

“OH, YOU’RE PART OF THE HUMAN GANG TOO”

THE EXPERIENCE OF SCHWARTZ CENTER ROUNDS®: AN INITIATIVE TO
PROMOTE COMPASSIONATE HEALTHCARE.

By

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Overview

This thesis is submitted in partial fulfillment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D) at the University of Birmingham. The thesis consists of two volumes.

Volume I

This volume has three parts. This first part consists of a systematic literature review investigating the evidence for psychological interventions for adults with advanced cancer experiencing psychological distress. This is followed by an empirical study exploring the experience of Schwartz Center Rounds[®] amongst hospice staff, as an initiative to promote compassionate healthcare. Finally, a public domain briefing document provides an accessible summary of the literature review and empirical paper.

Volume II

Five clinical practice reports are presented in this volume. The first report details the case of 30-year-old woman experiencing depression and self-harming behaviours, formulated from cognitive-behavioural and psychodynamic perspectives. The second report presents a service development needs assessment, designed to identify the learning and developmental needs of service users in a women's medium secure forensic service. The third report details the case of a 28-year-old male with a mild learning disability and anxiety, offering formulation and detailing intervention using the compassion-focused model of shame. The fourth report describes how leadership and consultancy competencies were gained as a Trainee Clinical Psychologist working in a Community Macmillan Specialist Palliative Care Team. The fifth is an abstract of an oral presentation given to describe the case of a 10-year-old girl with anxiety associated with Diabetes Mellitus (Type 1). A single case experimental design was used to evaluate a cognitive-behavioural intervention.

All names and identifying features have been changed to maintain confidentiality.

Dedication

To David,

I dedicate this theme to you: *The Hope of Acknowledgement*.

Acknowledgements

I would like to thank my supervisors Dr Ruth Howard and Dr Helen Guy, for their inspiration, ideas and continued support – I have learned so much from you both.

To my participants, thank you for your time and honest reflections. I have discovered something so valuable from your words.

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Volume I

Literature Review

What is the evidence for interventions for psychological distress in people with advanced cancer? A systematic review of empirical studies

Abstract

Background: Psychological distress, including anxiety, depression and demoralisation, is frequently experienced by those with advanced cancer. Psychological interventions may help to alleviate such distress, thus improving patients' quality of life. However, little is known about the effectiveness of these interventions, owing to a lack of recent comprehensive reviews of the empirical literature.

Aims: The current review aims to evaluate the effectiveness of psychological interventions in reducing psychological distress in patients with advanced cancer.

Methods: Systematic searches of three electronic databases were conducted using a search term strategy specific to psychological distress, psychological interventions and advanced cancer. Studies were screened against inclusion criteria, with included studies appraised for their methodological quality.

Results: Twenty-three studies evaluating 15 different psychological interventions were identified. Cognitive-behavioural interventions were most consistently reported to be effective in reducing psychological distress. A number of meaning-focused interventions were also found to be effective.

Conclusions: This review supports the use of psychological interventions in advanced cancer populations. Meaning-Centred Group Psychotherapy and Cognitive-Behavioural Therapy demonstrated the most potential to reduce psychological distress. Further good quality randomised controlled trials are needed before firm conclusions about efficacy can be made.

Keywords: systematic review, psychological distress, anxiety, depression, demoralisation, psychological interventions, advanced cancer, palliative care.

1.0 Introduction

Approximately 30% of all deaths in the UK are due to cancer (General Registrar Office for Scotland, 2013; Northern Ireland Statistics and Research Agency, 2013; Office for National Statistics, 2014). This is likely to increase as the prevalence of cancer increases, with a predicted rise in the number of cases from more than 2 million in 2010 to 4 million by 2030 (Maddams, Utley, & Møller, 2012).

When a cancer can not be cured, it is usually referred to as *advanced*, and typically reflects cancer that has spread (i.e., metastatic disease). Nevertheless, there is often treatment available to slow down the further spread of the cancer, sometimes for months or years. Treatment can also help to ease any symptoms and improve quality of life (Macmillan Cancer Support, 2014).

As such, when people with cancer move into the advanced stages of the disease, palliative care services are needed to provide this additional support. Dixon, King, Matosevic, Clark, & Knapp (2015) recently defined palliative care as, “the active, holistic care of people with advanced progressive illness, involving management of pain and other symptoms and the provision of psychological, social and spiritual support” (p. 15). It’s aim therefore, is to ensure the best possible quality of life for individuals and their families (Dixon et al., 2015).

This notion, that palliative care encompasses more than just attending to physical needs, is not a new one. Dame Cicely Saunders, founder of the UK modern hospice movement in the 1960’s, first introduced the concept of *total pain*, whereby a person’s entire being can be affected by a life threatening illness. Therefore, to treat pain effectively, care must encompass the whole person, including the physical, psychological, social and spiritual (Clark, 1999).

This model of palliative care informs most UK specialist palliative care services today, whereby *total active care* is provided by a multi-disciplinary team (MDT). Although this can vary, the team is typically formed of a doctor, nurse, social worker, physiotherapist, clinical psychologist, liaison psychiatrist, chaplain and occupational therapist (Twycross, 2013).

1.1 Psychological Care

Psychological suffering is thought to be experienced by nearly all patients at the end of life (Block, 2006). Whilst feelings of grief, sadness, despair, fear, loss and loneliness are experienced on a spectrum of normal responses, prolonged episodes of distress can become burdensome. Indeed, studies suggest that psychological responses such as depression, anxiety and hopelessness can become as frequent, if not more so, than pain and physical distress (Jaiswal, Alici, & Breitbart, 2014).

Estimated prevalence rates of anxiety and depression in those with advanced disease vary, ranging between 15-28% and 9-26%, respectively (Breitbart, Chochinov, & Alici, 2010; Mitchell et al., 2011; Wilson et al., 2007). Many prevalence studies also report a higher rate of mixed anxiety and depressive symptoms rather than just depression or anxiety alone (Wilson et al., 2007).

Alongside anxiety and depression, patients may also suffer with a sense of hopelessness, a desire for hastened death and loss of meaning. These phenomena have been conceptualised as *demoralisation* (Clarke & Kissane, 2002; Kissane, Clarke, & Street, 2001). This concept is distinct from that of depression and is a form of existential distress experienced by those with advanced illness (Robinson, Kissane, Brooker, & Burney, 2016). A recent systematic review reported prevalence rates of demoralisation between 13% and 18% in cancer and palliative care patients (Robinson, Kissane, Brooker, & Burney, 2015).

Prolonged episodes of depression, anxiety and demoralisation in those with advanced cancer is associated with negative outcomes including reduced quality of life, (Breitbart, Pessin, & Kolva, 2011; Robinson et al., 2015). Therefore, access to psychological support is essential. However, the nature of psychological care can vary greatly from informal education to formal psychological therapy.

In the UK, the National Institute for Health and Clinical Excellence (NICE) has structured psychological care within a four-tier stepped care model (NICE, 2004). This defines intervention according to the level of skill required by the professional working with the patient (refer to Table 1 for details of each of the four levels of care). Essentially, all staff working in cancer services are expected to be able to provide good enough emotional support and information to patients (Level 1). As problems and emotions become more difficult and patients are seen to experience significant distress, so too the type of psychological care offered becomes more advanced (Levels 2, 3 and 4).

1.2 The evidence so far

Regardless of the type of care provided or type of professional delivering it, all psychological care should be evidence-based. Whilst there have been recent reviews of psychological interventions for a general population of patients with cancer (e.g., Faller et al., 2013; Hart et al., 2012), there have been very few that have focused specifically on the field of advanced cancer and palliative care. Furthermore, where reviews have been conducted, each one has had very different objectives. For instance, outcomes of interest varied between quality of life (Uitterhoeve et al., 2004), existential distress (LeMay & Wilson, 2008) and depressive symptoms (Akechi, Okuyama, Onishi, Morita, & Furukawa, 2008; Lorenz et al., 2008).

Despite these differences, it appears that psychological interventions do benefit patients with advanced cancer or illness to varying degrees. For example, there is evidence that Cognitive-Behavioural Therapy (CBT), supportive-expressive psychotherapy and problem solving therapy are effective at reducing depressive symptoms in these populations (Akechi et al., 2008; Lorenz et al., 2008). Similarly, in addressing existential concerns at the end of life, supportive-expressive group therapy was found to be effective (LeMay & Wilson, 2008).

The one review which has included a broader range of outcome variables, including social, spiritual and existential aspects of quality of life, concluded that CBT was the most effective psychosocial intervention (Uitterhoeve et al., 2004). However, as nearly all trials included in the review evaluated CBT-related interventions, little can be inferred about non-CBT techniques. Furthermore, given it's been over a decade since this was published, the need to review *recent* evidence, is of key importance.

Whilst these reviews offer some preliminary evidence about the effectiveness of psychological interventions in advanced cancer, an up-to-date, comprehensive overview of what works best in helping with a broader range of psychological distress, including anxiety, depression and demoralization in this specific patient group, is lacking. Moreover, there is no clear picture of whether the current evidence reflects what is recommended for clinical practice; in other words, little discussion has been given to the level and skill of the healthcare professionals delivering the interventions and whether this reflects national guidelines such as NICE in the UK.

1.3 Aims

The current review aims to evaluate the effectiveness of psychological interventions in reducing psychological distress in patients with advanced cancer. It will also aim to clarify whether the existing evidence reflects what is recommended for UK clinical practice.

Table 1

The four tier model of psychological support as outlined in the NICE guidance for supportive and palliative care (2004).

Level	Who should provide it?	What should be assessed?	What is the intervention?
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communications and general psychological support.
2	Health and social care professionals with additional expertise (including clinical nurse specialists)	Screening for psychological distress	Using standardised screening tools e.g., the Distress Thermometer, Hospital Anxiety and Depression Scale etc.
3	Trained and accredited professionals	Assessments for psychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety management and solution focused therapy, delivered according to an explicit therapeutic framework.
4	Mental Health Specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behaviour therapy.

2.0 Method

2.1 Search Strategy

Initially, computerised databases PsychINFO, Medline (including Pubmed) and EMBASE, were searched using the following procedure. Subject specific keywords used to describe patients, interventions and outcomes were selected. Terms were mapped to subject headings where possible, using the thesaurus function of the database. Free text words were also included, using the * to expand if necessary. See Table 2 for a detailed list of the search terms used.

The keywords for patients (group A), interventions (group B) and outcomes (group C) were separately combined, using the Boolean operator *OR*. The three searches were then combined, using the Boolean operator *AND*. The search was limited to journal articles written in the English language, published within the past 10 years (between 2005 and 2015).

2.2 Inclusion Criteria

Retrieved studies were assessed against the inclusion criteria, which are summarised in Table 3 in line with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). Clarification of what constitutes a psychological intervention in the context of psycho-oncology and palliative care was adapted from Watson's (2012) formal definition:

The primary focus of the intervention is to work with people to increase their personal resources in dealing with aspects of [their illness] that cause undue stress/distress and in this

respect, targets for change will be behavioural, emotional, cognitive and interpersonal.

(Watson, 2012, p. 98).

2.3 Methodological Quality

Quality appraisal criteria were based on the Quality Assessment Tool for Quantitative Studies (Thomas, Ciliska, Dobbins, & Micucci, 2004), as seen in Appendix 1. This enables the type of quantitative design to be appraised in line with the general hierarchy of evidence in interventional research, whereby randomised controlled trials are usually given more weighting than non-randomised controlled trials, and other quantitative designs such as cohort studies (Petticrew & Roberts, 2006).

Studies are rated as *strong*, *moderate* or *weak*, using predefined criteria, on the following domains: selection bias, study design, confounders, blinding, data collection methods, withdrawals and dropouts. The criteria were adapted for the purpose of the current review to include sample size as indicator of quality, with 0-50 participants classified as small, 50 – 100 as moderate and ≥ 100 as large.

Further adaptations to the original tool were made by the author, one of which included the decision not to assess participation rates or study completion rates in the quality appraisal. This reflects the well-known difficulties of recruitment and retention of patients with advanced disease in research studies (see Jordhøy, Kaasa, Fayers, Underland, & Ahlner-Elmqvist, 1999; Rinck et al., 1997). Although studies were appraised in terms of whether or not they reported participation and retention rates, the actual rates themselves were not taken into consideration.

The overall quality rating for each study was assessed in line with the Quality Assessment Tool for Quantitative Studies guidelines (Thomas et al., 2004). As such, studies

were categorised as *strong* if they had four strong ratings with no weak ratings; *moderate* studies had less than four strong ratings and only one weak rating; studies assessed as *weak* had two or more weak ratings.

2.4 Data Extraction and Synthesis

Data was initially extracted using a data extraction form, designed by the reviewer to capture key characteristics of each paper (see Appendix 2). Extraction of the data was performed according to the PICOS framework, as specified within the PRISMA guidelines (Moher et al., 2009).

It was envisaged that studies would be too heterogeneous to carry out meta-analysis. Therefore, a narrative review was performed. The results are summarised by the type of intervention used and outcome variables assessed. Synthesis of psychological outcomes, intervention and participant characteristics were initially conducted, to ascertain which specific factors were likely to be related to study findings.

Table 2

Search terms used in electronic database search

Group A	Group B	Group C
Hospice	Psychotherap*	Mental health
Palliative care	Humanistic Psychotherapy	Psychiatric
Terminally ill	Brief Psychotherapy	Psychiatric symptoms
Death and dying	Analytical Psychotherapy	Depressi*
End of life	Individual Psychotherapy	Anxiety disorder
Terminal cancer	Interpersonal Psychotherapy	Anxi*
Advanced cancer	Psychodynamic Psychotherapy	Death anxiety
Advanced disease	Supportive Psychotherapy	Distress
	Group Psychotherapy	Psychological distress
	Integrative Psychotherapy	Psychological wellbeing
	Eclectic Psychotherapy	Existential distress
	Cognitive Therapy	Existential suffering
	Cognitive Behaviour Therapy	Demoralization
	Behaviour Therapy	
	Cognitive Analytic Therapy	
	Psychotherapeutic Techniques	
	Psychoanalysis	
	Family Therapy	
	Couples Therapy	
	Systemic Therapy	
	Existential Therapy/Psychotherapy	
	Meaning-Centred Therapy/Intervention	
	Meaning Making Therapy/Intervention	

Table 3

Inclusion Criteria in line PRISMA reporting guidelines, specifying Patients, Interventions, Comparators, Outcomes and Study Design (PICOS).

Inclusion criteria

Participants

A study population of adult patients (≥ 18 years of age) with cancer in the advanced stage of the disease (described as *advanced, terminal, end-of-life, palliative* or *stage III* or *stage IV disease*).

Studies which have used palliative care patients with other non-malignant conditions were excluded if less than 80% of the sample had an Advanced Cancer diagnosis.

Studies which used non-patient samples (e.g., family members, carers or healthcare professionals) which did not also report on patient outcomes were excluded.

Interventions

Studies that employed only ‘psychological’ interventions in the experimental condition, whereby targets for change were behavioural, emotional, cognitive and interpersonal, as specified in criteria proposed by Watson (2012).

Studies that used interventions that were not strictly psychological, such as relaxation training or complementary therapy were excluded.

Comparators

For studies that had a comparator condition, this included treatment or care as usual, wait-list control or other physical, social or psychological intervention.

Outcomes

At least one outcome was psychological (including depression, anxiety, hopelessness, desire for hastened death, suicidality and dignity).

Studies that assessed only variables that were not strictly psychological (e.g., spiritual, physical or social wellbeing) were excluded.

Study Design

Quantitative studies which measured efficacy or effectiveness of psychological interventions.

3.0 Results

3.1 Search Results

Searches of PsychINFO, EMBASE and Medline databases provided a total of 943 citations. After adjusting for duplicates 830 remained. Of these 608 were discarded after screening the title. A further 187 were discarded after reviewing the abstracts because it was apparent that these papers would not meet the criteria. The full text of the remaining 35 articles were examined in more detail and 16 of these did not meet the inclusion criteria as described (see Table 4.).

A total of 22 studies were identified for inclusion in the review. Four studies were identified by screening the references list of relevant papers and review articles. The remaining 18 included studies were identified by database searching. Figure 1 depicts the systematic search process in line with PRISMA guidelines. Excluded studies are listed with reasons for exclusion in table 4.

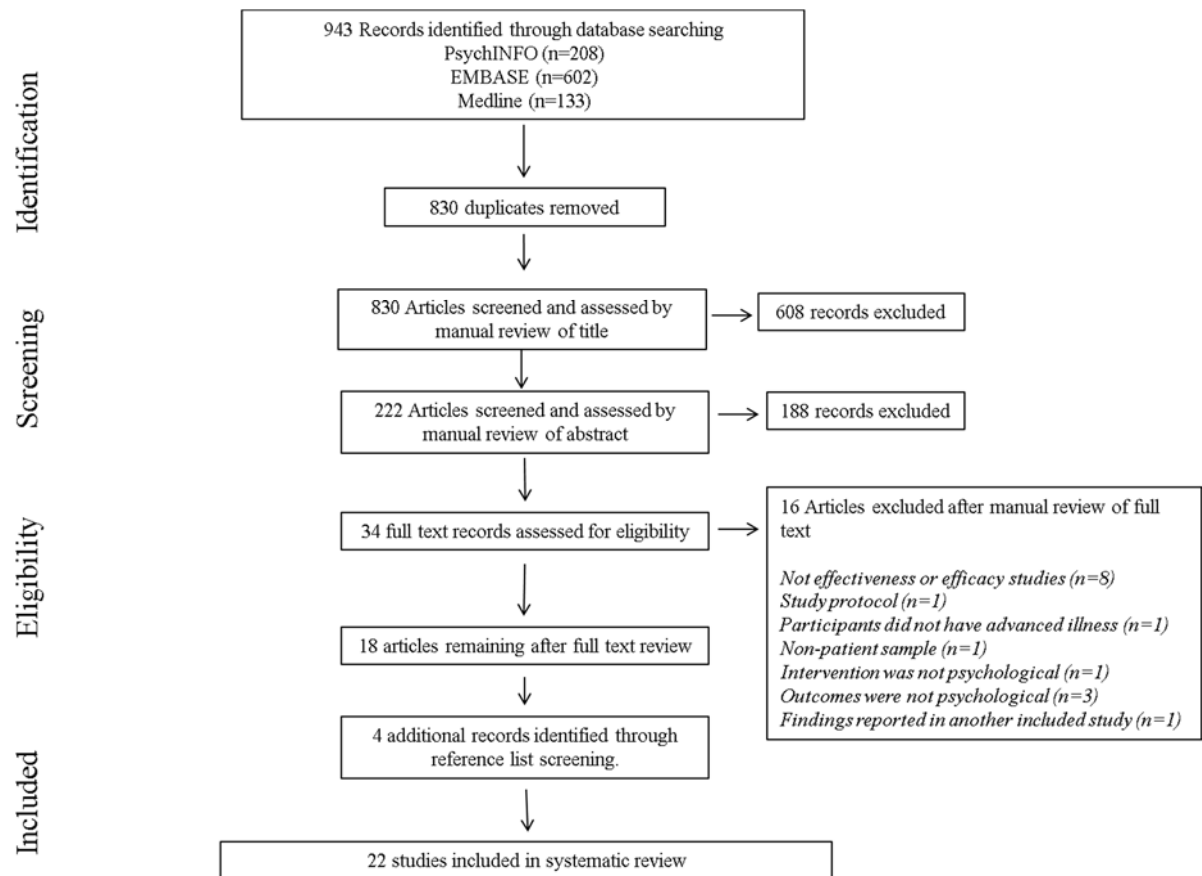


Figure 1. PRISMA flow diagram depicting the systematic review process

Table 4

Studies not included in the review with reasons for exclusion

Reason for exclusion	Study
Interventional studies which did not measure efficacy or effectiveness	Akechi et al. (2012) Cluver, Schuyler, Frueh, Brescia, and Arana (2005) Johns (2013) Lindqvist, Threlkeld, Street, and Tishelman (2015)
Qualitative studies	Chadwick, Newell, and Skinner (2008) Hall, Goddard, Martin, Opio, and Speck (2013) Lethborg, Schofield, and Kissane (2012) Nissim et al. (2012)
Study Protocol	Chambers et al. (2013)
Participants did not have advanced illness	Hall, Goddard, Opio, Speck, and Higginson (2012)
Non-patient sample	Kissane et al. (2006)
Intervention was not psychological	Tsang, Mok, Ching, and Lee (2012)
Outcomes were not psychological	Kwekkeboom et al. (2012) Ando, Tsuda, and Morita (2007) Mok, Lau, Lai, and Ching (2012)
Outcomes were reported in another included study.	Juliao, Barbosa, Oliveira, Nunes, and Vaz Carneiro (2013)

3.2 Description of Included Studies

Characteristics of the included studies are shown in Tables 5, 6 and 7.

3.2.1 Setting

The included studies were conducted across a range of countries including the United States of America (Breitbart, Rosenfeld, et al., 2010; Breitbart, Poppito, et al., 2012; Breitbart et al., 2015; Greer et al., 2012; Northouse et al., 2005), Canada (Henry et al., 2010; Lo et al.,

2014; McLean et al., 2008; McLean et al., 2013; Savard et al., 2006), the United Kingdom (Anderson et al., 2008; Galfin et al., 2011; Lloyd-Williams et al., 2013; Moorey et al., 2009), Australia (Chambers et al., 2012; Kissane et al., 2007), Denmark (Houmann et al., 2014), Hong Kong (Cheng et al., 2010), Japan (Ando et al., 2008) and Portugal (Juliao et al., 2014). Two studies were conducted across more than one international site, including the USA, Canada and Australia (Chochinov et al., 2005; Chochinov et al., 2011). Participants were recruited through a range of inpatient and outpatient settings, including hospices, palliative care units, oncology centres, general hospital clinics, day hospices and community care teams.

3.1.2 Participants

The average age of patients ranged from 48 to 81 years. In 16 studies (73%), a higher proportion of the overall participants were female. Four studies included only females and concerned patients with breast cancer (Kissane et al., 2007; Northouse et al., 2005; Savard et al., 2006) and ovarian cancer (Henry et al., 2010). One study included only male participants and concerned patients with prostate cancer (Chambers et al., 2012).

Aside from those stated above, most studies used participants with an advanced cancer diagnosis of various types (n=13, 59%). Five studies used mixed samples, whereby most participants had a cancer diagnosis but patients with non-malignant conditions receiving palliative care were also included (Anderson et al., 2008; Chochinov et al., 2011; Galfin et al., 2011; Houmann et al., 2014; Juliao et al., 2014). Typically, these included a small number of patients within the sample with diagnoses of advanced Motor Neurone Disease (MND) and/or Chronic Obstructive Pulmonary Disease (COPD).

3.1.3 Interventions

Narrative/Meaning-focused Interventions

Twelve studies used narrative or meaning-focused interventions. These interventions are derived from early existential theory, which establish existential distress as a significant component of quality of life (Frankl, 1961; Yalom, 1980). Combined with the principles of Narrative Therapy (Freedman & Combs, 1996; White, 1988, 2007), these approaches use storytelling or life review to enhance or create meaning for individuals who are nearing the end of life.

One such intervention is Dignity Therapy (DT). Developed to create a sense of dignity and well-being when death approaches, this brief, individualised intervention aims to address psychosocial and existential distress (Chochinov, 2002; Chochinov, Hack, Hassard, et al., 2002; Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Chochinov, 2004).

