff.

Below is a list of codes from Deborah's transcript. Each code is followed by a line number in brackets referencing the location in the transcript from where the code originated. Codes are grouped into subthemes (*italicized and underlined*), which themselves are grouped into themes (in **Bold**). Descriptions of all themes and subthemes can be found in Appendix 3R.

The job, and what she bring so it
The work she does
She has experience in palliative care (3)
Not all her time has been spent in palliative care (5)
She doesn't just have cancer patients (6)
Not all her work is end of life (7)
She also sees patients end of life patients (10)
She has spent a long time in the NHS (17)
Professionally, she knows patients wont get better (266)
They are able to work on patients problems that other people haven't done (554)

Disgust in different settings
She has found disgusting things in non palliative care settings (20)
Disgust is not limited to palliative care (22)
She has found a lot of things disgusting over the years (28)
Disgusting symptoms are always different (293)
There are lots of different disgusting things in palliative care (625)

Emotional as well as physical care
Although treatment wouldn't do much medically, she wanted to do something to make her feel better – that someone was caring (79)
The patient wanted to see her every day – emotional boost part of her job (83)
Professionally, treatment will do little, little point in doing it, but personally, has big emotional impact (181)
Battle between professional and personal views on whether to give treatment – empathy wins (184)
She has to balance medical and psychological needs of the patient (188)
Psychological benefit to patients from knowing someone is trying to help (553)

Wanting to help people
She tried to help, but couldn't cure her – sadness (73)
She is frustrated that treatment is not going to be effective (198)
She wants patients to get better – both professionally and personally (265)
Hopes the treatment has helped – feels more personal than professional (270)
Knows patients are going to get worse, despite what she does. Some sadness (280)
She has to do it for the patient (451)
Her job can be sad (502)

Wanting to deliver best patient care
She is in a caring job (154)
She wants to be seen as a good professional (156)

She does not want to make things worse – maintain prof standards (267)
Anxiety over whether patients are better or worse – empathic? Personal? (271)
Wanting to have not made things worse – anxiety? Profesional identity? (276)
She wants to retain high standard – not make any mistakes and always give very best patient care (277)
She admits the severity of the smell, and focuses on helping (314)
She can treat disgusting symptoms, and thereby improve the patients QoL (325)
Primary aim is patient comfort (541)
They try and make life easier for the patient (551)
Important that she is seen as empathic and caring (both personally and professionally (648)
Focus on the patient, not herself (650)

Developing a relationship with patients
What she does is very intimate – very close to their face (90)
She wants to see the whole person (157)
Seeing the whole means seeing how bad her symptoms are (160)
She has to be honest with patients, (188)
When asked, she had to admit the smell – she couldn't lie to her patients (313)
She didn't give away disgust, but acknowledged the symptom (314)
As a professional she can't be judgmental (342)
She doesn't want to impose her view or judgment on people – she is there to help them (351)
Patients she gets to know well get closer to her – harder to deal with disgust then (477)
She can develop long term relationships with patients (479)
She thinks about patients at home, but not emotional (480)
Wants her patients to get the right care from others (481)
Doesn't think about patients much after work – keeps her home and work separate (484)
Still thinks about clients at home on occasion – professional empathy?
Patients have minimal impact on her home life (488)
Wants to ensure they get best care from others (490)
She has to manage patient/family expectations - lot living up to what is expected (531)
She has to be very patient (533)
She has to disappoint families at times (535)
She has to disappoint patients (538)
She uses humour to develop a relationship with patients (542)
She needs to break the ice – interpersonal as well as prof relationship? (545)
She adapts to patients personalities – develops an interpretational relationship (547)

Working Empathically
Vocational empathy
Her job needs her to put herself in her patients shoes (44)
She uses empathy to work as a better nurse (92)
Part of being a professional is being empathic, but harder to be empathic with disgusting symptoms (104)
Her job is about empathizing and trying to make patients lives better (153)

Not having that empathy would make her show some difference with clients during treatment (213)

The ability to empathize with her patients is important (214)

She wanted to do something – personal empathic response to improve this woman's live (330)

Disgust implies lack of empathy, which she is meant to be as a prof (640)

Important that she is seen as empathic and caring (both personally and professionally (648)

Understanding how her patients feel

She was aware of how the patient felt about how they looked, and trying to put her at ease (52)

Unspoken communication – she knew the patient knew what she was thinking – guilt? Not wanting to make it worse, but doing so (60)

The patient is aware of the disgusting nature of their symptoms (130)

She has empathy with her patients (211)

Worried about how her patients will feel – empathic (659)

Understanding what her patients world is like

She is empathic, trying to understand how they deal with it (34)

Knows how difficult it must be for patients to keep going, keep living (71)

The patients was aware that it smelled bad and wanted to hide that (306)

She is thinking about the patent as a person, and how this is affecting them more personally (320)

She talked to the patient to understand how the symptom was affecting them – very personal (322)

Horrible for the patient, disgust doesn't weigh in (636)

Sympathy for what they have to go through

Thinking about how people live with these conditions – empathic, and concerned (37)

Worried about how patients cope dealing with symptoms 24/7 (38)

Empathy for the person having to live like that (71)

Glad it is not her/her family – appreciates how bad this must be for the patient (112)

She admires how patients deal with it – empathy? (148)

 'How is she managing to cope' – not sure what to do with this… (274)

Patients have to live with their symptoms – sympathy (297)

The is thinking about what it is like for the patient to have to live with this condition (317)

Imagining herself dealing with those symptoms

She can't imagine how she would deal with having the symptoms herself – too horrible to think about (147)

Fear – thank god it's not me. Fear over how they would cope, that it could happen to them (171)

Worries about family/herself getting the condition (496)

Worries about getting the condition an immediate reactionary thought, not a rumination (496)

Tends to worry about getting condition more if similar to her in some way (497)

She knows it could happen to anyone, she is just more aware of it/reminded of it (500)

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Dealing with disgust

Approaching disgusting symptoms
Often get to stand behind patients – can hide emotions easily (62)
She had to stand in front, she didn't have anywhere to hide (64)
She couldn't avoid seeing the symptom (126)
She has to approach and 'deal with' disgusting symptoms (128)
She couldn't hide the symptoms away, she had to confront them (308)

Preparation for seeing disgust
She had to build herself up to seeing this patient (84)
She would make sure she had eaten before seeing the patient (85)

Detaching empathy
She doesn't think about disgust when faced with something disgusting (29)
Putting herself in patients shoes makes symptoms/patient difficulty more salient (44)
She had to detach from the situation – remove empathy and see it as a medial procedure (91)
She couldn't have that empathy here, as that made the symptoms worse (94)
She tried to distance herself from the situation (emotionally) (102)
She detaches by trying not to think, just do (110)
Her thinking changes when she is on autopilot - tries not to think(114)
She doesn't like admitting she has to work without empathy sometimes (121)
She detaches by seeing the task and disease, not the person (124)
She usually thinks about the person, but can't when detaching (124)
She detaches by removing empathy (124)
She sees the person as an object – no empathy (135)
She has to detach and be less empathic (196)
She has to focus on the practicalities of what she has to do (197)
Disgust doesn't change how she sees the patient (207)
Only detaches during treatment – still sees patients the same, they just stop being patients for a while (213)

Personal disgust profile
She feels shock at symptoms (34)
Her difficulty is with fungating wounds (36)
It is the appearance of wounds, more than the smell that she finds disgusting (37)
The size of the tumor has a strong effect on her (41)
It is the visual of what she saw (symptoms) that she remembers (43)
Dimorphic cancers are hard for her to look at (46)
Size of the cancer important in mediating disgust (51)
She had to touch what she found disgusting with no barrier – make it harder (55)
Sputum made things worse, but not focus of disgust (66)
The smell has an effect on disgust (69)
Most smells she can deal with (96)
The smell of the symptom makes it worse (129)
Disgust lessens as she gets used to it – shock factor? Adjust to smell? (139)

Disgust is lessened in a clinical environment – smell less and easier to see patient as patient, not a person (163)
Environment plays a role in disgust (163)
Smell doesn't make her feel sick (189)
Smell has a powerful effect on her – has to give herself time to adjust (191)
Sight more than smell is the bother (241)
Smell causes her to pause (296)
Smells can be really bad (305)
People being sick causes her disgust (376)
Has some difficulty with phlegm (380)
Vomiting and phlegm two 'core' weaknesses (387)
Not much disgusts her (475)

Disgust is intermittent
She only has to deal with symptoms for a short while (38)
Difficult/disgusting cases don't last long – people die quickly (588)
She doesn't need to deal with disgust regularly – short sharp bursts (590)

Moving on
She only thinks about disgust on later reflection (30)
Uses distraction post intervention to get through disgust (221)
Hard to find time for distraction in clinics (223)
She feels pressure to see patients quickly and not have time to recover (225)
She find distraction while prepping the room for the next patient (227)
When switching environments, she finds time for distraction (229)
She needs to give herself time to recover (232)
She gets a 'breather' when doing home visits (245)
Has to find an excuse for a breather in clinics (247)
Talking to other staff to get a distraction (250)
Distraction is what she feels she needs (258)
Distraction is more important when seeing lots of patients one after the other (or just harder to get) (259)
Distraction allows her to let those thoughts/feelings go until she sees that person again (260)

Professional views on disgust
"Disgust" is unempathic
Uses the word horrendous, rather than disgusting – some tact with her words? (44)
Disgust is a strong word that she doesn't want to use with patients (70)
She doesn't like using the word disgust (450)
She won't use the word disgust (561)
She uses words like hard and difficult (581)
Feels disgust is not good/compassionate word to use (562)
She would never use the word disgust (574)
She doesn't use the word disgust much anyway (575)
'that's terrible' sounds better – more empatahetic (633)
Society uses the word terrible rather than disgusting (641)
That's terrible is more empathic than that's disgusting (640)
Disgusting is uncomfortable to use (653)

Feeling it is unprofessional to show disgust
She tries to avoid showing disgust (32)
She doesn't want to show disgust to patients (33)
She doesn't think she has shown disgust to patients (33)
The did her best, but didn't feel it lived up to the standards she wanted to (68)
She acknowledges that she feels disgust, and that it is ok on a personal level (337)
Disgust is a physical reaction that has to be suppressed (388)
She doesn't want patients to see her disgust (390)
Doesn't want something automatic to give the wrong impression (395)
She has to control her disgust (448)
She wouldn't deliberately show disgust (556)
She wants to do the best possible job for her patients – that means not showing disgust (566)
Disgust might come out accidently (567)
She feels she isn't meant to be disgusted (570)
Does not want to loose face by showing disgust (572)
Disgust is unprofessional (606)
Worried disgust will offend patients (657)
Worried disgust will 'burden' patients, make them feel worse (658)

Disgust is taboo
Fears colleagues would judge her for using the word disgust (564)
Worried colleagues would think she can't do her job/not a good nurse (569)
She couldn't say something is disgusting to her colleagues (576)
She feels saying something is disgusting reflects badly on her as a person and a nurse (577)
People in palliative care know about disgust (602)
Disgust is taboo, so they don't talk about it (602)
Nobody openly talks about disgust (604)
It is unprofessional to talk about – unsafe (604)
It is understood, but avoided, people skirt round it (608)
People know and understand disgust (611)
People can't use the word disgust (613)
She is afraid of being judged by colleagues for showing disgust (620)
She wants to talk about disgust more, but feels she can't (620)
People are aware of disgust (623)
It's expected that you don't use the word disgust (631)
Doesn't know how other professionals feel about disgust – not talked about (653)

Palliative care professionals can handle anything
She has to deal with whatever is put in front of her (29)
She didn't want to look at the patient, but had to (48)
Symptoms physically impede communication (50)
She HAD to go in (53)
She had to treat the patient (53)
One time she couldn't touch the lady without gloves – professional requirements giving way to personal disgust (54)
She found it difficult to see this persons symptoms (86)

She doesn't want to be seen as failing the patient (ie leaving early, not talking to them about other needs) (157)
Her focus is on doing the best job she can, she can stop disgust affecting that (203)
Disgust is a weakness (373)
Disgust as a weakness (383)
She doesn't like treating disgust, but she has to do it (383)
She can't be picky about her patients (383)
She has never said she cant do/see a patient (446)

Has to 'get on and do it'
She is pushing herself to do the intervention (132)
She feels she has got to do this – no choice (197)
She has to push through disgust (294)
Just get on with it attitude (374)
She has to deal with it – no choice, its what her job is. Pressure and expectation that she has to handle it (381)
She has to get on and do the job (450)
 'getting on with it' (525)
She has to get on with her job (540)

Getting support
Open and supportive team
They are an open team – they can talk about anything they need to (366)
The team can swap patients, although hesitation about doing so (367)
She has never needed to swap patients (369)
Never wanted to swap patients – she wants to help them more than she is disgusted (369)
The team know each others weaknesses – there is some talk about it (373)
Able to talk about difficult cases with the team (403)
Feels part of a close team (403)
She doesn't think she would be judged (404)
Feels the team is supporting her (411)
Talking about 'really hard day', but not explicitly about emotions (417)
She feels she can discuss anything with her colleagues (459)
She feels supported by the organization (507)

Talking with a patient focus
Can talk about clients symptoms, (371)
Can discuss how to make cases easier – patient focus, with some implicit acknowledgement of feelings (406)
Wants feedback on difficult cases – wants to improve patient care (409)
Talking about 'really hard day', but not explicitly about emotions (417)
Talk can be about medical problems, and getting advice on medical problems (418)
Gets reassurance that she is doing the right thing professionally vis a vis treatment (422)
She sometimes doubts her ability/technique (424)
Colleagues support and advise each other (427)
She works in a specialist field – not many people she can go to for professional advice (428)
Can get advice/info/conformation from colleagues (430)

Consulting with colleagues to give best patient care (435)

Support through colleagues/checking in
Offloading is about how bad it is for the patient, not herself (236)
She finds time to talk to colleagues to offload (235)
'get on and do it' – can't get worked up over disgust, she has to do the job (294)
Informal support most common (437)
Does not talk about disgust in clinical supervision (440)
Disgust support is more informal (444)
She seeks support from colleagues (458)
She gets enough support at work (460)
She has is able to access support (507)
Support lacking when she is the last one out – nobody to talk to (508)
Would be useful to have more people she could talk to about disgust (512)
She never needs to offload immediately, but would be useful (514)
She can talk to other palliative care staff without any worries (516)
If she needs to offload, she will go and find someone (518)
Checking in works for her (529)
Sometimes offloading does not work (583)
If she can't offload, she has to 'put up and shut up' - getting on with it (585)
Back up plan is to get on with it because it won't last for long (589)

