

Exploring Oncology Nurse Perceptions of the Relationship
Between their Self-Efficacy and the Quality of Communication
with their Patients

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By

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Abstract/Summary

Objectives. To explore oncology nurses' perceptions of their approach to communication with patients, their self-efficacy for different types of communication and meeting the various associated support needs of their patients, the consequences they associate with their communication approach, and the relationships therein.

Methods. Semi-structured interviews were conducted with eight oncology nurses. QOL measures were appraised by nurses during the interviews in terms of potential utility to prompt communication during consultations. A qualitative thematic content analysis was used to identify patterns and themes that emerged from the data.

Results. The nurses described the importance of self-efficacy when communicating with patients about their support needs, including the roles that mastery experiences, vicarious experiences, persuasion, previous nursing experience, continued learning and reflection have on this. Quality of communication and self-efficacy are also impacted by the nurses' perceived competence of their communication skills and their ability to build a relationship with and appropriately obtain useful information from their patient/client. The nurses also discussed the importance and use of coping resources when facilitating feelings of perceived competence and self-efficacy. Challenging conversations and the individual differences of their patients/clients support needs provided barriers to these feelings. QOL measures were considered useful for identifying issues and allowing responses to be measurable. However, their structure was also an impediment to nurses' conversational flow, leading to suggestions that they be used as an aid or conversational prompt rather than a questionnaire.

Conclusion. Based on these results the author has concluded that an oncology nurse's self-efficacy and perceived competence are important factors in terms of communication which successfully meets the needs of the patient/client. Support-line nurses and face-to-face nurses can and should learn from each other to influence their best practices in supportive communication; findings from this study can contribute to this professional practice development. A number of the current findings confirm the results of previous studies, whilst others offer opportunities for future research to substantiate and test them through either quantitative or qualitative means.

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Chapter One

Introduction

From a cancer patient's perspective the importance of good communication from their nurses and healthcare practitioners is crucial to their treatment experience. For instance, when receiving the initial life-changing diagnosis, the patient's prognosis and their treatment options should be clearly stated and understood, including the sharing of feelings and fears following this (Ragan, Wittenberg-Lyles, Goldsmith, & Sanchez-Reilly, 2008). When perceived well, communication can be beneficial to the patient, as accurate and consistent information allows them and their family to make informed decisions (Angelini, 2011). Conversely, poor perceived communication can impede or be detrimental to the patient's treatment, recovery and overall experience through their cancer journey. This can result in compromised psychosocial care for the patient and family, potentially leading to the development of associative disorders (Chen & Raingruber, 2014). Nurses require competent communication abilities with patients so that they can fully understand their needs and issues around their quality of life to provide the best care (outcome) possible. There can be barriers and difficulties to being able to achieve successful discussions with patients, including poor self-efficacy. How important, therefore, is the nurse's self-efficacy and belief in their abilities when striving to achieve successful communication? And are there best practices that allow for the most effective development – possibly through formal training, Continuing Professional Development (CPD) or supervision – of nurse competency in communication skills and self-efficacy? Following on, how is the value and potential use of Quality of Life (QOL) measures perceived by oncology nurses as an aid to their communication?

This study will aim to gauge nurse perspectives on the impact of their self-efficacy when communicating with patients and its effect on their perceived competency in this domain. The study will also ask for their perceptions of the utility of QOL measures in practice. A thematic analysis of semi-structured interviews with the nurses will explore emerging themes related to oncology nurse self-efficacy, competence and communication, practical perceptions of QOL measures and the

perceived consequences on patient quality of care thereof. This will allow the author to provide recommendations for the application and further study of the findings.

1.1. Background

Not to downplay the unique experiences of individuals suffering from a cancer at a different site(s), but the literature suggests a set of important common symptoms and experiences. Frequently reported symptoms include pain, fatigue, drowsiness, difficulties with sleeping and worrying (Stark, Tofthagen, Visovsky, & McMillan, 2012). The more these symptoms persist, the worse the patient experience gets, impairing the Quality of Life (QOL) including activities of daily living, engagement in relationships and activities that improve social and emotional well-being (McMillan & Weitzner, 1998). Concerns about death and pain also increase, as well as factors such as greater financial constraints and worries (Alifrangis, Koizia, Rozarioi, Rodney, et al, 2011). Differences in distress by cancer type are generally modest (Carlson, Waller, & Mitchell, 2012) and are more often related to gender and age, rather than cancer type (Lavelle, Ismail, Doherty, Bowler, Mohammad, & Cassidy, 2017). Given these similarities – and to provide sufficient focus for this particular literature review – the writer has decided to concentrate on lung cancer. Lung cancer has received rising attention over recent years, especially in Wales where its prevalence rates rank it 3rd for all cancer types (Welsh Cancer Intelligence and Surveillance Unit, 2015). Hence, the literature review can be considered a case study or microcosm of what could be a much broader review of all cancers.

Receiving a lung cancer diagnosis is an unimaginably emotional event, and mental health problems including clinical levels of anxiety and depression often accompany diagnosis and treatment (Mitchell, Ferguson, Gill, Paul, & Symonds, 2013). Even at the sub-clinical level, poor psychological wellbeing and distress can contribute to amplification of physical symptoms and poorer levels of general functioning (Baliouis, Rennoldson, & Snowden, 2016). Notwithstanding the physical side-effects of treatment, it is almost inevitable that, under these conditions, lung cancer patients' QOL is threatened. Distress and QOL concerns can be considered 'patient experiences'

during their cancer journey that nurses (and carers) seek to alleviate, often simply by how they communicate with the patient as their communicative behaviours can facilitate the cognitive and affective needs of patients being met (Kruijver, Kerkstra, Bensing, & van de Wiel, 2000). The National Comprehensive Cancer Network (NCCN) Distress Management Guidelines defined distress as: “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope with the cancer, its physical symptoms and its treatment.”