Four of the included studies evaluated the use of DT in individuals with life-threatening illness (Chochinov et al., 2005; Chochinov et al., 2011; Houmann et al., 2014; Juliao et al., 2014). These studies carried out the DT intervention according to the original protocol as described by Chochinov (2002). This encompasses a facilitated interview, which aims to orient the individual to a number of themes including *continuity of self, role preservation, maintenance of pride, and hopefulness*. The interview typically occurs over one or two sessions within one week and is followed by the production of an edited transcript of the interview (i.e., the *generativity* document). This is returned to the patient for them to share with individuals of their choosing.

Three studies reported that their interventions are based on DT, but utilised adaptations to the original protocol. Ando et al. (2008) evaluated the use of constructive life review interviews in Japan. Here patients reviewed their own childhood, adolescence, adult life, and current situation. Yet in a second part to the interview, patients were able to re-evaluate, re-construct and appreciate their life. A similar narrative intervention by Lloyd-Williams et al. (2013) is centred on a focused interview whereby the patient was encouraged to tell their story and prompted to discuss perspectives on their sense of meaning and their psychological, physical, social and spiritual wellbeing.

In another adaptation of DT, Cheng et al's (2010) evaluation of Anticipatory Grief Therapy (AGT), used a group format to deliver the intervention, as opposed to previous individualised approaches. This enabled the therapists to incorporate a number of experiential and expressive activities over the four sessions, alongside the life review (e.g., playing a symbolic game). These served to provide additional support and comfort.

Other group interventions included Meaning-Centred Group Psychotherapy (MCGP; Breitbart, 2001), which was evaluated by Breitbart, Rosenfeld, et al. (2010) and Breitbart et al. (2015). Grounded in Frankl's (1961) Logotherapy, which encourages reflection on *creative, experiential* and *attitudinal* values, MCGP uses didactics, discussion and experiential exercises across eight sessions. MCGP has also been adapted to an individual therapy, in the hope that missed sessions and attrition would reduce. Meaning-Centred Psychotherapy (MCP) as evaluated by Breitbart, Poppito, et al. (2012) uses the same psychotherapeutic techniques as MCGP but was conducted over seven, rather than eight, individual sessions.

Two further individualised interventions have been evaluated within the included studies. The Meaning Making Intervention (MMI; Henry et al., 2010), and the CALM

intervention (Managing CAncer and Living Meaningfully; Lo et al., 2014) appear to emphasise support and reflective space for the processing of thoughts in relation to both the practical and the existential questions that face individuals with advanced disease. Though similar in their theoretical stance, the MMI is a briefer intervention, with between one and four intervention sessions offered; the CALM intervention offered three to eight sessions.

Of all the included studies using narrative/meaning-focused interventions, the majority used healthcare professionals to conduct the interventions. These included Clinical Psychologists, Clinical Psychology Doctoral Trainees, Psychiatrists, Oncologists, Palliative Care Physicians, Social Workers, Specialist Nurses and Counsellors. All studies reported that those who delivered the intervention received specialised training and supervision. This was delivered by the Clinicians/Researchers who developed the intervention (e.g., Chochinov in the case of Dignity Therapy) or by Clinical Psychologists or Psychiatrists who themselves had received training in the intervention. Only one study reported that they used a researcher to deliver their intervention (Lloyd-Williams et al., 2013). The researcher's background was not stated and it was unclear whether this individual had received training in the intervention.

Cognitive Interventions

Six studies used cognitive interventions. Four of these were individualised Cognitive Behaviour Therapy (CBT) programmes incorporating traditional components of CBT, including problem definition, goal setting, structuring sessions, and use of collaborative empiricism, guided discovery and homework (Anderson et al., 2008; Greer et al., 2012; Moorey et al., 2009; Savard et al., 2006). As is standard in CBT, interventions were brief, ranging from four to eight individual sessions across the included studies.

Of these, two studies based their intervention on Moorey and Greer's (2002) CBT for cancer model, alongside other recommendations from the literature (Anderson et al., 2008; Moorey et al., 2009). This model proposes that the person's interpretations of their cancer will influence how they respond to it. Because cancer can threaten the fundamental assumptions of a person's life, these interpretations can become unhelpful.

Typically, the CBT programmes focused on helping patients manage cancer-related worries and progressive disability whilst developing optimistic but realistic attitudes to their illness and situation. Additional therapeutic exercises such as 'redefining life goals', were conducted alongside more traditional CBT exercises (e.g., psychoeducation, activity planning, identifying negative thoughts; Savard et al., 2006).

Most of the CBT interventions were either delivered and/or supervised by experienced Clinical Psychologists or Clinical Psychology Doctoral Trainees (Anderson et al., 2008; Greer et al., 2012; Savard et al., 2006). However, in the case of Moorey et al. (2009), Clinical Nurse Specialists (CNSs) received training in CBT and incorporated the skills as part of their established community palliative care service. The CNSs received their training and supervision from a Consultant Psychiatrist.

Another study evaluated an individual cognitive intervention, though this was not drawn from the exact same theoretical underpinnings as CBT. Galfin et al. (2011) conducted an evaluation of Concreteness Training (CT); an intervention based on models of emotional processing, whereby pathological rumination and worry is thought to be characterised by abstract thinking about unattained goals (Philippot, Schaefer, & Herbertte, 2003; Watkins, Moberly, & Moulds, 2008). As such, CT is derived from the premise that the negative effects

of abstract rumination can be reduced by training patients to think more concretely (Watkins et al., 2012).

This approach utilised face to face and audio instructions to facilitate repeated practice of mental imagery exercises aimed at helping patients think in a more concrete way about emotional events. The intervention as evaluated by Galfin et al. (2011) involved one initial 30 minute training session with a researcher, followed by 10 minutes of daily practice and weekly phone calls from the researcher for the subsequent four weeks.

The only group based cognitive intervention was a Mindfulness Based Cognitive Therapy (MBCT) programme, evaluated in men with advanced prostate cancer (Chambers et al., 2012). This followed a cancer-specific programme based on the manual by Segal, Williams, and Teasdale (2002) for MBCT, with novel specific components developed for men with advanced prostate cancer (e.g., ‘adjustment to progressive illness’, ‘treatment side effect bother’). The group ran for eight sessions and was led by Psychologists with experience in cancer services and professional training in MBCT.

Relational/Attachment-focused Interventions

Four studies used relational or attachment-focused interventions. Two of these were evaluations of Emotion Focused Therapy (EFT) for couples (McLean et al., 2008; McLean et al., 2013). EFT, which has been modified and manualised for advanced cancer (McLean et al., 2008), is based on the premise that the separation distress experienced by affected couples is related to insecure attachment bonds. Needs are therefore left unmet when rigid patterns of relating to one another restrict emotional engagement in this time of crisis.

Using a synthesis of experiential and systemic techniques, EFT aims to promote mutual understanding, repair emotional engagement and change habitual and distressing patterns of relating. In both evaluations of this intervention, couple dyads received eight sessions of EFT delivered by Psychologists and Doctoral Trainee Psychologists in Canada.

Another family intervention, evaluated by Northouse et al. (2005), recruited patient-caregiver dyads. However, this intervention, called the FOCUS programme, differed in its theoretical underpinnings to the EFT intervention. FOCUS is instead guided by the stress-appraisal model adapted from the work of Lazarus (1984, 2000). Here, stressors, which can include person, social and/or illness related factors, influence how people appraise and cope with their illness, which in turn affects their quality of life.

The FOCUS programme therefore provides psychoeducation and teaches the skills required to cope with the stressors encountered during terminal illness, with an emphasis on strengthening familial relationships. It covers five content areas; *Family involvement*, *Optimistic attitude*, *Coping effectiveness*, *Uncertainty reduction* and *Symptom management*, with each area forming the FOCUS acronym. The dyads in this programme were engaged with a therapist (a Nurse with Masters level training) for five contacts, three of which were face to face, with two over the telephone.

Finally, the Supportive Expressive Group Therapy programme evaluated by Kissane et al. (2007) was also considered to be a relational/attachment focused intervention because of its emphasis on improving relationships with family, friends and healthcare professionals. Nevertheless, this approach, which was originally developed by Spiegel and Spira (1991), is less structured than other interventions; an open group programme offered weekly sessions for one year or more, allowing members to create a new network of support and develop

coping skills. However, for the purpose of the evaluation reviewed here, Kissane et al. (2007) evaluated outcomes at 6-monthly intervals. Therapists were drawn from a range of healthcare professionals including Psychiatrists, Psychologists and Social Workers.

3.1.4 Study Design and Comparators

Of the studies included in the review, the majority were randomized controlled trials (RCTs) with one intervention group and one comparison group (n=13, 59%). However, one study used a 3-arm randomized controlled design with one intervention group and two comparison groups, one of which was treatment as usual (i.e., Treatment as usual). The other comparison group, 'client-centered care', consisted of a more supportive approach, engaging patients in discussions of 'here and now' issues (Chochinov et al., 2011).

In one RCT, undertaken by Moorey et al. (2009), Clinical Nurse Specialists were randomized to either receive training in CBT, or continue their usual clinical practice. Patient outcomes were therefore compared according to nurse allocation, as opposed to intervention allocation, as in the other RCTs.

Of the 2-arm RCTs, the majority offered treatment as usual to their control group, with no additional intervention (n=6, 46%). A further three of these studies (23%) used a wait-list control group whereby the study intervention was provided to their control group once the intervention group had completed the study (Galfin et al., 2011; Greer et al., 2012; Savard et al., 2006). Savard et al. (2006) also conducted a pre-post analysis of their pooled dataset once their original wait-list comparison group had received the intervention.

Of the studies offering alternative interventions to their comparator groups, two of these provided Supportive Group Psychotherapy (Breitbart, Rosenfeld, et al., 2010; Breitbart et al., 2015). This was described as a support group which was led by a therapist, focusing on

themes relating to the cancer diagnosis and treatment. Other studies offered physical relaxation based interventions to their control groups. Kissane et al. (2007) offered three sessions of progressive muscular relaxation and guided imagery. Breitbart, Poppito, et al. (2012) offered a course of therapeutic massage sessions with a licensed massage therapist.

The remaining studies were cohort studies, using one group of participants who received the same intervention, whereby pre-post analyses of outcome variables were undertaken (n=8, 36%).

3.1.5 Outcomes

Due to the heterogeneity in psychological outcome variables across the studies, these have been grouped into the following overarching constructs for the purpose of synthesizing study findings: *Anxiety and depression* and *demoralisation*.

Anxiety and Depression

The most commonly measured outcome was level of anxiety and/or depression. Twelve measures were used to assess this variable across the studies. Because many of the studies did not distinguish between anxiety and depression in reporting of their outcomes, these two constructs are reported together.

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used most frequently because of its suitability for use in physical health populations; 13 studies used this measure. Anxiety and depression was also measured by the Beck Depression Inventory (BDI; Beck, 1961), the Beck Depression Inventory Fast-Screen (BDI Fast-Screen; Beck, Guth, Steer & Ball, 1997), the Brief Edinburgh Screen for Depression (BEDS; Lloyd-Williams, Shiels & Dowrick, 2007), the Generalised Anxiety Disorder-7 (GAD-7; Spitzer,

Kroenke, Williams & Lowe, 2006), the Geriatric Depression Scale-Chinese Version (GDS-Chinese Version; Lee, Chiu, Kowk & Leung, 1993), the Hamilton Anxiety Rating Scale (HAM-A; Shear et al., 2001), the Hamilton Depression Rating Scale (HDRS; Williams, 1988), the Impact of Events Scale (IES; Horowitz, Wilner & Alvarez, 1979); the Impact of Events Scale-Revised (IES-R; Weiss & Marmar, 1997), the Memorial Anxiety Scale for Prostate Cancer (MAX-PC; Roth et al., 2003) and the Patient Health Questionnaire-9 (PHQ-9; Kroenke, Spitzer & Williams, 2001).

Demoralisation

Studies also measured distress that was specific to palliative care or end-of-life populations and included various aspects of demoralisation, as conceptualised by Kissane et al. (2001). Ten studies (45%) measured at least one aspect of demoralisation. This variable was assessed by the Beck Hopelessness Scale (BHS; Beck, Weissman, Lester & Trexler, 1974), the Hopelessness Assessment in Illness Questionnaire (HAI; Rosenfeld et al., 2011), the Death and Dying Distress Scale (DADDS; Lo et al., 2011), the Schedule of Attitudes Towards Hastened Death (SAHD; Rosenfeld et al., 1999) and the Structured Assessment for Symptoms and Concerns in Palliative Care. This includes the constructs of *dignity, desire for death, suffering, hopelessness, depression, suicidal ideation, sense of burden to others* and *sense of wellbeing* (SISC; Wilson et al., 2004). The construct of dignity was also measured separately, using the Patient Dignity Inventory (PDI; Chochinov et al., 2008). were used to measure this variable.

3.1.6 Quality Appraisal

The methodological quality of the included studies is summarised in Tables 5, 6 and 7 where a colour coding system is employed for clarity.

Overall Quality

The majority of studies were considered to be of moderate quality (n=15, 68%). Five studies (23%) were considered to be strong (Breitbart et al., 2015; Chochinov et al., 2011; McLean et al., 2013; Northouse et al., 2005; Savard et al., 2006) and two studies (9%) were assessed as weak (Anderson et al., 2008; Ando et al., 2008).

Selection bias

In five studies (23%), participants were considered to be likely to be representative of the target population given that recruitment took place across more than one site, through a number of recruitment methods including clinician referral. Eligibility criteria were considered to be flexible in these studies, meaning there was reduced potential for selection bias. Thus, these studies were assessed to be strong on this criterion (Breitbart et al., 2015; Chambers et al., 2012; Lloyd-Williams et al., 2013; Moorey et al., 2009; Savard et al., 2006).

Conversely, studies that were graded weak on this criterion (n=4, 18%) used participants who were carefully selected by the researchers. For example, Ando et al. (2008) stated that some participants were excluded because the intervention did not feel appropriate. Others report very strict eligibility criteria, which limit entry because of various sample characteristics (Anderson et al., 2008; Juliao et al., 2014; Lo et al., 2014).

The majority of studies were assessed to be moderate on this criterion (n=13, 59%). Whilst there was potential for selection bias, some effort had been made to ensure participants were representative of the target population (e.g., using more than one method of participant recruitment).

Study Design

Studies graded strong in study design (n=5, 23%) were those which used randomized controlled designs, where randomization procedures were described and considered appropriate. They also had larger samples (Breitbart, Poppito, et al., 2012; Breitbart et al., 2015; Chochinov et al., 2011; Kissane et al., 2007; Northouse et al., 2005). Studies graded weak in study design (n=5, 23%) were cohort studies using pre and post analysis with small sample sizes (Anderson et al., 2008; Ando et al., 2008; Chambers et al., 2012; Cheng et al., 2010; McLean et al., 2008). The majority of studies (n=12, 54%) were considered moderate in study design, and were RCTs with smaller samples or cohort studies using larger samples.

Confounders

Of the RCT's, studies were found to be strong if the authors reported that the groups were balanced at baseline with respect to confounding variables (e.g., demographic or illness-related factors (n=11, 79%). If they were not equal in this respect, these variables were controlled for in the analysis. Studies graded as moderate (n=2, 14%) reported that groups were equivalent on most, but not all of these variables (Henry et al., 2010; Savard et al., 2006). One study (7%) was graded as weak in this respect because the authors did not report statistical analysis of baseline demographic and illness-related variables (Breitbart, Poppito, et al., 2012).

Blinding

In many of the RCTs (n=6, 43%) it was not clear whether the outcome assessors were aware of the intervention status of participants. However, five studies (36%) were graded as

strong because procedures used to minimise detection bias are described (Chochinov et al., 2011; Greer et al., 2012; Henry et al., 2010; McLean et al., 2008; Savard et al., 2006). Studies were considered to be weak (n=2, 14%) or moderate (n=1, 7%) on this criterion because either no effort had been made to ensure outcome assessors were blind to allocation status (Galfin et al., 2011; Kissane et al., 2007) or only partial effort had been made (Juliao et al., 2014).

Data Collection Methods

All studies used at least one outcome measure that was shown to be reliable and valid; hence all studies were graded as strong on this criterion (n=22, 100%).

Withdrawals and Dropouts

Thirteen studies (59%) were considered to be strong on this criterion because numbers and reasons for participant withdrawal and/or non-completion of the intervention were clearly stated. Studies that report withdrawal and completion statistics, but do not report reasons for withdrawal or non-completion, were assessed as moderate (n=8, 36%). One study (5%) was graded weak on this criterion, because the authors did not explicitly state the number of participants that completed the intervention (Lloyd-Williams et al., 2013).

3.1.7 Effects of Interventions

Narrative/Meaning-focused Interventions

Anxiety and depression

Measures of anxiety and depression were used in 11 of the 12 studies evaluating narrative or meaning-focused interventions. Seven studies (64%) showed a statistically

significant intervention effect for levels of anxiety and depression. This effect was observed at post-intervention (Ando et al., 2008; Breitbart et al., 2015; Cheng et al., 2010; Juliao et al., 2014) at 4, 15 and 30-day follow up (Juliao et al., 2014), at 4-week follow up (Lloyd-Williams et al., 2013) and 2-month follow-up (Breitbart, Rosenfeld, et al., 2010; Breitbart et al., 2015). Lo et al. (2014) also reported a reduction in depressive symptoms over the course of their intervention. Study interventions include Short-term Life Review, Meaning-Centred Group Psychotherapy, Anticipatory Grief Therapy, Dignity Therapy, Narrative Interview and the MAnageing Cancer and Living Meaningfully (CALM) intervention . Studies were appraised as moderate (n=7) and strong (n=1) and weak (n=1) quality.

The remaining four studies (36%) reported no significant intervention effect for anxiety and depression. In a strong quality RCT, conducted across three international sites, Chochinov et al. (2011) found no significant effect for depression and anxiety between patients receiving Dignity Therapy, client-centred care or treatment as usual. Houmann et al. (2014) also reported no significant change in patients HADS scores following a Dignity Therapy intervention in Denmark.

The Meaning-focused Intervention, an individual programme, evaluated by Henry et al. (2010), also had no effect on HADS scores in comparison to the treatment as usual group. Breitbart, Poppito, et al. (2012) also found no significant difference in HADS ratings between participants who had received Individual Meaning-Centred Psychotherapy and those in the Therapeutic Massage control condition. This is despite a group format of the same intervention, Meaning-Centred Group Psychotherapy, generating significant reductions in anxiety, and depression, as written up in two of the included studies (Breitbart, Rosenfeld, et

al., 2010; Breitbart et al., 2015), respectively. The studies by Breitbart, Poppito, et al. (2012) and Henry et al. (2010) were both RCTs of moderate quality.

Demoralisation

Six of the 12 studies evaluating narrative/meaning-focused interventions, measured aspects of demoralisation. Of these, five studies (83%) reported a significant reduction in level of distress associated with advanced illness, as defined by the constructs of *death anxiety, desire for hastened death, dignity, feeling like a burden to others, and will to live*.

This effect was observed at post-intervention (Breitbart et al., 2015; Chochinov et al., 2005; Lo et al., 2014), 2-week follow up (Houmann et al., 2014) and 2-month follow up (Breitbart, Rosenfeld, et al., 2010). These studies were of moderate (n=4) and strong quality (n=1) and included evaluations of Meaning-Centred Group Psychotherapy, Dignity Therapy, and the individualised CALM intervention. However, one large study, of strong methodological quality, found no significant difference in SISC scores between participants who received Dignity Therapy, Client-centred care or Treatment as usual, at post-intervention or follow-up assessments (Chochinov et al., 2011).

Three studies, which evaluated narrative/meaning-focused interventions, also measured hopelessness. When using the BHS, no significant effect was observed between groups (Breitbart et al., 2010; 2012). However, in a later study, which used the HAI to measure this construct, a statistically significant reduction in scores was observed over time, between groups (Breitbart et al., 2015). This study was of strong methodological quality.

Cognitive Interventions

Anxiety and depression

All six studies evaluating cognitive interventions, assessed levels of anxiety and depression as measures of psychological distress. However, none of these studies measured aspects of demoralisation.

All studies (100%) demonstrated a statistically significant intervention effect for levels of depression and/or anxiety. These effects were observed at post-intervention (Anderson et al., 2008; Galfin et al., 2011; Greer et al., 2012; Savard et al., 2006), at 3-month follow-up (Chambers et al., 2012; Savard et al., 2006), 4-month follow-up (Moorey et al., 2009), and 6-month follow up (Savard et al., 2006).

These studies included evaluations of three individualised CBT interventions, one CBT skills training package delivered to Clinical Nurse Specialists, one Mindfulness Based Cognitive Therapy group programme and one Concreteness Training intervention. Study quality ranged from weak (n=1) to strong (n=1), with the majority appraised to be moderate (n=4).

Relational/Attachment-focused Interventions

Anxiety and depression

Three of the four studies evaluating relational/attachment focused interventions, measured levels of anxiety and depression. Results were mixed in relation to this outcome variable. Findings by the two studies evaluating Emotion Focused Therapy with couple dyads, are inconsistent. In a study of moderate quality, which utilised a pre-post cohort analytic

design, a significant reduction in BDI scores was observed from baseline to 3-month post-intervention (McLean et al., 2008). However, when the same intervention was compared to a ‘treatment as usual’ control group within a RCT of strong methodological quality, no significant effect was observed at any post-intervention assessment (McLean et al., 2013).

In an evaluation of a different intervention, Supportive Expressive Group Therapy, Kissane et al. (2007) reported that participants in the intervention group were more likely to remain ‘depression free’ at the first follow-up assessment (89%). This is compared to 70% of participants in the control group who received Relaxation Therapy (70%). However, comparison at later time points revealed that the effect was not maintained. This study was of moderate quality (Kissane et al., 2007).

Demoralisation

Three of the four studies evaluating relational/attachment focused interventions, also measured hopelessness. The two studies evaluating Emotion Focused Therapy reported no significant effect for the intervention on levels of hopelessness, as measured by the BHS (McLean et al., 2008; McLean et al., 2013).

Northouse et al. (2005) evaluated the family-based FOCUS programme and found a significant decrease in hopelessness scores on the BHS for those who had received the intervention, compared to those who received treatment as usual. Whilst this effect was observed at the 3-month follow-up assessment, it was not maintained at 6 months. This study was a large RCT of strong quality.

Table 5

Characteristics of included studies using Narrative/Meaning-focused Interventions (n=12).

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
Weak – W Moderate – M Strong - S Unclear- U							
Ando, Morita, Okamoto, and Ninosaka (2008) Overall: W Selection bias: W Study design: W Data Collection: S Withdrawals: M	Pre/post design. Palliative care units of general hospitals and home care clinic in Japan.	Cancer (various).	Total (n=30) Mean Age: 74 (SD=9.1) Range: not stated Male: 27% Female: 73%.	Short term life review. 2 life review sessions occurring over 1 week. Delivered by a Clinical Psychologist.	none	Depression and Anxiety; HADS. Baseline, Post-Intervention.	Depression and anxiety significantly decreased over time.
Breitbart, Rosenfeld, et al. (2010) Overall: M Selection bias: M Study design: M Confounders: S Blinding: U Data Collection: S Withdrawals: M	2 Group Pilot RCT. Outpatient clinics at US Hospital.	Cancer (various).	Intervention (n=49) Comparator (n=41) Total (n=90). Mean Age: 60.1 (SD=11.8) Range: 21-84. Male: 49% Female: 51%.	Meaning-Centred Group Psychotherapy (MCGP). 8 weekly group sessions. Groups led by Psychiatrist or Clinical Psychologist. Co-facilitated by Psychology Doctoral Trainee or other Psychologist.	Supportive Group Psychotherapy (SGP)	Depression and Anxiety; HADS. Hopelessness; BHS. Death Anxiety; SAHD. Baseline, Post-Intervention, 2-month follow up.	Significant reduction on anxiety scores in the MCGP group compared to the SGP group at 2-month follow-up No significant differences between groups on levels of hopelessness. Significant reduction on death anxiety scores in the MCGP group compared to the SGP group at 2-month follow up.