Don't talk to family about disgust
Does not talk about work at home (456)
Family wouldn't understand the medical stuff (457)
She skims over work at home – no detail, not used for support (461)
Doesn't need to talk about work at home (460)
Family couldn't deal with what she deals with – can't get support from them (467)
She doesn't talk about work at home (521)
Feels she would be burdening her family by talking about work at home (521)

Appendix 3R:
Summary of Deborah's subthemes

The job, and what she brings to it
These subthemes relate to her experiences of her job, what it involves, and what she brings to it as a person

Subtheme	Description
The work she does	She is experienced in palliative care and has spent a long time working in the NHS. While not all of her patients are actively dying, she knows that many of her patients will not get better.
Disgust in different settings	She has encountered disgust in palliative care settings, as well as in other settings, such as psychiatric care. She has, however, experienced more disgust in palliative care than in other settings.
Emotional as well as physical care	She sees an important part of her job as improving the emotional, as well as their physical health. Often the work she is doing may only have a minimal effect, and would not ordinarily be carried how. However, the effect on patients of knowing someone is caring and trying to help has a profound positive impact on their emotional state
Wanting to help people	She has a genuine desire to help people. However she also knows that most of her patients will get progressively worse, which can sometimes lead to frustration (particularly at patients who will not help themselves), but more commonly sadness.
Wanting to deliver best patient care	Professionally, she wants to deliver the best possible standard of patient care. As a result, she does feel some anxiety over whether or not she has lived up to that standard. For her, that means her focus is very much on the patient, and on how she can improve their quality of life.
Developing a relationship with patients	In the course of doing her job she develops relationships with patients. This is very important to her, as it puts patients at ease, and allows her to work more holistically, and provide better care. To maintain this relationship, she does not want to impose her own views/judgment on patients, or lie to them. This relationship also enables her to better communicate with patients. Despite the depth of this relationship, it is purely professional, and has minimal impact on her home life (ie, thinking about patients at home)

Working empathically

These subthemes relate to the use of empathy in her work

Subtheme	Description
Vocational empathy	For her, part of this job involves working empathically. In order to be a good nurse, she needs to empathize with her patients, put herself in their shoes, and understand their situation. Beyond this, it is this empathy that drives her to make her patients lives better
Understanding how patients feel	For her, part of working empathically means understanding how her patients feel about their symptoms
Understanding what her patients world is like	For her, part of working empathically means understanding how her patients symptoms are affecting their lives more broadly, how their personality, hopes and desires are impacted by their symptoms
Sympathy for what her patients have to go through	She often feels sympathy for her patients, for what they have to go through, as well as admiration for how the cope living with the condition 24 hours a day, 7 days a week, when she gets to 'clock off'.
Imagining herself dealing with those symptoms	While she knows it could happen to anyone, her job means she is more aware of what can happen to the human body. As a result, she does worry about how she or her family would cope. However, this is so extreme that it is hard for her to imagine.

Dealing with Disgust
These subthemes relate to how she feels disgust, and how she deals with it in her work

Subtheme	Description
Approaching disgusting symptoms	In her work, there is often no way to hide from symptoms she finds disgusting. Instead, she has to actively approach disgusting symptoms. This could be either visually, mentally (see detaching empathy), or physically (touching what she finds disgusting, often without gloves)
Preparation for seeing disgust	For patients she knows will have symptoms she finds disgusting, she will talk herself up, and ensure she has already eaten before going to see the patient
Detaching empathy	By putting herself in her patients' shoes, the disgusting symptoms become more salient. As a result, when she is confronted by a patient with disgusting symptoms, she has to detach herself from the person. For the time she is giving the treatment, her patient is an object, and she has a practical job to do. This minimizes how much she has to focus on the symptom, and what it means, thereby minimizing her disgust. Once the treatment is done, she will re-engage empathy, and see the person as a patient.
Personal Disgust Profile	She finds a lot of symptoms disgusting, including fungating wounds, vomiting, and sputum. For her, sight, more than smell is the mediating factor for how intensely she feels disgust. There is an initial shock reaction to seeing something disgusting, however as time goes on, that shock passes, and her body adjusts to the smell and sight. Environment also plays a role, with a patient's symptoms seeming less disgusting if they in a clinic, as opposed to a home.
Disgust is intermittent	She often only has to deal with disgust for a short while, as patients who have particularly disgusting symptoms are often approaching the end of life. Therefore, she tends to have to deal with disgust in 'short sharp bursts', as opposed to regularly throughout her work
Moving on	After the event she uses distraction to move on from what she has just experienced. During home visits, this is easy to do as she has to travel from client to client, and can listen to the radio. In a clinic, this is harder to achieve, as the next patient will be waiting and know she has finished her last treatment, leading her to feel she needs to find excuses to have the time to move on

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Professional views on disgust

These subthemes relate to how disgust is seen in a professional context

Subtheme	Description
"Disgust" is unempathic	There is a feeling that the word 'disgust' is a strongly emotive word, and unempathic. As a result, she feels very uncomfortable using the word disgust, preferring instead to use phrases such as 'that's terrible' (as opposed to 'that's disgusting') as these feel more empathic.
Feeling it is unprofessional to show disgust	While she acknowledges that she feels disgust, and feels ok showing it on a personal level, she feels it is unprofessional to show it as a professional – that they are not meant to show disgust. She will go to great effort to avoid showing disgust to patients, although her disgust may have been shown accidently at times. Her main worry is that she will offend patients, damaging their relationship, or that she will add to their problems, when her main aim is to try and minimize their problems.
Disgust is a taboo	While people in palliative care know about disgust, nobody talks about it – it is taboo. Talking about disgust is seen as unprofessional. While she wants to talk about disgust, she fears being judged as being a bad person or a bad nurse for just using the word, let alone opening up about it.
Palliative care professionals can handle anything	She feels an expectation that she should be able to handle anything. It is acknowledged that symptoms can impede communication, or make it difficult to 'see' the person through the symptoms. However she is expected to be able to go in and treat the patient, no matter what symptoms or difficulties the patient presents with. As a result, she does not want to be seen as failing the patient by succumbing to disgust (it is a weakness), and not delivering best patient care
She has to 'get on and do it'	She feels that she has to 'get on and do it'. She has to push through disgust, and any other difficulties she has and do the job.

Getting support
These subthemes relate to how she gets support from colleagues and family

Subtheme	Description
An open and supportive team	She feels she is part of an open and supportive team that she can talk to about anything she needs to, without feeling judged. She feels that the team is supporting her both in just being around for debriefings, and in more practical ways. For example, she feels she could swap patients with a colleague if she ever needed to. Additionally, she can consult colleagues over medical matters, which gives her confidence in her own approach and technique
Talking with a patient focus	Talk with colleagues is always patient focused: how can they make the patients lives easier, how can we best treat the symptoms, what advice can colleagues share that might benefit patients. While there is some implicit acknowledgement of feelings, this is not in depth or a significant part of what is talked about in the team
Support through colleagues/checking in	She seeks support from colleagues to deal with disgust. This takes the form of brief informal support. This, however, still has a patient focus, and so the conversation tends to be about how bad it must be for the patient, but not about her own feelings. This support is usually enough, although there have been times when people have not been around and it has therefore been hard to access. She will generally actively seek out this informal support for other palliative care colleagues if she needs it. When it does not work, she feels she has to 'put up and shut up'
Don't talk to family about disgust	She feels she would be burdening her family if she were to talk about disgust, or seek support for it at home. Equally, she feels that family would not understand what it was like, and would not be able to deal with it. However, usually informal support as work is sufficient, so she does not need to talk about work at home.

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Below is a list of codes from Elizabeth's transcript. Each code is followed by a line number in brackets referencing the location in the transcript from where the code originated. Codes are grouped into subthemes (*italicized and underlined*), which themselves are grouped into themes (in **Bold**). Descriptions of all themes and subthemes can be found in Appendix 3T.

Disgust
Her thoughts about disgust
She isn't sure whether disgust at sputum is 'normal' – not talked about (114)
She acknowledges everyone feels disgust (118)
People are different in what they find disgusting (408)
She doesn't notice what most people find disgusting (651)
She feels that disgust is something self imposed, a stale of mind, she should be able to battle through and undo that (461)
Disgust is an individual thing – she can do things others cant (469)

Difficulty dealing with disgust
She will avoid sputum if she can (101)
There have been times she has struggled to deal with sputum (106)
She wants to avoid disgust where possible – wants the patient to be treated, but not by her (151)
She was glad she was away and didn't have to treat the patient, but feels guilty because of this (158)
She doesn't know if she could have coped with this patient (162)
She feels she could have done better work if there wasn't sputum (185)
She doesn't know if she could have coped with symptoms got worse (186)
She doesn't know if she would have coped if she had to touch/massage/treat (186)
Despite her worries/fears/panic, she would have treated the patient if she needed to (190)
She never thinks she can't treat a patient (196)
Easier when she doesn't have to approach/touch the symptom (252)
She has never left a patient before the assessment was completed (275)
Wearing gloves gives some distance from the symptom – feels different (443)
She has always felt she can deal with anything she is presented with (505)
She never thought she couldn't do something (507)
Might have wanted to withdraw if disgust has been worse (595)
She is keen to emphasize that she would never refuse to see a patient (865)

The Phenomenology of disgust
Disgust is offensive – you are offended by the smell (74)
She does notice bad smells, but they don't bother her (83)
Disgust is a physical thing, a bodily response she can't control (136)
Disgusting things upset her (136)
Feeling initial shock at symptoms (179)
She feels panicked by the thought of treating that patient (189)
She expects to be shocked (197)
Disgusting symptoms are offensive (287)

Disgust 'takes over' her body- it is involuntary, something's she can't control (292)
She still finds disgust upsetting (404)
She doesn't get anxious when she is disgusted (417)
Disgust makes her feel sick (419)
Her feelings of disgust are physical, not emotional (421)
She doesn't get panicked when disgusted (424)
She doesn't need to run when disgusted (424)
She has never been sick because of disgust (440)
Talking about disgust makes her feel sick (456)
She can't relaxed when around disgust (583)
She is more comfortable when she isn't having to deal with disgust (555)
She didn't want to withdraw because if sputum (592)

Personal disgust profile
She feels she isn't disgusted by much (60)
She doesn't have a problem with wounds (63)
She gets disgusted by sputum (68)
Wounds can be 'nasty' but not disgusting (70)
Smells around wounds can cause difficulty (73)
Most disgusting things she doesn't notice (74)
Sputum is the only thing she is disgusted by (99)
Lots of sputum is a difficulty for her (107)
Disgust (sputum) makes her feel sick (117)
Acknowledgement that she 'doesn't like' sputum, still not disgust though (242)
She doesn't like sputum, doesn't want to say she is disgusted by it (232)
She doesn't have a problem with trackies, just sputum (256)
Disgust is worse if sputum is coming out of a trachie (491)
She finds eyes hard to touch (510)
Wounds don't bother her (548)

Disgust mediators
She is more aware of smells now (71)
She is used to bad smells (85)
Smells are more noticeable in the clinic (90)
She is more aware of smells now than in the past (92)
Disgust is a matter of degrees – smell is disgusting, but not enough to provoke a reaction (94)
Disgust reaction is proportional to the size of sputum (102)
Home made disgust worse (152)
She desensitized to disgust over time (198)
Disgust is more of an issue at treatment (228)
Texture important to disgust (443)
Disgust is short lived – stops when stimuli goes (449)
She doesn't feel sick after the event – because removed from situation or because of focusing on something else (534)
She is desensitized to disgust (653)

Reactions to disgust
She may have given nonverbal cues about her disgust (62)
Disgust distracts her from her work/the patient (134)

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She doesn't believe anyone has seen her disgust (649)
She doesn't think she shows disgust (657)
She can't control her non verbal signs of disgust (647)
She may have shown the shock reaction to disgust inadvertently (679)
She feel the shock of disgust is harder to control – she may have given that away by accident (665)

Developing a relationship with patients
Importance of having a relationship with clients
It is important to her to maintain contact with her clients, to see them through the course of their care (48)
She develops a relationship with clients (49)
She sees a patient regularly – will form relationship (333)
She gets attached to patients – she forms relationships with them (329)
Intense treatment gets you involved with family and patient (329)
Having that connection important – can't have it with lots of different staff only seeing a patient once or twice (377)
Patients need to trust their nurses – that comes through that connection/relationship (378)

Thinking about how patients feel
She is actively thinking about how her patients might feel (20)
She worries how patients will react coming to a PC centre (25)
She wants to find out how patients feel (30)
She considers the persons family life (155)
You cant do this job without empathy (391)
People have empathy to a greater or lesser degree, but it is required for this job (392)
She wants to treat people how she would like to be treated (395)
She worries about how the assessment is for the patient – she wants to understand how it is for them. Empathy (600)

She adapts to the patient and their symptoms
Symptoms changes how she interacts with patients (586)
She changes how she works to react to patients symptoms (588)
She only changes her interventions to adapt to patients, not around her own disgust (594)
She wants to put the patient at ease, and will adapt to do so (597)
Communication problems change how she acts around patients (606)
She acts differently with patients, but not just because of disgust – to adapt to them and their needs (615)
Communication problems make assessments harder (622)
She has to adapt to the person (624)
She focuses on how the person is struggling and how she can help with that (624)
She is aware of the persons problems, and wants to adapt to help (627)
Adaptation to the situation, not because of disgust (629)
She has to be more formal to adapt to the patient (630)
Adaptation because of communication, not disgust (635)
She wouldn't change how she acts because of disgust (637)
Constant awareness of how things are for the patient, and adapting to that (639)

The emotional side to a relationship with clients
She is sad when their relationship with clients is cut short (51)
She gets to carry on that relationship with clients until end of life (53)
She is happy she gets to continue that relationship until end of life (55)
She can detach for patient/family, but still thinks about them – professional relationship with personal elements (331)
She can keep patient relationships contained, but some spill over into personal (335)
She had a strong empathic connection with her patients – she even comes in specially to see them (369)
She felt protective over the patient – that she was the best person to deal with this (376)