Quality of Life (QOL) is defined by the World Health Organisation (WHO) as an “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 2019). One’s perceived QOL encapsulates six important life domains; physical health, psychological well-being, level of independence, social relations, environmental and spiritual/religious. A lung cancer diagnosis and subsequent treatment regime tend to negatively impact all six life domains (e.g. pain, nausea, distress, dependence on others and resultant relationship strain, etc.), although variability exists for individuals (Osoba, 2011). The prefix ‘health related’ is often added to QOL (HRQOL) to indicate the centrality of health in one’s overall QOL. Factors which impinge on the patient’s HRQOL include poor psychological well-being and psychological distress. A number of large scale studies (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001) found prevalence estimates for heightened distress in cancer patients to exceed 30%, with evidence suggesting that it is associated with a number of negative outcomes, including poorer adherence to treatment (Kennard, Stewart, Olvera, Bawdon, hAilin, Lewis, & Winick, 2004), lower satisfaction with care (von Essen, Larsson, Oberg, & Sjoden, 2002) and worse QOL (Skarstein, Aass, Fossa, Skovlund, & Dahl, 2000). A relationship has also been shown between heightened distress (in the form of greater depressive symptomology) and poorer survival in people with cancer (Steel, Geller, Gamblin, Olek, & Carr, 2007). One systematic review found that 20-30% of long-term survivors (those without treatment for 5 or more years) still reported physical and psychosocial problems associated with cancer (Foster, Wright, Hill, Hopkinson, &

Roffe, 2009), showing the impact that lung cancer diagnosis and treatment places on its sufferers – potentially seeing the effects for years to come even if they do survive. In an oncology context, psychosocial can be defined as a “discipline that is concerned with all clinical and scientific attempts to clarify the significance of psychological and social factors in the development and course of cancer” (Mehnert & Koch, 2005, p.580).

These statements qualify the frequent observation that, when living with and even beyond cancer, individuals tend to experience a variety of needs that they might not have had or thought much about previously (e.g. physical, psychological/emotional, family-related, social, interpersonal/intimacy, practical, daily living, spiritual/existential, health system/information, patient-clinician communication, cognitive; Paterson, Robertson, Smith, & Nabi, 2015). Specific difficulties, such as declines in performance status and functional activity, problems in carrying on one’s own daily activities, poor concentration, memory impairment, or altered sexuality, can have a significant influence on the psychological response of the cancer patient (Caruso et al., 2017).

The risk of the onset of psychological distress is further exacerbated during the different phases of a cancer presentation: finding and reporting a suspicious symptom; receiving the diagnosis; awaiting treatment; transition between changes in or end of treatment; being discharged; surviving the cancer; treatment failure; recurrence of disease; advanced stages of the cancer; and approaching end of life (NCCN, 2017). This means that throughout the illness trajectory a multitude of emotional effects are experienced with a loss of certainty, dependence on others, lowered self-esteem and the threat of death leading to a change in perspective about the future and an instability in one’s own emotional status (e.g. fears, anxiety, worries and sadness; Grassi, Spiegel, & Riba, 2017). Some individuals who are perhaps more spiritual than others can also experience changes to the meaning given to their own life and existence and their perceptions of time and being, which can have a major impact on their whole set of personal values, creating further distress as they attempt to redefine the meaning of their existence and overcome this internal unrest (Grassi et al., 2017). A poor adjustment to the disease is also associated with hopelessness,

anxious preoccupation and denial again leading to higher risk of distress. In stark contrast, good adjustment is seen in those patients exhibiting signs of “fighting spirit” (Nipp et al., 2016), clearly indicating a need for best practices in how to effectively encourage and support this mindset during the cancer experience.

Given the almost inevitable existential and psychological turmoil wrought by a cancer diagnosis, the emotional needs of the patient are often more powerful than the instrumental (e.g. the need for disease information and how to adapt to the lifestyle implications). Therefore, cancer services which help patients cope on an emotional level whilst also meeting more practical needs will stand a good chance of alleviating psychological distress and contributing to a positive HRQOL, in turn helping patients adhere to challenging treatments, tolerate pain and symptoms, adapt to lifestyle recommendations which improve their overall health and wellbeing, and ultimately, require less use of other healthcare services (DiMatteo, Haskard-Zolnierek, & Martin, 2012; Han, Yabroff, Guy, Zheng, & Jemal, 2015). Importantly to individual health boards and NHS Wales, this would provide a substantial cost offset (Carlson & Bultz, 2004).

Cancer is an all-too prevalent disease: as previously mentioned, lung cancer is the third most common cancer in Wales (after prostate and breast cancer), as well as being the most prevalent cancer in the world (Welsh Cancer Intelligence and Surveillance Unit, 2015). In 2012 lung cancer accounted for approximately 1.8 million new cases of cancer globally, resulting in 1.6 million deaths or almost 20% of all cancer-related deaths (Ferlay et al., 2015). Emotional distress without appropriate psychological intervention is implicated in many aspects of the treatment of lung cancer which demand additional healthcare resources, for example, poorer treatment adherence and reduced pain and symptom tolerance (Baliouisis et al., 2016; DiMatteo et al., 2012). This is contrasted by the benefits that have been found by providing psychosocial care to the patients and their families, reducing the distress and psychosocial morbidity associated with cancer, fostering better QOL during and after treatment and ultimately increased survival (Bultz et al., 2014). A study in the US (Kutikova et al., 2005) showed that over a 2-year period, lung cancer patients had more emergency room visits, outpatient office visits, radiology procedures, laboratory

procedures, pharmacy-dispensed drugs and generally greater use of healthcare services compared to non-cancer patients (the control group). Not all of these behaviours are necessarily inevitable, however, and a sizeable proportion of the associated costs can be attributed to patient distress, QOL, and effectiveness of psychosocial support received. Kutikova et al found that over the two years the overall cost per person for the non-cancer patients was \$2,907, significantly lower than the overall cost per person of the cancer patients which came to \$45,897. It is very expensive to treat people for chronic illnesses, especially cancer, but if this cost can be reduced in any way without reducing the quality of care then it should be explored.

Kutikova et al. (2005) concluded that the economic burden of lung cancer could be alleviated through the implementation of new strategies that aim to reduce hospitalisation rates. Macmillan Cancer Support agree, estimating with evidence from meta-analyses that there will be a cost-benefit for healthcare services of up to 20% when psychological services and holistic (treatment of the whole person, not just the disease), psychologically-informed care pathways are implemented within cancer care outside the hospital setting (Transforming Cancer Services Team for London, 2018). This is supported by findings that the introduction of QOL measures could be cost effective since there would be fewer medical errors and unnecessary costs thanks to the high quality of care (Kotronoulas et al., 2014).