Table 5

Characteristics of included studies using Narrative/Meaning-focused Interventions (n=12).

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
<p>Weak – W</p> <p>Moderate – M</p> <p>Strong - S</p> <p>Unclear- U</p>							
Breitbart, Poppito, et al. (2012)	2 Group Pilot RCT.	Cancer (various).	Intervention (n=64) Comparator (n=56) Total (n=120).	Individual Meaning-Centred Psychotherapy (IMCP). 7 weekly individual sessions. Delivered by Clinical Psychologists or Clinical Psychology Doctoral Trainee's.	Therapeutic Massage (TM)	Depression and Anxiety; HADS. Hopelessness; BHS. Baseline, Post-Intervention, 2-month follow up.	No significant differences between groups in levels of depression or anxiety. No significant differences between groups in levels of hopelessness.
Overall: M	Outpatient clinics at US cancer centre.		Mean Age: 54.4 (SD=11.6) Range: 21-82. Male: 39% Female: 61%.				
Selection bias: M							
Study design: S							
Confounders: W							
Blinding: U							
Data Collection: S							
Withdrawals: M							

Table 5

Characteristics of included studies using Narrative/Meaning-focused Interventions (n=12).

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
Weak – W Moderate – M Strong - S Unclear- U							
Breitbart et al. (2015) Overall: S Selection bias: S Study design: S Confounders: S Blinding: U Data Collection: S Withdrawals: M	2 Group RCT. Outpatient clinics at US cancer centre.	Cancer (various).	Intervention (n=132) Comparator (n=121) Total (n=253). Mean Age: 58.2 (SD=11.0) Range: 27-91. Male: 30% Female: 70%.	Meaning-Centred Group Psychotherapy (MCGP). 8 weekly group sessions. Delivered by a Psychiatrist, Clinical Psychologist or Social Worker. Co-facilitated by 2 nd clinician or Clinical Psychology Doctoral Trainee.	Supportive Group Psychotherapy (SGP)	Depression and Anxiety; HADS, BDI. Hopelessness; HAI. Death Anxiety; SAHD. Baseline, Post-Intervention, 2-month follow up.	No significant differences between groups in levels of anxiety. Significant reduction on depression scores in the MCGP group compared to the SGP group over time (measured by BDI). Significant reduction on hopelessness scores in the MCGP group compared to the SGP group over time. Significant reduction on death anxiety scores in the MCGP group compared to the SGP group over time.
Cheng, Lo, Chan, and Woo (2010) Overall: M Selection bias: M Study design: W Data Collection: S Withdrawals: S	Pre/post design. Hospital day hospice and hospitals for the elderly in Hong Kong.	Cancer (various).	Total (n=29) Mean Age: 81.8 Range: 66-97. Male: 31% Female: 69%.	Anticipatory Grief Therapy (AGT). 4 weekly 90-minute group sessions. Facilitated by a Counsellor and Social Worker.	none	Depression; GDS-15. Baseline, Post-Intervention, 4-week follow up.	Significant improvements in depression scores were observed post-AGT.

Table 5

Characteristics of included studies using Narrative/Meaning-focused Interventions (n=12).

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
Weak – W							
Moderate – M							
Strong - S							
Unclear- U							
Chochinov et al. (2005)	Pre/post design.	Cancer (various).	Total (n=129)	Dignity Therapy.	none	Psychological Distress in Palliative Care; SISC.	Significant improvement over time was observed on constructs of <i>suffering</i> and <i>depressed mood</i> .
Overall: M	Hospital and community palliative care services in Australia and Canada.		Mean Age: 63.9 (SD=14.2) Range: 22-95. Male: 56% Female: 44%.	Brief individual time frames, acknowledging the patients' limited life expectancy. Approx. 2 sessions before creating a generativity document. Delivered by Psychiatrist, Psychologist and Palliative Care Nurses.		Baseline, Post-Intervention.	No significant change was observed on constructs of <i>dignity, hopelessness, desire for death, will to live</i> and <i>suicide</i> .
Selection bias: M							
Study design: M							
Data Collection: S							
Withdrawals: S							

Table 5

Characteristics of included studies using Narrative/Meaning-focused Interventions (n=12).

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
<p>Weak – W</p> <p>Moderate – M</p> <p>Strong - S</p> <p>Unclear- U</p>							
<p>Chochinov et al. (2011)</p> <p>Quality:</p> <p>Overall: S</p> <p>Selection bias: M</p> <p>Study design: S</p> <p>Confounders: S</p> <p>Blinding: S</p> <p>Data Collection: S</p> <p>Withdrawals: M</p>	<p>3 group RCT.</p> <p>Hospital, hospice or community palliative care services in Canada, USA and Australia.</p>	<p>Palliative care patients: Diagnoses of Cancer (n=429) and other non-malignant terminal illness, not specified (n=12).</p>	<p>Intervention (n=165)</p> <p>Comparator 1: (n=140)</p> <p>Comparator 2: (n=136)</p> <p>Total (n=441).</p> <p>Mean Age: 65.1 (SD=14.4)</p> <p>Range: 22-102</p> <p>Male: 49%</p> <p>Female: 51%.</p>	<p>Dignity Therapy.</p> <p>Brief individual time frames, acknowledging the patients' limited life expectancy. Approx. 2 sessions before creating a generativity document.</p> <p>Delivered by a Psychiatrist, Psychologist or Palliative Care Nurse.</p>	<p>Comparator 1: Treatment as usual.</p> <p>Comparator 2: Client-Centred care.</p>	<p>Depression and Anxiety; HADS, ESAS.</p> <p>Dignity Related Distress; PDI.</p> <p>Psychological Distress in Palliative Care; SISC.</p> <p>Baseline, Post-Intervention.</p>	<p>No significant differences observed between groups on levels of depression and anxiety.</p> <p>No significant differences between groups in levels of psychological distress in palliative care.</p> <p>No significant differences between groups in levels of dignity related distress.</p>

Table 5

Characteristics of included studies using Narrative/Meaning-focused Interventions (n=12).

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
<p>Weak – W</p> <p>Moderate – M</p> <p>Strong - S</p> <p>Unclear- U</p>							
<p>Henry et al. (2010)</p> <p>Overall: M</p> <p>Selection bias: M</p> <p>Study design: M</p> <p>Confounders: M</p> <p>Blinding: S</p> <p>Data Collection: S</p> <p>Withdrawals: S</p>	<p>2 Group Pilot RCT.</p> <p>University teaching hospitals in Canada.</p>	<p>Ovarian Cancer.</p>	<p>Intervention (n=15)</p> <p>Comparator (n=13)</p> <p>Total (n=28)</p> <p>Mean Age: 55 (SD=9.7)</p> <p>Range: not stated</p> <p>Female: 100%.</p>	<p>Meaning Making intervention (MMi).</p> <p>1-4 individual sessions.</p> <p>Delivered by a Psychologist.</p>	<p>Wait-list control.</p>	<p>Depression and Anxiety; HADS.</p> <p>Baseline, 1-month Post-Intervention, 3-month follow up.</p>	<p>There were no significant differences between groups on levels of depression or anxiety at post-intervention or follow-up.</p>

Table 5

Characteristics of included studies using Narrative/Meaning-focused Interventions (n=12).

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
Weak – W Moderate – M Strong - S Unclear- U							
Houmann, Chochinov, Kristjanson, Petersen, and Groenvold (2014) Overall: M Selection bias: M Study design: M Data Collection: S Withdrawals: M	Pre/post design. Palliative care services in Danish Hospice and Hospital.	Cancer (various).	Total (n=80). Mean Age: 65 (SD=12.5) Range: 23-94. Male: 37% Female: 63%.	Dignity Therapy (DT). Time allocated for intervention was tailored to accommodate the patients' health and estimated illness progression. Delivered by Psychologists.	none	Depression and Anxiety; HADS. Psychological Distress in Palliative Care; SISC. Dignity Related Distress; PDI. Baseline, Post-Intervention, 2 week follow-up.	There was no significant change in levels of depression or anxiety over time, as measured by the HADS. There was a significant improvement over time on the construct of <i>dignity</i> , as measured by the SISC. There was a significant increase in the construct of <i>depression</i> over time, as measured by the PDI. There was a significant improvement on the construct of <i>sense of burden to others</i> at 2-week follow up, as measured by the PDI.

Table 5

Characteristics of included studies using Narrative/Meaning-focused Interventions (n=12).

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; Timing of measurements	Psychological outcome findings
Weak – W							
Moderate – M							
Strong - S							
Unclear- U							
Juliao, Oliveira, Nunes, Vaz Carneiro, and Barbosa (2014) Overall: M Selection bias: W Study design: M Confounders: S Blinding: M Data Collection: S Withdrawals: S	2 Group RCT Palliative care inpatient unit in Portugal.	Palliative care patients: Diagnoses of cancer (n=74), Non-cancer diagnoses (n=6).	Intervention (n=39) Comparator (n=41) Total (n=80) Mean Age: 66.1 (SD=12.9) Range: 28-90. Male: 46% Female: 54%.	Dignity Therapy Brief individual time frames, acknowledging the patients limited life expectancy. Approx. 2 sessions before creating a generativity document. Delivered by a Palliative Medicine Physician.	Treatment as usual.	Depression and Anxiety; HADS. Baseline, 4-day follow up, 15-day follow up, 30-day follow up.	Compared to the control group, those receiving DT demonstrated significantly lower anxiety and depression ratings at all follow-up assessment periods.

Table 5

Characteristics of included studies using Narrative/Meaning-focused Interventions (n=12).

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
<p>Weak – W</p> <p>Moderate – M</p> <p>Strong - S</p> <p>Unclear- U</p>							
Lloyd-Williams, Cobb, O'Connor, Dunn, and Shields (2013)	2 Group Pilot RCT. Day hospice services in the UK.	Cancer (various).	Intervention (n=49) Comparator (n=51) Total (n=100). Median Age: 66 Range: 31-89. Male: 32% Female: 68%.	Narrative (meaning-focused) interview. Delivered by a Researcher. Researcher background not stated.	Treatment as usual.	Depression and Anxiety; BEDS, ESAS. Baseline, 2-week follow up, 4-week follow up.	At each follow-up assessment the intervention group demonstrated significant improvements in scores for depression and anxiety on the ESAS. The greatest improvements were observed at 4 week follow up.
Overall: M							
Selection bias: S Study design: M Confounders: S Blinding: U Data Collection: S Withdrawals: W							
Lo et al. (2014)	Pre/post design. Cancer Centre in Canada.	Cancer (various).	Total (n=50) Mean Age: 52 (SD=12) Range: not stated. Male: 24% Female: 76%.	CALM – Managing Cancer and Living Meaningfully. 3 – 8 individual sessions. Delivered by Social Workers, Psychiatrists and Oncologists.	none	Depression; PHQ-9. Death anxiety; DADDS. Baseline, Mid-way through intervention (3 months), Post-Intervention (6 months).	There was a statistically significant decrease in depressive symptoms over time. There was a statistically significant decrease in levels of death anxiety over time.
Overall: M							
Selection bias: W Study design: M Data Collection: S Withdrawals: S							

Table 5

Characteristics of included studies using Narrative/Meaning-focused Interventions (n=12).

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
Weak – W							
Moderate – M							
Strong - S							
Unclear- U							

Note. BEDS = Brief Edinburgh Scale for Depression; BHS = Beck Hopelessness Scale; DADDS = Death and Dying Distress Scale; ESAS = Edmonton Symptom Assessment Scale; GDS-15 = Geriatric Depression Scale-Chinese Version; GSES = General Self Efficacy Scale; HADS = Hospital Anxiety and Depression Scale; HAI = Hopelessness Assessment in Illness Questionnaire; PDI = Patient Dignity Inventory; PHQ-9 = Patient Health Questionnaire-9; SAHD = Schedule of Attitudes towards Hastened Death; SISC = Structured assessment for symptoms and concerns in palliative care. SD = Standard Deviation.

Table 6

Characteristics of Included Studies using Cognitive Interventions (n=6)

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
Weak – W Moderate – M Strong - S Unclear- U							
Anderson, Watson, and Davidson (2008) Overall: W Selection bias: W Study design: W Data Collection: S Withdrawals: S	Pre/post design. Northern Ireland Palliative care service.	Palliative care patients: Diagnoses of Cancer (n=10) and Motor Neurone Disease (n=1).	Total (n=13) Mean Age: 65. Range: 28-84. Male: 27% Female: 73%.	CBT 4 individual sessions. Duration of intervention ranged from 2-14 weeks. Delivered by a Specialist Registrar in Palliative Medicine. Supervised by a Clinical Psychologist.	None	Depression and Anxiety; HADS. Baseline, Post-Intervention.	9 of 11 patients showed significant improvements on levels of depression and anxiety.
Chambers, Foley, Galt, Ferguson, and Clutton (2012) Overall: M Selection bias: S Study design: W Data Collection: S Withdrawals: S	Pre/post design. Urban and regional cancer centres in Australia.	Prostate Cancer.	Total (n=19) Mean Age: 67 (SD=6.5). Range: 58-83. Male: 100%	Mindfulness Based Cognitive Therapy (MBCT) Groups. 8 weekly 2-hour group sessions. Delivered by Psychologists.	none	Depression and Anxiety; HADS, IES-R, MAX-PC. Baseline, Post-Intervention, 3-month follow up.	There was a significant reduction from baseline to 3-month follow up for anxiety (HADS) and avoidance (IES-R) after the MBCT intervention. There was no significant change in depression scores over time.

Table 6

Characteristics of Included Studies using Cognitive Interventions (n=6)

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
Weak – W							
Moderate – M							
Strong - S							
Unclear- U							
Galfin, Watkins, and Harlow (2011) Overall: M Selection bias: M Study design: M Confounders: S Blinding: W Data Collection: S Withdrawals: S	2 Group RCT. UK Hospice settings.	Palliative care patients: diagnoses of Cancer (n=31), Motor Neurone Disease (MND; n=2) and Chronic Obstructive Pulmonary Disease (COPD; n=1).	Intervention (n=19) Comparator (n=15) Total (n=34) Mean Age: 65. Range: 49-87. Male: 44% Female: 56%.	Concreteness Training. 4 week guided self-help intervention. Delivered by a Researcher. Researcher background not stated.	Wait-list control.	Depression and Anxiety; BDI-Fast Screen, GAD-7. Baseline, Post-Intervention.	Participants receiving concreteness training reported significantly greater reductions in anxiety than wait-list controls. No significant effect was found on depression.
Greer et al. (2012) Overall: M Selection bias: M Study design: M Confounders: S Blinding: S Data Collection: S Withdrawals: M	2 Group Pilot RCT. Cancer centre in US general hospital.	Cancer (various).	Intervention (n=20) Comparator (n=20) Total (n=40) Mean Age: 55.9 (SD=10.89) Range: 31-81. Male: 30% Female: 70%.	Cognitive Behaviour Therapy. 6-7 individual sessions. Delivered by Clinical Psychologists and Clinical Psychology Fellow's with at least 4 years' experience in CBT.	Wait-list control.	Depression and Anxiety; HADS, HAM-A, IES. Baseline, Post-Intervention.	At post-intervention, participants assigned to the CBT group had a 35% reduction in anxiety symptoms measured by the HAM-A, in contrast to an 11% reduction in the control group. Participants in the CBT group also reported greater reductions in anxiety symptoms at post-intervention, based on HADS and IES, compared to the control group.

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
Moorey et al. (2009)	2 Group Cluster RCT.	Cancer (various).	Intervention (n=45) Comparator (n=35) Total (n=80).	Clinical Nurse Specialists trained in Cognitive Behaviour Therapy - administered as part of usual home care consultation.	Treatment as usual.	Depression and Anxiety; HADS.	Patients in the CBT group had significantly lower anxiety scores over time compared to the control group.
Overall: M Selection bias: S Study design: M Confounders: S Blinding: U Data Collection: S Withdrawals: M	UK Palliative Care service.		Mean Age: 64 (SD=12.6) Range: not stated. Sex: not reported.	Supervised by a Consultant Psychiatrist/CBT Psychotherapist.		Baseline, 6-weeks, 10-weeks, 16-weeks.	

Table 6

Characteristics of Included Studies using Cognitive Interventions (n=6)

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
Weak – W							
Moderate – M							
Strong - S							
Unclear- U							
Savard et al. (2006) Overall: S Selection bias: S Study design: M Confounders: M Blinding: S Data Collection: S Withdrawals: S	2 Group RCT + pre/post analysis of pooled data set after control condition received intervention.	Breast cancer.	Intervention (n=25) Comparator (n=20) Total (n=45) Mean Age: 51 (SD=8) Range: not stated. Female: 100%.	Cognitive Therapy. 8 weekly sessions plus 3 booster sessions, timed at 3 weekly intervals following the intervention. Delivered by Psychologists.	Wait-list control.	Depression and Anxiety; HADS, BDI, HDRS. Baseline, Post-Intervention, 3-month follow up, 6-month follow up.	Participants in the intervention group had significantly lower scores on the HDRS than the control group at post-treatment. No significant differences between groups were observed on BDI or HADS. Pre/post analysis of pooled data demonstrated significant reductions in depressive symptoms and anxiety scores over time on all outcome measures. Significant effects were sustained at the 3 and 6 month follow up evaluations.

Note. BDI = Beck Depression Inventory; BDI-Fast Screen = Beck Depression Inventory-Fast Screen; GAD-7 = Generalised Anxiety Disorder-7; HADS = Hospital Anxiety and Depression Scale; HAM-A = Hamilton Anxiety Rating Scale; HDRS = Hamilton Depression Rating Scale; IES = Impact of Events Scale; IES-R = Revised Impact of Events Scale; MAX-PC = Memorial Anxiety Scale for Prostate Cancer. SD=Standard Deviation.

Table 7

Characteristics of Included Studies using Relational/Attachment-focused Interventions (n=4)

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
Weak – W Moderate – M Strong - S Unclear- U							
Kissane et al. (2007) Overall: M Selection bias: M Study design: S Confounders: S Blinding: W Data Collection: S Withdrawals: S	2 Group RCT. Hospitals in Australia.	Breast cancer.	Intervention (n=147) Comparator (n=80) Total (n=227). Mean Age: 51 (SD=9) Range: 25-69. Female: 100%.	Supportive-expressive Group Therapy (SEGT) Weekly 90-minute group sessions for one year or more. Delivered by Psychiatrists, Psychologists and Social Workers.	Relaxation Therapy.	Depression; MILP. Psychological Distress; IES. Baseline, 6-months, 12-months, 18-months, 24-months.	Participants in the SEGT group were significantly more likely to remain 'depression free' at the first follow up than those in the comparator group. Comparison at later follow-ups show that the effect was not maintained over time. For those with a baseline diagnosis of depression, there was a significant improvement in the SEFT group, in intrusive thoughts as measured by the IES.
Northouse, Kershaw, Mood, and Schafenacker (2005) Overall: S Selection bias: S Study design: S Confounders: S Blinding: U Data Collection: S Withdrawals: S	2 Group RCT. Oncology Centre's in USA.	Breast Cancer.	Intervention (n=94) Comparator (n=88) Total (n=182). Mean Age: 54 (SD=11) Range: 22-86. Female: 100%.	Family-based FOCUS intervention. 5 contacts (3 face to face and 2 telephone follow ups). Delivered by a Nurse with Masters level training.	Treatment as usual.	Hopelessness, BHS. Baseline, 3-months (after initial phase of intervention), 6-months (after completion of the intervention).	Participants who received the family intervention reported a significant decrease in their appraisal of illness and hopelessness scores from baseline to 3 months. These differences were not sustained at 6 months.

Table 7

Characteristics of Included Studies using Relational/Attachment-focused Interventions (n=4)

Reference and Quality Rating	Study design/ setting	Diagnosis	Sample	Psychological intervention	Comparator	Psychological outcomes; measures. Timing of measurements	Psychological outcome findings
Weak – W Moderate – M Strong - S Unclear- U							
McLean et al. (2008)	Pre/post design.	Cancer (various).	Total couples (n=16).	Emotionally focused couple therapy.	none	Depression; BDI. Hopelessness, BHI.	There was a significant reduction in BDI scores from baseline to 3 months' post-intervention in all participants.
Overall: M Selection bias: M Study design: W Data Collection: S Withdrawals: S	Cancer Centre in Canada.		Mean Age (patient): 48.1 (SD=11.65) Range: 30-69. Male: 44% Female: 56% (patient).	8 – 20 sessions with couple dyads. Delivered by Psychologists and a Doctoral Student.		Baseline, After 4 sessions of therapy, After 8 sessions of therapy, 3-month follow up.	There was no statistically significant change in BHS scores over time.
McLean, Walton, Rodin, Esplen, and Jones (2013)	2 Group RCT.	Cancer (various).	Intervention (n=42) Comparator (n=20) Total (n=42)	Emotionally focused couple therapy. 8 sessions occurring with couple dyads.	Treatment as usual.	Depression; BDI. Hopelessness, BHI.	There was no significant difference between EFT group and treatment as usual group on depression scores at post-intervention or follow up.
Overall: S Selection bias: M Study design: M Confounders: S Blinding: S Data Collection: S Withdrawals: S	Cancer Centre in Canada.		Mean Age (patient): 50.64 (SD=10.76) Range: not stated. Male: 45% Female: 55% (patient).	Delivered by a Psychologist.		Baseline, Post-Intervention, 3-month follow up.	There was no significant difference between groups on hopelessness scores at post-intervention or follow up.

Note. BDI = Beck Depression Inventory; BHS = Beck Hopelessness Scale; IES = Impact of Events Scale; MILP = Monash Interview for Liaison Psychiatry. SD=Standard Deviation.

4.0 Discussion

This review aimed to evaluate the effectiveness of psychological interventions in reducing psychological distress in patients with advanced cancer. The findings of the review are summarised below with recommendations for further research and clinical practice.

4.1 Narrative/meaning making interventions

The majority of studies which evaluated narrative or meaning-focused interventions, reported a significant effect for psychological distress, including outcomes related to depression, anxiety and demoralisation. However, due to the heterogeneity of interventions described within this category, it is difficult to draw conclusions about which specific intervention is the most effective. The most common intervention to be evaluated was that of dignity therapy (DT) or tailor-made interventions that were theoretically underpinned by DT (e.g., Anticipatory Grief Therapy, Short-term life review, and Narrative Interview).

In consideration of the findings from dignity therapy-based studies, the evidence is mixed. Whilst many cohort studies using only pre and post analysis were able to demonstrate a significant reduction in psychological distress following DT, studies that used a control group failed to generate significant differences. For instance, when DT was compared to treatment-as-usual and client-centred care in a large RCT of strong methodological quality (Chochinov et al., 2011), no significant effects were observed. Therefore, until further trials of this nature are reported, it isn't possible to conclude that DT is effective in reducing psychological distress for those with advanced illness.

This conclusion is in line with a recent review of DT-only interventions which suggested that it is not yet possible to say whether DT is efficacious (Fitchett, Emanuel, Handzo, Boyken, & Wilkie, 2015). However, this review also considered a broader range of

outcomes than just psychological distress and found that in a small number of trials that also explored satisfaction with DT, participants who received DT reported increased meaning in life, quality of life and spiritual well-being following the intervention (Fitchett et al., 2015). This implies that DT interventions may be more effective in reducing other aspects of *total pain* in advanced disease. Specifically, elements of spiritual wellbeing are likely to be promoted by the DT intervention, which includes spiritual as well as psychosocial elements.