Thinking about patients at home
She does not get upset about patients at home, but does think about them (337)
She thinks about patients who have died (338)
What patients had to go through/suffered mediates whether they stay with you
She thinks about patients outside of work (328)
She compartmentalizes her life (495)

Her views on disgust in palliative care
Cannot show patients disgust
Doesn't want to show her patient disgust (123)
Its worse for the patient, so you can't show disgust (124)
She is scared/frightened of showing disgust to patients (139)
Doesn't want to show the patient she us upset (139)
Afraid of retching/doing something she can't control that gives her disgust away (140)
Doesn't want to upset the patient by showing disgust(142)
The patient has enough to worry about without her adding to her problems (142)
She is there to support the patient, not add to their problems (143)
She can cope physically with disgust (316)
Her work is designed to reduce disfigurement/stigma (352)
Profs aren't meant to show disgust/be disgusted (655)
She doesn't want to show her disgust to patient (683)
She feels showing disgust would offend her patients (684)
Her patients are already suffering – she doesn't want to add to that (685)
She would feel guilty about adding to their burden by showing disgust (688)
She is here to help the patient, - remove their problems, not add to them (689)
'horrified' to think she had shown disgust (690)

Her focus is on patient are
She adapts to how patients want to be treated (34)
Her job/role is to treat the patient – there is an expectation to live up to (116)
She wants what's best for the patient (150)
It's not about her, it's about the patient (201)
She doesn't want to create more problems for the patient (222)
She has to have effort from patient to give care, but that has to be balanced with the benefit they will receive (222)
Her focus is on the patient (243)
She has to focus on the patient anyway – to give best treatment (267)

Her focus is giving patients best care, which means continuity, which means coming in on her days off (371)
Focus is on the patient (559)
She might review her performance for the patient, but disgust does not come into it (568)
Focus on job/patient (570)
Post assessment – what's next for the patient (574)
She worries about doing her job well, and to the best of her ability (585)
She does her job, even if she needs to change how she works to fit the patient (617)
She had to adapt to the situation (619)
She wants to emphasize that her focus is always the patient (863)

Being upset by patients symptoms/situation/plight
She is sad that the person has to deal with this (200)
The patient isn't just dying, they've got all this other stuff to deal with – sorry/sad for both these reasons (202)
A lot of patients symptoms are visible, creates social problems on top of existing problems (207)
She gets upset by patients symptoms, that they are going through this (295)
She sees patients deteriorate over time – sad (300)
Disgust isn't an issue – is the sadness for the person and their suffering (311)
She finds it upsetting to see patients battling through disease (315)
Emotionally, she gets upset about her patients, and what they have to go through (316)
Disgust is overridden by sadness, but both caused by the symptoms (320)
She feels empathy for her patients – sad they are going through what they're going through (322)
Patients have to live with being scared by the cancer, she feel sorry for what they have to go through (345)
She feels it must be hard for the patient to deal with the condition, let alone condition plus disfigurement (348)
People can see the disfigurement, she worries/is empathic about the social stigma (351)
She wants to reduce patients disfigurement/the additional probs of cancer (353)
What upsets her is the way that person has to die – the visual signs and what they have to deal with (362)
She feels sympathy for the person having to deal with the disfigurement and disease (367)

Focus on patient care overrides disgust
As a nurse, nothing is about her, it is all about the patient (201)
Its not about her, it's about the patient (208)
Disgust is not her main concern (212)
Her focus is the work/patient (214)
Disgust is not the main issue for her – it's how patients are coping (225)
'it wasn't about me, it's about her' (245)
Only focuses on what is important – the patient (268)
Her reactions to sputum/wounds are unimportant, the symptoms themselves are part of the patient and therefore important (272)
Always worse for the patient – empathy (476)

After interview she is focusing on what needs to be done for the patient, not her own feelings (526)
Her focus is on how the department supports patients, not herself (832)

She HAS to deal with disgust
She has to deal with sputum – no choice (100)
She is expected to be able to deal with sputum (100)
Disgust wont' stop her treating a patient (115)
If she had to do it/nobody else around, she would do it (115)
She does it, even if it makes her feel sick (117)
You have to do the job in spite of disgust (122)
'you just do it' – (195)
She has been able to deal with whatever is thrown at her (274)
She HAS to deal with this stuff – no choice (402)
She has to be able to rise above disgust to do the job (404)
If she has to do something, she will do it, even if it makes her feel sick (446)
She will do what people need her to do, regardless of her own feelings about it (496)
She has to just get on with it (538)

Working with disgust
Confidence in her abilities
Training helps her deal with disgust (276)
She knows she can do it, - confidence from past experience (478)
She knows she is going to do it – she has confidence she can suppress and hide her disgust (493)
She would panic over having to touch eyes – unsure if she could do it (511)

Preparing
She is warned of difficult symptoms (166)
She was warned because of the communication issue, not because of disgust – gossip? Need to know? (166)
She knew the medical symptoms, rather than that they were disgusting (170)
The description allows her to prepare for going face to face (172)
Warnings can make things worse – imagine the worst, getting anxious (172)
Not having warning can make things worse – shock (172)
Knowing prevents/muffles initial shock (178)
Knowing in advance can make it worse (180)
Even if you know what to expect, it doesn't prepare you for the initial shock (181)
She doesn't feel nervous about seeing patients (212)
She has to get over the initial shock (254)
She can't control her reaction to thinks she wasn't expecting well (675)

Coping in the intervention
Frustration at communication problems making it harder for the patient (119)
Focus is how the patient feels, and how bad it is for them (124)
She has to put how she feels to one side (125)
She 'bypasses' disgust during the assessment (235)
She can feel disgust, but doesn't focus on it (235)
She focuses on the patient/assessment/job (238)
She changes her focus – initially on shock of disgust, then pull back to the job (241)

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Looking past/blocking out the symptom (250)
She doesn't focus on her disgust (277)
Focusing on something else has always worked for her (281)
She has always been able to concentrate on the person (293)
Empathy effects disgust (398)
To do the job, she doesn't focus on disgust, she focuses on the job (406)
She has to deal with disgust (439)
She shuts out her emotions and focuses on the job (445)
Even with distracting herself, she still feels sick (455)
She feels some control over her disgust – she wouldn't be sick (458)
She uses empathy to overcome disgust (485)
She has to work to be able to cope with certain situations (528)
Changing focus to the patient, not the symptom (250)
She has to shut down her emotions/thinking about it (261)
She focuses on the patient, blocking out disgust (266)

Moving on
Thinking about sputum/disgust happens after the intervention (234)
She doesn't stop to think about disgust (523)
Her focus is still on the patient after the intervention (529)
She doesn't need to reflect on disgust (536)
She doesn't reflect on disgust (537)
She doesn't get much, if any time to reflect (543)
No real time to reflect (546)
No real time to move on (560)
Very little moving on post intervention (565)

Doing the job, and doing it well is personally important for her
Disgust makes assessments shorter –she wants to leave (145)
She wouldn't walk out on a patient (147)
Disgust makes the appointment more concise, but everything still gets done (149)
She needed to do it – she needed to feel she was doing something for that patient (380)
Fighting through disgust do to something important to her – caring for the sick (472)
She is highly driven (535)
She gets a sense of achievement for dealing with a difficult case (545)
Her job enhances her life (787)
Her job takes some thing from her, but also gives her something back (789)
She does the job because she gets something from it – she loves it (791)
The job enriches her life, gives her perspective (792)

Working within a PC MDT
The experience of working in PC
She is experienced in PC (3)
She has worked in different PC settings (5)
She has had a lot of experiences (12)
Palliative care is tiring, drains her of energy (14)
She enjoys working in PC (15)
She enjoys where she works (44)
Wound care is part of her life – it doesn't bother her (63)

Most people couldn't deal with the sort of symptoms she has to deal with (400)
They do come across disgust more than other teams (808)

Checking in informal support
Talking to colleagues about patients is standard practice (695)
Can talk to colleagues about cases being difficult, but not in a negative way (698)
Support is unstructured, informal (701)
The team provide a support mechanism (703)
She recognizes difficult cases need to be talked about (704)
She talks through difficult cases with the team – informal support (705)
She gets reassurance and feedback from the team – professional rather than personal support (706)
Staff don't recognize that they talk about difficult cases for support (709)
Staff to talk about difficulties – part of the routine (710)
Debriefing is the most important element to her (712)
Informal checking in is all she has ever wanted/needed (722)
Talking to colleagues about the medical side helps her reflect on the case and how she can improve (739)
Informal debriefing is the best support for her (741)
Informal support is fast (742)
Informal support needed even if isolated (747)
Informal support easy to get (749)
Informal support provides protection (750)
She has always been able to access support when needed (753)
Informal support allows her to 'unburden' herself (758)
It is the reflective component of informal support that is important for her (759)
You need support to do this job (761)
Informal support is important for her to have (763)
Everybody needs some support (763)
Getting support is part of the routine – not something people are aware of (766)
There is an acknowledgement that others find things difficult (815)
She doesn't always have time to deal / process / get support for disgust (822)
Support is through getting perspectives/advice from colleagues (846)

Professional views on disgust
She is uncomfortable admitting her disgust (92)
She wants to make it clear sputum is her only problem – sees it has bad, wants to minimize (99)
She prefers to talk about other peoples disgust, rather than hers (109)
Disgusting situations are 'difficult' (112)
She sees stalking about disgust as complaining/moaning/unprofessional (523)
She has been paying more attention to her actions since agreeing to do the interview (660)
She didn't think about disgust before this study (804)
You don't think about disgust in PC (805)
Disgust itself isn't understood, but individual difficulties are (817)
She doesn't know how others deal with disgust (861)

Benefits of a palliative care multidisciplinary team
She bring other depts. In PC to help (155)

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If she can let someone else handle something disgusting, she will (488)
She is part of a team that can talk about anything (702)
Colleagues understand the situation – formal support might not (725)
Working in PC gives good peer support (726)
Working on an office helps with peer support (728)
She can get support from PC profs (728)
People know the patients you are talking about – easier to talk to, no loss of confidentiality (730)
Support by getting other perspectives (733)
MDT approach helps find solutions (736)
It is important to be close (physically) to the people she wants support from (737)
PC provides a wrap around service, so more cross over, so better support for staff (745)
Talking to the team provides confidentiality (754)
Staff can take difficult cases off each others hands (810)
Staff work to their strengths/weaknesses (811)
The team helps each other out (812)
Department is good at supporting their staff and patients (825)
The department brings different professionals together to provide support (829)
The department is very good at supporting patients (832)
She feels this department is better at support than others (838)
Can take an MDT approach to difficult cases (842)
She has never needed to use an MDT for a difficult case (843)
She feels there are resources there to support her, but doesn't need them (849)

Debriefing alternatives
There are sources of support other than informal checking in (721)
Family wouldn't understand what she is talking about (757)
She has clinical supervision, but does not use it for disgust (841)

Effect of work on home life
She is able to keep home and work life separate (770)
The job may take up home time, but home and work life are separate (771)
Bad days blur home/work barrier – stressed, etc (774)
Sometimes needs to calm down after work (776)
Family know what she does and give her space – no direct support (779)
Needs time to herself sometimes (782)
Indirect support at home, she can't talk about work at home (784)

Appendix 3T:
Summary of Elizabeth's subthemes

Disgust
These subthemes relate to how disgust is thought of and experienced

Subtheme	Description
Her thoughts about disgust	While she is aware that people feel disgust, and that different people find different things disgusting, she feels disgust is wrong. She is not sure whether her disgust at sputum is normal, and suggests that disgust could be something self imposed – a state of mind that she should be able to control and undo
Difficulty dealing with disgust	She is pulled in two directions. On the one hand, disgust makes her want to withdraw from disgust; she will avoid sputum where she can, and in doing so may pass on patients to other professionals, although she may feel some guilt when doing this. On the other hand, she feels as a professional that she needs to be able to deal with disgust, and so was keen to emphasize that she would never refuse to see a patient, and would never compromise a patients care by succumbing to disgust and leaving early. However, despite these claims, she does admit that there is a limit to her abilities, and she might not be able to cope with particularly disgusting events.
The Phenomenology of disgust	For her the hardest part is the initial shock at the symptoms, as this is accompanied by a strong physical bodily response she finds hard to control. More generally, she finds disgust 'offensive' (although offense is not directed at the patient), and while she claims not to be anxious about disgust, she also admits she cannot relax with disgust. She does not want to touch or approach the symptom she finds disgusting, but does not need to withdraw, likely due to an overriding desire to help her patients.
Personal disgust profile	She thinks she is not disgusted by much, and can deal with most things well. In particular, she is proud of the fact she no problem with wounds and could 'eat her dinner off them'. However, she does find sputum, (particularly when coming out of tracheotomies) hard to deal with, and this is what causes the majority of her disgust.
Disgust mediators	She believes that disgust is a matter of degrees, and that while there are many things that she recognizes are disgusting, they do not elicit a significant disgust reaction. This scale changes over time, and she has become gradually desensitized to things that most people would find disgusting. In contrast to this, she is more aware of

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	smells now than she was before (although these are not necessarily disgusting). Her disgust reaction is proportional to the amount of sputum, whether it is coming out of a tracheotomy or not, and whether or not she has to touch/approach it. However, her disgust is also short lived, diminishing after she has completed the task, or moved away. Equally, talking and thinking about what she finds disgusting is enough to trigger a response
Reactions to disgust	Disgust, particularly the initial shock at seeing the symptom causes an immediate disgust reaction that she finds hard to contain. As a result, while she hopes that nobody has picked up on her disgust, but admits she may have given off some nonverbal cues about her disgust, which she would have rather not given

Developing a relationship with patients

These subthemes relate to the importance and effects of developing a relationship with patients

Subtheme	Description
Importance of having a relationship with clients	During the course of delivering care, she will naturally develop a relationship with clients (and their families), given the regularity with which she sees them. She feels this is an important, both in delivering the best quality care, but also in putting the client at ease. Patients need to trust their nurses, and that is only developed through this relationship
Thinking about how patients feel	As part of this relationship, she is very aware of how her clients might feel, both individually, and more generally (ie coming to a palliative care centre). Empathy allows her to understand how the patient would like to be treated, what their problems or worries may be, and allows her to better adapt her treatment to the client. She believes that you cannot do the job without empathy, and it is important to her work
She adapts to the patient and their symptoms	She wants to put patients at ease, and by working empathically; she is able to understand how she can adapt her working to achieve this. While she may need to adapt because of symptoms (ie, tracheotomy causing communication problems), her adaptations are always to make things easier for the patient, never for her own disgust
Emotional side to a relationship with clients	As a result of having an empathic relationship, her relationship with clients does carry emotions for her. She is sad when she is unable to continue treating a client/has to let someone else treat her client, as that is an end to that relationship and she is no longer sure that person is getting the best care (which they would get from her). This protective feeling is so strong, that she will even come in on her days off to see clients, in order to continue that relationship, and ensure they get the best treatment. She admits that this relationship does sometimes spill over into her personal life, but on the whole, she seems able to keep this professional
Thinking about patients at home	She tries to compartmentalize home and work, however because of the relationship she has with patients, she does sometimes think of them at home. These thoughts tend to be more focused on patients who have suffered considerably, or who have recently died, suggesting they are a result of the empathic connection she has with patients. Despite this, these thoughts are not emotional, and she does not get upset about patients at home.