Part of the evaluation of new strategies or instruments involves appraising cost per Quality-Adjusted Life Years (QALYs; Ara & Brazier, 2011) which are defined by the National Institute for Health and Care Excellence (NICE) as a “measure of state of health of a person or group in which the benefits, in terms of length of life, are adjusted to reflect the QOL. One QALY is equal to 1 year of life in perfect health.” Health state utility values (HSUVs) are used as part of the measurement of QALYs, created from an individual’s preferences or valuations for being in specific health states, and are proven to be clinically useful (Soler, Wittenberg, Schlosser, Mace, & Smith, 2011). HSUVs are often used by health economists as they are an important aspect in economic evaluations and cost-effectiveness research (Torrance, 1986). As health services are largely funded by the taxpayer it is deemed appropriate to consult the public on valuations or preferences (Stein et al., 2014). HSUVs can be empirically

generated through these valuations from the general public, and are known as generic preference-based measures (PBM). An example is the EuroQol Five Dimension Scale (EQ-5D), a standardised measure of health status developed by the EuroQol Group as a way of generating a simple, non-specific measure of health for clinical and economic appraisal (The EuroQol Group, 1990). However, cancer-specific health states might not be captured when using generic PBMs, so the use of more specific tools can identify those clinical and domain-specific effects that could be missed (NICE, 2016).

Holistic, psychologically-informed care pathways which work towards positive HRQOL certainly complement and augment the medical treatment received. Unmet supportive care needs are “those which lack the level of service or support an individual perceives is necessary to achieve optimal well-being” (Carey et al., 2012, p.208). This includes psychological well-being which if detrimentally impacted can reduce QOL and calls into question the efficacy of the physically gruelling treatment procedures because the benefits are potentially undermined. A meta-analysis of the prevalence of depression in cancer patients (Krebber et al., 2014) found a mean ranging from 8% to 24% (depending on the type of assessment tool, cancer, and treatment phase). In comparison, the prevalence of depression in the general population is just 4% (Waraich, Goldner, Somers, & Hsu, 2004). Elevated levels of psychological distress often go unrecognised by oncology professionals (Jacobsen & Ransom, 2007) and therefore it would be reasonable to suggest that higher reported levels of depression or anxiety amongst cancer patients could be due to QOL issues going undetected and gradually developing to more clinical states (Derogatis et al., 1983). Fallowfield et al. (2001) conducted a study evaluating the ability of 143 physicians to detect heightened distress in 2297 cancer patients. Only 29% of the patients who exceeded the cut-off point for distress were identified by the physician as having heightened levels of distress. Communication may be the key. Despite course textbooks (Kurtz, Silverman, & Draper, 2004) and recent interventions (Han, Lee, & Demiris, 2017) devoted to improving communication skills in medicine, communication in cancer care may not be up to the standard that it needs to be to facilitate optimal patient outcomes.

Communication needs are but one form of patient need (i.e. the need for open, honest communication). As described previously, lung cancer patients are likely to experience needs which fall under various categories (e.g. physical, social, spiritual, cognitive, communication), but for individuals in the care team to work towards fulfilling these needs, communication skills will be essential. Good communication is “the glue that binds it all together.” The burden that distress and unmet supportive care needs have on the patient can often be overwhelming and detrimental to their recovery. According to some studies, the unmet support needs of lung cancer patients are significantly greater than other cancer patients (Hill, Amir, Muers, Connolly, & Round, 2003; Li & Girgis, 2006). Lung cancer patients struggle to be able to work and experience/learn new tasks and skills as the exertion of these tasks is often too much for them and they therefore rely on the competence of others to complete these tasks for them. They are often unable to take part in social activities which can lead to a sense of loneliness, and they can also feel a lack of control over their body that “healthy” individuals take for granted, unfortunately a severe characteristic of the illness.

Self-determination theory (SDT) (Ryan & Deci, 2000) has been widely employed to understand topics in health psychology. SDT encompasses the types of issues reported by lung cancer patients, asserting that all people have innate ‘basic psychological needs’ (BPN) for competence (their own but also that of those they rely on), relatedness, and autonomy, the fulfilment of which contribute to *self-determination* (the process for motivating and having a sense of control of one’s own destiny). According to SDT, “autonomy” reflects the need to engage in behaviours with a sense of choice or personal endorsement and is often referred to as the degree of self-determination of one’s behaviour (Deci & Ryan, 1985); “competence” represents the need to feel optimally challenged and capable of achieving one’s goals by successfully navigating one’s environment (White, 1959); “relatedness” reflects the degree to which an individual feels connected to and understood by others in important domains of life (Baumeister & Leary, 1995; Ryan, 1995). When an individual fulfils their BPNs they experience positive physical, psychological and social well-being (Ryan & Deci 2017; Reeve, 2012). Of course, the

negative alternative also exists, and herein lies the threat for lung cancer patients: if they and their healthcare team are not working optimally together – perhaps because of communication barriers – unmet needs will detract from the fulfilment of their BPNs, and a diminished sense of self-determination and motivation towards coping with the challenges they face in living with cancer will ensue. From the nurse's perspective this could be due to a low support self-efficacy (Bandura, 1994) that reduces their belief in their ability to communicate in an autonomy-supportive manner that fulfils the patient's BPNs. The nurses fulfil their need for relatedness through emotional support and therapeutic/empathetic communication. In addition, the patient's autonomy is fulfilled through educational communication that supports and promotes the patient's self-care away from the hospital or the support-line (Peplau, 1991).

The poor motivation (and in the case of lung cancer patients, their reduced physical capability) to engage in activities or mindsets that could combat this becomes restricting, preventing them from overcoming their issues, a feeling that is unfortunately all-too-familiar for cancer patients. Patients can begin to feel that they are losing control of their lives: in SDT terms this reflects an external locus of control and loss of autonomy, which counteract motivation and coping efforts. When Burg et al. (2015) analysed cancer survivors' responses about unmet needs, personal control emerged as a dominant theme. This theme developed from responses expressing needs related to maintaining autonomy and independence while dealing with their physical problems and functional limitations. The frequency of this unmet need was significantly higher in men and older survivors. Of course, non-survivors are unable to reflect on the extent to which their support needs were met, and perhaps due to ethical issues, longitudinal research across the cancer trajectory has not adequately captured this data. These unmet support needs compounded by the stress of cancer treatment (e.g. chemotherapy/radiotherapy) can significantly reduce the QOL of the patients (Heydarnejad, Hassanpour, & Solati, 2011). Research suggests that many at-risk patients are still not receiving the psychosocial support services that they need (Zebrack et al., 2015).