Aside from dignity-based therapies, the current review highlights evidence that the meaning-based therapies, ‘CALM’ and ‘Meaning-Centred Group Psychotherapy’ (MCGP), are effective in reducing psychological distress in patients with advanced cancer. Two studies evaluated MCGP, one of which was a strong quality, large RCT (Breitbart et al., 2015). Given that this intervention was compared with supportive group psychotherapy in both trials, it suggests that something over and above group support is acting as an effective mechanism for change. However, an individual format of the same intervention, Individual Meaning-Centred Psychotherapy, did not yield significant reductions in outcomes relating to psychological distress (Breitbart, Poppito, et al., 2012).

The differences between the two formats may therefore reflect unique benefits of a group-based interventions in advanced cancer populations. Another group-based intervention, Anticipatory Grief Therapy, also yielded significant reductions in psychological distress over time (Cheng et al., 2010). However, a lack of control group in this study and the absence of further studies of group-based interventions in this category, means that again, it is difficult to draw any firm conclusions at this stage.

4.2 Cognitive Interventions

Six studies evaluated cognitive interventions and all reported significant reductions in anxiety and/or depression. Because none of these studies measured outcomes related to demoralisation, conclusions about a broader range of psychological distress in advanced cancer, cannot be drawn.

Individual, manualised CBT was most commonly evaluated. However, study quality was variable, and certain study characteristics mean that firm conclusions about effectiveness cannot be drawn. For instance, two of the three studies were RCTs, yet within these, the intervention was compared to a wait-list control and was therefore unable to control for non-specific therapeutic effects (Greer et al., 2012; Savard et al., 2006).

Other cognitive interventions effective in reducing anxiety and/or depression were concreteness training, mindfulness-based cognitive therapy and a CBT skills training programme for Clinical Nurse Specialists. However, because only one of each type of intervention has been evaluated, further trials are needed before conclusions can be made.

4.3 Relational/Attachment-focused interventions

Four studies evaluated three different relational or attachment-focused interventions. Only Supportive Expressive Group Therapy (SEGT), as evaluated by Kissane et al. (2007) was observed to be effective in reducing psychological distress. Where other interventions did produce significant effects, these were not maintained over time.

SEGT was observed to both ameliorate existing cases and prevent new cases of major depression in women with metastatic breast cancer. However, because of the specific sample, these findings are unlikely to generalise to men or patients with other forms of cancer. Furthermore, the control condition in this study consisted of a 3-session relaxation therapy

intervention, with little opportunity for patients to develop a relationship with the therapist. The study is therefore limited by its inability to demonstrate that findings are due to non-specific intervention effects.

It is noted that SEGT is a group intervention; like other meaning-focused or cognitive group interventions that were found to be effective, it may be the group format, rather than specific interventional components, which acts as the therapeutic driver for change. Benefits of group interventions are thought to relate to the participants' sense of sharing a common experience and identity, and associated feelings of universality. Furthermore, feelings of hopefulness are likely to be fostered by viewing how group members have coped successfully, thus enhancing a group effectiveness in reducing distress (Breitbart, Chochinov, & Alici, 2012).

4.4 Overall

Overall 15 different psychological interventions were reviewed within 22 studies. Cognitive-behavioural interventions were most consistently reported to be effective in reducing psychological distress. This is in line with the findings from previous reviews (e.g., Akechi et al., 2008; Uitterhoeve et al., 2004). However, research in this area remains sparse; within the last decade, only six empirical studies of cognitive interventions in advanced cancer could be identified. Therefore evidence is still limited owing to a lack of large, strong quality trials to draw conclusions from.

It appears that in recent years focus has turned towards interventions based on meaning and dignity. A total of 13 studies evaluating these interventions were identified. Many of these were observed to be effective in reducing psychological distress. Specifically, Meaning-Centred Group Psychotherapy is the most promising intervention. Due to the

heterogeneity of interventions within this category, findings for other interventions need to be replicated before conclusions about their effectiveness can be made.

4.5 Is the evidence in line with clinical recommendations?

This review also aimed to clarify whether the existing evidence reflects what is recommended for UK clinical practice. The NICE guidelines outline that only specialised mental health professionals should deliver Level 4 psychological interventions such as CBT (NICE, 2004). Within the studies that have been evaluated, the majority utilised Clinical Psychologists or Psychiatrists to lead the intervention with the support of Trainee Clinical Psychologists or other healthcare professionals as co-facilitators. This suggests that research interventions are being delivered in line with current recommendations for clinical practice.

Where Level 4 professionals did not directly deliver an intervention, they provided training and supervision for Level-2 or Level-3 professionals in their delivery of a less formal approach. For instance, in the evaluation of a CBT skills training package for Clinical Nurse Specialists, supervision was offered by a Consultant Psychiatrist (Moorey et al., 2009). This study successfully demonstrated that nurses can learn to integrate CBT techniques into their clinical practice, with associated positive outcomes for patients. Thus, these findings would support the use of clinical practice in line with the NICE four-tier model.

Furthermore, this review found that interventions varied significantly in their duration and intensity, with some models requiring just one therapeutic session with a patient, whereas others continued to offer weekly sessions for one year or more. Such variation between interventions appears to reflect a stepped-care approach to psychological care, whereby different types and levels of care are provided according to patient need and staff training and skills, rather than a 'one size fits all' approach.

Nevertheless, the evidence reviewed here does not necessarily offer insight into which interventions are being used with patients in routine clinical practice. Indeed, Moyer, Sohl, Knapp-Oliver, and Schneider (2009) claim that empirical evidence contrasts with the services available to cancer patients. Moreover, whilst an intervention might be found to be effective in reducing psychological distress, that is not to say that the intervention is *acceptable* to those who use it.

For instance, whilst the Meaning-Centred Group Psychotherapy intervention was able to generate significant reductions in psychological distress, there are significantly large rates of attrition associated with the intervention (Breitbart, Rosenfeld, et al., 2010). It is felt that this may reflect the demanding and inflexible nature of the group format, leading patients to drop out early (Breitbart & Applebaum, 2011). Indeed, it is a well-known issue in cancer and palliative care research, that more complex interventions are not always feasible to implement in patients with advanced disease (White, Hardy, Gilshenan, Charles, & Pinkerton, 2008).

It was beyond the scope of the current review to investigate the acceptability of the interventions to patients. However, when considering whether to implement an intervention into clinical services, service managers should look towards a wider range of research, including empirical studies, qualitative studies and service evaluations. The aim is to clarify both the effectiveness and acceptability of psychological interventions in everyday clinical care.

4.6 Recommendations for clinical practice

In line with NICE four-tier model, assessment of psychological need should be routinely offered to all patients as part of supportive and palliative care services (NICE, 2004). In accordance with the findings of the current review, where psychological needs are

identified during assessment, patients should be offered empirically evaluated interventions in accordance with their level of individual need. Formal psychological interventions should be offered where patients are identified as suffering from significant psychological distress (Levels 3 & 4) and specialist psychological interventions should be provided by Level-4 professionals, including Clinical Psychologists and Psychiatrists.

Level-4 professionals should also aim to train and supervise level 1 & 2 professionals, enabling them to provide psychological support and information to patients. Finally, continued audit and evaluation of psychological intervention should be undertaken. Findings should be disseminated widely to inform evidence of acceptability and effectiveness of interventions in clinical practice.

4.7 Limitations

In keeping with the recommendations from Ellwood, Carlson, and Bultz (2001), this review only included quantitative studies to ensure that only empirically supported treatment was being evaluated. However, whilst both cohort studies and RCTs were included to ensure a comprehensive overview of all psychological interventions was offered, the use of non-RCTs increases the variability in study quality.

The methodological quality of the studies was assessed using the Quality Assessment Tool for Quantitative Studies (Thomas et al., 2004). Nevertheless, to ensure a wide coverage of psychological interventions was captured, all studies were included in the review regardless of their quality rating. Inevitably this means that weaknesses in study methodology limit the conclusions that can be drawn.

Further limitations include lack of cultural diversity represented in the studies, with the majority conducted in Western nations and only two conducted in Japan and China.

Women are also over-represented in the studies, with the majority reporting a higher ratio of female to male participants. It is noted therefore that conclusions about the effectiveness of studies may have differed had the current review considered the evidence in accordance with the gender of participants.

4.8 Conclusion

This review has found evidence that psychological interventions are effective in advanced cancer populations. Meaning-Centred Group Psychotherapy and Cognitive-Behavioural Therapy demonstrated the most potential to reduce psychological distress. Other therapeutic modalities also showed promising findings but until further good quality randomised controlled trials are carried out, conclusions about efficacy can not be made.

The variability in empirically evaluated interventions supports the operationalisation of psychological care as outlined in the UK NICE guidelines (2004), whereby different levels of intervention are offered according to patient need. Further effectiveness and acceptability studies will ensure that psychological interventions are feasible to implement in clinical practice.

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Empirical Research Paper

'Oh, you're part of the human gang too':

The experience of Schwartz Center Rounds[®]; an initiative to promote compassionate healthcare.

Abstract

Background: Schwartz Center Rounds[®] were introduced to UK health services as an initiative to facilitate and promote compassionate care. Existing literature suggests that they are valued amongst those who use them and that they foster communication, reflection, teamwork and understanding of the social and emotional aspects of care. However, little is known about the psychological mechanisms which work to bring about these changes.

Aims: To explore how hospice staff experience Schwartz Center Rounds[®], paying particular attention to underlying mechanisms which may facilitate compassion in healthcare.

Methods: Eight semi-structured interviews were conducted with clinical and non-clinical hospice staff. Interview data was analysed using Interpretative Phenomenological Analysis.

Results: Three super-ordinate themes emerged from the data, 'Becoming Integrated', 'Becoming Visible' and 'Letting Go'. Schwartz Center Rounds[®] were experienced as space to become integrated within the organisation, to become visible amongst colleagues and to achieve compassionate acceptance towards oneself and others. Facilitators play a central role in containing anxiety and giving permission to share. Finally, self-critical perceptions of self-compassion are likely to impact on inpatient nursing staff's engagement with initiatives such as Schwartz Center Rounds[®].

Keywords: Schwartz Center Rounds[®], Schwartz Rounds, compassion, palliative care, qualitative.

1.0 Introduction

1.1 The climate for compassionate care

Within the UK health services there is a current drive towards compassionate care (Care Quality Commission, 2011; Crawford, Gilbert, Gilbert, Gale, & Harvey, 2013; Gilbert, 2009; Royal College of Nursing, 2012). This appears to have been driven by a succession of failures in the delivery of safe and effective care, recently highlighted in the British media. For example, the cases of abuse at Winterbourne View and Mid-Staffordshire National Health Service (NHS) Foundation Trust, have been well publicised.

The Francis Report, written following the mid-Staffordshire NHS scandal, highlighted that one of the key failures in this case was a lack of compassion embedded within the organisation and its workforce (Francis, 2013). Given the large body of evidence supporting the view that compassionate healthcare is essential for patient recovery and satisfaction (e.g., Matthews, Suchman, & Branch, 1993; Sanghavi, 2006), this finding is unsurprising. It seems that without a compassionate approach to care, patients are at high risk of poor outcomes, including negligence and death.

Following the publication of the Francis Report, there have been renewed attempts to conceptualise compassion as applied to healthcare. For instance, Cole-King and Gilbert (2011) published an article in which the 'Compassionate Mind' model (Gilbert, 2009), is applied within such a context. This proposes that to be skilled in the use of compassion, one must understand and interact with the minds of others. In order to do this, the key attributes of *empathy, non-judgment, distress tolerance, sympathy, sensitivity* and *motivation* are required (Gilbert, 2009).

The ‘Values Based Recruitment’ framework proposed by Health Education England (2014), suggests that training providers attract and recruit “students and employees on the basis that their values align with those of the NHS Constitution” (p.4.). This therefore assumes that the qualities of compassion, as conceptualised by Gilbert (2009), are traits that are either present or absent in the individual. However, this view contrasts with findings that healthcare professionals commence their training with many compassionate qualities but that this reduces significantly either during the course of training or soon after qualifying (e.g., Maben, Latter, & Macleod Clark, 2007).

Inferred from this therefore, is the notion that the compassionate qualities which healthcare professionals possess when they start out in their careers, require careful nurturing to allow them to be maintained. Given the high levels of stress, burnout and depression in healthcare workers (Guveli et al., 2015; Tucker, Weymiller, Cutshall, Rhudy, & Lohse, 2012; Vijendren, Yung, & Sanchez, 2015), the case for increased use of self-care is clear (Mills, Wand, & Fraser, 2015).

One central aspect of self-care is the ability to use *self-compassion*. Conceptualised as self-kindness, mindfulness and common humanity (Neff, 2003), or more simply, “giving the same kindness to ourselves that we would give to others” (Germer, 2009, p. 33.), self-compassion is considered equally as important as compassion for others. Indeed, the link between self-compassion and compassionate care for patients is well established (e.g., Heffernan, Quinn Griffin, McNulty, & Fitzpatrick, 2010; Şenyuva, Kaya, Işık, & Bodur, 2014).

Despite the clear need for healthcare professionals to nurture their compassion skills, starting with compassion for themselves, the organisation which they work for will

undoubtedly influence their ability to do so. Essentially, where organisations are willing to foster the compassionate qualities of their employees, compassionate healthcare is much more likely to be practiced with patients (Crawford, Brown, Kvangarsnes, & Gilbert, 2014).

However, in today's healthcare climate, this is easier said than done. In an argument offered in response to the Francis report, Evans (2014) proposes that there has been an erosion of systems/roles within the UK health service. Such erosion of roles which would ordinarily help contain primitive anxieties (illness, death, fragmentation), together with increased anxiety about targets and an organisation's survival, has led to a persecutory environment where anxiety and blame are commonplace. Clinical staff have to deal with these anxieties with little support, acknowledgement and containment. When undigested, these anxieties may be acted out with patients (Evans, 2014), and the desire to express empathy is likely to be reduced (Shapiro, 2008).

In response to this, organisations are now looking to adopt initiatives which can offer staff a space to discuss their work-related problems and feelings. Ideally, such initiatives would allow self-care practices to become visible, so that a culture of self-compassion and compassion to others is modelled within the whole organisation. Should this be achieved, the potential for the mindlessness and detachment which has previously characterised staff/patient interaction, would be greatly reduced (Garner, 2014).

1.2 Schwartz Center Rounds[®]

One recent and favourable initiative is that of the Schwartz Center Rounds[®] (referred to as *Schwartz Rounds* or *Rounds* hereafter). Schwartz Rounds are based on the theoretical understanding that to be able to provide compassionate care to patients, staff must, in turn, feel supported in their work. Described as a forum for staff to come together, their aim is to

promote discussion and reflection on the non-clinical aspect of caring for patients, including the emotional and social challenges associated with their jobs (Goodrich, 2012).

Following his own experience of treatment for terminal cancer, Kenneth Schwartz set up 'The Schwartz Center' in the US in the late 1990's. Soon after, Schwartz Rounds were created. Following the publication of the Francis Report, there has been a drive to establish Rounds in UK hospitals and hospices. Indeed, their popularity has risen since the Point of Care Foundation received funding in 2013 to develop their infrastructure in the UK.

Lasting one hour and occurring once a month, Schwartz Rounds are typically facilitated by a Senior Doctor, Clinical Psychologist or other psychosocial practitioner. Each Round begins with a series of short presentations from a panel of up to four people, addressing a particular clinical case, scenario or theme. Following this, discussion is opened up to the audience, made up of all members of the organisation (including non-clinical staff).

The first pilot evaluation of Schwartz Rounds in two UK hospitals was conducted by the Point of Care Programme at the Kings Fund (Goodrich, 2012). These findings were consistent with those of previous US studies, such that Schwartz rounds are successful in fostering interdisciplinary communication, reflection, teamwork and support by enhancing a shared purpose and connection in the care of patients (Lown & Manning, 2010; Moore & McCole Phillips, 2009). Additionally, attendees also reported increased confidence in their ability to engage with patients in relation to the social and emotional aspects of care, thus implying that the Rounds *do* have the potential to promote compassionate patient care (Goodrich, 2012).

Further evaluation of the Rounds was also recently undertaken at a UK hospice (Reed, Cullen, Gannon, Knight, & Todd, 2015). Findings of the mixed methods study were

promising with 78% of respondents rating the Rounds as excellent or exceptional. The qualitative component of the study, whereby transcripts of focus groups were analysed thematically, alludes to some of the underlying processes by which the Rounds are thought to generate more compassion-focused practice.

Specifically, witnessing presenters' vulnerability enabled attendees to see colleagues at a 'human level', which was felt to relate to a positive shift in the understanding of these individuals and where they sit in the organisation. In addition, the attendees' experience often resonated with that of the presenters, promoting connectedness between the workforce (Reed et al., 2015).

The findings of these studies are indeed promising and indicate that the Rounds are valued on both an individual and organisational level. To gain a more in-depth understanding of the processes that occur during or after a Schwartz Round and explore how these might, in turn, promote compassionate healthcare, a deeper level of analysis is required. Exploration of the direct *experience* of the Rounds amongst their attendees is one opportunity to facilitate this.

Interpretative Phenomenological Analysis (IPA) is the most equipped method of achieving this, through its inherent idiographic and exploratory research process (Smith, Flowers, & Larkin, 2009). Given the potential for Schwartz Rounds to have a positive impact on staff on many levels, it is of key interest to also explore them further in this way.

1.3 Aims

The aim of the study was to explore how hospice staff experience Schwartz Rounds, paying particular attention to underlying mechanisms which may facilitate compassion in healthcare

2.0 Methodology

2.1 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is concerned with the *lived experience* (phenomenology) of the participants - that is, their unique subjective life-world (Smith & Osborn, 2003). Adopting a double hermeneutic stance, the activity of the researcher is to *interpret* and make sense of the participants' attempts to make sense of their own experience (Smith & Osborn, 2003; Smith et al., 2009).

The inductive, yet interrogative nature of IPA aims to contribute to and build on existing psychological research, whilst there is no attempt to test out previously established hypotheses (Smith, 2003). This lends itself well to the context of the present study, where IPA would enable the researcher to generate and engage with the meaning and centrality of participants' subjective experiences of attending a Schwartz Round.

2.2 Design

A small, homogeneous sample of participants was recruited by purposive sampling in accordance with IPA methodology (Smith & Osborn, 2003). Semi-structured interviews were conducted and audio-recorded. Recordings were transcribed verbatim and then analysed using IPA (Smith et al., 2009).

2.2.1 Recruitment

Participants were recruited from Marie Curie Hospice in the West Midlands. Poster, flyer and email advertising was used to generate interest in the study. Interested participants

gave the researcher permission to contact them directly to discuss the research further and arrange interviews if appropriate.

2.2.2 Eligibility Criteria

Participants were included if they were aged over 16 years and were paid or voluntary employees of the hospice. Those working in clinical roles (e.g., doctors, nurses and allied health professionals) and non-clinical roles (e.g., porters, catering staff and administrators), were included, given that *everyone* within the organisation is invited to attend Schwartz Rounds.

Participants' were required to have attended and/or presented at, at least one Round within the previous six months. This cut-off was established to ensure that participants were still able to recall the thoughts and feelings elicited by the Schwartz Round. Participants were required to be English speaking due to the inherent nature of IPA to draw on the use of language in providing a rich account of their experiences.

2.2.3 The sample

In line with the recommended sample of an IPA research study, a total of eight participants were recruited and interviewed (Smith et al., 2009). Details of the participants are outlined in Table 8. Of the eight participants, one was male and seven were female. Of the six clinical staff recruited, the disciplines of medicine, nursing and other allied health professionals were represented. Two participants were non-clinical employees. Gender neutral pseudonyms have been attributed to the participants to protect confidentiality and anonymity. Quotes have also been anonymised in some cases, to ensure anonymity is maintained at all time.

Table 8

Participant Information

Participant / Age range	Type of professional (i.e., clinical or non-clinical)	Years worked in palliative care (including experience outside of the hospice)	Role within a Schwartz Round
Alex / 50 – 60 yrs	Clinical	15 years	Attendee and Presenter
Sam / 50 – 60 yrs	Clinical	3 years	Attendee and Presenter
Frankie / 60 – 70 yrs	Clinical	15 years	Attendee and Presenter
Jessie / 40 – 50 yrs	Clinical	11 years	Attendee and Presenter
Georgie / 40 – 50 yrs	Clinical	1 year	Attendee
Pat / 40 – 50 yrs	Non-clinical	2 years	Attendee and Presenter
Kris / 40 – 50 yrs	Non-clinical	19 years	Attendee and Presenter
Nicky / 30 – 40 yrs	Clinical	4 years	Attendee

2.3 Ethical Considerations

Sponsorship and ethical approval was granted by the University of Birmingham (see Appendix 3 and 4). NHS research and development approval was also granted from the Heart of England NHS Foundation Trust, as some of the staff based within the hospice were employed by this trust. Additionally, research and development approval was given by Marie Curie Hospice West Midlands (see Appendix 5 and 6).

Standard research procedures were followed to ensure the research was conducted ethically, including giving participant information, taking informed consent and offering a debrief (see Appendices 7 – 10). Participants were made aware of the intention to use anonymised quotes within the research thesis and that this would be a semi-public document in accordance with the University of Birmingham's guidelines. They were also advised that the report may be published in a scientific peer-reviewed journal. Participants were sent a copy of their transcribed interview and asked if they would like to request any of their data to be removed at that stage; none of the participants requested the removal or withdrawal of their data. The researcher monitored participant distress throughout the interviews; none of the

participants became distressed in a way that it felt necessary to pause or terminate the interviews.

2.4 Data Collection

2.4.1 Semi-structured interviews

Research interviews were conducted in a private room within the hospice. Each participant was interviewed once, with each interview lasting between 25 and 55 minutes. In order to ascertain the participants' experience of attending or presenting a Schwartz Centre Round, the questions on the interview schedule asked them consider a recent Schwartz Round that they attended and/or presented at. Because the participants were asked to reflect on that experience, the initial questions served to provide some context reinstatement, focusing on the time and location of the Round and the topics which were discussed on that occasion (see Appendix 11).

Further questions were used to guide participants in reflecting on the discussion which took place within a Round which they felt were relevant to their role in the hospice. Their thoughts and feelings related to this were explored and they were prompted to consider what they may have gained or 'taken away' from the experience of being at a Round. Questions were open and non-leading and the researcher used cues offered by the participant to elicit their sense of meaning about that experience.

2.5 Data Analysis

Data analysis followed IPA procedures recommended by Smith et al. (2009). Initially, the process of reading and re-reading the initial transcripts was undertaken. Following initial noting of ideas and observations, a more detailed line-by-line analysis was conducted. In this

stage, descriptive, linguistic and conceptual comments were noted and distinguished between, allowing experiential claims to be generated about the objects of concern. An example of an excerpt from one participant's transcript can be seen in Appendix 12, which illustrates this process.

The above process was repeated for each participant before emerging themes were identified, clustered and arranged into ordinate and super-ordinate themes. Excerpts of the transcript were then re-examined to ensure the internal validity of the themes. Regular meetings with two supervisors aided the process of triangulation. In these meetings, excerpts of the transcripts were given to the supervisors for their own analysis, following which discussion about emerging themes took place. Super-ordinate themes were also shared with the supervisors for their thoughts and opinions about the fit of these in representing the whole sample. Both supervisors work clinically in palliative care and have experience of conducting and supervising IPA research.