Her views on disgust in palliative care

These subthemes relate to her beliefs around disgust in palliative care, and how it is dealt with

Subtheme	Description
Cannot show patients disgust	She is a professional, and as such believes that she is not allowed to show disgust. Her patients are suffering, and as a result she has no right to be disgusted. Showing disgust would only add to the patients suffering, when she is there to alleviate it. As a result, she is scared of loosing control and showing disgust, and is horrified by the thought that she might have shown it in the past.
Her focus is on patient care	She is always keen to emphasize that her focus is on the patient: how can she adapt how she works for them, how can he improve her delivery of care, what is the best thing for the patient. As a result, she believes that this is not about her, it's about the patient. She takes this to a point where it feels like she is almost neglecting her own wellbeing because she feels she does not matter – all that matters is the patient
Being upset by patients plight	Due to the relationship she has with patients, gets upset by their plight. This can be broken down into three areas; that they are dying; that they have unsightly/painful/uncomfortable symptoms because of their illness, and the social stigma attached to the more visual signs of their Illness. She is hugely empathic for what they have to go through, and does feel upset for them. As a result, she feels an empathic drive to try and reduce the stigma and pain they suffer.
Focus on patient care overrides disgust	Her "it's not about me, it's about [the patient]" view means that her disgust (and other feelings) are irrelevant to her. Her focus is purely on supporting the patient, and as such she will try and do that, no matter how she feels.
She HAS to deal with disgust	Because the focus on patient care overrides her own disgust, she HAS to deal with her disgust. As a result, she will do what she is required to, even if they make her feel sick. She has to just get on and do the job – it is expected of her (and she expects it of herself) to be able to deal with the patient and their symptoms, so she takes the view that 'you just do it'

Working with disgust
These subthemes relate to how and why she tackles disgust in her job

Subtheme	Description
Confidence in her abilities	On the surface she is confident in her ability to do the job. While she knows she might experience disgust, she is confident, based on her previous experiences, she can control her disgust, and deliver high quality patient care.
Preparing	She can only prepare when forewarned. Sometimes, colleagues will give her a medical description if there is reason to (ie tracheotomy causing communication issues). She will therefore know that she may find what she is going to see disgusting, and can prepare for the shock of seeing the symptoms, allowing her to control her reaction. However, this also means she will get more anxious and worked up over the patient she is about to see, making things worse. As a result, she is not sure whether or not she would rather know in advance or not.
Coping in the intervention	To cope with disgust, she has to bypass how she feels; shut it down, and put it to one side. Her focus is purely on the patient, how bad it is for them, and on doing the best job she can. Often the shock of first seeing symptoms pulls the focus of attention away from the patient and her tasks and towards the feeling of disgust, but she is able to refocus it back to the job in hand. Even while focusing on the patient and symptoms, she does still feel sick.
Moving on	Any thinking or reflecting about sputum/disgust happens after the intervention, but this tends to be minimal Instead, her focus is still very much with the patient, and what she needs to put in place for them, or on to the next patient. While this could be to avoid experiencing any residual disgust, it appears this is purely due to her intense focus on the patient, disregarding herself
Doing the job, and doing it well, is personally important to her	She fights through disgust because she has to do it in order to do something important to her – caring for the sick. She feels she NEEDS to help the patient, and does it by doing her job to the very best of her ability. While she admits that this job 'takes something form her', it also enhances her live, and gives her perspective. The only area where disgust may affect her care is in making assessments more concise, but she would never walk out on a patient, as she still wants to ensure they get the best possible treatment.

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Working within a palliative care MDT

These subthemes relate to how she experiences and gets support from working in a multidisciplinary palliative care team

Subtheme	Description
The experience of working in palliative care	She is experienced in working in palliative care. Here, disgusting symptoms are a lot more common and extreme, to the point at which most people outside healthcare could not deal with them. It is also tiring, but she enjoys the job, and where she works
Checking in – informal support	She recognizes that everybody needs some support, and she believes that informal support is the best way to do this. This is just talking about a patient to colleagues in an unstructured, informal way, which has become standard practice. For her, it is the best and only support she has needed, as it allows her to reflect and unburden herself. However, the support is focused around giving best patient care; there is a lot of talk about the medical side, and perspectives how to deal with tricky cases. While staff can sometimes talk about difficult cases, this is done carefully and 'not in a negative way', and there does not appear to be much talk about the professional, only the problem and the patient.
Professional views on disgust	She believes that talking about disgust to other professionals is seen as moaning, complaining, or otherwise unprofessional. As a result, she feels uncomfortable talking about disgust, and is unsure how others deal with disgust. Disgust is simply not thought about in palliative, and she had not thought about it or recognized it before taking part in this study
Benefits of a palliative care multidisciplinary team	For her, one of the key advantages of working in a palliative care MDT is the ability to get support and other perspectives. Unlike other staff, those in palliative care know the patients (protecting confidentiality), and know what it is like to do the job, and so are able to best support her. The staff are aware of each others strengths and weaknesses and work to support each other, taking clients off each other if needed. Finally, the team is physically close, making accessing this support easier.
Debriefing alternatives	She is aware of alternative sources of support, and that she could bring disgust issues to clinical supervision, but she does not use these – informal support feels more comfortable (perhaps because it is less explicit/deep) Equally, she does not feel she can talk about disgust at home, as her family would not understand what she was talking about, or what it was like
Effects of work on home life	While for the most part she is able to keep home life and work life compartmentalized, sometimes work time does spill over into home. Equally, after bad days, she may need time at home to be left alone in order to calm down after the days work. Home support is indirect, and not explicit.

Below is a list of codes from Fiona's transcript. Each code is followed by a line number in brackets referencing the location in the transcript from where the code originated. Codes are grouped into subthemes (*italicized and underlined*), which themselves are grouped into themes (in **Bold**). Descriptions of all themes and subthemes can be found in Appendix 3V.

The experience of working in palliative care
Her history in PC
She has worked in PC for 15 years (3)
She didn't plan on getting into PC (6)
Her early experiences lead her towards PC (6)
Her interest in PC started when she got more qualified in it (9)
She is qualified/knowledgeable in PC (9)
She enjoys her job (15)
She will never enjoy some aspects of her job (384)

PC is a tough, specialized field
Not everyone can do PC (13)
PC is specialized – she can't do other nursing work, they can't do hers (13)
Her work is improving quality of life, rather than preventing death (17)
She is trying to control something that cannot be controlled – the disease (17)
Fungating wounds and their odors are something disgusting you only really encounter in PC (27)
She believes that, even with disgust, she has had a net positive effect on the patient (85)
Disgust is like palliative care – it is something you minimize, not get rid of (197)
Her focus is symptom management (453)

Patient focused working
Her focus is on the needs of the patient (138)
She is aware of her patients likes and dislikes – she gets to know them (215)
She has to accept that patients are individuals and will see different things as problems (409)
She has to support the patient how they wanted to be supported (414)
She has to adapt to the patient (414)
She sees the whole person, and identify their needs as individuals (419)
The symptom is part of the patient, but the patients is a lot more than just the symptoms (421)
She is there for the patient (436)
She tries to hide the smell – make it better for patients and the patient (not herself?) (535)

Staff talk about and act on 'difficult' cases
Staff will trade disgusting jobs based on personal difficulty (217)
The team share disgusting issues – take turns (229)
She is able to say she finds something difficult easily (236)

Talking about difficult cases is part of the norm (236)
Patients can be difficult for various reasons, not just disgust (238)
The team is open about difficulties, but don't talk about disgust (239)
Talking to colleagues allows for medical advice/consults (240)
Difficult cases are acknowledged and talked about (243)
The team will try to react to personal difficulties and support her (278)
If she couldn't manage the medical side, she would ask for help (438)
She feels others would be able to help if she asked for it (440)
She uses other professionals for help – ie comp therapy (536)

PC profs don't talk about feelings
She doesn't feel she can talk about her feelings (253)
She can talk about 'difficult' things, or that she was struggling, but not the emotions behind it (253)
Discussions don't explore emotions (254)
She doesn't disclose her feelings (264)
She never talks openly about much in her life (267)
She doesn't use the word disgust must outside of work (251)
She finds it hard to imagine talking about disgust at work (489)

Disgust in patients taboo
Feeling that in society, as well as in PC you can't acknowledge something is disgusting about someone (194)
Disgust is an issue they can't talk about but have to deal with (197)
symptoms can't be spoken about (208)
She doesn't use the word disgust professionally (250)
She would talk about disgusting smells as offensive, not disgusting (252)
Disgust at non medical things colleagues can make light of, disgust at medical
Disgust not targeted at the patient (256)
Different people find different things disgusting (411)
Disgust isn't talked about in PC (459)
Disgust is something they feel and have to deal with, but can't talk about (460)
Disgust is taboo (471)
Disgust in PC is like cancer is to normal people – taboo (472)
Disgust is something hidden, it can't be talked about/shown (473)
Just as people with cancer might not seek help, people with disgust don't seek help when they need it (474)
Each person copes with disgust differently (511)
She is aware other people feel disgust (511)

Disgust is a weakness
She feels vulnerable when confronted with disgust (53)
Disgust is a weakness (282)
She doesn't feel she can show weakness (disgust) to her subordinates (282)
Can let superiors pick up on emotions (282)
Disgust is a failure in the service – she has not conformed to what is expected of her (465)
She couldn't talk to a group of people about disgust – she would feel exposed, ashamed (482)
Disgust is a weakness, a failure on her part (484)

Disgust is very personal – something that needs safety and trust to be discussed (484)
She doesn't usually talk about her feelings (525)

Getting the right support
She doesn't feel there is enough support for people in PC (511)
She can talk about something disgusting if she needs to, she has adequate support (514)
She needs to talk about her disgust FAST, not waiting for supervision (515)
Clinical supervision isn't always at the right time (516)
Debriefing is best because it is regular (518)

Disgust
Personal disgust profile
She is aware of what she finds disgusting (25)
She has a problem with stomas (26)
Odors from fungating wounds are disgusting (27)
Homes can be disgusting through disease side effects (30)
Rudeness can be disgusting (37)
Disgust due to how someone lives (42)
Disgust due to insanitary/dirty conditioned caused by illness (46)
Talking about what she finds disgusting makes her show disgust – it is actively being processed/thought about, hence disgust (81)
Smell is what disgusts her the most (124)
Visual scenes can be disgusting, but not as much as smell (125)
She is disgusted by rice pudding (201)
Disgust isn't just at what something is, but where it is – places it shouldn't be (207)
Touching disgusting things makes them more disgusting (218)

The phenomenology of disgust
She worries about her own hygiene when in disgusting situations (30)
She is concerned with her own health/hygiene (51)
She worries about her own health/hygiene (55)
Her face gives her away – she can't control that aspect of the disgust (82)
Shock at symptoms (89)
She is surprised by the disgusting symptom (109)
She has to steady herself – shock reaction (116)
The first time she sees someone with disgusting symptoms is the hardest (177)
She gets desensitized to that persons symptoms over visits (177)
Disgust feels like a weight. She has to put effort into holding her thoughts and feelings about disgust together (355)
She feels she needs to let out her feelings of disgust (372)
She wants to withdraw from disgusting stimuli (432)

The psychological smell
Smell feels like it stays with you – she can't get rid of it (129)
Smell clings onto her – she cant get rid of it until she has a shower (131)
The smell says with her, even if there is no smell – it's a psychological smell (138)
She has to distract herself from the psychological smell (141)
The psychological smell works like disgust (144)

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The psychological smell comes back when she is relaxed/unfocused (145)
Only smell stays with her – psych smell (169)
The feels she can smell it in her hair – a constant reminder she can't get rid of (170)
When she isn't focused/distracting herself, the psychological smell comes back (300)
When she is relaxing, the smell comes back (301)
When she is talking about the case, the smell comes back (302)

She has a disgust limit
She has a limit to how much disgust she can take, which she has yet to reach (211)
She feels there is a limit on how much disgust she can take (439)

Pressure she puts on herself to endure disgust
She needs to be able to do the job despite of disgust (89)
Disgust makes it harder to do the job – if it prevents you, you can't do it (89)
Leaving patients early is selfish – expecting someone else to do it (93)
She sees her work being effected by disgust as a very negative thing (373)
She feels she should be able to do it – she has been trained to (428)
She feels she needs to help whoever and whatever comes in – regardless of her feelings (437)
She is not an individual she is a service, she isn't allowed to feel disgust (464)
For her, disgust is a personal failure to meet professional standards (481)
If she shows any signs of disgust, it is a failure, so she can't show it (497)

How disgust affects her work in PC
Importance of delivering best care in spite of disgust
She tries to avoid disgust (while still doing her job) (69)
She has never had to leave a patient before completing the treatment (90)
Leaving patients early is unacceptable, and unprofessional (93)
She will try and do her job, even if it means approaching something disgusting (210)
She wants to be able to deliver best care without letting disgust effect that (386)
She doesn't want to be bothered by disgust – she wants to be able to do the job without it affecting her (386)
She is focused on the patient – giving them best care is how she judges her performance (405)
She prides herself on her holistic approach (420)
She makes sure she does the medical side to her work (435)
She gets upset when she feels she hasn't been fair to her patients/given best treatment (504)

She is empathic and sympathetic
She is worried about how her patients cope with her symptoms (193)
She is thinking about the patient before herself (216)
An important part of her job is listening to patients and understanding them (356)
Trust between her and her patient is important to her personally, and to her work (376)
She wants to develop a rapport with patients (387)
Talking about a patient one to one doesn't seem right (gossiping) but she can't talk about her disgust in groups (490)
She is very ware of how other patients might feel at someone else's symptoms – empathy? (527)