Understandably, patients often phone a support line or come to their lung cancer clinic in a distressed state, and it can take time for the nurse to get to the “root of the problem” – time that is limited and pressured. It may be that their primary reason for calling/visiting is not covered in that time. Consequently, the patient’s support needs may be thwarted, their outlook on treatment and their self-management negatively impacted, and their distress may not be sufficiently alleviated (with all the attendant risks). A validated QOL measure administered prior to clinic, whether electronically or in pencil-and-paper form, or that the caller can submit online prior to calling the support line or alongside requesting a call-back, should improve the quality of nurse-patient communication, theoretically *directing* their interaction and improving its effectiveness and efficiency. Indeed, as intended, patients’ responses to such measures have been shown to act as a prompt for nurses to broach areas of particular concern that have been identified by the patient (Vachon, 2006). Such a tool would theoretically support the autonomy needs of the patient – *they* have control over how their time with the nurse is spent; they are actively engaged in their care – and the competence needs of the nurse, by giving them material to help with preparation and confidence that they are equipped to meet their patient’s true underlying support needs. A recent systematic review demonstrated that distress screening and relevant referral improves recognition and management of psychosocial distress and reduces psychological morbidity in patients with cancer (McCarter et al., 2015). However, referral is not always necessary. Lynch, Goodhart, Saunders and O’Connor (2010) found that some individuals identified as distressed turned down referral to psychosocial services because conversations with either the doctor or the Clinical Nurse Specialist (CNS) had left them with “a good understanding of their distress and how best to manage it” (p.199). This could suggest that simply talking to the patients about their responses to a QOL measure could alleviate symptoms of worry and anxiety and potentially reduce referral rates and associated costs.

Internationally, much descriptive research has used questionnaire-based tools to quantify psychological distress, psychological well-being, and QOL in cancer patients, and some research has evaluated their use in practice and/or intervened to

improve their use. Macmillan Cancer Support and NICE advocate the systematic use of such tools but we are far from widespread recognition and implementation of this guidance. This could be linked to the finding that cancer care professionals tend to still only partially endorse spiritual and cultural assessment and management of psychosocial assessment as important priorities for high-quality services (Bickel et al., 2016).

1.2. Lung Cancer: Symptoms, Diagnosis and Treatment

Lung Cancer commonly begins with a symptom-free course before non-specific and bothersome symptoms arise, such as a persistent cough, coughing up blood (haemoptysis), chest pain, weight loss, shortness of breath (dyspnoea), feeling tired or weak and infections such as bronchitis and pneumonia. Unfortunately, because of the initial symptom-free course, lung cancer is often diagnosed at an advanced stage with the symptoms having a significant impact on QOL (Corner, Hopkinson, Fitzsimmons, Barclay, & Muers, 2005). The poor prognosis resulting from the late diagnosis also negatively affects patient psychology (Lehto, 2017). On top of this, the effects of the treatment, specifically chemotherapy, have also been found to have a major negative influence on an individual's QOL (Damm, Roeske, & Jacob, 2013).

The most common form of lung cancer is non-small cell lung cancer (NSCLC) which accounts for roughly 80-85% of all cases (Molina, Yang, Cassivi, Schild, & Adjei, 2008). NSCLC has different stages (I, II, III, IV) based on the size of the primary tumour and if and where the cancer has spread. There are different forms of NSCLC such as adenocarcinoma – which begins in the cells that form the lining of the lungs and has gland-like properties – and squamous cell carcinoma, which begins in thin, flat cells that line passages of the respiratory tract. However, the fastest and most aggressive form is large cell neuroendocrine tumours which form in the hormone-releasing cells; the hormone delivers messages to organs and neuroendocrine tumours create an overabundance of the hormone (Klimstra, Modlin, Coppola, Lloyd, & Suster, 2010).

The other 15-20% of lung cancer cases are neuroendocrine tumours with cells that are smaller in size than most other cancer cells, known as small cell lung cancer

(SCLC). This type of cancer is fast growing and spreads to other parts of the body with the two stages of SCLC being limited and extensive (Kalemkerian et al., 2011). TNM staging is one of the most common ways of assessing how big the tumour is and how far it has spread (Brierley, Gospodarowicz, & Wittekind, 2016): TNM describes the size of the Tumour, whether there are cancer cells in lymph Nodes, and whether the cancer has spread to different parts of the body (Metastasis) (Rami-Porta, Crowley, & Goldstraw, 2009). This form of staging mainly refers to NSCLC – as previously mentioned the terms ‘limited’ and ‘extensive’ refer to the different types of SCLC (Rami-Porta et al., 2009). SCLC is described as limited if cancer is contained in a single area that can be treated with radiotherapy, which means that with lung cancer the cancer is only in the lungs and possibly in nearby lymph nodes (Fried et al., 2004). If SCLC is described as extensive this means that the cancer has spread beyond a single area that can be treated with radiotherapy (Slotman et al., 2007). It might have spread within the chest (to the other lung or lymph nodes) or to other parts of the body, or there may be cancer cells in the fluid around the lung, known as malignant pleural effusion (Roberts, Neville, Berrisford, Antunes, & Ali, 2010).

Chemotherapy can cause maladaptive coping and abnormal illness behaviours (e.g. irritability, denial, disease conviction; Grassi, Rosti, Albieri, & Marangolo, 1989) which have been associated with psychiatric conditions, negative effects on treatment adherence, health behaviour and QOL (Caruso et al., 2017). Responses to chemotherapy have been shown to decrease when cancer patients are diagnosed with depression, suggesting a possible relationship between psychological disorders and a higher risk of recurrence and decreased overall survival (Giese-Davis et al., 2011). So, whilst anti-cancer therapies may prolong survival, it often comes at the expense of QOL. It is, therefore, important to find a balance between survival and QOL when patients are selecting their treatment (Koller et al., 2015).