2.6 Reflexivity

The reflexive account that follows is written in first person prose to facilitate the readers' sense of the researcher and their experience in relation to the research.

I am a 31-year-old White British female trainee clinical psychologist with a special interest in palliative care. In particular, I am interested in how we look after ourselves as professionals who work in this field and come face to face with our own mortality on a regular basis. Having done my specialist placement in the very hospice where I conducted my research, I was all too aware of the challenge that my fellow professionals are facing when they do their very best to give their patients the best death they can hope to give - especially when we ourselves are facing our own pain and loss.

My Father, like many others, had received treatment for an aggressive form of prostate cancer prior to the start of my placement at the hospice. Fortunately, his treatment was successful and the disease was not considered terminal. Yet when I witnessed first-hand the suffering of patients and their families I was drastically reminded of what could have been.

Having the support of my clinical supervisor on placement allowed me to feel entirely supported and contained in the midst of the inevitable anxieties. This made me reflect on the other staff who worked in the environment and how they accessed their own support. Whilst I knew that many of them did have supervision, there was a sense that what I had was something quite privileged; I felt that as a Psychologist in training, I did have a lot more than everyone else. As you read through the findings then, it may become apparent that one of the themes in particular, *Perceptions of Indulgence*, was genuinely shared within my own experiences. Nevertheless, I have considered this in great depth and been careful not to let my own biases influence my interpretations of what the participants themselves were experiencing. In this respect, it was the participants' data and their experience which has generated the findings of this research.

3.0 Analysis and Discussion

3.1 Overview

Three superordinate themes emerged from the data, illustrated in Table 9. In the narrative account that follows, the super-ordinate and ordinate level themes are explored and illustrated by relevant quotes from participants. As is recommended in qualitative research, the analysis describes the idiosyncratic variations of the participants amongst the wider general ideas within the sample (Elliott, Fischer, & Rennie, 1999). A full list of participant quotes in relation to the super-ordinate themes can be seen in Appendix 13.

Table 9.

Super-ordinate and sub-themes

Super-Ordinate Theme	Sub-Theme	Contributors
Becoming Integrated	1. Conflicts about going to Schwartz Rounds: Perceptions of indulgence	Everyone except Jessie
	2. Conflicts within Schwartz Rounds: Split Positions	Alex, Sam, Pat & Kris
	3. 'All in it together'	Everyone
Becoming Visible	1. The conflict of exposure: Being vulnerable versus being acknowledged	Everyone
	2. Working out the boundary	Sam, Frankie, Jessie & Nicky
	3. Being seen	Everyone except Georgie
Letting Go	1. The feelings left over	Everyone except Nicky
	2. Acceptance	Alex, Frankie, Jessie, Georgie & Kris

3.2 Super-Ordinate Theme: Becoming Integrated

This theme embodies the participants' struggle with internal conflicts about their own position in relation to that of their colleagues. These conflicts were evident both in the participants' perceptions about what Schwartz Rounds represent, and in relation to the

'...' indicates a pause in the flow of a participant's speech and [text] is information added to aid clarity for the reader

different narratives that emerge during a Schwartz Round. The reflective processes that occur both during and after a Round often facilitated the resolution of these internal conflicts; the majority of participants were able to feel secure and accepting of their own and others positions in time, thus experiencing a sense of integration within the organisation.

3.2.1 Conflicts about going to Schwartz Rounds: Perceptions of Indulgence

Evident within the participants' views of Schwartz Rounds, was a perception that this kind of reflective forum, whereby staff members are offered time and space to think and share, was an indulgent luxury.

To be honest the first time I went I thought 'God this is a little bit... it feels a bit... indulgent'. Because you know, to have an hour to discuss that. And I looked around the room and I thought, 'oh God, you think how much money is in this room, hourly rate sort of thing'. And it did feel a little indulgent. I was thinking 'God, I can't believe, you know, that this hour has been put aside'. It's quite shocking how looked after you are in this environment (Georgie).

The language here expresses just how shocked Georgie felt when first attending a Round and being offered a new experience; it's evident that being "looked after" was something quite unfamiliar and perhaps almost sinful ("God"). Reference to an "hour put aside" and "hourly rate", signifies just how precious time is in this context, with a sense that to be deserving of a salary, something other than just 'discussion' has to occur.

Amongst the other participants there was also a perception that some of their colleagues viewed Schwartz Rounds as a place to talk about "airy-fairy stuff" (Nicky) that is comparable to "just supervision" (Alex). A perceived divide between the inpatient staff, who did not have "time to go" (Kris) and the non-inpatient staff, who were perceived to have more freedom and opportunity, intensified feelings of guilt amongst the participants when they did

attend. Sam's speech here, illustrates this split, with a clear distinction between 'them' (the ward nurses) and everyone else:

I think they moved it to the ward in the hope that the ward staff would go, but they didn't go. Cos I think it would be really helpful for them, and it seems sad that there are... there are loads of nurses on the ward, that they have been part of the hospice, and yet they don't go (Sam).

This notion, that self-care is indulgent, alludes to a perception that to engage in such things as Schwartz Rounds, would be to do something rather *selfish*. Indeed, the term 'responsible selfishness' has previously been used to describe self-care practice in nurses (see Adam & Taylor, 2014). A culture whereby self-care is seen as selfish has recently been identified as something common to the nursing profession (Mills et al., 2015). In this respect, the lack of participants from the inpatient nursing team in this research can be understood. For if taking time out to care for oneself is seen as selfish, then so too must the idea of taking time out to participate in research about the same issue.

Clearly, perceptions of self-care and self-compassion practices as being selfish and indulgent, are likely to account for the guilt experienced when attending a Schwartz Round. But is there further explanation as to why only the ward staff are so reluctant to attend? The answer to this question may lie in the interpretation of Pat's narrative. Here, the split in positions amongst the hospice staff was evident in the retelling of a story about becoming close to a patient who was coming to the end of their life:

The last I heard, she had gone downhill and she might not make the holiday and I just thought, 'I don't want to know anymore... don't tell me anymore'. But I can do that, I have that luxury whereas [the in-patient nurses] don't, they have to follow it through right till the end (Pat).

Within the text, there seems to be an acknowledgement that being able to *choose* one's level of exposure to psychological pain is a luxury, indeed one which the in-patient nurses and healthcare assistants are perceived not to have. As discussed by Menzies-Lyth (1988) and Fabricius (1991), continuous contact with patients who are sick, distressed, disfigured and dying means that these professionals, who are attending to patients continuously, are repeatedly confronted by their own mortality and vulnerability.

Given such depth and intensity of the psychological disturbance which can accompany advanced disease, the hospice nurses' work can be profoundly challenging. Inevitably, there will be times when the stresses and anxieties of caring for these patients are deeply defended against (Lanceley, 2013). In the classic study by Menzies-Lyth (1988), it was observed how the uniforms and procedures of modern practice acted as organisational barriers for nurses to hide behind for their own emotional protection. Further research has also highlighted that many nurses cope by distancing themselves from patients (Mackintosh, 2007).

Thus we can see how Schwartz Rounds seem to represent not only an unjust indulgence, but also a huge risk. For being open to talk and feel involves letting go of these defences, and how will they know that their distress and anxieties will be contained or even tolerated? How easy will it be to go back to the job again? Will they be able to once again close themselves off, shielded from such pain outside of the allocated hour? For if they can't, then what are the consequences?

3.2.2 Conflicts within a Schwartz Round: Split Positions

Splits between staff members were also evident in the participants' accounts of being inside a Schwartz Round. However, in this context, the splits occurred when participants had a realisation that one's own version of reality was different to that of their colleagues,

illustrated here by Alex: “I kept thinking, ‘well I’m looking at it a different way to everyone else...’”.

The sense of being on a different track to others within a Schwartz Round could also be experienced more subtly:

I think I can generally tell when I think someone has said something. I think, ‘well that’s really good, that’s just captured something, the essence of it. And that’s good that they’ve said that and it leads onto something, sometimes it being quite powerful. Yeah but then sometimes someone will say something and you think uh... it’s sort of spoiled the moment’ (Sam).

Here, Sam alludes to a feeling of disappointment experienced when one’s own reality is not aligned to somebody else’s. Implicit within the text is the view that there is potential for a powerful connection to occur when one is in tune with the others position. Yet, when misalignment occurs, there is a sense of frustration that the other person has “spoiled the moment”.

This can lead to a process of questioning oneself, which was described by another participant who recalled having a conversation with a colleague about a Schwartz Round they had attended:

We talked about it and she said, “Am I wrong? – I wanted to say something but I didn’t”. Because she didn’t know whether it was her, “Am I alone with thinking this?”, “Why is everybody talking about it in that way?”. And she felt something quite different (anon).

Here this participant describes how their colleague sought them out after the Round, to seek answers to their questions, perhaps to regain a sense of security in one’s own view.

Another participant described a similar need to speak to somebody else in an effort to resolve their own internal conflict relating to a topic discussed in a Schwartz Round:

I think that's why I had to go and speak to somebody. Because the way it came across was just so different to how it was in reality (anon).

From these descriptions the discomfort experienced from misalignment in relation to others positions is apparent. The battle between being *right* and questioning oneself appears to lead to an ongoing internal dilemma which may last long after the Schwartz Round has ended.

Such conflicts can be explained in the context of attachment research. In particular, the concept of *Mentalising* (Fonagy & Target, 1996), may explain why such a struggle between positions may emerge. This purports that at times of threat we may revert to early modes of functioning, namely the *psychic-equivalent* mode or the *pretend* mode. These modes equate to the individuals' difficulty in separating their internal world with external reality. As such, when we are in one of these modes, beliefs and facts are not differentiated between, as in the case of some of the participants, ("the way it came across was just so different to how it was in reality").

Thus we can see how certain modes of functioning can be activated in light of new and emerging information heard within a Schwartz Round, particularly when this information represents a threat to our existing internal world. Of course, this will be mediated by the individuals' own attachment style and relationships. Nevertheless, the implication here is that there must be opportunity for reparative action to be taken either during or after the Schwartz Round, so that we are able to move back into a *reflective* and therefore *empathic* mode of functioning (i.e., able to mentalise).

3.2.3 'All in this together'

So far, we have seen how the open nature of a Schwartz Round has forced participants to come face to face with conflicts about where one positions themselves amongst colleagues and within the organisation itself. However, for all of the participants, there is some evidence that it has also presented opportunities for individuals to move closer together.

Whilst guilt has often got in the way of feeling truly secure in one's decision to attend Schwartz Rounds, the inclusive nature of the Rounds has gone some way to alleviate those feelings: "That's what I thought is lovely, is that everybody is being looked after here" (Georgie).

In the context of Georgie's earlier statement about feeling so shocked by being looked after, a change in position is now apparent. Here, being looked after is "lovely", but this can only be so if everybody is looked after. Indeed, accounts from other participants were indicative of a sense of satisfaction that the Rounds are reaching a broad audience:

What's been really good has been giving everyone in the hospice the opportunity. So even the sort of cleaners, the kitchen staff, the maintenance men, an opportunity to say their bit, tell their story. That's been great and I think it gives you a sense of, 'we're all in this together' (Sam).

Nevertheless, moments of genuine connection can occur between professionals, implicit here in reflections from Kris: "I felt I could really identify with that", and Frankie: "It's being able to recognise, 'oh, you're part of the human gang as well'". This is what compassion theorist Neff (2003) calls common humanity; a form of social referencing that allows us to see that our fantasies, anxieties and depressions are shared as part of the human condition. Such a process of normalisation can generate great reassurance that we are indeed

‘normal’ or ‘just like everyone else’ (Gilbert, 2010). Indeed, this is a key compassion process in group psychotherapy (Bates, 2005).

Such is the power of social referencing, that this may be enough to prompt staff members to re-engage in the process of attending a Schwartz Round, even where fear and guilt have been experienced previously. Georgie’s description of listening to another staff member present at a Schwartz Round illustrates this:

For me I love this job because I get a buzz out of helping people. You know, people I know, especially you know, friends and that lot, ‘how on earth can you, you know... working with, you know, with people who are gonna die’. And I’m going, ‘if I can help I really do get a buzz out of that’. And obviously this girl has got a buzz as well, cos she’s helped somebody and made a difference and that made her glow. And that was nice. And I thought, ‘well yeah’. Cos you feel a bit strange... well I feel a bit strange thinking that’s why I enjoy my job’ (Georgie).

Georgie’s account here, tells again of the insecurity that one may feel in misalignment (“I feel a bit strange thinking that’s why I enjoy my job”). It seems that for Georgie, a feeling of being misunderstood by others was dominant (“how on earth can you?”). Yet in that moment, when listening to the presenter, a sense of feeling validated occurred with the realisation that something was shared (“she had got a buzz as well”).

Even where staff members have remained misaligned in their unique perspectives, and so haven’t necessarily received the desired validation, they may be able to come to an acceptance that more than one (their own) position can exist. Not only this, that different perspectives can also be appreciated and learned from:

So you can have a complaint like that and one person can be really upset by it but somebody else can shrug it off and rationalise it. So I think the Rounds have helped me to remember that, everybody can react differently to the same situation (Sam).

Sam's narrative here is a clear indication of the reflective mode of functioning. In this mode, we have the ability to revise our mental representations of external reality as new information comes to light. Furthermore, with the emergence of the mentalising capacity comes a growing potential to consider the relationship between internal and external reality (Allen, Fonagy, & Bateman, 2008).

Thus Schwartz Rounds may indeed offer that opportunity for reparative action to be taken following the emergence of split positions. The open nature of the Round seems to generate the very conditions required for the processes of social referencing and validation to occur, meaning there is much potential for Schwartz Rounds to bring people closer together.

3.3 Super-Ordinate Theme: Becoming Visible

This theme represents the participants' desire for their work to be acknowledged and understood by others. Yet in the hope of acknowledgment, therein lies a dilemma; to be truly *seen* by others one must risk exposing their own vulnerability – something which the participants often battled with during Schwartz Rounds. The process of working out the boundary between being professional and being human was experienced by all participants. Once this had been worked through, many were able to experience new understandings of themselves, their colleagues and their patients.

3.3.1 The conflict of exposure: Being vulnerable versus being acknowledged

The hope of acknowledgement is apparent in the participants' descriptions of their job role. Pat talks about going unnoticed by some colleagues whilst doing a job well:

It can be forgotten because it runs that smoothly it can just sort of, right okay, we are working to do our bit, all that has been done somehow. It's like at home with the

washing; [they] just think it miraculously appears (laughs)... It's washed, it's ironed, it's put away... weird, so it's done (Pat).

Analogous to getting the job done without being seen, is Pat's description of doing the laundry at home. This exemplifies how one can do such a chore where the end result is achieved after an arduous process ("it's washed, it's ironed, it's put away"), without the rest of the household (the organisation) giving a second thought to how it got there ("it miraculously appears").

Others speak of perceiving that colleagues don't value what they do ("I think people thought well... always sort of laugh about [the task]... what's that matter?" Alex) or of feeling that others don't really understand what they do ("My role is, you know, a different beast really... What I do is, a lot of erm, a lot more fluffy." Frankie).

Dissatisfaction with traditional methods of acknowledging one's job role was evident in Alex's description of using outcome measures to record patient care: "it's very difficult to actually capture the things that matter at the end of the day". It may be that Schwartz Rounds present a new unique opportunity to be heard; to tell one's story in a way that really matters to them. This is illustrated again by Alex when recalling being approached by a facilitator to consider presenting at a Schwartz Round: "My thoughts just ran rampant, if you like. All the different examples of how we help people".

The drive to gain acknowledgement for one's own work can be understood in the context of the 'Compassionate Mind' model, where three affect regulation systems are described (Gilbert, 2009). One of the systems, the *incentive and resource-seeking, drive excitement* system functions by motivating and pleasuring us by seeking out, consuming, and achieving. The drive to achieve status and recognition is acknowledged as one of our main motivating forces.

However, this drive can at times be thwarted or blocked when threats are encountered. This was illustrated by the participants in their dilemma of actually *being seen* within a Schwartz Round. For with the desire to share one's achievements with others, comes the realisation that "you're making yourself vulnerable" (Sam). Fears around exposure were prominent in many of the participants' narratives:

Nobody wants to be thought of as a nut case (laughter). So, so they don't want to talk about those things, for fear of erm, being misunderstood (Frankie)

The time before, the first Schwartz Round, it was really emotional, a couple of people cried. And I thought of things [to say]. [But] I thought, 'oh I can't, cos I know I'll sit there and blubber' (Georgie)

Inferred from these comments is the understanding that opening oneself up involves taking a great risk. There seems to be a perception that being seen as a "nut case" or losing control of emotions is shameful – further indicated by use of the word "blubber" to illustrate the messiness and ugliness of such an act.

In respect of the compassion-focused model of shame, these perceptions represent elements of internal and external shame (Gilbert, 2006). For instance, internal shame refers to internal fears and beliefs of one's own inadequacies and failures or as Georgie alludes to, fears of losing control of one's emotions. On the other hand, external shame, as Frankie describes, is concern over how one is perceived *in the mind of others*.

In any case, experiences of internal or external shame are likely to trigger our *threat and self-protection* system. Like the 'drive excitement system', this is one of the three affect regulation systems described in the Compassionate Mind model (Gilbert, 2009). This explains how, when the threat system is activated, we will experience a flood of feelings such as

anxiety, anger and disgust. These feelings change the physiology of our bodies, urging us to act to self-protect.

Thus we can see how the potential for the experience of shame within a Schwartz Round would lead us to avoid (or at least want to avoid) exposure. The anxiety response that one is likely to experience when faced with such a challenge will prompt a strong ‘flight’ reaction, in an effort to self-protect. Forcing ourselves to resist this urge and stay with the anxiety is immensely challenging.

Nevertheless, whilst showing one’s own vulnerability may be a terrifying prospect, seeing it in others is valued:

I’m not the kind of person who likes to talk about what I’m experiencing, but I don’t mind other people telling me about them because I find that interesting. But I also find it challenging on a personal level. It’s sort of like, I don’t mind taking other people’s blood but I don’t like it when people want mine (Nicky)

Nicky’s analogy of taking blood highlights just how invasive and personal this kind of exposure can be, for blood is something taken from deep within us, only reachable through penetrating many layers of skin. Yet this is something we seek from others; we want their blood, we want to see what’s underneath. The nature of seeking out opportunities to understand ourselves through others whilst maintaining a self-preserving fear of exposure is something we perhaps all share:

For some people it might be a real treat because they get an insight into your own feelings which they’ve never had before. I think it’s a little bit like the way people love watching EastEnders. You know, they love to see the drama, but they don’t wanna actually... experience it. It’s like, ‘oh yeah, that’s real life you know, I love watching that’. But actually your own involvement is a whole different ball game (Frankie).

3.3.2 Working out the boundary

“Well I think it made me think... where do my boundaries, where are my boundaries, where do I stop and start?” (Sam).

Inevitably, this kind of internal dilemma, articulated here by Sam, takes some working out. Defining how much of ourselves we give is a blurred line, encountered in many aspects of our work. However, the open nature of a Schwartz Round prompts ongoing conflicts about how much of our own vulnerability we should allow others to see. This is illustrated here by Frankie’s comment about presenting at a Schwartz Round:

If you crack up in the room it’s not gonna help anybody (laughter, intake of breath). Or it might, it might be the one thing that really helps everybody? (Frankie).

Many of the participants commented on how the Schwartz Round facilitator was instrumental in containing such anxieties. This is evident in Jessie’s narrative, who at the time of the interview, was due to present at an upcoming Schwartz Round. The comment here relates to the input received from the Rounds facilitators’ in planning the presentation:

I wasn’t sure which patient to do the reflection on but I’ve gone with my heart. So I’ve... th... they’re sort of guiding me the best way to do it. Erm... they sort of tied it all up (Jessie).

The risk that Jessie has taken to show the true self during the presentation is evident here; the ‘heart’, like the ‘blood’, being something uniquely personal, found deep within us. However, the role of the facilitator has served to keep things neat (“tied it all up”). The language here signifies the need to avoid the mess and ugliness that may underlie such honest exposure.

The facilitators' role in containing fears around exposure is also central within a Schwartz Round, when members of the audience are checking out whether it is safe to be vulnerable. As described here in Frankie's reflection, the presence of the facilitator can ease some of the internal conflict by giving permission to share:

There's often the remarks made, 'well I'd like to say this but I know I'm gonna get emotional'. It's like [having the facilitators there] gives them that permission to say (Frankie).

Thus the 'facilitating environment' that can be enacted within a Schwartz Round, whereby the facilitators act as containers for anxiety and fellow colleagues are able to mirror and reflect back their own emotions, can represent opportunities for individuals to be heard. This is not dissimilar to findings of psychotherapy research whereby, the therapist, like the facilitators, contains the anxiety of the patient allowing new understandings to emerge (see Rizq & Target, 2008a).

Indeed, participants did speak of finally taking the risk and sharing their own thoughts and opinions during Rounds. Nicky, for example, recalls getting to a place (internally) where it was safe enough to share, despite the level of bravery required to do so:

I didn't speak up straight away. I had to feel a little bit... after hearing other people contribute. Erm, I think it went down okay. Erm, I do remember sort of scanning people's faces just to see if what I had said, you know, seemed to be completely out there or whether it was received okay. Erm, I still to this day, I don't know how it really went down, what people really thought of what I was saying. But I just said it anyway (Nicky).

3.3.3 Being Seen

The power of being valued and appreciated by others is demonstrated here in Jessie's account of caring for a patient:

I get very passionate about what I do and I think that, that sort of comes across. Yeah cos I think this role is very humbling and it's very... it's an honour and a privilege because when you get some patients and you, you know, I'm just doing what I can for them – I'm doing the best that I can. And then all of a sudden somebody says out of the blue, 'oh I love you'. And it's just so... (loud intake of breath), (laughs), it's like, you know... 'I'm just there to help with your symptoms and have a chat' (Jessie).

Such is the sense of gratitude that one has been acknowledged for "just doing what I can", that words cannot be articulated here. Only evident through the body ('loud intake of breath') is the effect of such recognition on Jessie.

Whilst this example demonstrates the power of being acknowledged by patients, there is evidence that a similar process can occur during Schwartz Rounds, when the fear of exposure is overcome and participants have risked sharing their own vulnerability. When participants' have shared, their sense of being seen, respected and valued was felt to increase:

It's given me an opportunity to think, 'yeah, we are doing a really good job and it is important'. So I think it has given me that, and a sense of being, feeling included as well (Kris).

It was good to pick up afterwards, erm, that people had understood, my stuff better... my work better, how I feel about my work. And, and I sensed that there was perhaps more respect for what I did because they understood, because they understood... they could see me better... not understand, cos people can understand that sort of thing, it's not rocket science. But it's erm, being able to see you... in a new light (Frankie).

The soothing nature of being heard and understood is demonstrated here, with the evidence that the participants' felt others had seen their views as articulate, valid and

something to be paid attention to. Perhaps more importantly, a sense of not being overridden or dismissed has emerged. Thus, it seems that attending a Schwartz Round can help us to move into the final affect regulation system described in the Compassionate Mind model – the *soothing, contentment and safeness* system. For when we feel we have gained the recognition we have wanted, we can be satisfied, soothed and content (Gilbert, 2009).