She has to be very aware of how her patients are and what they are experiencing (529)

Disgust interferes by damaging communication/trust/rapport
She doesn't want to offend patients (30)
She does not want to insult/upset people by showing disgust (54)
She doesn't show disgust while with a patient (75)
She can't let out disgust because it would offend damage her relationship with patients (62)
She wouldn't be able to treat her patients if she showed disgust (64)
She hopes patients don't notice any change to their care because of disgust (249)
When carrying the weight of disgust, you can't listen properly (358)
Her work is patient focused, disgust disrupts that (359)
Disgust, felt or shown threatens her relationship with patients (377)
Disgust stops her having a good report with patients (388)
She doesn't think of patient differently because of disgust (404)
She finds it difficult to communicate with patients with disgusting symptoms (427)
Disgust means she doesn't have the same level of social contact with patient (434)

Disgust interferes with the care she can give
She sees disgust as doing harm to the patient (84)
She doesn't want to change how she interacts with patients because of disgust (176)
She thinks she does changes how she interacts with patients because of disgust (176)
She hopes disgust doesn't affect her level of care too much (247)
Carrying the burden of disgust can mean she doesn't see patients as quickly/often as she might otherwise (363)
Disgust impedes her ability to do her job to the best of her ability with other patients (363)
Disgust may mean she spends less time with the patient (432)
The social side to her work suffers as a result of disgust (434)
She doesn't take as much time over her care of disgusting symptoms (449)
Her first priority is the medical treatment, second is the social interaction (449)
Social interaction is important because of the stigma attached to symptoms (451)
Social interaction is a bonus – if it can't happen because of disgust then it's a shame, but it is acceptable (454)
If she doesn't do the medical and social side to her best, or hurts her relationship with clients, it is a failure in her eyes (495)
She feels that if she feels disgust, she is treating that person differently, which is unfair (502)
People with disgusting symptoms don't get as much time for their care, which is unfair (503)

She can't break the taboo – she has to wait for patients
She doesn't feel she can talk about disgusting symptom until the patient does (70)
She talks to the person about their symptoms – nervous, worried about how it will be seen (539)
Sometimes she cant talk to patients about their symptoms – not appropriate, taboo, insulting (539)

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She has to reduce disgust for everyone, but in doing so risks insulting the patient (541)
She is nervous about talking to patients about disgust (545)
She is unsure of the patient is aware of disgust – therefore might feel insulted (546)
Once they have talked about it, she feels it is easier to talk to the patient about disgust (547)
The second time, she doesn't have to have the full discussion – no broken taboo? Know how they are going to react? (548)

How she deals with disgust
Preparing for disgust
She has to turn away to 'steady herself' – composing herself for what she is about to do (91)
She has to prepare for approaching something disgusting (98)
Turning away for a second allows her to prepare/psych herself up (99)
Turning away allows her to calm herself (100)
When turning away, she visualizes what she is going to do (106)
She needs to take a moment to think about how to tackle the symptom/compose herself (109)
Once she has started working on something disgusting, she doesn't want to stop – it will prolong it (116)
Knowledge of what is coming makes it easier for her to cope with/prepare (179)
When she first sees something disgusting, she has to steady herself/she feels shock (182)
Her only change to her actions is stepping back to prepare (191)

Compartmentalizing patients contains disgust
She sees each case as being separate – once done with one, she moves onto the next and doesn't think about the earlier one (159)
Compartmentalizing interventions helps her to contain disgust to disgusting patents, and so it doesn't affect her other work (160)
She is in the room – she focuses on what needs doing NOW – nothing else enters her mind (161)
She compartmentalizes her work – once she is done with one patient, it is done, she can forget about it (185)

She has to work to keep her emotions to herself
She has to 'keep a lid' on her emotions – she can't let hem out (54)
She feels she can't show her feelings of disgust (62)
She can't 'let out' her feelings – not just to patients, but to staff? (62)
Disgusting situations are things she would ruminate on (77)
She has to "carry" disgust on her shoulders – a weight, something she has to actively hold together (77)
She feels she has to work to keep her feelings of disgust in (372)

Ignoring/denying disgust
She ignores her disgust (66)
She is trying to se the situation from a medical/empathic point of view, rather than focusing on her disgust (66)
After talking, her only alternative is distracting herself from disgust (292)

Even after the intervention, she is trying to distract herself from disgust (294)
She tries to focus on anything but the disgust/memory (304)
She has to avoid thinking about disgust else she experiences it (304)

She has to let out her emotions/talk to someone
She HAS to talk to someone about her experience – she has to offload (75)
She is glad when someone gives her an opening to let her emotions out (281)
She can't deal with disgust effectively (295)
She needs to have someone she has a trusting relationship to be able to talk to them about disgust (392)
She doesn't feel that she can talk about disgust to anyone else in the team (393)
She wants to talk about disgust with staff more (469)

Debrief with supervisor
She only feels comfortable sharing her feelings with one member of the team (270)
The person knows her well, and knows how she feels, even if it is not volunteered (271)
She doesn't feel she should talk about her feelings, but when a trusted person gives her an opening, she will (272)
She has built up a trusting working relationship with this person (her senior)(275)
She doesn't need to say anything about how she feels, the other person will pick up on it and invite her (276)
Her only support is through her supervisor (292)
She debriefs with her supervisor regularly to remove the weight (368)
She doesn't have to carry the weight for more than a few days (369)
Her supervisor helps her see the positives in her work (373)
Her supervisor helps her turn guilt/annoyance at her disgust into positives (378)
Talking to her supervisor provides containment (383)
Her supervisor lets her unload her disgust (373)
She would feel intimidated/unsafe talking to someone about disgust that she didn't know and trust (491)
She couldn't talk about disgust until someone else breaks the taboo first (491)

Shower as a watershed between home and work
Showering for her is a cleansing ritual – it gets rid of the psychological smell (149)
She is able to keep home and work separate (313)
Her shower is the watershed between home and work (316)
For her, the shower is a literal washing off of the days stress and worries – cleansing disgust (316)
For her, taking a shower is cathartic, taking away the stress of the day (319)
She feels very relaxed when she has a shower (319)
The shower takes the problems and washes them away (320)
The shower is the last thing she does about the problem – it gives her closure and stops them interfering at home (322)
When in the shower, the doesn't reflect on the day, it is purely cathartic (322)
After the shower, the problems are closed – she doesn't need to worry (325)
She feels relief during her shower (328)
Problems at work stop in the shower – it is the barrier between home and work (333)
The shower is a coping mechanism against lots of things, including disgust (339)

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Appendix 3V:
Summary of Fiona's subthemes

The experience of working in Palliative Care

These subthemes relate to how she has experienced working in Palliative Care, and the issues around disgust within it.

Subtheme	Description of subtheme
Her history in palliative care	While she did not plan on getting into palliative care, her early experiences guided towards the field. She has worked in palliative care for 15 years, and while there are some parts of the job she will never enjoy, she does take pride in her job, and enjoys most of it
Palliative care is a tough, specialized field	Palliative care is highly specialized, and as such, it is a job that other nurses might find hard to transfer into, and she would find hard to transfer out of. Her job is focused on trying to control symptoms that often cannot be fully controlled, and improving quality of life for the patient. It is also tough – odors from fungating wounds are something only really encountered in palliative care, and are something not everyone could cope with
Patient focused working	She sees patients as individuals, each with their own likes, dislikes, needs, and wants. As such, she has to adapt how she works to best fit each individual patient. While the symptom makes up part of who the patient is, it is not all the patient is, and she does get to know them on a more personal level. As such, she is always focused on the patients needs, and what she needs to do for that patient
Staff talks about and act on 'difficult' cases	Staff can freely talk about difficult cases. Cases can be difficult for many reasons, not just disgust, however the focus is always on the fact that something is proving a problem to delivering best treatment, and how that can be overcome, rather than addressing any feelings or personal issues. Staff will talk about difficult cases in groups, and support each other by sharing difficult cases around, redistributing cases, or getting advice from other staff members
Palliative care Profs don't talk about feelings	She does not feel she is able to talk about her feelings to other staff members. This is partly because she has always been a very private person, but also because she does not feel safe doing so, or that is acceptable to do so
Disgust in patients is taboo	She feels that in society, as well as in palliative care, there is something taboo about finding something about someone disgusting. As such, in palliative care, disgust is an issue they have to deal with, something they all experience. While they know each other experiences it, they are not allowed to talk about it. Disgust is there, but

	not acknowledged.
Disgust is a weakness	There is a feeling in palliative care that disgust is a weakness. To show it or feel it is a failure on her part, and a failure in the service as she has not performed to expectations (she is not human, but the arm of the service). As such, she cannot show weakness to her subordinates, although feels she can sometimes let her supervisors pick up on her disgust
Getting the right support	While she has established a support mechanism that works for her, in general, she does not feel there is enough support for people in palliative care. More formal support, such as supervision is often not at the right time, as when she needs support, she needs it NOW. Therefore, regular informal debriefings work best for her.

Disgust
These subthemes relate to how she feels disgust, and her beliefs around it.

Subtheme	Description of subtheme
Personal disgust profile	She finds stomas, odors from fungating wounds and rice pudding to be particularly disgusting. How someone's home has been affected by the disease (incontinence, smells, etc) can also be disgusting. She will even feel disgust when thinking/talking about something disgusting. There appears to be a pattern that her disgust is worsened by things being where they are not supposed to be. She also finds some interpersonal things, such as rudeness disgusting
The phenomenology of disgust	She feels a shock at a person's symptoms when she first sees them, which is hard to control and hide. The first time she sees these symptoms in the person is the hardest, but she gets desensitized to it over successive visits. She wants to withdraw from disgust, but cannot allow herself to do so. She worries about her own health/hygiene. Most importantly, disgust feels like a weight she has to carry around during and after her visits, until she is able to offload with her supervisor.
The psychological smell	After visiting patients with an odor, she feels the smell stays with her. While there may be some physical element to this, there also appears to be a psychological one. Often, if she is working or distracted, she will not notice the smell. However, if she is relaxing, talking or thinking about the case, the smell will come back to her. She reacts to this the same way as she would any other disgusting. This psychological smell stays with her until she has a shower at the end of the day
She has a disgust limit	She feels that there is a limit to how much disgust she can endure, and while she has never had to turn away a patient, she does feel that it could be possible for her to be presented with something that she physically could not do because of disgust
Pressure she puts on herself to endure disgust	She feels that she needs to do the job in spite of disgust – it is what she has been trained to do, and what she is expected to do. If she lets her work be affected by disgust, or shows any disgust, she sees that as a failure on a personal level (not giving the care she wants to), and a professional failure (not delivering the standard expected). She sees herself as part of a service, rather than a person, and a service should not be allowed to fail the patient.

How disgust affects her work in palliative care

These subthemes relate to how disgust affects her ability to work in palliative care

Subtheme	Description of subtheme
Importance of delivering best patient care in spite of disgust	For her, it is personally and professionally important that she delivers the best care possible, regardless of disgusting symptoms or her own feelings. She judges herself by whether or not she has given this best care, and is upset when she feels she has not met these standards. She thinks it is unacceptable, selfish and unprofessional to leave patients early because of disgust. While she will avoid disgust if she can, she will always make sure she does the medical side of her job, although the social support side may be reduced
She is empathic and sympathetic	Trust, and a personal connection is important to her personally, and to her work. She wants to develop a rapport with her patients, as this helps her improve the level of service she can deliver. Therefore, she is sympathetic and empathic – she wants to understand their problems, and she feels for how her patients feel.
Disgust interferes by damaging communication/ trust/rapport	Both feeling and showing disgust damages her ability to have that rapport with patients. When she feels disgust, her view of the patients does not change, but she does not have the same level of social contact with patients. Showing disgust would more explicitly damage the trust between patients, and she is very worried about offending or insulting patients them by showing disgust.
Disgust interferes with the care she can give	Because of the damage or threat of damage to her rapport with patients, the level of care she gives decreases. While she ensures she does the medical part of her job fully, the social support she gives by taking her time, and talking more with the patient becomes an added bonus she is not able to give. However, she recognizes that the social aspect is an important part of her work, given the preexisting stigma attached to many of the patients' symptoms. Therefore, she sees disgust as doing harm to the patient.
She can't break the taboo – she has to wait for patients	She feels that talking about some of the disgusting effects (visual/smell) of a patient's symptom is taboo. Doing so would risk insulting her patients or increasing their stigma, particularly as they may have lived with it for a long time, so not notice it as much. She only feels comfortable talking about this when the patient themselves has brought it up. However, on occasion, she has had to bring this up with patients. When doing so for the first time, she is nervous about their reaction, but subsequent times, it is easier, as she knows how they are going to react.

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How she deals with disgust

These subthemes relate to how she deals with disgust in her work.