1.3. Self-Efficacy and Oncology Nursing

Social Cognitive Theory (SCT) (Bandura, 1977), which began as the Social Learning Theory (SLT) (Bandura, 1977), states that humans learn in a social context

through interaction between themselves, the environment and their behaviour. SLT was developed based on five constructs: (1) *Reciprocal Determinism* – the dynamic and reciprocal link between the learned experiences of an individual (the person), their external social contexts (the environment), and their responses to stimuli when striving to attain personally important goals (the behaviour); (2) *Behavioural Capability* – the knowledge and skills that an individual holds that allow them to perform certain behaviours, they learn from the consequences of their behaviour; (3) *Observational Learning* – reproducing the behaviours of others through observing them, this is considered “modelling” of behaviours; (4) *Reinforcements* – this is based on the response that an individual gets to their behaviour (internally or externally and positive or negative) and determines whether they then reproduce that behaviour; and (5) *Expectations* – this is how an individual believes that their actions will be perceived and the anticipated consequences of these, outcome expectations are either health-related or not. Nurses undergo their initial training being taught in the classroom and during placements, by tutors, supervisors, and patients alike. Due to the different individuals involved in this interpersonal context no two initial training course experiences will be the same, yet the goal of passing the course is a shared one. Nursing is a vocational qualification and students “learn by doing” in a scaffolded environment – there are often very powerful lessons to be learned by the consequences of their developing nursing practices. Nurses will form judgements of their skills and knowledge based on how they compare to influential role models and the reinforcements their behaviours elicit, forming expectations of the outcomes they should expect from their various practices. Some nurses will choose to specialise in cancer nursing, which will expose them to a *new* work context yet one that shares much in common with the wider profession of nursing. SCT is thus a valid lens through which to investigate the experiences of cancer nurses and to learn about the transferability of valuable insights between support line and face-to-face nursing.

Self-efficacy theory was later added during the development of the SCT. Self-efficacy and self-confidence are different constructs, but self-confidence is often used to describe things that more accurately reflect factors which impact an individual’s self-efficacy judgements for a given task rather than their global self-confidence, and

as Lundberg (2008) states, authors often use the term self-confidence over self-efficacy due to its greater familiarity amongst readers. Bandura (1994) defined self-efficacy as “people’s beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives” (p. 1). These beliefs are important determinants of how individuals feel, think and motivate themselves and ultimately how they act (behave). When considering an oncology nurse’s ability to care for their patients, and the benefits to the patient, it is vital that the nurse has a sense of self-efficacy surrounding these abilities (Hoffman, 2013). There are four major processes that are considered to produce self-efficacy beliefs and the effects associated with those: these are *cognitive*, *motivational*, *affective* and *selection* processes (Bandura, 1994). A cognitive process is the mental action or process of acquiring knowledge and understanding through thought, experience and the senses. The stronger an individual’s perceived self-efficacy, the higher the difficulty of goals that people set leading to a greater commitment to completing them. The motivational processes help guide people’s actions by developing beliefs about what they are capable of – they determine the goals that are set, the effort put in to achieving them, perseverance through set-backs and resilience to failures. Affective processes are important in determining how we regulate our emotional states and the resulting emotional reactions. Selection processes refer to how the activities and environments that individuals choose are influenced by their efficacy beliefs, avoiding those they believe to exceed their capabilities and involving themselves in those that they believe to be within their skill set and capabilities, thus developing different competencies, interests and social networks. A nurse’s self-efficacy has been shown to play a significant role on their processes (Robb, 2012; Alavi, 2014).

Efficacy expectations can be defined as “the conviction that one can successfully execute the behaviour required to produce the outcomes” (Bandura, 1977, p.193). One’s efficacy expectations are considered to vary along three dimensions: the *magnitude* of their self-efficacy for the task reflects the difficulty level they believe themselves to be capable of performing at; the *strength* of these expectancies refers to how convinced they are that they can perform a certain

behaviour and meet their goal; and *generality* describes how much success or failure in specific experiences can influence self-efficacy expectations in similar future behaviours and contexts. Furthermore, these efficacy expectations were thought to originate from particular sources which Bandura described as: *performance accomplishments* – based on the individual’s own mastery experiences and which will raise efficacy expectations should they be repeatedly perceived as successful; *vicarious experiences* – when efficacy information is gained from observing the completion of a task by another individual as “modelling displays convey information about the nature and predictability of environmental events” (Bandura, 1982, p.127); *persuasion* – when teachers, coaches and/or peers employ techniques to influence the learner’s behaviour, with the credibility, prestige and expertise of the persuader influencing the impact of these techniques; and *physiological states* – particularly how arousal affects behaviour through the efficacy expectations derived from the information with which the individual is supplied. Maddux and Gosselin (2003) later added two other sources of self-efficacy: *imaginal experiences* – the individual’s ability to perform imagery; and *emotional states* – the control the individual has over their emotional symptoms.

The NHS released guidance on the roles and responsibilities of cancer CNSs (Strategic Clinical Network, 2015) and stated that there are four main aspects to the CNS role in oncology: clinical/direct patient care; leadership and collaborative practice; improving quality and developing practice; and developing self and others. When considering these aspects in relation to self-efficacy, it is clear that the CNS role is considered one of the most challenging and difficult. The nurses must, therefore, believe themselves to be capable of handling the associated challenges (*magnitude*), they must have a strong belief in their ability to perform their roles (*strength*) and these beliefs need to transfer across all their different roles (*generality*). Nurses high in self-efficacy see obstacles not as a threat, but rather as an opportunity (Zhang et al., 2015). Instead of showing task avoidance behaviours in certain situations, they look to overcome the difficult situation (McLaughlin, Moutray, & Muldoon, 2008). This highlights the importance of the magnitude of their self-efficacy and being able to

generalise their self-efficacy to these difficult situations by using examples of successful communication and delivery of care from past experiences.

For oncology nurses to work at their optimum and provide the best care for their patients, their own mental health and well-being needs must be met. These nurses are at increased risk of psychological distress due to emotional stress and the morbid nature of their role (Moya del Pino, 2012), and are at particular risk of burnout, compassion fatigue and moral and occupational distress (Wahlberg, Nirenberg, & Capezuti, 2016). However, self-efficacy can be considered a positive resistance resource that can buffer the effects of stress (Bisschop, Kriegsman, Beekman, & Deeg, 2004) and has been shown to mediate the relationship between stressful events and symptoms of depression (Maciejewski, Prigerson, & Mazure, 2000). As well as protecting the nurses, self-efficacy has also been found to have a positive significant relationship with a nurse's clinical competency (Yoo, Son, Yoo, & Hong, 2006; Mohamadirizi, Kohan, Shafei, & Mohamadirizi, 2015). The self-efficacy of nurses is considered an important aspect in how they behave in their role and their desire to achieve successful/beneficial outcomes with their patients.