3.4 Super-Ordinate Theme: Letting Go

Powerful feelings were often felt by the participants in relation to their work in palliative care. When unprocessed, such raw emotional experience was often carried around as a burden. Schwartz Rounds were experienced by the majority as an opportunity to process these experiences. Having the time and space to gain new insights and re-evaluate things helped participants achieve acceptance and growth. Thus, this theme describes the process by which this occurred, detailing the conflicts participants went through before being able to finally let go.

3.4.1 The feelings left over

You think you're doing a good job and yet you're very vulnerable because people are grieving and looking for someone to blame (Sam).

You don't feel you have done enough (Pat).

A lot of it was about the clinicians - the guilt the clinicians had if they weren't able to fulfil a promise, or if a family asked them to promise something and they felt they couldn't. It was almost like a burden (Kris).

The above descriptions provide examples of the themes that have been discussed at Schwartz Rounds. Through these the nature of working in palliative care is revealed; the guilt, blame and shame that inevitably arise through one's work, being all too clear. The ability of

such experiences to penetrate deep within us (“underneath”; “inside me”; beneath the “layers”), is implicit within the speech of Alex and Pat:

I almost felt so strongly about it underneath... [it] hurt me so much somehow (Alex).

I just felt anger inside me, that’s what I remember more than anything else (Alex).

We are full of layers aren’t we? We are full of layers and trying to break them down and get to the core of things and let go is difficult (Pat).

Often such powerful emotion can last long after the event was actually experienced: “And that sort of stayed with me for quite a while” (Jessie); “It just played on my mind all night” (Alex). The ability of such experiences to remain as sensory and emotional memories can be seen in Pat’s speech. Here, a strong connection to a patient was felt by Pat, such that the patient’s death was experienced as a painful loss: “She was a lovely lady, really lovely. I can see her face now” (Pat).

Jessie’s account highlights the need to put on hold the processing of these experiences:

I may think, ‘oh well I’ll think about that later’, cos you’ve got other things to carry on with. So then I probably do that later in the day, then come back to it and think about it. You can’t always just go, ‘oh I’ll think about that’ (Jessie).

In healthcare this is not unusual, nor indeed unadvisable; taking care of others’ basic needs quite rightly has to occur before we can attend to our own psychology. Nevertheless, a certain amount of time and space to process our own emotions is widely associated with being a more compassionate, empathic and emotionally intelligent practitioner (e.g., Heffernan et al., 2010; Şenyuva et al., 2014)

Schwartz Rounds can be one opportunity to have such dedicated time and space to facilitate the required reflection and processing. However, even within such a defined opportunity, the conditions within this space have to facilitate sharing. Many participants, for instance, felt that on one occasion, when the focus of the Schwartz Round was pre-determined to emphasise one's good work and positivity, there was no space left to share what is difficult:

Because it was all so positive, it didn't leave any room for people to share honestly. There was no space for that. And so it was just like, 'oh yeah I did this which was good', you know, 'I did this – this was very positive', 'yeah I did that'. And then people in the audience... 'yeah I did that', 'that was a very positive thing', 'we feel really good'. But I felt it missed a dimension (Sam).

I found having, having been in the meeting and heard all these great things, erm... there was the other side of the coin, which I felt was left unsaid. So I went away with this sort of baggage (Frankie).

Again, this can be understood in the context of the Compassionate Mind model (Gilbert, 2009). For when the nature of working in palliative care leads one to expect loss after loss, the fear of positive emotion is continually reinforced. Therefore, as a safety mechanism, our threat affect regulation system serves to inhibit any activity that may lead to positive feelings and self-enhancement (Gilbert, 2009).

Perhaps then, the reluctance to engage in positive talk reflects a conditioned fear of positivity in the face of continual pain and suffering that one comes into contact with on a daily basis. The need to immerse ourselves in negativity may actually represent a protective function, to prepare us for the inevitable. Indeed, Pat's reflective statement illustrates such a tendency: "Because of what we do we see the negative side of things. And it's quite easy to lose yourself in that mind-set".

3.4.2 Acceptance

Despite the likelihood of an ingrained fear of positivity, the accounts of the participants tell of opportunities within for this to be overcome. This is illustrated in Alex's narrative, when describing the process of meeting with a Rounds' facilitator before presenting:

To actually sit down and say how much you've done and how much you really helped somebody... I suppose it's like praising yourself isn't it? I found that really, really difficult to do... and it was really interesting just working through that process... and the sort of questions she was asking and getting you to feedback. So to me, it was almost more beneficial, the actual build up to the session and going through that reflective process (Alex).

It's clear that although there was a struggle, Alex was able to engage in a process of acknowledging one's own good work. Georgie describes a similar sense of accepting positivity in relation to the Schwartz Round titled, 'The Best Day':

At the moment I don't find [the work] hard because I, you know, I, I, I... no matter... even if somebody is dying, you can ensure they are dying where they want, in that peaceful way... I find job satisfaction in that. So yeah, it was good to reflect and to know, even if I did it in my own head, to know actually yeah, that was a good day (Georgie).

Whilst the hesitancy in the speech highlights the difficulty in explicitly stating such positivity, the reflection here suggests that it is indeed possible to get to a point of acceptance. In this instance, it was achieved in one's "own head", and therefore may also occur without the direct prompting of a Schwartz Rounds facilitator. This is also evidenced in further statements by Georgie and Jessie, whereby a process of internal reflection has facilitated a contentedness and acceptance of any previous turmoil:

I resolved it in my own head. It brought up things that I remembered and I resolved it in my own head (Georgie).

Reflecting on that now, I don't feel I could have done anything differently under the circumstances, so I feel quite at ease now (Jessie).

Here we can see the relief that is achieved through gaining insight from reflection.

Insight is an emotional experiential process whereby we can step back to refocus our thoughts (Gilbert, 2010). Schwartz Rounds therefore, through facilitating the processing of insight, can help us to find inner peace and reach compassionate acceptance.

4.0 Further Discussion

This study aimed to explore how hospice staff experience Schwartz Rounds. To the researcher's knowledge, no other studies have used IPA to understand the underlying mechanisms that are experienced within a Round, and if and how these processes promote compassion towards the self and others. Thus, this research contributes to new understandings in the literature. Three super-ordinate themes emerged from the data; 'Becoming Integrated', 'Becoming Visible' and 'Letting Go'.

Within Schwartz Rounds it seems there is great potential for the process of validation to aid the integration of individuals within the organisation. In this study this was achieved through a shared sense of what Neff (2003) describes as 'common humanity'; that is, when the participants realised that their own feelings, thoughts and desires were experienced by others too. The potential for these processes to have a reparative effect following the emergence of internal conflicts about one's position was evident. Indeed, many of the participants' narratives were indicative of a shift into a more reflective mode of functioning.

What's also clear is that Schwartz Rounds can act as a facilitating environment for individuals to show more of their humanity. Although this was experienced as a big risk, it's one that many of the participants felt they were able to take, allowing them to feel heard, understood and respected by their colleagues. The role of the Schwartz Round facilitator was central to the participants' need to feel secure in doing this; the facilitators' ability to contain anxieties and give permission to share was of great importance.

In establishing this safe, secure and containing environment, the Schwartz Round is felt to be a space for sharing and processing difficult feelings that arise in one's work. Whilst the Round's facilitator often had to work hard to prompt participants to engage in a process of

self-compassion, many of the participants were able to achieve this through the insights and reflections that occurred within a Round. A state of compassionate acceptance was reached by many participants, and painful feelings were able to be *let go*.

It appears then, that aligned with the goal of individual Compassion-Focused Therapy, Schwartz Rounds, on a wider, systemic level, are instrumental in generating the ability of their attendees to balance their three affect regulation systems – *drive*, *threat* and *soothe* (Gilbert, 2010). For in experiencing the *drive* to seek recognition, overcoming the *threat* of exposing one's vulnerability and feeling the *soothing* contentedness gained from acceptance, a healthy balance of all the aspects that make us human, can be achieved through the process of attending a Schwartz Round. In this respect, it can be stated that Schwartz Rounds can and *do* facilitate self-compassion.

The potential for these processes of self-compassion to transcend to compassion towards others is huge. We know from the literature that being seen, being validated and feeling secure builds a greater capacity for us to tolerate previously unknown or unwanted parts of the self. The individual's capacity to engage, empathise and work with parts of them now seen in their patient is therefore greatly enhanced (Rizq & Target, 2008a, 2008b). Warm, affiliative and empathic interactions with patients are therefore much more likely to occur (Gilbert, 2010).

Despite these positive findings, this research is limited in that it does not represent the views of the inpatient nursing team as they did not volunteer to take part. Whilst the participant data generated much discussion about why this might be, without hearing the voice of someone from the inpatient nursing team, the ideas expressed in the analysis are only hypotheses, albeit based on the other staff members' experience.

Nevertheless, findings of research that has explored barriers to self-compassion in nursing staff, suggests that the ideas discussed within the theme *Perceptions of Indulgence* are fairly universal in today's healthcare culture. For instance, McPherson, Hiskey, and Alderson (2016) conducted a qualitative study using ten participants of nursing background working on older adult dementia wards. They report that barriers to self-compassion included a sense of professional responsibility not to express emotions at work, intense time pressure and a lack of organisational modelling of compassion in action.

The implication here therefore, is that there is the potential for Schwartz Rounds to be accepted and engaged with over time, should the whole organisation continue to model the compassionate practices and greater humanity that are opened up within. Recommendations for further research will outline ways that this might be explored and facilitated.

4.1 Clinical Implications

Whilst IPA does not aim to make claims of global generalisations, it is hoped that the findings of this research will contribute to the emerging literature about the value of Schwartz Rounds in promoting compassionate care. There is the potential for Schwartz Rounds to positively influence not just the individuals who attend them, but over time, the whole culture of the organisation. In this respect, it is recommended that Schwartz Rounds are implemented in many other healthcare contexts and maintained in those that already use them.

One key finding of this study was the importance of the Schwartz Round facilitator in creating and maintaining the safe and secure environment that encourages sharing. With this in mind, it is of key interest to ensure that Schwartz Round facilitator continues to be well trained and supported in fulfilling their role. Often professionals with psychology or social work backgrounds undertake this role; it is felt that this is an appropriate and justified pre-requisite

to facilitator training, given the need to tolerate and contain uncertainty, anxiety and conflicts which may emerge in a Round.

4.2 Recommendations for research

As discussed previously, the voice of the inpatient nurse or healthcare assistant is missing from this study. In this respect, further research would aim to capture their views and experiences about attending a Schwartz Round. It is however acknowledged that recruitment of nursing staff to research studies of this kind is difficult. The issues highlighted within the theme *Perceptions of Indulgence*, whereby self-compassion practices are viewed in a *self-critical* light as something rather selfish and indulgent, would perhaps also inhibit these staff from taking part in such research.

Given the emerging literature supporting the use of Acceptance and Commitment Therapy and Compassion-Focused Therapy for shame and self-criticism (see Luoma & Platt, 2015), it may be that training programmes for nurses based on these models, could prompt re-evaluation of self-compassion and how these populations experience self-care. Further research could serve to develop and evaluate such interventions.

Finally, whilst this study has demonstrated that there is great potential for Rounds to generate compassionate practice in healthcare, measurement of patient related outcomes would serve to confirm this link. Large scale studies using control conditions may indicate whether there is any difference in patient perceptions of compassion between staff or organisations who have attended or implemented Schwartz Rounds and those who have not. Further research in other specialities (e.g., general medicine, mental health, and paediatrics), would also generate evidence for the use of Schwartz Rounds in other settings.

4.3 Conclusion

This study, which captured hospice staff's experience of Schwartz Rounds, suggests that they offer a space to achieve integration, visibility and compassionate acceptance. Schwartz Rounds have the potential to transform the healthcare professional's capacity for compassion towards their patients. Further research is needed to explore their impact on members of inpatient nursing teams, amongst other ways of moving cultures of self-criticism into cultures of self-compassion.

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Public Domain Briefing Document

Psychological Aspects of Palliative Care

Public Domain Briefing Document

Psychological aspects of palliative care; reviewing psychological interventions for adults with advanced cancer and exploring hospice staff's experience of Schwartz Center Rounds® as an initiative to promote compassion.

This document provides an overview of the thesis submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D.) at the University of Birmingham. A summary of a systematic review of all psychological interventions for adults with advanced cancer experiencing psychological distress is provided. Following this, an overview of a research paper exploring the experience of Schwartz Center Rounds® (termed Schwartz Rounds, or Rounds hereafter) amongst hospice staff is presented.

Overall context

Psychological suffering is thought to be experienced by nearly all patients with advanced cancer. Yet prolonged episodes of distress can become burdensome; responses such as depression, anxiety and hopelessness can become as frequent, if not more so, than pain and physical distress. Psychological interventions, developed to support patients experiencing such distress, can vary greatly in their nature, duration, mode of delivery and intensity. However, there is no up-to-date review of the literature to examine which intervention is the most effective.

UK national guidance recommends that all staff working in palliative care are able to provide good enough emotional support and information to patients. However, it is well recognised that for staff to be able to provide compassionate care and be attuned to all aspects of patients' needs, including the psychological, they must, in turn, feel supported in their roles.

Schwartz Rounds are one initiative which have been recently established in the UK in an attempt to provide this support and enable staff to be more compassionate in their interactions with patients. An in-depth understanding of the processes that occur during or after a Schwartz Round is required so that it can be explored how these might, in turn, promote compassionate healthcare. Thus, this research has the potential to influence the future use of Schwartz Rounds in palliative care settings.

Literature Review

Introduction

Psychological distress is frequently experienced by those with advanced cancer. Psychological interventions may help to alleviate such distress, thus improving patients' quality of life. However, little is known about their effectiveness, owing to a lack of recent comprehensive reviews of the empirical literature. The current review aimed to address the gap in knowledge and explore the effectiveness of psychological interventions in patients with advanced cancer.

Method

A search of the relevant literature identified 23 studies that evaluated 15 types of psychological intervention designed to help patients experiencing depression, anxiety and existential distress at the end of life. A narrative review synthesised study findings according to the patients, intervention, comparator group and outcomes. Attention was also given to whether the interventions were delivered in line with current UK national guidelines.

Findings

Cognitive-behavioural interventions were most consistently reported to be effective in reducing psychological distress. A number of meaning-focused interventions were also found to be effective. The interventions reviewed were being delivered in line with current UK recommendations for clinical practice. However, it is acknowledged that research evidence does not necessarily reflect what is *actually* provided in routine clinical practice.

Conclusions

This review supports the use of psychological interventions in advanced cancer populations, although further good quality randomised controlled trials are needed before firm conclusions can be made.

Research Study

Introduction

Schwartz Rounds were introduced to UK health services as an initiative to promote compassionate care. Existing literature suggests that they are valued amongst those who use them. However, little is known about the psychological processes which may work to bring about increased compassionate interactions towards the self and patients. To address this gap, the current study aimed to explore how hospice staff experience Rounds, paying particular attention to aspects that may facilitate increased compassion.

Method

Eight semi-structured interviews were conducted with clinical and non-clinical hospice staff. Interview data was analysed using Interpretative Phenomenological Analysis (IPA), which allows for in-depth exploration of the individuals unique *lived experience*.

Findings

Three overarching themes emerged from the data, 'Becoming Integrated', 'Becoming Visible' and 'Letting Go'. Schwartz rounds were experienced as space to become integrated within the organisation; to be seen, valued and respected by colleagues, and to resolve any psychologically painful feelings associated with working in a palliative care setting. Each of the themes contained sub-themes detailing how these specific processes were experienced by the participants.

Conclusion

Schwartz Rounds were experienced as a place to achieve compassion towards the self by promoting feelings of integration, value and acceptance. They have the potential to

transform healthcare professionals' capacity for compassion towards their patients, though further research is needed to confirm this direct link.

Appendices

Literature Review

Appendix 1: Quality Appraisal Criteria

Description of Quality Appraisal Criteria, based on the Quality Assessment Tool for Descriptive Studies (Thomas, Ciliska, Dobbins, & Micucci, 2004).

Criteria	Appraisal
Selection Bias	Very likely
Are the individuals selected to participate in the study likely to be representative of the target population?	Somewhat likely
	Not likely
	Can't tell
Study Design	
Classify the sample size.	0 – 50 participants: Small
	50 – 100 participants: Moderate
	≥100 participants: Large
Indicate the study design.	Randomised controlled trial
	Controlled clinical trial
	Cohort analytic (two group pre and post)
	Case-control
	Cohort (one group pre and post)
	Interrupted time series
	Other specify
	Can't tell
Was the study described as randomised?	No, Yes.
If yes, was the method of randomisation described?	No, Yes.
If yes, was the method appropriate?	No, Yes.
Confounders	
Were there important differences between groups prior to the intervention?	Yes, No, Can't tell.
If yes, indicate the percentage of relevant confounders.	80 – 100%
	60 – 79%
	Less than 60%
	Can't tell
Blinding	
Were the outcome assessors aware of the intervention or exposure status of participants?	Yes, No, Can't tell.
Data Collection Methods	
Were data collection tools shown to be valid and reliable?	Yes, No, Can't tell.
Withdrawals and Dropouts	
Were withdrawals and dropouts reported in terms of numbers and reasons per group?	Yes, No, Can't tell

Each section graded as strong, moderate or weak. Section ratings are then summarized to attribute a global rating of strong, moderate or weak for each study.

Appendix 2: Data Extraction Form

Reference	
Setting or environment where participants were recruited	
Diagnosis	
Stage of illness	
General study design	
Participants	
Demographics (age, mean or median; sex: males % and females %)	
Number of participants in intervention group	
Number of participants in comparator group (if applicable)	
Participation rates	
Retention rates	
Eligibility criteria for study participation	
Intervention	
Theoretical orientation	
Who delivered the intervention	
Duration of intervention	
Number and frequency of sessions	
Description of comparator condition (if applicable)	

Outcomes	
Primary psychosocial outcome measures	
Timing of outcome assessments related to intervention	
Summary of primary psychosocial outcome findings	
Other notes	

Appendices

Empirical Research Paper

Appendix 3: Sponsorship Agreement Letter

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Appendix 4: Ethical Approval Letter

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Appendix 5: NHS Local R&D approval letter

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Appendix 6: Marie Curie Local R&D approval letter

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Appendix 7: Recruitment Flyer / Expression of Interest Form

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Appendix 8: Participant Information Sheet

Title of Project: The experience of Schwartz Centre Rounds®: An initiative to promote compassionate care.

Lead Researcher: Joanne Almeida (Trainee Clinical Psychologist), *Academic Supervisor:* [REDACTED] [REDACTED] (Senior Academic Tutor/Clinical Psychologist), *Clinical Supervisor:* [REDACTED] [REDACTED] (Clinical Psychologist). *This study is being carried out as part of a Doctoral qualification in Clinical Psychology at the University of Birmingham.*

You are invited to take part in a study about 'Schwartz Centre Rounds®', which are an initiative designed to promote or facilitate compassionate interactions between healthcare staff and patients. I am interested in people's experience of attending or presenting at a 'Round'. Before you decide whether or not you wish to take part in the research, please take time to read this information sheet, which will explain why this research is being carried out and what it will involve.

- What is the purpose of this research?

Schwartz Centre Rounds® are increasingly being set up in UK hospitals and hospices. Research shows that the Rounds are valued by staff working within these environments and the organisations themselves. However, little is known about the way in which the Rounds actually facilitate compassion. It is therefore the aim of the current study to explore how hospice staff experience Schwartz Centre Rounds®. It is hoped by exploring their experience we may gain more insight into how these might promote compassionate interactions between staff and patients.

- Why have I been invited to take part?

You have been invited to take part because you work or volunteer within Marie Curie Hospice, West Midlands, and you have attended or presented at, at least one Schwartz Centre Round in the past 6 months. I am interested in the views of any member of staff or volunteer working within the hospice who has experienced a Round. I hope that between six and eight staff members will agree to take part and share their experiences for this study.

- What will happen to me if I agree to take part?

If you are interested in taking part, please contact me using the details on page 3 of this sheet. You may ask for more information if you wish or you may book a meeting with me at a private room in the Marie Curie Hospice, West Midlands. During this meeting you are able to ask questions and discuss any queries you may have. If you are happy to take part, I will ask you to sign a consent form to state that you agree to be a participant of the study.

The next part involves taking part in an interview with me. This will last approximately one hour and can take place straight after you have signed the consent form or at a later date, according to your preference. During the interview you will be asked questions about the last

Schwartz Centre Round you attended. You will be asked about your experience of it and any thoughts or feelings you had in relation to the topics being discussed. You will also be asked about your role within the hospice and how your experience of the Round might relate to that. The interview will be audio-recorded.

After the interview you will be offered the opportunity to ask any further questions or discuss any concerns you may have.

- What will happen to this information?

The recording of the interview will be typed out (transcribed) so that the information can be looked at in detail. This is done to identify any themes that are important in understanding the experiences you have shared. The audio recording and written transcripts will be made anonymous using a unique code that only the lead researcher is aware of. These will be saved in a secure location at the University of Birmingham.

To assist me with the analysis, some sections of the information collected from the interview may be looked at by my supervisors and other Trainee Clinical Psychologists. They may also be looked at by representatives from academic and professional assessment bodies in order to ensure the quality of this project. These sections will be made anonymous beforehand.

As part of my Doctoral qualification, I will write up a report of the study. In this report I will include anonymous extracts of the interview to illustrate themes that have been identified. These extracts will not include any information that could identify participants. The report may also be submitted for publication in an academic journal or presented at conferences.

The findings of the study may also be presented at staff meetings, away days, conferences and newsletter and email publications. Again, all interview data referred to will be anonymised and no information which could identify participants will be included.

- Can I withdraw from the study during the research interview?

You are able to withdraw from the study at any point during the research interview and you do not have to give a reason if you do not wish to. Your decision of whether to take part or withdraw from the study will not affect your work within the hospice or your right to attend future Schwartz Centre Rounds®.

- Can I withdraw my data from the study after the interview?

After I have typed out your interview, I will send you a copy of the written transcription. This will be sent to you by secure email or post to ensure it remains confidential. You are given a period of two weeks from the date the transcription is sent to you, to review this for accuracy. At this point, you are able to request for specific parts of your interview not to be quoted in any of the reports. You may also decide that you would like some or all of your interview data to be withdrawn. In this case you are able to request for this to be removed from the study, whereby your data will not be used in the analysis and will be permanently deleted.

As it is not possible to withdraw data once the analysis has started, you are not able to request withdrawal of your data after the two week deadline. The deadline will be made clear to you when I send you the transcription. You will also be reminded of the researcher's contact details at this point to ensure you can request to withdraw if you wish.

If I do not hear from you by the end of the two week deadline, I will treat this as confirmation that you are happy for me to analyse your original interview data.

Your decision of whether to take part or withdraw from the study will not affect your work within the hospice or your right to attend future Schwartz Centre Rounds®.

- Are there any risks or disadvantages to taking part in this study?

You will be asked to discuss your experience of Schwartz Centre Rounds® in detail. It is recognised that some of the issues discussed in the Rounds may potentially be distressing, and as you will be asked to think about these in the interview, you may experience some further distress. Every measure will be taken to minimise this and you will be offered the option to take a break or terminate the interview if you wish. You will be offered support by the researcher at this time and you will also be given a list of other sources of support available should you wish to access them.

If during the interview, you disclose information that suggests there are concerns about certain practices within the hospice which involve wrongdoing or poor standards of care, I am obliged to raise and/or escalate this, in the interest of protecting vulnerable patients and colleagues. This will be carried out in accordance with my employer's policies and guidance from relevant professional bodies.

There is no obligation for you to answer questions which you do not feel comfortable in answering. You may request to skip questions if you wish.

- Are there any benefits to taking part in this study?