Subtheme	Description of subtheme
Preparing for disgust	When in the room and about to commence treatment, she has to turn away for a second (usually with the excuse of putting gloves on). This gives her a moment to steady herself, and to think through what she is going to do. Once she has started, she will not stop – she wants to get it done, and stopping will 'only prolong the pain'. It is easier to cope if she knows what is coming, but often when she first sees a patient, she will need that moment to collect herself
Compartmentalizing patients to help contain disgust	She compartmentalizes her patients and her visits, which helps to contain disgust. Once she has seen one patient, she will move on to the next and not give any thought to what she has just done. Importantly, it helps her focus on the patient she is with now, rather than the patient she was with previously. While she says this is effective, there is also evidence that disgust does affect her later patients, and so may not be fully effective
She has to work to keep her emotions to herself	She feels she has to 'keep a lid' on her emotions, and not show any signs of disgust either patients or staff. This means she can ruminate on these memories, and feels she has to actively "carry" disgust with her. This is an effortful process.
Ignoring/denying disgust	Both during and after the intervention, she will try and ignore or distract herself form thinking or talking about the incident. If talking or debriefing has failed to address her issues, she sees ignoring it as her only remaining alternative.
She has to let out her emotions/talk to someone	She feels that she needs to talk to someone about what she has experienced in relation to disgust – this is the only way to get the weight of disgust off her, which will allow her to move on. However, she does not feel she can talk to just anyone in the team about this – she needs to have a trusting relationship with someone to be able to open up and let her feelings out.
Debrief with supervisor	The only person she can open up to about her feelings is her supervisor. She knows her well, and her supervisor can read her like a book. This means that she does not have to say she needs to offload, but her supervisor will pick up on it and offer it. This way, she is not breaking the unspoken rule about not talking about feelings/disgust. Her supervisor provides containment, taking the weight of disgust off her shoulders. Her supervisor also turns her shame, guilt and annoyance at feeling disgust/disgust affecting her work, into positives by finding positive

	aspects of the work she did, and emphasizing she and a net positive effect. She does not know what she would do if this person left.
Shower as a watershed between home and work	For her, taking a shower when she gets home from work is a watershed – it not only gets rid of the psychological smell, but acts as a barrier between home and work. When in she shower, she talks about seeing her problems/stresses washing down the plughole. After taking the shower, she does not think about work – any problems can wait until the following day. Her shower does not involve any reflection, it is purely a cathartic relief, and works for all aspects of work, not just disgust

Appendix 3W:

Individual subthemes contributing to collective subthemes

The analyses of each interview were used to generate a collective analysis. The aim was to create an analysis that describes the themes present across interviews, and uses individual differences and similarities between interviews to create a rich, detailed description of how participants experienced disgust in palliative care. The "Summary of participant subthemes" tables for each interview were used. Subthemes from each interview were grouped together according to the description of each subtheme to create collective subthemes. Where an individual subtheme contributed to more than one collective subtheme, the individual subtheme was duplicated, and placed in each collective subtheme to which it contributed in some way. The table below lists each collective subtheme, the individual subthemes that contributed to it, and the interview the subthemes came from.

Collective Subtheme	Subtheme Contributors					
	Alex	Briony	Caroline	Deborah	Elizabeth	Fiona
Disgust is Unprofessional	Professionals don't show disgust Disgust uses cognitive resources	Professionals don't show disgust PC professionals should be able to handle anything	Professionals can't show disgust Fear of not living up to that expectation [that professionals don't show disgust] Approaching disgusting symptoms	Palliative care professionals can handle anything She has to 'get on and do it' Feeling it is unprofessional to show disgust	Cannot show patients disgust Difficulty dealing with disgust She HAS to deal with disgust Professional views on disgust	Disgust is a weakness Pressure she puts on herself to endure disgust
Disgust damages relationships with patients	Professionals don't show disgust Disgust makes it harder to hear The empathic professional	Professionals don't gossip about patients Disgust destroys the personal connection	Professionals can't show disgust	Feeling it is unprofessional to show disgust Palliative care professionals can handle anything	Cannot show patients disgust	Disgust interferes with the care she can give Disgust interferes by damaging communication/ trust/ rapport She can't break the taboo – she has to wait for patients
The Phenomenology of Disgust	Disgust is a reflex	The feeling of disgust	Feelings comorbid to disgust	Personal disgust profile	Reactions to disgust	The phenomenology of disgust

	Disgust makes her want to withdraw Disgust is a personal challenge			Disgust in different settings	Difficulty dealing with disgust The Phenomenology of disgust	Importance of delivering best patient care in spite of disgust
Disgust Mediators and moderators	Personal disgust profile	Working with disgust Personal disgust profile	Personal disgust profile Disease and person as separate entities	Disgust is intermittent Personal disgust profile Approaching disgusting symptoms	Disgust mediators Personal disgust profile Difficulty dealing with disgust	She has a disgust limit The psychological smell Personal disgust profile
The importance of being an empathic professional	Disgust as a judgment on someone The empathic professional	An empathic, personal connection Professionals don't gossip about patients	Empathy from patients Vocational empathy	"Disgust" is unempathic Understanding what her patients world is like Developing a relationship with patients Sympathy for what her patients have to go through	Being upset by patients plight Importance of having a relationship with clients Thinking about how patients feel	She is empathic and sympathetic Her history in palliative care

				Vocational empathy Understanding how her patients feel Confidence in her abilities		
Emotional Entanglement	Psyching herself up Giving best patient care Fear of compromising patient care Professional persona as a tool/shield	Person centered working Her personality suits her job Being on occupational therapist in palliative care	Being part of a team Disease and person as separate entities	Wanting to help people Wanting to deliver best patient care Emotional as well as physical care Palliative care professionals can handle anything Support through colleagues/checking in Developing a relationship with patients	Her focus is on patient care Focus on patient care overrides disgust She adapts to the patient and their symptoms Checking in – informal support She HAS to deal with disgust Being upset by patients plight Doing the job and doing it well is personally important to her	Palliative care is a tough, specialized field Importance of delivering best patient care in spite of disgust Patient focused working Debrief with supervisor

					Emotional side to a relationship with clients Moving on	
Holding it together	Disgust uses cognitive resources	The empathic connection affects her Holding herself together The feeling of disgust	Professionals can't show disgust Post treatment moving on Feelings comorbid to disgust Indirect support from family Making it personal Emotions aren't processed	Imagining herself dealing with those symptoms Wanting to help patients Developing a relationship with patients	Being upset by patients plight Doing the job, and doing it well, is personally important to her Emotional side to a relationship with clients Thinking about patients at home Effects of work on home life	She has to let out her emotions/talk to someone The phenomenology of disgust She has to work to keep her emotions to herself
Disgust is taboo	Professionally acceptable words for disgust Cannot use 'disgust' in palliative care	Other professionals find other things disgusting	Professionals can't talk about disgust Breaking the taboo Professionals	Disgust is taboo	Her thoughts about disgust	She can't break the taboo – she has to wait for her patients Disgust is a weakness Disgust in patients

			don't think about disgust			is taboo
	Disgusting symptoms as 'things'		Professionals feel disgust Professionals can't show disgust Responsibilities as manager			
How touch palliative care is	Challenging job – the norm Camaraderie between palliative care professionals	Mutual support from people who know what it's like Palliative care professionals should be able to handle anything	How extreme some cases can be Being part of a team Approaching disgusting symptoms Working in palliative care Couldn't understand it if you weren't there	The work she does Don't talk to family about disgust	The experience of working in palliative care Benefits of a palliative care multidisciplinary team	Palliative care is a tough, specialized field
Talking about difficulties, not	Informal support only	Professionals don't talk about	Emotions aren't processed	Talking with a patient focus	Checking in – informal support	Staff talk about and act on 'difficult'

disgust	Talking about difficulties is important Talking about difficulties is easy Discussing difficulties can improve patient care	disgust, professionals stalk about patients and their symptoms	Not talking about emotions			cases Palliative care professionals don't talk about feelings
Preparing	Psyching herself up Using a mask to hide disgust	The feeling of disgust	How extreme some cases can be Responsibilities as manager	Preparation for seeing disgust	Preparing	Preparing for disgust
Distraction	Disgust uses cognitive resources	Pain better than disgust Post event distraction	Controlling emotions by focusing on treatment	Detaching empathy Moving on	Moving on Coping in the intervention	Compartmentalizing patients to help contain disgust The psychological smell Ignoring/denying disgust
'Checking in'	Informal support only	Professionals don't talk about disgust, they talk about	Checking in support	Don't talk to family about disgust An open and	Checking in – informal support Debriefing	Debrief with supervisor Getting the right

'Checking in'	Informal support only	Professionals don't talk about disgust, they talk about patents and their symptoms Post event distraction Building supportive relationships in palliative care	Checking in support	Don't talk to family about disgust An open and supportive team Support through colleagues/checking in	Checking in – informal support Debriefing alternatives	Debrief with supervisor Getting the right support
Passing on patients	Negotiation who takes who Giving best patient care Anxiety over passing on patients Passing on as a coping mechanism	Mutual support from people ho now what it's like	Being part of a team	An open and supportive team	Benefits of a palliative care multidisciplinary team Difficulty dealing with disgust	Staff talk and act on difficult cases
Keeping home and work life separate	Camaraderie between palliative care professionals	Work can't be allowed to touch home	Emotions aren't processed Indirect support		Thinking about patients at home Effects of work	Shower as a watershed between home and work

Appendix 3X:
Summary of collective subthemes

Professional views on disgust

This theme refers to the views participants had of disgust when identifying with the role a palliative care professional.

Subtheme	Description
Disgust is unprofessional	Disgust can affect participants in three ways; by feeling it, by showing it, and by allowing disgust to affect their work. While feeling disgust is simply undesirable, showing disgust or allowing it to affect one's work was felt to be highly unprofessional. To combat this, participants minimise the importance of their own feelings in believing that they just have to 'get on and do it'.
Disgust damages relationships with patients	Disgust hinders participant's ability to work empathically in two ways. Firstly by 'clouding' participants' ability to be empathic and gain a holistic understanding of their patients needs. Secondly while empathy drives participants to stay and provide socio-emotional support, disgust works in opposition to this to drive participants to leave patients early, reducing that support.

The personal experience of disgust
How disgust is felt by participants and influenced by working in PC

Subtheme	Description
The phenomenology of disgust	The actual experience of disgust. As predicted, this included a desire to withdraw/not approach, and feelings of nausea. However, disgust also included feelings of shock and sadness, which were not predicted. Participants' shock was characterized by a hard-to-mask reflex reaction to seeing something disgusting. Participants' sense of sadness appeared to stem from assuming and taking on their patient's emotions.
Disgust mediators and moderators	Disgust was affected by mediators (disgust triggers) and moderators (factors affecting the degree of disgust felt). Mediators were most commonly sputum, followed by disfigurement. Descriptions of disgust triggers were primarily visual, but participants emphasized that smell was also an important disgust trigger. Moderators included having to approach/touch something disgusting, the location/quantity of disgusting stimuli (ie sputum down front as opposed to dribbling), elaboration of disgust (thinking, ruminating or remembering disgust) and desensitization to disgust (both in the room, and over years)

An empathic connection makes them vulnerable

How seeing patients and particularly having an empathic connection with them elicits emotional reactions, and how that affects their lives

Subtheme	Description
The importance of being an empathic professional	It is personally and professionally important for participants to be empathic. This helps them deliver best patient care, both in gaining a holistic understanding of their patients needs, but also in providing socio-emotional support. "It is a caring profession – you need to care". An empathic connection or relationship often naturally forms with clients, particularly when seen regularly
Emotional entanglement	Their focus as professionals is *always* on the patient, and ensuring they get the best possible support. However, this, coupled with their empathic connection, means that participants often neglect their own emotional needs, arguing that they are unimportant, compared to the patient. They also start to imagine themselves in the same situation as their patients, leading them to experience distress
Holding it together	By having an empathic relationship, participants are vulnerable to becoming emotionally entangled with patients. Participants feel that because disgust cannot be expressed, they have to 'keep a lid on it'; suppressing how they feel. Equally, because participants do not generally talk about their emotions in palliative care, and believe those outside palliative care would be unable to understand, it is difficult for them to find an outlet for their emotions. This results in them having to 'hold it together' both during and after their time with the patient. While participants do experience some containment through 'checking in' support, this is not fully effective.

Working in palliative care

How disgust is seen and dealt with in wider context of a palliative care team

Subtheme	Description
Disgust is taboo	Participants believed that disgust was taboo in palliative care. While people acknowledge it by avoiding the topic, they have to use words such as 'difficult' and 'challenging' as bywords for disgust. Participants' feared that by breaking the disgust around taboo, they would risk being judged for being unprofessional. On the rare occasions where participants did break the taboo, it was usually because someone else had broken it first. Often, this was a patient, in which case participants would talk about the aesthetics of a symptom, but still not use the word disgust. The only time disgust was discussed directly was when it was brought up by a manager
How tough palliative care is	They understand palliative care is a tough area to work in both medically and emotionally. They have to deal with some horrific things, and they feel that people outside palliative care would not understand what it was like, so they seek support from others in palliative care, regardless of their profession. While palliative care was tough, it did also lead to a sense of camaraderie; that in palliative care knew what it was like, and understand what others in palliative care have to go through.
Talking about difficulties, not disgust	Staff talk about difficulties, not disgust. The focus is very much on the patient's problems, or on problems delivering the intervention, very little time appears to be given to thinking about how the professional feels, and their personal difficulties. As a result, participants appear to project their feelings onto their patients, either to get support, or without realizing. Despite this, there is some implicit acknowledgement and support for disgust.

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Coping with disgust

These more descriptive themes relate to how participants cope with disgust on a daily basis

Subtheme	Description
Preparing	There is not much they can do to prepare for the shock factor of disgust, but what preparing they can do tends to be focused around composing themselves to not show that initial disgust. Often, participants felt it was best not to warn others in palliative care about disgusting symptoms, for fear of labeling the patient. Equally, sometimes participants would prefer not to be warned, as it may cause them to ruminate on what they are facing. As a result, participants rarely had a chance to do much preparation for disgust
Distraction	Distraction was participants' main way of coping with disgust. This involved disengaging their attention from disgust, and then refocusing focusing on the job in hand. Alternatives included using mild pain to distract from disgust, or detaching empathy, thereby seeing patients as an object, rather than a person.
'Checking in'	Informal 'checking in' support was by far the most common way of accessing support. This is a quick informal debrief with *any* palliative care professional. Although this stays within the confines of 'difficult' or 'challenging', there seems to be some implicit acknowledgement of the professionals feelings, and support for that.
Passing on patients	Participants could ask colleagues for short-term help with an intervention. This was not seen as unprofessional, and so participants were happy to do this. There was also an unofficial system whereby staff could pass patients onto another colleague long term, if they had real difficulty with that case, either due to disgust, or other reasons. However, while participants were happy to receive patients from colleagues, they were still very nervous about passing on patients long-term .
Keeping home and work life separate	Participants often felt it was important to keep home and work separate, although this was not always perfectly done. Sometimes work would bleed onto home life, either through stress, or through becoming upset at a patients plight. While participants' families were aware of their difficulties, they were not in a position to be able to offer effective support.

"I don't think it's unprofessional to <u>feel</u> disgust, of a physical symptom that you find distressing, but I think its unprofessional to, erm, to show it, if you can. And it's certainly unprofessional to allow it effect how you are dealing with that patient" [A156]

Alex describes three levels of disgust; feeling disgust, showing disgust, and letting disgust affect her work, each of which are discussed in turn.