1.4. Communication in Oncology Nursing

“Oncology nurses across all areas of practice including clinical care, research and education, can play a significant role in achieving positive outcomes by being a part of the paradigm shift to meet the dynamic needs of cancer patients with effective patient-provider communication” (Jenerette & Mayer, 2016, p.140).

Communication is an essential part of the patient-centred focus, and is defined in the present study as a two-way process involving the exchange of information, thoughts and feelings among people using speech or other means (Kourkouta & Papathanasiou, 2014). It also assists in the performance of accurate and consistent nursing work, ensuring both the satisfaction of the patient and the protection of the nurse (Kourkouta & Papathanasiou, 2014). As the psychosocial aspect of cancer care is the main focus of the present research, the quality of the communication that nurses have with their patients is considered a crucial component in the identification

of clinical levels of psychological disorders (e.g. depression). Many cancer patients do not often expect to have emotional discussions or counselling as part of their psychosocial care from their nurses but appreciated it when nurses paid attention to this (Chan, Wong, Cheung, & Lam, 2018). Patient-centredness is considered one of the six core elements identified by the Institute of Medicine (IOM; 2001) as important for high-quality health care. As long as the information shared is accurate (Repetto et al., 2009), most cancer patients, particularly men, prefer and expect full disclosure of their prognosis and diagnosis (Rao et al., 2016) even if the information is negative, stressful or extremely troublesome (Tuckett, 2004). However, it has been shown that patients were more at risk of developing an affective disorder when they perceived the information provided about their treatment and illness to not match their needs (Fallowfield, Hall, Maguire, & Baum, 1990).

The patient conveys their fears and concerns to the nurse and helps them make the correct diagnosis. The nurse takes this information and in turn transmits other information back to the patient with discretion and delicacy as to the nature of disease, advising treatment and rehabilitation plans for health promotion (Papagiannis, 2010). Therefore, effective and caring communication is essential for: establishing therapeutic relationships; providing accurate, consistent information about the diagnosis and treatment; and empowering patients and families to make informed decisions, with confidence in the care provided (Angelini, 2011). It has also been shown that effective and compassionate communication between clinicians and patients has been associated with an improved compliance with medication regimes and treatments, patient coping and decision making (Breaking Bad News Foundation, 2016). A study on communication challenges that oncology nurses face further stated that effective communication in oncology settings has been shown to have benefits in terms of increasing the overall well-being of patients and healthcare professionals, improving treatment adherence, psychological functioning and patient recovery (Banerjee et al., 2016). By having an effective communication style, the nurse is able to meet the support needs of the patient (Sibiya, 2018).

Nurse communication is an ongoing process including non-verbal communications, such as facial expressions, gestures and posture (Evans, 2003). The

support and care provided through the discussions can be improved by the nurse being sensitive to the patient's verbal, physical and emotional cues (Ptacek & Ellison, 2000).

Focus groups were conducted with experienced paediatric oncology nurses (five or more years) to understand their perceptions of communication during palliative care and end-of-life care (Montgomery, Sawin, & Hendricks-Ferguson, 2016). The experience of the nurses provided them with the knowledge and skills to fulfil their roles of communication, caring and advocacy for children and their families. This is possible if the nurse: understands the evolution of palliative care and end-of-life care; has developed their intuition; has expanded the essence of their caring; acts as a committed advocate; and if they value the individual responses of grief.

Nurse perspectives of palliative care/end-of-life (PC/EOL) communications with paediatric oncology patients produced six themes (Hendricks-Ferguson et al., 2015). Hendricks-Ferguson et al. found that nurses believe they have a sacred trust to care for the patient and their family by staying committed to providing quality PC/EOL care and having a desire to foster meaningful family memories during this period. However, nurses often felt burdened by role tension and uncertainty around communications related to PC/EOL. They struggle with the unknowns as they have to bear witness to repeated and extended difficulties for the patient and their family, causing feelings of trepidation and uneasiness when dealing with emotional responses during PC/EOL care and continued uneasiness with the personal responses to a patient's death. Having an understanding that the process of EOL care is complex and that there can be some difficult learning curves when preparing the family for a patient's death is an important consideration for oncology nurses. Nurses look to learn about the process of death, EOL and the best communications practices from mentors – however, this process is a life-long journey. Finally, Hendricks-Ferguson et al. found that nurses must maintain hope and minimise the emotional distress caused to a patient. This can be achieved through a commitment to support nurses caring for patients during PC/EOL, including support from their multidisciplinary team members.

Despite acknowledging positive aspects of their interactions, nurses are still often self-critical of their communication abilities (Bumb, Keefe, Miller, & Overcash,

2017). In fact, healthcare professionals have previously admitted to being unsure about how to establish the information that their patients require (Maguire and Faulkner, 1988). Nurses' uncertainty over their ability to talk openly with patients prevented them from using interview behaviours known to increase patients' disclosure of concerns (Wilkinson, 1991), and due to their behaviours inhibiting discussion, the concerns of patients remained undisclosed, thereby potentially raising the risk of developing an affective disorder (Fallowfield et al., 1990).

Other research has shown that oncologists infrequently respond to the patients' cues, despite them tending to express negative emotions during consultations (Adams, Cimino, Arnold, & Anderson, 2012; Morse, Edwardsen, & Gordon, 2008), and patient complaints about healthcare professionals focus on the perceived failure of communication and the inability to sufficiently convey a sense of care (Lussier & Richard, 2005; Moore, Rivera, Bravo-Soto, Olivares, & Lawrie, 2018). The unpredictability and idiosyncracies of patients and their often fluctuating emotional presentations might help explain why nurses can feel insecure, threatened, even worthless, and ashamed that they feel this way, all negatively influencing their self-efficacy in the future (Vatne & Fagermoen, 2007). If left unaddressed, this can develop into an overwhelming burden, interfering with the nurse's ability to perceive patient concerns (Heaslip & Board, 2012) and causing them to distance themselves from openness and sensitivity when patients exhibit vulnerable behaviours. This can contribute to them acting in a non-caring way (Vatne & Fagermoen, 2007) which is obviously contradictory to the fundamental nature of nursing.