You may find it useful to have the opportunity to speak to someone and share your experience of attending a Round. Although you may not experience any direct benefits from taking part, the study will add to the evidence around the effectiveness and use of the Rounds in healthcare organisations.

- What happens if I have any concerns?

If you have a concern about any aspect of this study, you may contact me and I will try my best to answer your questions. Alternatively you may contact my academic or clinical supervisors at the details below.

Thank you for taking the time to read this information sheet.

(other logos removed for confidentiality purposes)

Appendix 9: Consent Form

Participant Identification Number:

Title of Project: The experience of Schwartz Centre Rounds®: An initiative to promote compassionate care.

Researcher: Joanne Almeida

Please initial box

1. I confirm that I have understood the information sheet dated (version 1.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview, without giving any reason, without my employment or legal rights being affected.
3. I understand that the research interview will be audio-recorded.
4. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data.
5. I understand that direct quotes from my interview may be published in any write-up of the data, and used for training purposes, but that my name will not be attributed to any such quotes and that I will not be identifiable by my comments.
6. I understand that I have a period of two weeks from the date I receive a transcription of my interview to request for some or all of my interview data to be withdrawn from the study.
7. I understand that the researcher is obliged to raise and/or escalate any concerns relating to wrongdoing or poor standards of care within the research site, in interest of safeguarding vulnerable patients and employees.
8. I agree to take part in the above study.

..... Name of participant Date Signature
..... Name of researcher Date Signature

(other logos removed for confidentiality purposes)

Appendix 10: Further Support for Participants

Title of Project: The experience of Schwartz Centre Rounds®: An initiative to promote compassionate care.

Thank you for taking part in this study. This research will add to the development of knowledge about Schwartz Centre Rounds® and their use as a mechanism for promoting safe and effective healthcare.

I hope that you have found the research interview a valuable opportunity to share your experience of attending or presenting at a Schwartz Centre Round®. However, I recognise that some of what has been discussed may have been uncomfortable or upsetting. You may find it helpful to speak with your supervisor at work or your GP about any issues you would like support with. I have also provided some contact details for additional sources of support, should you wish to access them.

Clinical Psychology within Marie Curie, West Midlands

██████████ (Clinical Psychologist)

Tel: ██████████

Email: ████████████████████

Occupational Health Services within Marie Curie, West Midlands

Tel: ██████████

MIND charity

MIND provides advice and support for anyone experiencing mental health difficulties or stress.

Web: www.mind.org

Tel: 0300 123 3393

Email: info@mind.org.uk

Text: 86463

Appendix 11: Interview Schedule

The experience of Schwartz Centre Rounds®: An initiative to promote compassionate care

Semi-Structured Interview Schedule

When was the last time you went to a Round?

What time of day was it held?

Where was it held?

Where did you sit?

Did you go alone or with anyone else?

Can you tell me who was presenting that day?

Can you tell me what topics were discussed that day?

How did you come to attend/present at a Round? (What made you decide to go?)

What did you do during the Round? (Can you take me through what happened?)

How did you feel listening to/giving the presentations?

How did you feel listening to the reflections from the audience?

Did you offer any of your own reflections?

- How did that feel?

Did you ask any questions to the panel?

- How did you feel about the answers to your questions?

How did you feel when the Round had finished?

How do you feel about the Round now?

Have you discussed the Round with anyone else since you attended/presented the last one?

What has changed since the Round?

- *Prompts:* in relation to your work, your role, your interactions with patients/carers/families/colleagues.

What have you taken away from the whole experience?

Appendix 12: Transcript excerpt showing process of analysis

Overleaf

Emerging Themes	Original Transcript	Exploratory comments
<p>Feeling separate to everybody else.</p> <p>The realisation that one is valued.</p> <p>To feel valued is to feel integrated.</p>	<p>Participant: I can't remember what the other thing is I presented at the time? But all I can remember is presenting it and the discussions and saying everybody else presented something big that had happened [hmm] and I just sat there and it was that interest from getting that feedback from people afterwards [hmm] that I actually realised that it's not just the big things that make a difference, it's actually the little things that can [yeah] actually help as well.</p>	<p>She doesn't remember (or want to talk about) the content of what she presented, but it's important to her that she is able to express what she took from the experience of presenting.</p> <p><u>The distinction between her and 'everybody else' (them and I).</u></p> <p>"I just sat there" – it was at that precise moment, when she was "sitting there" <u>that she had a realisation. The realisation that what she does matters too!</u></p> <p><u>She felt aligned with 'them'. The integration of 'them and I' of 'her and everybody else'.</u></p> <p>She does the small things – but they matter too! <u>The feedback gave her that confirmation, that acknowledgement that she had been seeking, that her role was also valued.</u></p>
	<p>Interviewer: What was it like getting that feedback?</p>	
	<p>Participant: It was good getting the acknowledgment because you're not looking</p>	

Emerging Themes	Original Transcript	Exploratory comments
Confirmation of one's self-worth.	<p>for personal acknowledgment it's actually, the thing what I wanted to get across, or to me what mattered was the fact it's the little things that mattered and makes such a difference [hmm] and when certain people in the audience actually realised that. I just felt good because it started them to think about it's the little things that mattered then it sort of went onto other discussions well how do you record that, where's the evidence for it etcetera... [hmm] you know it's almost a big thing how to record the benefit how you've made a difference to [yeah] the patients [that's true yeah] it lead onto those discussions [okay] but I'm not there to solve those sort of things [no] but again it just got you thinking more. We now as [healthcare professionals] because that's what we do, all day everyday try to make a difference to people [hmm] so we just record it in notes and we've got our own, (pause) suppose personal satisfaction that you can help somehow [yeah] but then we don't go in and do formal [not like measures] assessments and measures and things</p>	<p>Exploratory comments</p> <ul style="list-style-type: none"> - Descriptive comments: the content of what is said (i.e., the object of concern (normal text). - <i>Linguistic comments</i>: exploring the specific use of language by the participant (<i>italics</i>). - <u>Conceptual comments</u>: the meaning associated with the 'things that matter'/the objects of concern. i.e., the experiential claim (<u>underlined</u>). <p>She isn't asking people to say that she herself matters, she is asking them to say that what she does, matters. <u>Her self-worth is in her job role.</u></p> <p>The critical point was when other people had a realisation that what she does is important – when they became aligned with her own views.</p> <p><u>She was able to confirm her own self-worth, when others views became aligned with hers.</u></p> <p>The feedback on her presentation. Discussions about how to measure the benefit to patients.</p>

Emerging Themes	Original Transcript	Exploratory comments
<p>Us versus them.</p> <p>Defending one's role.</p>	<p>because its palliative care [yeah] [yeah]</p>	<p><u>That's not where she gets her value from.</u></p> <p>Being committed to making a difference. Working hard to make a difference.</p> <p><i>Use of 'we' when referring to her professional group suggests that she is aligning herself to her professional group. <u>Is she doing this to strengthen her position? Perhaps she is saying that only 'we' get it and 'we' don't need to do formal measures because 'we' have 'our own satisfaction' that is valued above all else'.</u></i></p> <p>Justifying why formal measures are not used. <u>Is perhaps defensive against the feedback received ('they (i.e., those not in her profession) don't get it', 'only we do').</u></p>
	<p>Interviewer: that's really interesting</p>	
	<p>Participant: It was interesting how some people would actually see that its little things but other members of the audience still latched onto it's the big things that matter [really] or I felt that</p>	<p><i>The difference between those who were able to 'see' versus those who 'latched onto' their old perceptions.</i></p> <p><i>Being able to 'see' – positive connotations of being open-minded,</i></p>

Emerging Themes	Original Transcript	Exploratory comments
The frustration of misalignment.	[yeah] because that's what they latched onto.	<p><i>awakened.</i></p> <p><i>'Latching onto' – negative connotations of being stuck, clinging tightly, not being able to release.</i></p> <p><u>Does she feel a sense of resentment/frustration towards those who were unable to 'see'; those who were not aligned to what she values?</u></p>

Appendix 13: Master Table of Themes

Overleaf

Theme	Column
Super-ordinate Theme: Becoming integrated	
Sub-Theme: Conflicts about going to Schwartz Rounds - Perceptions of indulgence	
Alex: Cos you hear it said. Erm... they just say that its supervision. Uh ah, lots of people say that – it’s just supervision. And also lots of people say lots of negative things about it... it’s a waste of time and whatever. I think it depends on how you want to take it	180
Alex: I know lots of people say because you are sitting there talking about your feelings and things, they say it’s supervision... if I’m honest	180
Sam: All the other disciplines in the hospice, they may not have the same opportunities, so I really enjoyed seeing them being given the opportunity	56
Sam: I thought, actually it doesn’t seem too long ago since the last Round, are these becoming a bit too frequent? So yeah, I did wonder that for the first time and I never felt that before. I suddenly thought, well because we are quite a small number of people in the hospice, can we... is it... are we going to like... are we putting them on too often?	74
Sam: It’s sad that the ward nurses don’t go, although that day – the last one, three new staff had started that week. Two of them the day before or something. So they were, they were allowed to go. And I think they moved it to the ward in the hope that the ward staff would go, but they didn’t go. Cos I think it would be really helpful for them, and it seems sad that there are, there’s loads of nurses on the ward, that they have been part of the hospice, and yet they don’t go	76
Sam: I think some people may be put off by the formality of it. I think you need it structured but I think you can make it a bit warmer	92
Frankie: There’s a certain amount of cynicism about Schwartz Rounds. You know, ‘oh yeah, Schwartz Rounds... we can talk at any time you know’	77
Frankie: I think if we could see how it works and how it fits in improving practice, people will be more likely to want to come along	79
Georgie: I’m still grateful for actually having the time to have... you know, we get supervision to be able to discuss how we are feeling. To be honest the first time I went I thought God this is a little bit... it feels a bit... indulgent. Because you know, to have an hour to discuss that. And I looked around the room and I thought, oh God, you think how much money is in this room, hourly rate sort of thing. And it did feel a little indulgent. I was thinking God, I can’t believe you know that this hour has been put aside. It’s quite shocking how looked after you are in this environment. Whereas if you think of, you know, not just nurses, those other disciplines out there. Actually they still come into contact with just as many palliative care patients, who get just as involved... but have nothing at all. So I felt a bit guilty really. Cos the first time I felt... this is really... indulgent. I know that sounds a strange word but that’s how I felt	33

Georgie: And I felt bad afterwards. I thought I should be embracing this, And I did, and I think as time goes on I will feel that. But coming from somewhere that just doesn't talk about feelings, cos we just get on and do... And that's wrong, I know that's wrong and I know you've got to look after yourself and this is the right way to do it. But you know, it's quite strange to do it	35
Georgie: It was alien to me I suppose	75
Georgie: It will be interesting from your research what benefit people will get. Cos it's lovely and it's... you know... I can see the benefit of reflecting but erm... And that's something that research has shown that we should be doing	75
Georgie: I love the fact that everybody is included and I think that's really, really important. And I don't know whether any of the nursing staff have supervision on the ward or anything. I don't know, I really don't know. But I think to me that's really reassuring that people have got the chance to reflect and discuss	63
Pat: The last I heard, she had gone downhill and she might not make the holiday and I just thought, 'I don't want to know anymore... don't tell me anymore. But I can do that, I have that luxury whereas they don't, they have to follow it through right till the end	47
Kris: I just wish people would be a bit more open to it, because I think there is that kind of... I know 'X' has had to kind of bribe people to go. But going back to that clinical, non-clinical thing, I almost feel like the non-clinical people are more engaged in it than the clinical staff, especially from the inpatient unit. And that doesn't surprise me because it would have been the same where I worked before, because that was sort of the feeling – 'well, we haven't got time'. Well actually it is so valuable that you should make time, for reflection and everything else	90
Nicky: I don't think they would appreciate anything like this. They'd see it as, 'what are you talking about, all this airy-fairy stuff, you just get on with the job'.	62
Nicky: Would I attend a Schwartz Round in the future? If I'm honest I don't think it would be my priority on the list of things. But that's just because of time constraints really	66

Sub-Theme: Conflicts within a Schwartz Round - Split positions

Alex: It was interesting to see that it's the little things... but other members of the audience still latched onto it's the big things that matter. Or I felt that, because that's what they latched onto	81
Alex: People sort of latched on more to the bigger things, about the 'X' and sort of, perhaps things that they had been involved with	89
Alex: I suppose basically when you present at a Schwartz Round, you're given your topic and you go with your own ideas if you like... or how it relates to you and what your work is and what your profession is. Because I sat there at one stage and I thought, they're all presenting different things to me. But it's how they interpret the question, what they feel they want to present. I think looking back at the Rounds I've been to as well... you get your own role, heading, subject, discussion and its always interesting how people present and what they present under that	107

heading

- Alex: I was right cos I'd been here so long, I'd got more experience. She couldn't necessarily see things 134
- Alex: I kept thinking afterwards, well did I fail as a person not accepting that she couldn't see things? Or have I got it completely wrong or what? 136
- Alex: I think that's why I had to go and speak to somebody. Because the way it came across was just so different to how it was in reality. I was just questioning myself so much, thinking am I that wrong? So I had to go and speak to somebody about it 148
- Alex: And I kept thinking, well I'm looking at it a different way to everybody else cos they are all looking at it patient wise, but I hadn't got the guts to say it 156
- Alex: I suppose there's two sides to things... the fact it was just her – she failed... but it was a team thing 166
- Alex: It just made me think a bit more, about how she may have been thinking, or how she sees things 172
- Sam: I think I can generally tell when I think someone has said something. I think, well that's really good, that's just captured something, the essence of it. And that's good that they've said that and it leads onto something, sometimes it being quite powerful. Yeah but then sometimes someone will say something and you think uh... it's sort of spoiled the moment 44
- Sam: My experience of these Rounds has been that, sometimes people go off down a different track that I don't perceive as being that... helpful? Maybe you don't communicate in something. But that's taking it down another track that isn't really where it would be helpful for the topic to go 42
- Pat: I think it was quite profound what 'X' was saying in last weeks... 'mine doesn't seem as important as yours, I'm not involved in a patient so it just seems trivial in comparison'. And I think that's the impression I get from the admin side to the clinical side. But it's not the clinical saying that it's the admin people thinking that. Actually, what we do even though we are the foundation... it's not as... it does seem trivial because we haven't got the direct contact with patients and dealing with that. We are a lot more detached but the subjects can be very relevant to us as well 31
- Pat: I really felt for 'X' who was doing it. You could see that she felt uncomfortable because of the comparison to the previous story. I think she felt that talking about an 'X' and 'X' just wasn't as important, but it is important because without all that in place, you haven't got that initial club to err... help people in the clinical side do what they do 33
- Pat: You could just tell by her demeanour. And she also voiced it. She also said it... she said 'mine just seems trivial in comparison', and you could see she felt a little bit uncomfortable to talk about it. And that's why I mean, I really felt for her because I really understood where she was coming from. You do feel like it's not... like it's more of an arena for the clinical side of things – but it's not – and it shouldn't be seen as that. We should open it up to more people and say well actually no its relevant to everyone who works in the hospice 35
- Pat: The people in the audience tried to include. They were coming from a clinical perspective initially and then just adding on about the audit. 37

And I think again, they were very aware that we had got this divide and they were trying to be inclusive. But when they are clinical already it is hard for them to disentangle themselves, if you know what I mean, from that, from that, mind-set. But that's their field, or box (laughs). We try not to say boxes, we try not to do that don't we? But you are sort of, you're either clinical or you're not clinical and that's how you are banded.

Kris: I have definitely noticed that in all of the Schwartz Rounds, no matter what the topic, there is a difference between what clinicians and what non-clinicians feel 46

Kris: I think it is nice... it is nice for them to have a voice because sometimes their voice is lost for non-clinical or support staff. I think those people who participate and speak, usually speak a lot from the non-clinical point of view. And I think it is part of probably conversations that go on outside of the Schwartz Rounds, but it is never given much space because it is thought, well you are up there in this office, so you don't have to deal with the emotional stuff that goes on... on the ward for example. But actually sometimes they do erm, but there is a feeling that that is not so important or in the background. But actually I think they are more, but I think all non-clinicians should have some kind of erm, psychosocial training, or acknowledged for what they do. Because I think there have been clinicians that take it for granted that they are ok in conversations and stuff and just assume it won't affect people 50

Kris: Sometimes she has been to them before. And then I was on annual leave and she would say, 'do you mind if we talk about the Schwartz Round that I went to because I really didn't like what I heard, but I don't know if it is just me so I am interested in your thoughts' 80

Kris: I think she felt that the presenter took it personally and took it... oh and she said that it almost felt like 'how dare a family criticise us because we are doing this kind of thing. And she didn't like that. And she was like, 'well who are we to say how a family feel, it isn't personal. They are angry and scared and if they are angry, they are angry. And it is not about us'. Yeah so she was left feeling a bit, 'hang on, what are we here for? Are we here because we want families and patients to treat us in a certain way or should we be here to respond to what they want regardless of what that is?' It left her feeling quite angry 82

Kris: So we talked about it and she said, 'am I wrong? – I wanted to say something but I didn't'. Because she didn't know whether it was her, 'Am I alone with thinking this?', 'Why is everybody talking about it in that way?'. And she felt something quite different 84

Kris: She was quite... not angry, but she was frustrated by it. And she didn't know what to do with those feelings because nobody seemed to be feeling the same way she was 86

Kris: A couple of people said, 'oh, can we swap jobs'. Yeah they said, 'oh can we do your job instead then?' Because I think my role is quite privileged because you do get to do the little things that make a big difference, and you don't have to worry about symptom control. We kind of get to do the nice bits. Which is why it feels a little, or mine felt a bit positive, because you don't have to worry about discharge planning or ordering equipment. 56

Sub-Theme: 'All in it together'

Alex: I suppose if you look back on it, it's actually being aware of people and where they have come from and their experiences. I'd say it helps me get an understanding of how people think in their roles. You can become very insular in your own roles. I think sometimes it gives you insight into how they work and how they think, which you perhaps forget about and don't perhaps get to hear or see, not always. So because you know that, that can sort of implement a little bit into sort of what you do and what you think 176

Sam: I think it, it helps me to understand that people react differently to the situation. So you can have a complaint like that and one person can be really upset by it but somebody else can shrug it off and rationalise it. So I think the Rounds have helped me to, sort of remember that, everybody can react differently to the same situation 66

Sam: Those that don't have the opportunities, I've sort of sensed that they've walked away and I heard them say 'oh well that was really good' and you know, 'we don't talk like this'. It's almost like it was a foreign experience for them 58

Sam: What's been really good has been giving everyone in the hospice the opportunity. So even the sort of cleaners, the kitchen staff, the maintenance men, an opportunity to say their bit, tell their story. That's been great and I think it makes you have a sense of, we're all in this together. And to hear that they, sort of, are affected by what goes on as well. And you think, well they're just from the kitchen and do the cleaning or something... so that's been really valuable 80

Frankie: I think it's about realising the truth that we are all human, we've all got our struggles and our triumphs and it's being able to recognise, 'oh you're part of the human gang as well'. 38

Jessie: It's just really nice to listen to other professionals, other multi-professionals when they talk about their personal experiences and how they felt. And it, it's sort of bringing everybody together. And that...that's what I like about Schwartz Rounds. It just... you know you're not alone. Although you do a job on your own a lot, you know that when you're in that room, for that hour, we've all got a similar sort of... not stories, but personal experiences, and I think that's what brings the group closer together 34

Jessie: So the last time there was a child support worker and the admin manager and one of the other admin team. Erm... I think that was 'the best day'. And... seeing all the different perspectives of their good days and how one person could have a good and how that knocks onto everybody else. But also, if somebody has a bad day and how that knocks onto everybody else as well. And everybody's role is just as important as everybody else's. And I think that's what it puts across, that it doesn't matter what role you have within the hospice, it's important because it's all part of team working. Erm... but it's nice to listen to, to other people's experiences, that's what I like about it. And how open and perhaps sometimes how vulnerable they actually feel. You know with sharing what's happened. You know, so that's what I like about it 58

Jessie: I think it's just the connectedness of everybody in the room. Yeah I think that's the difference. I mean with your clinical supervisor it's one on one so you can just talk about whatever you need to talk about. Err... with every couple of months, but this is like every month so it's like a bit of a top up, but it is with everybody 78

Georgie: What I think's lovely about the Rounds, is that everybody, everybody is invited... and actually what she ex... you know, experienced 45
with patients, she actually... It meant something to her, it had an impact on her and how she felt. And that's what I thought was lovely, is that
everybody is being looked after here.