The first level of disgust, feeling disgust, was not seen as unprofessional, but certainly undesirable. Indeed, several participants described feeling disgust as a "weakness" [C280, D373/383, F283/484], but they always strived to overcome. However, Alex points out that once that feeling of disgust is shown, or worse affects their work, it becomes highly unprofessional

"You, you wouldn't, you wouldn't want to would you really, you wouldn't want them to think, because I like I said, their suffering much much worse aren't they? Me having to deal with it is nothing like them living with it. So I would hate to think that somebody picked up that I was… not liking what was happening, yeah. Because it, that's isn't what I'm here for is it? I'm here to help them, not make them feel worse. So yes, I would be horrified" [E684]

When asked how she felt about showing disgust, Elizabeth said she would be "horrified"; a sentiment echoed by her peers. Her view of herself as a professional is that she is "here to help them, not make them feel worse", the latter of which she risks doing if she shows disgust. This goes directly against her view of herself as a palliative healthcare professional, making the idea of showing disgust highly unprofessional to participants.

"Right, I've got to do this, I've go to get in there and do what I've got to do and get out', you know?" [D196]

The third level of disgust, allowing disgust to affect their work, was seen as the most unprofessional consequence of feeling disgust. Participants' refused to allow this to compromise their work, and ignored or minimised their own feelings to do so. Indeed, Deborah's view that "I've got to do this" was not unusual. Participants felt pressured by an expectation that they HAD to be able to deal with anything, and as a result, dealt with whatever was put in front of them, regardless of how they felt.

"I would never refuse to do anything, you wouldn't do it, because if the patient needed it you'd do it, do you know what I mean? So it will be interesting. Really interesting" [E864]

Finally, although participants volunteered for this study knowing they were going to be asked about disgust, they were often very defensive talking about the subject. They would often prefer to talk about other peoples' disgust, symptoms they do not find disgusting, or would try to minimize the strength of their own disgust.

Furthermore, on hearing the interview had come to an end, participants were often anxious to ensure that I understood that they did their job well, and they do not (generally) let disgust affect their ability to do their work. Often this would mean abrupt changes of subject to return to this point. For example, on being asked if there was anything she wanted to add before the interview ended, Elizabeth talks for ten lines about her curiosity for seeing the results. However, right before she finishes, she suddenly interjects that "would never refuse to do anything" because of disgust, and that she would always do what she needs to do for the patient, before returning to her original point. The degree to which participants felt uncomfortable admitting and discussing their "weakness" in depth, and their desire to ensure they are seen as a 'good' professional is indicative of how strongly participants felt it was unprofessional to be affected by disgust.

Appendix 3Z:

Detailed description of the subtheme *Disgust mediators and moderators*

Changes in participants' experiences of disgust were subdivided into two groups: mediators (stimuli that triggered disgust) and moderators (factors changed the intensity of the disgust response).

<u>*Mediators*</u>

Five out of the six participants reported that sputum, mucus or phlegm were particularly strong mediators, highly likely to trigger a disgust reaction. Less commonly, participants were disgusted by disfigurement due to fungating wounds, particularly when located on a patient's face. Participants often gave long, moving, but primarily visual descriptions of disgusting cases, suggesting images of disgusting stimuli were particularly salient. However, participants also emphasized the smell disgusting stimuli was also likely to trigger a disgust reaction.

> *"This is nothing to do with patients, but looking on, like where, when I'm telling you that it makes me feel a bit sick but I could do it. Well, we, I don't have animals, but I know that I couldn't pick dog poo up. I wouldn't, I can't stand it. So that is somewhere that I know it would be no good me having a dog to take for a walk, because I know I couldn't do it. But for a dog lover, its easy isn't it?"* [E467]

While sputum and disfiguration were particularly strong disgust mediators, participants were aware of other symptoms that, while they knew they were

disgusting and did not enjoy treating, did not elicit a *significant* disgust reaction. Here, Elizabeth likens these weak mediators to a dog lover's ability to pick up their dogs droppings. While a dog lover may feel disgust at picking up their dog's droppings, it is not something they have difficulty with.

In this passage, Elizabeth also highlights that some people are able to do things (ie picking up dog droppings) that she would find extremely disgusting and be unable to do, and visa versa. This suggests that strong and weak disgust mediators will be different for different people. Equally, her use of the term "dog *lover*", suggests that wanting to own a dog (or work in palliative care) has a relationship with the types of disgust one can deal with. Supporting this, participants often spoke of how they could not do a different healthcare job, such as specializing in head and neck cancers [A182] or eye units [E514] as there would be too many strong disgust mediators. Equally, the fact that so many people in palliative care have the same strong disgust mediators suggests they are aware of what stimuli they find particularly disgusting, and are able to follow specialism's that minimize these stimuli.

Moderators

Moderator variables increased or decreased the intensity of participants' disgust experience on four dimensions: whether they had to physically approach disgusting stimuli; the location and quantity of disgusting stimuli; whether they had to think about the disgusting stimuli; and how desensitized they were to the disgusting stimuli.

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"When we're doing a manual lymphatic drainage, its skin on skin, so, so you're not to wear gloves. But there were, on occasions where I thought 'I just can't… touch this lady', without having any gloves on" [D54]

Whether participants had to physically approach something disgusting, or whether they could keep away affected the degree to which they felt disgust. In this example, Deborah has to touch something she finds particularly disgusting. While ordinarily her work is skin to skin, here she felt she needed to wear gloves to be able to do the work. These provide a physical barrier for her, and increase the distance between herself and the disgusting symptom. Similarly, other participants reported having to sit next to someone with a disgusting symptom as being harder than sitting opposite someone with a disgusting symptom.

"The tracheotomy doesn't bother me in itself, we have lots of patients with tracheotomies but unfortunately, obviously she'd got a lot of, erm sputum and exudates coming out as well, but it wasn't as bad as it got […] Obviously it did get a lot worse. So I don't know how I would have been if I had been put in the situation" [E162/256]

The location and quantity of disgusting stimuli also affected the strength of the disgust response. Here Elizabeth explains how one patient's tracheotomy had increasing levels of exudates as the patient deteriorated. Importantly, this symptom 'did get a lot worse' over time, and while Elizabeth was able to cope with that symptom when she did the assessment, she was unsure how she would have coped

had she had to treat that patient towards the end of her life, when the exudates were significantly worse

"So erm, so, I don't know if an awareness of it prepares me as well, you know, if you go into someone with a lung cancer who's got a bucket to one side, and is constantly bringing it up and putting it down. I don't want to focus on that, but it is part of my assessment, in that I need to understand what's restricting them in being able to do things" [B74]

Whether participants had to think about a disgusting symptom or whether they could pretend it wasn't there changed the strength of the disgust response. For example, here Briony explains how she doesn't want to "focus on" the fact her patient is bringing up phlegm and carrying it around in a bucket. However, part of her job means focusing on that, so she can understand how it affects them, and how she can help.

"You do gradually become desensitized. Even to the point now where I'm talking about it, there was a point that, you know, you would think about things, some people would think about it and, you know, something that might disgust them, and have a physical reaction. I don't get that anymore, [mhm] I remember there was a time when I would have done, but I don't now. [mhm] so, you know. A few years later." [B663]

Finally, how desensitized participants had become to patients wounds, either on a macro or micro scale affected their disgust response. On a micro scale, participants

reported getting used to the sight and smell of patients symptoms over the course of the intervention, although the intensity of their disgust would return when they next saw that patient. On a macro scale, participants reported gradually becoming desensitized to certain kinds of symptoms over a number of years, as Briony explains.

"So you focus don't you, you change to focus is yes, I know I don't like this, but I'm not here to deal with that, which I wasn't, I'm here to meet this lady, see if there is anything we can do for her edema. See if we can make things, quality of life a bit better for her so you transfer it, because it wasn't about me, it's about her" [E241]

Elizabeth explains how, even though she feels disgust at her patients symptoms ("I don't like this"), that is completely irrelevant to her ("it wasn't about me, it's about her"). Instead, her focus is with a patient – that she was there "to meet this lady, and see if there is anything we can do for her edema. See if we can make things, her quality of life a bit better for her". This desire to focus on the patient and their symptoms is seen across participants, is unsurprising given how important it was for participants to work empathically (see *the importance of being an empathic professional*). However, this focus on the patient also resulted in participants becoming emotionally entangled with their patients in two ways: neglecting their own feelings, and imagining themselves in their patients place.

"It's about equal opportunities and things, and if I've not, if I've got a patient that I'm disgusted in some way by, I don't feel they've had an equal opportunity to talk to me, and stuff, because of that. I perceive that as a failure. And that's quite a strong, to the point where it upsets me sometimes, emotionally" [F502]

By focusing so intensely on patients, participants started to neglect and diminish the importance of their own emotional state. Elizabeth's attitude of "it wasn't about me, it was about her" was common amongst participants. Often, this was used as a justification for participants ignoring their own feelings. Equally, as in Fiona's case, participants sometimes felt that their feelings were selfish. Here, Fiona explains how if she has not given a patient with disgusting symptoms the same opportunities for emotional support [because she left early because of disgust], she sees it as a failure –she has let that person down. For her, feeling disgust is selfish, as it takes away support she feels she should be giving to patients, and drives her to leave early, making her life easier. This attitude seems embedded in the belief that disgust is unprofessional (appendix 3Y), and as such it should be ignored, denied, or downplayed.

"You kind of put yourself into his position and think 'how, how do you live with that?' How do you… if that was a member of my family, how would I feel about seeing him in that position, and I've got no answer to that because I think your thoughts stop you from actually thinking. Its not a normal thing to think about is it? But… very upsetting. Yeah, and yeah I cried over him" [C105]

Participants' empathic connection involves thinking about how participants feel (see *the importance of being an empathic professional*). However, doing so often involves participants putting themselves in their patient's position, for example, considering how a symptom might affect their ability to go outside. Rather than imagining the patient's perspective, some participants imagined themselves in the same position as

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the patient. This is considerably more emotive, as it is about *them*, rather than their patient. For example, when Caroline thinks 'how do you live with that?', her thoughts are not practical and solution focused, but are about how *she* would feel in that position, and how she would cope, making this considerably more personal for her. Some of these thoughts were so distressing that 'your thoughts stop you from actually thinking' about it. However, even without fully exploring those thoughts, she still cried over her patient that night. By being so focused on the patients, and being empathetic, participants emotional wellbeing could, at times, become linked to the wellbeing of their patient.

Appendix 3AB:

Detailed description of the subtheme *Holding it together*

Through working empathically (see *The importance of being an empathic professional*), participants often neglect or minimize the importance of their own emotions in favor of focusing solely on the patient (appendix 3AA). However, participants also believed that showing disgust is unprofessional, meaning they would go to great lengths to hide their own disgust (appendix 3Y), and felt unable to discuss disgust openly with colleagues (see *Talking about difficulties, not disgust*) or with anyone outside of palliative care (Appendix 3AD). As a result, participants felt they had to hold onto their emotions, both during and after interventions.

"I think probably if it was more formal I could [talk about disgust]. But if it was friends, family, colleagues now, I just feel like what I witnessed back then was too horrific. I think it was so frightening to think that that can actually happen, that cancer can do that to you. I think its just too frightening for people, you know? Its kind of, and sometimes I probably think…. 'have I fully explored it enough or have I just kind of… dealt with it, put it to the back of my mind and just left it there?'" [C358]

Participants' inability to talk about their emotions can be seen in Caroline's interview. While she wants to talk about disgust, she feels 'what I witnessed was back then too horrific' to share with family or friends. As a result, she feels she may have "put it to the back of my mind and just left it there", suggesting that although some of the 'heat' of the emotions may have been processed, she still feels it is something she needs to

explore and comes to terms with, but does not have the support or opportunities to do so.

> *"For me personally, it's, it's about access to this particular person. If she's not there, I have to carry it, and depending on how long the carrying of it goes on for, it does sometimes effect your work […] it's like a big boulder sitting on your shoulders and it may be that you have a patient that you speak to that's got an awful lot of stuff that they want to offload onto you, and there are some days when I can't and I've got this issue […] so I'm not listening as attentively as I might be […] 'I can't come yet, I can't. I will come, but I can't come yet, bear with me', so… […] obviously the sooner I can get rid of it the better, but… I wouldn't want to be carrying it for more than a, well more than a few days, probably four days tops." [F346]*

Fiona provides a very vivid description of what it is like to "carry" the weight of emotions (not just disgust) she felt during interventions. The phrase "it's like a big boulder sitting on your shoulders" emphasizes how she has to work hard not just to contain these emotions, but in carrying them while continuing with other interventions. Because she needs to find containment to offload this weight, she is less to provide social-emotional support to patients. When listening to her describe to how she says to patients "I can't come yet, I can't, I will come, but I can't come yet, bear with me" there is a striking change to a stressed and hurried intonation. Equally, her language is sharp and broken, as can be seen from the transcript. Both these show the strain of carrying this weight, and being torn between her emotional needs,

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and those of the patient. Finally, the fact that she feels she would *need* to share this after four days points to the continual effort she has to put into carrying these emotions, and the importance of accessing support.

Fiona is unusual, as she was the only participant to have one person who she went to in order to talk about her emotions, and the way they affected her work. However, even here she felt unable to ask for this support, relying on this person to 'break the ice' and ask if she wanted to talk. Other participants accessed support predominantly through 'checking in' support with any palliative care professional (appendix 3AF), often with much less emotional content. Despite this difference all participants were still bound to talking about difficulties, rather than disgust. Given that Caroline still feels she may have "put it to the back of my mind and just left it there", this type of support seems only partially effective at providing containment for emotions, such as disgust.

Appendix 3AC:

Detailed description of the subtheme *Disgust is taboo*

"I think [disgust] probably, it's understood, but its just something almost a bit like a taboo sort of, subject. Nobody really says anything about it, openly, not that I'm aware of really" [D602]

For participants, the belief that disgust is unprofessional (appendix 3Y), meant that disgust became a taboo subject. As Deborah explains, it is something that staff are aware of, but that they do not feel they can openly talk about. Both Caroline [C420] and Alex [443] liken the taboo of disgust to the taboo of death, before palliative care became mainstream and normalized such words. Similarly, participants felt that they could not talk about disgust, only difficulties (see *talking about difficulties, not disgust*).