Despite this body of research being inherently negative, individuals who show success with their communication generally show good interpersonal relationships and high self-confidence (Hsu, Chang, & Hsieh, 2015). At least one empathetic response from the oncologist during a consultation showed significant improvement in patients' perceptions of communication with their oncologist (Malhotra et al., 2018). Research has found that nurses' communication abilities do not reliably improve with experience. Therefore, it is considered mandatory to complete Communication Skills Training (CST) during training programmes (Cantwell & Ramirez, 1997): it is possible to increase the interviewing skills, psychosocial attitudes and

beliefs regarding the power of communication of oncology nurses through CST (Fallowfield, Jenkins, Farewell, Saul, Duffy, & Eves, 2002). Furthermore, nurse training (general, not CST) has evolved over time to fit changing legislation, work conditions, patient expectations and more, so all nurses currently practicing will have received differing communication skills components to their training. Each health board, too, has different continuing professional development priorities, so post-basic training CST will also be different for each nurse. In any case, cancer nurses consider being comforting, supportive, empathetic and using appropriate touch to be facilitative behaviours for the affective side of their communication (Kruijver, Kerkstra, Bensing, & van de Wiel, 2000). However, Kruijver et al. also found that the emotional and life-threatening nature of cancer care complicated their communication and acted as a barrier to effective communication between the patient and nurse. They recommended, therefore, that CST be a structured and repeated process throughout a nurse's career.

1.4.1. Requirements for Effective Communication

Nurses are the members of the healthcare team who deal most with the provision of challenging information. They must, therefore, understand the specific concerns of patients and their families, how their information is being received and be able to provide clarification and additional information should it be required (Aungst, 2009). Effective communication requires an understanding of patient experiences and the nurse must be able to convey that they understand and accept the patient's message (Papadantonaki, 2006).

Nurse-patient communication includes encouraging the sharing of feelings and fears around the illness, treatment and prognosis; and helping patients and family members find a sense of control, meaning and purpose in life (Ragan, Wittenberg-Lyles, Goldsmith, & Sanchez-Reilly, 2008). Frankness and honesty are important requirements (Kourkouta & Papathanasiou, 2014) and one study found the most important patient-reported features of communication (Davison, Parker, & Goldenberg, 2004) to be: honesty; expertise of the provider delivering the bad news; and the type and extent of the treatment information provided. An appropriate

setting is also crucial and this requires a quiet and private area, free from interruptions, helping to convey respect and maintaining the dignity of the patient (Fujimori et al., 2005; Kaplan, 2010).

Confidence is an important factor in the communication of serious news and it is vital that nurses are confident in their PC/EOL care discussions (Hendricks-Ferguson et al., 2015). Practicing nurses become more confident over time when talking about PC/EOL care with patients and families (Dunn, Otten, & Stephens, 2005) but can also enhance their confidence through preparation, education and rehearsal (Mischelmovich et al., 2016).

Listening is crucial for high-quality nursing practice and requires concentration in order to perceive both the patient's verbal and non-verbal messages (Kourkouta & Papathanasiou, 2014). Nurses listen to assess the situation and problems facing the patient, enhancing their self-esteem, integrating both nursing diagnosis and process of care at all levels (Papadantonaki, 2006). The language a nurse uses is an important consideration, as patients can often be bombarded with technical vocabulary with little or no meaning to the patient (Kidd, Patel, Peile, & Carter, 2005). The language of the nurse should be at the level of the listener – who may be unable to access the nurse's scientific knowledge – so that they understand what they're being told (Papagiannis, 2003).

Across all cultures, the general preference of patients is that they have an experienced nurse who is empathetic and caring, offers hope and uses the correct/most appropriate wording in difficult conversations (Martins & Carvalho, 2013). Patients have been shown to desire clinicians who are well-trained and well-equipped to be sensitive to cultural needs during care (Dias, Chabner, Lynch, & Penson, 2003). Cultural differences mean that individuals from some cultures may prefer not to receive full disclosure in relation to their illness due to previous misconceptions of patients' wishes (Tse, Chong, & Fok, 2003; Tuckett, 2004) and lack of patient rights to decide on their own illness disclosure (Weunsch et al., 2013). Individuals from other cultures, however, may prefer complete disclosure, possibly to

help reduce the stigma surrounding cancer in their culture (Abazari, Taleghani, Hematti, & Ehsani, 2016; Abbszadeh et al., 2014).

1.4.2. Barriers and Consequences

Bad news is defined as any information that changes a patient's view of the future in a negative way (Buckman, 1984; Rosenzweig, 2012) and generally occurs when a diagnosis is shared with the patient. It can also include the communication of a new chronic diagnosis or information that the patient's condition has worsened (Rosenzweig, 2012). Patients can often react in anger, disbelief, moaning, aggression and denial of reality as defence mechanisms against bad news (Panagopoulou & Benos, 2004). The nurse is often the direct recipient of these reactions (Kourkouta & Papathanasiou, 2014).

Barriers to communication can result in compromised psychosocial care for the patient and family, due to nurses lacking the skills and knowledge to effectively use screening tools and approach sensitive topics (Chen & Raingruber, 2014). Palliative care nursing offers further challenges in terms of breaking bad news, such as the discussions of the cancer progression and time of survival. Unfortunately, these discussions tend to occur more often in palliative care settings, providing even more challenges (Bumb et al., 2017).

The message sent by the nurse may not always be the same as the message received, as interpretations are made according to the receiver's own code and not what the sender actually said or meant (Arapakis, 2006). In addition, one study showed that oncology nurses may not always be aware that they lack the adequate knowledge or expertise when communicating bad news (Adebayo, Abayomi, Johnson, Oloyede, & Oyelekan, 2013). Oncology nurses have also reported feeling uncomfortable and inadequate when talking to families about PC/EOL care (Davies et al., 2008), which can lead to hesitant disclosure of bad news, as the nurse looks to protect the patient and family (Al-Mohaimed & Sharaf, 2013; VandeKieft, 2001). Banerjee et al. (2016) also highlighted specific barriers that nurses face: dialectical tension – the conflicts that they have between opposing needs, whether they be

internal, a patient's own conflict or conflict between the patient and themselves; the burden of delivering bad news; lack of empathetic skills; perceived institutional barriers; challenging situations; perceived nurse-patient dissimilarities; poor communication among nursing team; inconsistent expectations between clinical staff; lack of empathetic care skills; challenge of assessing patient expectations; and initiating discussions about PC/EOL.