Georgie: I said to 'X' upstairs... she said 'I've never been to one'. I said 'you should go, you should. The amount of contact. I sit there and I 46
listen to her on the phone, especially when I first started, and I went to her, 'you are absolutely fantastic. She is so, so good. At signposting. I
said to her 'you really should'. Cos she gets no supervision. She does have, you know, a good half of her day I bet you, she's talking to patients
or relatives on the phone. So that was what I've... I think that was why there was an impact, because it was somebody from admin who, you
know, who talked about how they felt and what an impact it had on her. So that was why it really stood out

Georgie: For me I love this job because I get a buzz of helping people. You know people I know, especially you know, friends and that lot, 48
'how on earth can you, you know, working, you know, with people who are gonna die'. And I'm going 'if I can help, I really do get a buzz out
of that'. And obviously this girl had got a buzz as well, cos she's helped somebody and made a difference and that made her glow. And that
was nice. And I thought, well yeah. Cos you feel a bit strange thinking... well I feel a bit strange thinking that that's why I enjoy my job

Georgie: And actually I think what was heartening was actually, that everybody has, they have similar experiences. I think one of them was 59
'not letting... you know, finding it hard to let go of patients'. And it's nice, I think reassuring, that you are not the only one that feels that

Nicky: I think we all do experience a lot of grief in our work. Erm... even the people who aren't... it doesn't necessarily have to be related to 38
dying people, but actually just the process, there's a common process that's going on. A common experience. And it was good for me to see
that, you know, the kind of feelings that I may go through on a day to day basis are, sort of experienced by other people as well

Pat: It was interesting sitting there at the back and watching how it all unfolds. Initially it takes people to sort of go quiet while they sit there 63
and reflect on what they want to say, and then you get one or two who will start talking and bring their stories to the table, so to speak, and it
opens it up a little more. Then, people, usually in the last 15 minutes of it, start getting a lot more vocal and a lot more inclusive and relating to
each other's stories

Kris: I remember being at another Schwartz round and I think 'X' was presenting and he said, and there had been some big IT meltdown and he 46
had come in and worked hard to put it right and he come in and said actually he felt like for once, he was playing a really important role yeah
and I felt like I could really identify with that

Super-Ordinate Theme: Becoming Visible

Sub-Theme: The conflict of exposure - Being vulnerable versus being acknowledged

- Alex: You've got the tables – it's set out like a boardroom. But for this session it was very much a panel at the end of the room, this sort of, 49
long, narrow room... and all these faces looking at you
- Alex: In fact it stuck in my mind so much, that I felt more comfortable presenting when I had to present at a conference in front of Consultants, 53
than I did at this. It could have been because of the layout I think, because you were sitting there as a panel, then straight in front of you, you've
got all these rows of people
- Alex: I just feel strongly that in the hospice and palliative care, people forget about the small little things and how they can make a difference. 83
And I think some people thought well... always sort of laugh about putting your socks on... what's that matter? They don't necessarily see
beyond the person and what their needs are. I suppose it was what I call the psychological needs in patients
- Alex: I think in palliative care it's really hard to actually find a sort of, validated tool to actually show measurement, that improvement... 79
quality of life... There's several sort of outcome scales out there but it's very difficult to actually capture the things that matter at the end of the
day. I thought, I know what we're doing is to actually help somebody, so in some respect that's all that matters. You've just got to do your job
and measurements come second
- Alex: I hadn't got the guts to say it 156
- Alex: My thoughts just ran rampant if you like... all the different examples of how we help people 63
- Sam: I wonder if you can make it less formal. That would help people to feel that they can share their innermost (laughs). Cos that's what 96
you're doing often, they're your struggles and... yeah, yeah
- Sam: You can sort of, look at the room and think, they'll share, they'll share (both laugh). And they won't, they'll just sit there and take it and 100
not say anything. It's quite threatening. It's quite scary, thing to do. Not only talk, you know, if you're a panellist. Being in the audience and
talk about your feelings, if you're not used to that especially... you're making yourself vulnerable
- Frankie: If there would have been more time, if we'd had more time. And 'X' could see I was kind of (both laugh), chomping at the bit to say 44
something then 'X' chipped in and rounded it all off. So I thought, I didn't get my pennies worth.
- Frankie: You're very conscious that you are in a mixed group of people all with different, erm, boundaries, and erm, so, you are aware that for 34
some people, this may not be easy to listen to. Erm, for some people it might be a real treat because they get an insight on your feelings which
they've never had before. I think it's a little bit like, the way people love watching EastEnders. You know, they love to see the drama, but they
don't wanna actually... experience it (laughs). It's like 'oh yeah, that's real life, you know, I love watching that', but actually your own
involvement is a whole different ball game
- Frankie: It's kind of an invisible role so in a sense you can't see what's happening. You know, kind of, 'oh what do you do? You just go into a 67

room and have a chat, and have a cup of team and they feel better and that's it', so... so, erm... . Historically, you know, (my role) has been difficult to measure. But being on Systmone is quite erm, helpful because you can contribute to the patient notes and so on

Frankie: You do have to make sure people understand what you are doing and why you are doing it and what's happening. And so you write it down in a way that people get 69

Frankie: At another level it's again, sharing our innermost beliefs, that's a personal thing, that are at the centre of us and of first importance to us. Erm... they're often not, erm, allowed to be shared. Because of the fear of misunderstanding, of... our social, our culture... at the moment it does not encourage that 71

Frankie: Which isn't scientifically popular to talk about these sorts of things, cos they don't want to be thought of as slightly weird. Nobody wants to be thought of as a nut case (both laugh) so, so they don't want to talk about those things, for fear of erm, being misunderstood 73

Jessie: I always find it a big challenge talking in front of a lot of people, you know, I tend to go (gestures with hands), it's like 'stop looking at me!' (laughs) 40

Jessie: I suppose it's because I'm a really sensitive person anyway and... (long pause). I don't know really, it's erm... I'm okay with a few people but when there's a big crowd, I get quite self-conscious and err... embarrassed. But I shouldn't really because it's... I'm just speaking from experience 42

Georgie: I can't remember what I said (laughs). Yeah. And there was a couple of things that came in my mind and I think the time before, the first Schwartz Round, it was really emotional, a couple of people cried. And I thought of things, I thought oh I can't, cos I know I'll sit there and blubber (laughs). Erm... Yeah. So, and it is having the confidence within the group isn't it? 50

Georgie: I just don't like speaking in front of people... I can't. (Pause). Unless I know something really well. So I think in time, when I feel, yeah, I feel that the hospice is my home sort of thing, then I will be fine to do it. Erm... but, yeah, I can see the benefit of them but I'm still a bit dubious about going 67

Georgie: I think that we should go anyway to support everybody that goes and I think it's important, cos I think there'd be nothing worse if you were presenting and three people turned up. 68

Pat: Actually we have a very important role just as much in the running of the hospice, but just because you tend to just get on with it and not say anything it's just there its done and we make sure it is done and completed all the admin side, referrals etc., then that is how things run smoothly. But it can be forgotten because it runs that smoothly it can be just sort of right ok this is the norm we are working to do our bit, all that has been done somehow. It's like at home with the washing, he just thinks it miraculously appears (laughs)... It's washed, it's ironed, it's put away – weird – so it's done. 39

Pat: We were both nervous. I mean when she sat down she made me more nervous so it was like, 'oh I am really nervous'. Erm, but it's silly because we know these people, we work with these people every day but it is just the fact you are right in front and you have got all eyes on 55

you, so, and I usually like that don't get me wrong (laughs) because it is usually all about me (laughs).

Kris: So maybe that was why I was a bit nervous because I was exposing myself [laughs]. Well not exposing myself, but to an audience who I have probably said hello to but not much more than that 52

Nicky: I think as a professional you have a professional demeanour or a professional box around you. Erm, which you have to have for lots of reasons, self-protection etcetera, etcetera. To be able to function on a daily basis and actually I think for me as a person that's quite an important safety mechanism. So, I'm not the kind of person who likes to always talk about what I'm experiencing, but I don't mind other people telling me about them because I find that interesting [mmm]. But I find it also challenging on a personal level. It's sort of like I don't mind taking other people's blood but I don't like it when people want mine (both laugh). So, it's like ooohh, it's a similar sort of thing really. So erm, there is an element of opening yourself up to other people's erm... (Pause) not necessarily even judgment but other peoples, erm... gaze, if you wanna call it that [mmm]. And, erm... you know, sort of second guessing what other people might think of you. Does it, does it, erm, diminish your professional demeanour? (laughs), I don't know. But I think, yeah, I think... I think I felt like I put myself out there. I didn't necessarily... I was just sort of thinking in my head did I feel comfortable cos the other consultants had, sort of given their reflections. I don't think I did, I felt like I was going beyond what they were saying and it really being quite personal. But that might just be me. 42

Sub-Theme: Working out the boundary

Sam: So it was about a patient who I'd been involved with. Erm... told the story of that... and he's quite an unusual person, and asked me to... well he was very near to the end of his life and he wanted to get married to his partner. But erm... they were both quite... I don't know, yeah, not good at like... well the man was really poorly and his partner was always scared of talking to people 22

Sam: Well I think it made me think... where do my boundaries, where are my boundaries, where do I stop and start. And I think with them it's easy to get drawn into lots of things. But I think I became quite... with them, I learned that there are things I could do and things I couldn't do, so I was happy to say no. But because I thought it might be a case of asking about it, I said yes. But then I thought, it's really important for them and maybe I could help. So I did some investigation and actually it wasn't a lot of work in the end, it was just quite a few phone calls and I sort of found my way through it 26

Sam: I talked about the patient and his, sort of, wife... sort of set the scene. Their, erm... basically what was wrong with the chap, but then I also explained about their personalities. He'd had quite a colourful past 30

Sam: I think I sort of, talked the situation through before I put anything down on paper, or thought about what I was going to say 5

Sam: Sometimes, cos I can be in touch with my feelings, I think sometimes I say stuff and I think, oh I've said a bit too much (laughs). Or, you know, sometimes I worry about that 94

Frankie: I had the impression that she wanted to bring out the emotional reactions and found those perhaps, quite valuable, erm, reactions to focus on. So she picked up on things like anger, frustration, etcetera. Erm, rather than the mechanics of the erm, incident. And so I kind of got the clue, that we're... you know, we're meant to be sharing how we actually feel, as erm, like ordinary people in that setting 20

Frankie: It was helpful but at the same time slightly confusing because you were trying to work out what Schwartz Rounds were looking for. And so you weren't quite sure at what level to pitch things. I suppose I got the impression you can pitch it at any level as long as you're comfortable with it. And as long as of course, it doesn't cause mayhem in the audience (laughs). And so (laughs)... so I think it was all about working out, working out the level which was appropriate for sharing that particular case study. Erm... how it affects you and how it affects everyone else in the room. And obviously things like confidentiality need to be covered 22

Frankie: So there was a few times 'X' was drawing teeth trying to get me to talk about stuff which had affected me emotionally. Erm, and err, she... I think she succeeded in doing that 24

Frankie: Because we're afraid we may lose our own self-control. Erm.. our professional... ism. How do you get that level right? I think that might come out later but there is always that struggle between being human and being professional and where to pitch things 25

Frankie: There was a certain amount of restraint so you could share those emotions, but it's how you share those emotions. Whether you show them emotionally or verbally, it's different. You know, so you can talk about feelings but not feel upset, you know. And it's like how, how far you go down on that, erm, err, along that spectrum. Because obviously if you crack up in the room it's not gonna help anybody (laughs), (both intake of breath, both laugh). Or it might (both continued laughter), it might be the one thing that really helps everybody? Yeah, so it's... it's just knowing... at what level to pitch it 28

Frankie: I felt okay about presenting it. I was mindful of not, err... talk for too long. Erm... mindful about, erm, on the emotional scale to go to. Erm... erm... so that the thing can be shared appropriately 30

Frankie: I think, in Schwartz Rounds it's really important to, to get other people to feel, erm, challenged to engage emotionally, as they're watching it... it may give them that little bit of courage that they need to come and pipe up and say something. Cos the environment is allowing it... you give them the permission to do it 34

Frankie: If that level of openness is Okayed by the facilitators, then the other people in the room, erm... feel that it's okay. And that 'maybe I can say something that I've never said before'. And there's often, the remarks made "well I'd like to say this but I know I'm gonna get emotional" It's like it gives them that permission to say 36

Jessie: So I wasn't sure which patient to do the reflection on but I've gone with my heart. So I've... th... they're sort of guiding me the best way to do it. Erm... they sort of tied it all up. So I've just got my run through next Friday, ahead of the actual presentation on the following Tuesday, but I'm trying not to get emotional about it 22

Jessie: I think it was making sure that I got everything in the right order. And that I... cos I know it's only a 5-minute presentation, so I've done 26

my background bit and then I wrote... I did it in three headings. So background, what happened and what couldn't I let go. So I've done it like that

Jessie: Every patient is being assessed individually, you know, holistic care. And I suppose if they want to talk about other things then that's fine. Erm... cos it's all about getting that relationship going cos it does take a few visits for them to feel comfortable or you know, erm... It's that trust, it's building that trust, and it does take a little while. 66

Jessie: I suppose it is a little bit, erm... just making sure that I've got everything in the right order. I know I've got everything in the right order but just making sure that it's, that it's okay. That I'm just trying to get the point across that it's about (says title of presentation). That's why I've had to put the headings. So that, that's good, for me as a pointer. Erm and I think it's a growth opportunity really, although I find presenting quite nerve... never wracking. Although I think it will be good practice for me. Erm... and a growth opportunity for everybody. At the end of the day the Schwartz Round is to make us better practitioners I think 74

Nicky: I think that I did feel nervous about sort of putting it out there, because you are giving an insight into your own sort of potential vulnerability. So that was a bit... I have to say I didn't speak up straight away. I had to feel a little bit... after hearing other people contribute. Erm, I think it went down okay. Erm, I do remember sort of scanning people's faces just to see if what I had said, you know, seemed to be completely out there or whether it was received okay. Erm... I still to this day I don't know how it really went down, what people really thought of what I was saying but I just said it anyway 40

Sub-Theme: Being seen

Sam: I suppose it feels reassuring that you feel like you've actually managed to communicate clearly when somebody says something that you think, oh good, they've understood what I've said. So that's quite reassuring 40

Frankie: it was good to pick up afterwards, erm, that people had understood, my stuff better... my work better, how I feel about my work. And, and I sensed that there was perhaps more respect for what I did because they understood, because they understood... they could see me better... not understand, cos people can understand that kind of thing, it's not rocket science but it's erm... being able to see you... in a new light. 38

Frankie: I found it helpful because it helped me to relax, erm... more, in my role. Because people understood my role better when I shared, for instance. So the more people understand my role, and accept what I do, and understand what I do, and maybe appreciate what I do, in a way that hadn't been appreciated before, I found that quite affirming and erm, nice. Because people respect where you fit, in the team 65

Jessie: I get very passionate about what I do and I think that, that sort of comes across. Yeah, cos I think this role is very humbling and it's very... it's an honour and a privilege because when you get some patients and you, you know, I'm just doing what I can for them – I'm doing the best that I can. And then all of a sudden somebody says out of the blue, 'oh I love you'. And it's... it's just so (loud intake of breath), 46

(laughs), it's like... (laughs), you know...I'm just there to help with your symptoms and have a chat	
Jessie: I suppose I'm more open as well. Because I always used to think, you've gotta keep professional and not say anything about your own life'. Erm... but I've noticed as I'm more open... erm... then if I'm asked... personal questions and I feel it is appropriate then I'll answer it. Erm, and that, and I think that does strengthen the bond. You know, it's getting to know each other	66
Kris: It felt, yeah it almost... I felt doing that presentation also gave me a bit of a platform to talk about... that wasn't the purpose of it but maybe people will think about what we do a bit more - the important stuff that we contribute	60
Kris: it's given me an opportunity to think yeah we are doing really a good job and it is important [yeah] so I think it has given me that, and a sense of being, feeling included as well	88
Nicky: I have an interest in psychological stuff so, erm, I thought it would just be useful, and I was interested to see how all the team members were engaging in the Schwartz Rounds and whether it was an area where we could sort of discuss topics, and how they got discussed really. So just interest really, I was being nosy. (Both laugh)	30
Nicky: I think what I found really interesting was that inner dialogue, that inner sort of experience really, that erm... members in the hospice have, that are really erm... really powerful. But you don't see... see any of that as you pass them in the corridor, and actually that kind of insight into just how much is going on in peoples experience really. That was just really intriguing for me.	32
Nicky: I guess it was just a wander into someone's inner experience which you wouldn't otherwise... wouldn't get unless you had a sit down and a heart to heart with them.	34
Alex: I just sat there and it was that interest from getting that feedback from people afterwards that I actually realised that it's not just the big things that make a difference, it's actually the little things that can actually help as well	77

Super-ordinate Theme: Letting go

Sub-Theme: The feelings left over

Alex: I really started over night to sort of question me and my professional ability... was I missing something? It just played on my mind all night	134
Alex: I almost felt so strongly about it, underneath... hurt me so much somehow	138
Alex: Sometimes if I feel strongly I'll say something, but I kept quiet for all of that session	156
Alex: I was angry	28

Alex: I just felt anger inside me, that's what I remember more than anything else, and then, as time wore on, and you start reflecting like you do, it's more self-doubt, on me, and my abilities	162
Sam: The topic of discussion was how that makes you feel and how vulnerable you are. And you think you're doing a good job and yet your very vulnerable because people are grieving and looking for someone to blame. So I remember talking about that and feeling quite emotional about that	62
Sam: (Interviewer) – so, it sounds like it resonated with you, with your own experience? (Sam) – It did, and I saw how painful it feels when that happens	63/64
Sam: Because it was all so positive, it didn't leave any room for people to share honestly	48
Sam: There was no space for that. And so it was just like, 'oh yeah I did this which was good', you know, 'I did this – this was very positive', 'yeah I did that'. And then people in the audience... 'yeah I did that', 'that was a very positive thing', 'we feel really good'. But I felt it missed a dimension	50
Frankie: On reflection afterwards, I found having, having been in the meeting and heard all these great things, erm, there was the other side of the coin, which I felt was left unsaid, and needed to be said. So I went away with this sort of baggage	8
Frankie: Sometimes you go away from a meeting like that and if there is something you are desperate to say it's...sticks with you and it's like a load that you carry. And so I sort of wrote it down on the reflective note at the end, as much as I could, and hoped that it would kind of get heard	8
Jessie: And that sort of stayed with me for quite a while	26
Jessie: It's just sort of being in that moment with whatever you've got to do, and then thinking 'well I'll sort out how I'm feeling after'	30
Jessie: I may think, 'oh well I'll think about that later', cos you've got other things to carry on with. So then I probably do that later in the day, then come back to it and think about it. You can't always just go, 'oh I'll think about that'	62
Georgie: Probably, a lit bit, erm... not upset, but I think it has got the potential for things not to be said and for you to carry them away with you	59
Georgie: It brought up things that I remembered	59
Georgie: It's sad, and I remember it. I think it makes you, you know when you sit there, it makes you reflect back on patients you have met. It just makes you think about them so it does bring emotions back about... you know, cos there are certain patients that touch you more than others	60
Pat: I said to one of the nurses 'I don't want to know when she has gone' because it... she was the same age as me so I had that connection	47
Pat: I just thought, 'don't tell me anymore, I don't want to know anymore'... she was a lovely lady, really lovely, I can see her face now	47
Pat: We all draw on the negatives and I think it's like human nature that actually things we remember, like bad customer service, you always	59

remember bad service	
Pat: You don't feel you have done enough	43
Pat: But it's a very personal thing. Some things you can let go of and some things you can't. It's human nature. We are full of layers aren't we?	49
We are full of layers and trying to break them down and get to the core of things and let go is difficult	
Pat: It is professional how they conduct themselves but we are humans at the end of the day. We get emotionally attached about things, don't we? Especially if we, from a personal aspect, can relate to it	49
Pat: If you constantly feel like you are not doing enough, you are going to lose motivation. It is going to have a knock on effect, and I do think it is noticeable or has been in periods of staff shortage	61
Pat: Because of what we do we see the negative side of things, and it is quite easy to lose yourself in that mind-set	61
Kris: It sticks in my mind because one of the presenters got quite upset	66
Kris: I think there is a period of thinking and quite often I have found that I have conversations with people afterwards... I think it does stay with people, I think it has to. I think if you go open to listen about what other people have to say then it has to stay with you	78
Kris: I think that little thing she did, that family will never forget	76
Kris: A lot of it was about the clinicians – the guilt the clinicians had if they weren't able to fulfil a promise, or if a family asked them to promise something and they felt they couldn't. It was almost like burden	40

Sub-Theme: Acceptance

Alex: I just sat there and it was that interest... from getting that feedback from people afterwards, that I actually realised, it's not just the big things that make a difference, it's actually the little things that can help as well.	77
Alex: I think to go through the process of listening to what people say gives me insight of how they work and how they think as well. And how things matter to them	107
Alex: To actually sit down and say what you've done, and how much you really helped somebody... I suppose it's like praising yourself isn't it? I found that really, really difficult to do... and it was really interesting just working through that process... and the sort of questions she was asking, and getting you to feedback. So to me, it was almost more beneficial, the actual build up to the session and going through that reflective process	97
Sam: When people have got in touch with their emotions and so it's felt quite, you know, quite... yeah, it's often like 'wow', it was just	8

someone at the front saying, telling their story and yet that's lead to someone in the audience getting in touch with some strong emotion that they might feel

Jessie: I think it was in that hour that we had the chance to just reflect on everything, on how he felt and how the children had been, and I don't know why I mentioned it but I just felt really comfortable to actually say, well this is what I felt. Erm... that I felt that I couldn't, you know, do all the journey with her. Erm... you know, about what else to look for when she gets more poorly. And he said 'she wouldn't have wanted to know that'. 26

Jessie: That was my letting go then. Because on further sort of reflection it was... 'okay was that just me thinking I hadn't done my role properly?'. Thinking, 'oh, you've got to do da da da da da'. But actually it worked out well for her, and what she... you know... everything else was in place. It was just cos she deteriorated quickly that we didn't get the chance to do that and she was a fighter anyway. She wouldn't, I don't think she would have wanted to have known that, so, doing that bereavement visit helped me really let go 26

Jessie: Reflecting on that now, I don't think I could have done anything differently under the circumstances, so I feel quite at ease now 28

Jessie: When I did the initial talk about the patient I did cry. And I hadn't cried. Because there are some patients that really touch you and you can't help but get attached. 30

Jessie: I'm more open as well. Because I always used to think, 'you've gotta keep professional and not say anything about your own life'. Erm... but I've noticed I'm more open... erm... then if I'm asked personal questions and I feel it is appropriate then I will answer them, and that... I think that does strengthen the bond 66

Georgie: The girl who presented... she made me really think, she says 'you know, although we're not hands on with patients, we still speak to them over the phone... we still erm... get attached to people'. And I think that's, that to me, I thought you know, you're right 72

Georgie: She'd worked here for a long, long time, and how emotional she was and you know, how much it had touched her. Erm... and that's, and you don't, and I hadn't appreciated that at all 73

Georgie: I resolved it in my own head. It brought things up that I remembered and I resolved it in my own head 59

Georgie: It's nice, I think reassuring, that you are not the only one who feels like that 59

Georgie: At the moment I don't find it hard because I, you know, I,I,I... no matter...even if somebody is dying, you can ensure they are dying where they want, in that peaceful way... I find job satisfaction in that. So yeah it was good to reflect and to know, even if I did it in my own head, to know actually yeah, that was a good day 59

Frankie: And they are emotional, the audience, the members of the audience are emotional as well when they are talking about their own stuff. That is quite sort of... is cathartic the right word? But it seems to, erm, be helpful to people to release that stuff... to allow their humanity to come out 36

Frankie: I suppose there's a bit about, you know, being better than professional, in terms of being human as well, in our practice, which is 38

really, erm... when it all works very well in palliative care, people do share their humanity with each other and we do touch each other in a genuine way. We need the professionalism but without the humanity to go with it, it's kind of cold	
Frankie: That was the sense after the Schwartz Round... to feel, actually it's okay to feel that your work is being rejected as well	40
Frankie: When we are genuinely human with our service users, it becomes the best day	42
Frankie: To be able to share those... the buzz in the room is just amazing	71
Pat: I must admit the first time I went I was surprised because you think, 'I'm not going to get anything from this'. But I found it very interesting because you get to see other parts - or hear other parts of peoples roles	69
Kris: It was a story about an experience she had, that struck a chord with me	40
Kris: And I felt that through him I had learned something about myself if that makes sense. And when I looked back at the other people that were memorable to me, it generally was people I had thought I had learnt something from as well	30
Kris: You have the space to kind of...yeah... when I finished I thought, 'oh I quite enjoyed that actually'	38
Kris: I think that is a really useful process to do. Especially the one to one bit where you get to unpick it. That bit was the most important bit for me, it's where I got most from	62
Kris: A few probing questions from X or X makes you go, 'oh yeah why do I think that?' or 'I haven't noticed that'. So I think that is quite important that they do a little bit of probing as well. You don't really get that do you in your day to day work or life? You don't really get that time to think about your own thoughts and someone to ask those little questions	64
Kris: There was another one where one of the domestic staff talked about their experience of popping in and saying hello and seeing patients and you know, just take that for granted that people just do that. And then meet family and probably chat to family for a week or two weeks, and then the person dies and they go and clean their room and there is someone else in there. But how often do we actually ask them how they are?	70
Kris: I think it is good to expose that difference because it makes people think	76
Kris: I remember X coming up after one saying, 'oh it's really interesting that you said that'	78
Kris: It's given me an opportunity to think, 'yeah, we are doing a good job'	88
Nicky: I think what I found really interesting was that inner dialogue, that inner sort of experience really, that members of the hospice have, that are really erm... really powerful. But you don't see any of that as you pass them in the corridor and actually that kind of insight into just how much is going on in peoples experiences really, that was just really intriguing for me	32
Nicky: Something resonated with me and I actually felt I wanted to feedback about it	36
Nicky: I think just having that insight, I think it just adds... it gives you more of a kindness I guess, for other people, when they are having... I guess it gives you insight into the fact that other people are struggling with things and even though, you know, it might be tense or you might	52

have disagreements with people, there might be other reasons behind it rather than being a direct conflict about one issue. Erm... so just that sort of general insight into people I guess. The types of struggles they, as I said... go through – but you're not really aware of because it's not visible

Nicky: Even if you're not sort of into the whole being in tune with that sort of thing, maybe you can pick up insights, glimpses, that may potentially benefit you

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