"I wouldn't actually come out and say 'god that was absolutely disgusting', I would never say that to a, because I'd feel…. Not scared, not the right word, but I wouldn't want them to judge me on my, on how I am with patients […] But I wouldn't want my colleagues to think, 'oh god' you know 'what sort of a nurse is she if she can't, keep it, keep it together' or you know, 'because that disgusts her', and [mhm] I don't know, I think, I think you don't want to be shown to be loosing face almost" [D562]

Because participants had the view that disgust was unprofessional, they felt that talking about disgust would mean both admitting to unprofessionalism. Deborah

explains how she feared would be judged as a bad professional if she admitted that she had felt disgust. On a more personal level, her fears of "loosing face", point to the fact she has positive working relationships with her colleagues, which she fears might be damaged if she were to admit her disgust, possibly compromising her ability to access 'checking in' support (appendix 3AF). Finally, Deborah, and all participants recognized that others working in palliative care felt disgust. Therefore, their fear of judgment is not of because they felt that they were not allowed to *feel* disgust. Instead, they fear being judged for *talking* or *admitting* that they feel disgust.

It is interesting to note that the taboo of disgust is also highly specific. While the full quote is too identifiable to publish, one participant had a strong disgust reaction to an everyday item she came into contact with during the course of her work. Interestingly, she notes that her colleagues "take great fun in taking the micky out of me", highlighting that this form of disgust is accepted, and even joked about. Therefore, the taboo of disgust is specific to talking about patients disgusting symptoms, and not about more general feelings of disgust.

> *"It's almost like the last taboo. Where as in the general public, cancer is probably the last taboo, possibly disgust is our taboo in here. It's not talked about, so it gets hidden under the carpet, and…. [staff] don't potentially get help when they need it"* [F471]

The strength of the taboo of disgust in palliative care affected participants ability to access support. As discussed in *talking about difficulties, not disgust*, participants felt unable to talk explicitly about disgust, impacting their ability to get support for their

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emotions. However, Fiona believes that the taboo of disgust does not just affect the language staff use, but also their desire to seek support. Her point that disgust is 'hidden under the carpet' suggests that staff ignore the problem, pretending it doesn't exist, a theory supported by the "I've just got to get on with it" and "it's not about me" attitudes seen in *disgust is unprofessional* and *emotional entanglement* (appendices 3Y and 3AA). This could lead to staff's emotional difficulties becoming worse, potentially leading to staff burn out.

> *"A couple of members of the team really found [a case] difficult to deal with, yeah. You know, and when I've said to them, did you feel quite disgusted by that smell, and it was a yeah. But they would never have described it if I hadn't had used the word" [C435]*

While participants felt unable to talk explicitly about disgust, on a small number of occasions, Caroline felt able to break this taboo. When she did so, she was always in a position of authority. This may have served both to give her confidence that she would not be judged for using the word 'disgust', and to reassure staff that, they were allowed to use it too, as seen in Caroline's extract. It is also worth noting that Caroline [C234], Deborah [D311], and Fiona [F539] also started to break the taboo with their patients. Here, although they would still never explicitly use the word disgust, they would feel able to discuss the appearance or smell of a patient's symptom provided the patient themselves brought it up as an issue, thereby breaking the taboo.

Detailed description of the subtheme *How tough palliative care is*

"Its like being in a war zone sometimes. You keep these thoughts to yourself, and you don't share it with anybody" [C112]

As Caroline indicates, participants working in palliative care felt that their job meant working in particularly demanding situations, because of both disgust, and the emotional demands of the work. As such, there was a feeling that they could not share their thoughts with anybody outside of palliative care.

"Part of me is thinking, in the back of my mind, 'oh it'd be lovely if their, if their swelling had got a bit better', although I know that's not realistic […] So you're just hoping that whatever you did last time with the treatment, its helped a little bit [mhm]. Erm…. Yeah, I think that, and I just hope, all I do is I just hope that nothing's got worse since" [D265]

In addition to the difficulties produced by disgust already discussed (see, *The phenomenology of disgust*, and appendices 3Y, 3Z and 3AA), the frequency and intensity of disgust also presented more subtle emotional challenges. For example, Deborah describes how she is always hopeful that her patients have improved, and that her treatment has helped. But at the same time she knows "that's not realistic". A key motivator for her and other participants is an empathic drive to improve the quality of life for her patients – she hopes her treatment has "helped [the patient] a little bit". However, while her treatment does prolong the quality of her patients lives,

she is also aware that it is going to continue to degrade, and that she is watching her patients get progressively worse, not better. While participants appeared highly resilient to this, there was an inevitable, if unspoken sense of sadness to this aspect of their work

"You're only human, and we're going into some places that are challenging, and you know, are difficult. And you erm, I take, I find it very important that we have a wider support, a team that just understands that. [...] I've often found that team support from outside of my profession. [...] you're just with staff who just understand that, and know that, and they know that its reciprocated as well. so I think for me, that… is really important, that you have, erm, be part of a team that supports you, that respects you, that values you, that is there for you, that you are all in this together. And I think that's one of the real, erm, factors in any palliative care team, that resilience I guess." [B486]

Because participants believed palliative care presented unique challenges, they felt that they could not talk to those outside palliative care. As Briony explains, it is "very important that we have a wider support team that just understands that [difficulty]". She feels those outside of palliative care may have difficulty fully understanding the 'challenging' and 'difficult' situations they encounter. As a result, it is more important for her to access support from people in palliative care, regardless of their profession, rather than from people from the same profession. This also led to sense of camaraderie and "resilience" within the palliative care team: that they "are all in this together".

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This mutual understanding between palliative care staff may be why participants felt supported through 'checking in', without needing to explicitly talk about disgust (see *talking about difficulties*, and appendix 3AF). Rather than having to explain their own feelings of disgust, by talking about a patient's problems, others in the palliative care team may be able to infer participants' disgust. This could lead to an implicit discussion of emotions and support, without breaking the taboo of disgust. However, while this may offer some support, there is evidence that this is only partially effective (Appendix 3AB)

Detailed description of the subtheme *Preparing*

"You have to brace yourself to go in. Compose your face when you go in so you don't display revulsion" [A34]

Participants spoke of having to prepare for situations they know are going to be disgusting. As Alex explains, this was focused around composing themselves to avoid showing their feelings of disgust to the patient, and therefore avoid being unprofessional (appendix 3Y).

"I'm also conscious not to talk about it too much with other staff members. I'm conscious when I make referrals to other people to erm, if I'm aware it might be an issue for them, erm, I might mention it, but I wouldn't routinely, go out of my way […] I don't want to feel like I've set up people [patients]. […] when people come up and they give you referrals and they've framed it; 'oh they're lovely person, you're going to love to see them', or, […] 'oh, you're going to struggle with that, the smell is terrible', that sort of sets you thinking before hand, I don't, I don't do that, I try not to do that, unless it is something that particularly someone needs to know." [B210]

On receiving referrals from other staff members, participants would learn of patients' medical problems, and from this, would sometimes be able to predict whether they would feel disgust at a patient's symptoms and therefore prepare. However, participants would often refrain from giving too much information about patients in

referrals. For Briony, while she "might mention" symptoms staff are likely to find disgusting, she would avoid doing so where possible as she fears that by warning staff about disgusting symptoms, she will 'frame' the patient; leading staff to change how they treat with that patient. As such, staff would sometimes see patients without knowing the full extent of their symptoms, and how disgusting they may find it, making it impossible to prepare.

"I was warned. […].So almost, you're sort of prepared for it. Had it been a blind assessment, it may have been a bit more difficult, or then again, it may not have been. Because sometimes when you don't know you cope with it a lot better don't you, because sometimes you've prepared yourself for it haven't you, so you thinking it's worse than it actually is. So I don't know whether it would have been better to know or not to know. I think for the patient it's nice that we know, because you, you're prepared so that initial perhaps shock or something that you may show you wont, because you're expecting it, but then are you sort of making it worse in your mind than it actually is" [E116]

Participants were also unsure whether they would want to be warned of disgusting symptoms. Here, Elizabeth explains how being warned allows her to better prepare for the shock of seeing something disgusting. However, she also suggests that by being warned, she might start worrying by 'making it worse in your mind than it actually is'. Therefore, while Elizabeth does not *think* of the patient differently, by building it up, she could inadvertently treat the patient differently. This would confirm Briony's fears that warning staff does change how they interact with patients. It is therefore unsurprising that participants were often unable to prepare for disgust.

Appendix 3AF:

Detailed description of the subtheme *'Checking in' support*

"Sometimes I might just come and offload to one of my colleagues, erm, if they're about. Erm, and just say '[sigh] oh dear, how […] does she live with, with it?' or I don't know, 'how to… is there anything else I can [do?]'" [D235]

All but one participant (Fiona, who offloaded to only one person, see appendix 3AB) reported extensive use of informal 'checking in' support with other staff members in palliative care. As Deborah describes, this often involved talking about how bad a patients symptoms were (not how disgusting they were), as well as getting practical advice on how to improve their patient care.

"I personally don't have any anxiety because I think, you know the team know you well enough, […] I, wouldn't feel uncomfortable coming back and going into, you know, lymphodema or round the corner to the palliative nurses and just saying 'oh I've just had a bit of a time', you know? [laugh], for whatever reason. Erm. And.. and that…. You know, there's a, I think this checking in is just something that we all understand, and we all are aware of, and we'll all support really" [B509]

As Briony describes, participants who used this informal support did not feel any anxiety when accessing this support because they felt they knew the team around them, building on the sense of camaraderie discussed in appendix 3AD. While

participants would often work hard to build specific relationships to access this support when they first joined a palliative care team, overtime, these generalized to all those working within palliative care, as accessing checking in support was "just something that we all understand". This meant that support was ubiquitous, and therefore accessible quickly at a time convenient to participants.

Importantly, the fact that staff understood that everyone working in palliative care needed checking in support suggests that staff are aware of their own difficulties, and are able to infer that others working in palliative care have the same difficulties. Despite this, disgust was still unprofessional. However, the understanding between palliative care professionals supports the suggestion that it is possible for them to discuss disgust implicitly, and access some level of support for it (appendix 3AD).

"Luckily with the team I work with I can sort of say to one of them 'help' [laugh] 'would you do that for me', and their more than happy to do it because I know sometimes, if you're not feeling very well yourself, erm, I really have to" [C271]

Participants reported an understanding among palliative care staff that if someone has a particular issue with a case, whether due to disgust or otherwise, others would share or take over that case. This could be either a short term or a long-term measure. For example, here, Caroline has a particular difficulty assisting a patient, and asks her colleagues to help her by taking over that part of their treatment. This is a temporary solution, and would only last for the duration of that particular treatment. This support was seen as a part of working within a supportive team, and as such, participants did not experience any discomfort asking for help with such cases.

"I found smells more difficult to cope with, and they made me feel sicker. And I perhaps allowed, allowed those patients to be under the care of other colleges quite happily. Erm… I didn't, you know, I never went to see them, but I might have sort of, diverted a little bit." [A177]

In contrast, Alex describes how she passed patients onto other professionals on a long-term basis when she found their symptoms particularly difficult to cope with. While she would still see these patients when needed, they were placed under the care of someone else, giving her less time with symptoms she found particularly

difficult. This was considerably less common, but participants were aware that this option was open do them should they require it.

"That probably shouldn't go in your quote! [laugh, then jokingly] 'I deal with this by not doing it!' [laugh] I'm now in a situation where I can't do that anymore, you know, so actually, it is a bit naughty, but that is something about working with a team, isn't it, acknowledging, you know, that you don't mind this, so you're going to give them, actually, a better deal, than I am because I find it really difficult" [A192]

Participants who did pass on patients on a long-term basis often felt considerable discomfort about doing so. Here, after admitting she had on rare occasions passed patients on to other professionals care, Alex attempts to backtrack, and emphasizes that that is something that she cannot do in her current setting. This anxiety is rooted in her view that "it is a bit naughty" – that it is something she should not do, and is unprofessional. She then justifies passing on patients in terms of improving patient care, rather than looking after her own emotional wellbeing. Together, this suggests Alex views passing on patients as selfish, and unprofessional.

"If that was evident with regards to something they might find disgusting, that wouldn't be a problem, that would be ok as well. so if we have something that come in, that was particularly distressing and that person didn't want to do it, that's absolutely fine, and we would move the case between us, and we would do it that way. There is no problem in that what so ever" [B600]

In contrast, other professionals who had not passed on their own patients were very happy to receive such cases, and did not view it as selfish or unprofessional. As Briony explains, there is an understanding within the team that some people find certain patients particularly distressing (for disgust, and other reasons), and by working in a team, they are able to manage and distribute those difficulties. This contrast suggests a double standard between how participants judge themselves, and how they judge others. Therefore, while people working in palliative care may experience a supportive environment where they are able to pass on patients, they may not feel that the same support applies to them. As a result, they fear that in asking to pass a patient on long term, they will be judged, perhaps reducing their access to 'checking in' support (appendix 3AF).

Appendix 3AH:

Detailed description of the subtheme *Keeping home and work life separate*

"I try and keep work at work […], because what does he [husband] say, you know? 'that's very difficult', what else can you say? But yes, I think there is some informal support form home, but there is something about sharing it with people who know what you are talking about that's helpful" [A319]

Participants varied in how much they talked about work at home. Several, like Alex, would talk about work in general, nonspecific terms, and would receive some informal support. However, they often felt that their families could not offer substantial or significant support, as they needed to share with someone who knew what it is like to work in palliative care (appendix 3AD).

"I have always kept home and work as separate as I can. I'm quite strict about that, in that I have different bag, different purse, different debit card – I have a little debit card for work that I just use for petrol. […] I try and keep my work and private very separate. And there is always spill over, and there is always, you know, because there is going to be obviously, but I try and keep some sort of distance, just on the basis that, erm…. To support and protect me I guess, and what's important to me." [B539]

Others, such as Briony, felt they had to keep home and work completely separate, and would very rarely talk about anything work related at home. Indeed, Briony went to extremes to compartmentalize her life, including different bags, only working at set

times, and living outside of the area in which she worked in order to "support and protect" her, and what is important to her.

> *"I wouldn't go home and be upset, erm, in, physically upset, but yes, you do think about them constantly, and what they are coping with, and their families, and even when they've passed away. You still feel, you still, their still there in your mind I think, for the, for what they've had to go through"* [E336]

Occasionally, however, work could spill over to home life. Sometimes this was stress after a hard day, but several participants also reported being physically or emotionally upset by what their patients had to go through, or what they saw. Other times, participants, such as Elizabeth, found themselves "constantly" thinking about patients. Families would often be aware of this, and know that it was a result of work, but were unable to offer any meaningful support, other than give participants space and time to process what they felt. This emotional bleed over of work into home suggests that participants were not able to fully process their emotions at work.

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