Nurses have expressed difficulties in communication with patients in oncology settings due to the challenges and risks occurring through the diagnosis and treatment process (Banerjee et al., 2017). This is because the nurses are required to support the patients and families after they receive bad news (Rassin, Levy, Schwartz, & Silner, 2006), respond to patients' and family members' strong emotions, e.g. anger (Pilsworth, Blankley, & Faull, 2014) and feel caught in-between patients, families and physicians (Wittenberg-Lyles, Goldsmith, & Ferrel, 2013). Oncology nurses have reiterated these findings in other studies, showing that difficult family dynamics, patient behaviours and end-of-life care issues can interfere with psychosocial care (Traeger et al., 2013). Confidence can be impeded if the nurse is worried about losing control of the conversation during the delivery of bad news, negatively impacting the nurse-patient relationship (Friedrichsen & Milberg, 2006).

A lack of privacy in emergency department settings or a lack of time in busy outpatient offices can hinder communication, resulting in lasting effects for the patients (VandeKieft, 2001). An oncology outpatient clinic was observed for 70 hours, paying attention to nurse-patient interactions and interviewing nurses for their perceptions (Prip, Pii, Moller, Nielson, Thorne, & Jarden, 2019). The findings showed that the type and quality of communication can be impacted by the outpatient setting, as communication is efficient but spatially bound and generally treatment-centred. This may lead to psychosocial concerns not being met.

A survey of 108 oncology nurses and 44 oncologists explored the difficulties they face when taking care of culturally and linguistically diverse patients, including their perceptions of the utility of cross-cultural training (Weber, Suilstrarova, & Singy, 2016). All of the respondents reported difficulties in communicating with diverse patients. The most problematic challenges reported were: an absence of translated

written material for patients; the absence of a shared common language; and approaching sensitive topics (such as EOL and sexuality).

Ineffective communication can cause unnecessary distress to patients as well as causing them to doubt practitioners' competence (Brock & Allen, 2000) and has been associated with increases in patient uncertainty, dissatisfaction with care (Hagerty, Butow, Ellis, Dimitry, & Tattersall, 2005), and increased rates of depression and anxiety (Donovan-Kicken & Coughlin, 2011). In fact, ineffective communication when breaking bad news can have lasting negative effects on the providers, patients, family members and nurses (Bumb et al., 2017). Patient dissatisfaction with difficult conversations often coincides with a pessimistic or unsympathetic approach from the information-giver (Martins & Carvalho, 2013), with parents of paediatric oncology patients having reported experiences of coldness, contradictions, poor attitudes and other avoidance behaviours from their healthcare practitioners (Davies & Connaughty, 2002; Hendricks-Ferguson, 2007). This can cause parents to feel abandoned and question the accuracy of the medical information they are receiving. For the nurse, it can cause discomfort, a lack of role definition, a fear of taking away hope and a lack of training for proper discussions (Newman, 2016). In addition, nurses had higher stress levels, lower job satisfaction, and were at increased risk of emotional burnout when they perceived their communication to be ineffective (Emold, Schneider, Meller, & Yagil, 2011). The giving of bad news can be stressful for nurses, resulting in symptoms such as increased heart rate and perspiration. These stress responses can last for some time after the event (Shaw, Brown, Heinrich, & Dunn, 2013) with burnout and compassion fatigue being potential ramifications, causing distressing consequences to the nurse's health and professional performance (Bumb et al., 2017).

Banerjee et al. (2016) made recommendations for improving nurse communication and the empathy surrounding this communication. They recommended that nurses identify and acknowledge their own emotions when caring for patients and that they improve their knowledge and skills on how to assess the individual and various communication needs of patients and family members. The nurse should look to understand and accept the mechanisms which serve the patient's

underlying anxiety and, therefore, respond with information, awareness and readiness to provide assistance (Kallergic, 2000).

1.4.3. Communication Skills Training

By providing specific communication skills training, communication between the nurse and the patient can be enhanced (Kourkouta & Papathanasiou, 2014). For instance, when engaging in a serious discussion with a patient, education and training on breaking bad news and the necessary follow-up support can improve the nurses' communication skills and their effectiveness during such discussions (Reed et al., 2015). Nurse communication training programmes are limited (Wittenberg, Reb, & Kanter, 2018) but have tended to focus on self-efficacy in empathetic responses (Pehrson et al., 2016) and discussing death, dying and EOL care goals (Coyle et al., 2015).

However, oncology nurses rarely receive formal instruction on communications as part of their clinical training (Newman, 2016) and training for communicating bad news to patients and families in practice environments is perceived as inadequate by many nurses (Paul, Clinton-McHarg, Sanson-Fisher, Douglas, & Webb, 2009; Al-Mohaimed & Sharaf, 2013; Ptacek & Ellison, 2000). Also, palliative care-focused communication has not been well addressed meaning crucial areas, such as how to include family members, discussing social, psychological and spiritual care topics and delivering care as a team, are not being covered (Ragan et al., 2008). This lack of communication skills training can cause difficulties in separating work and personal life, possibly transferring one's own problems on to the patient (Panagopolou & Benos, 2004). Nurses have stated a clear need for further communication skills training (Jors et al., 2016), including cross-cultural training. Weber et al.'s (2016) survey of cultural challenges that nurses and oncologists face identified a high level of interest for all aspects of a proposed cross-cultural training programme, including task-oriented skills, background knowledge, reflexivity and attitudes.

A Cochrane review of communication skills training for oncology health care professionals found that effective programmes focused on the acquisition of communication skills (Moore, Rivera Mercado, Grez-Artigues, & Lawrie, 2013). However, the studies reviewed were limited as they did not report whether there were nurses involved in the development of the programme or curriculum. They focused on general or basic communication skills and required longer time commitments from the nurses as they could take days or weeks to complete.

Banerjee et al (2017) developed a Comskil Training Programme which focused on three areas throughout the one-day curriculum: communication of empathy with patients and families; discussions of death, dying and end-of-life goals of care; and navigating through difficult family interactions. 90% of the nurse participants strongly agreed with five of the six evaluation items that were used to assess the usefulness of the course and the majority rated each individual module component as an aid to their learning. Overall, nurse self-efficacy improved through the training and in general there were good increases in the empathic skills of the nurses (including encouraging the expression of feelings, and normalising and praising patient efforts). These training programmes have thus shown their feasibility and acceptability in a major cancer centre with a significant impact on the participants' self-efficacy and their uptake of communication skills.

The COMFORT communication curriculum (Wittenberg & Goldsmith, 2016) is a train-the-trainer programme funded by the National Cancer Institute, aimed at improving patient-centred communication in oncology care (Wittenberg, Ferrell, Goldsmith, Ragan, & Buller, 2018). COMFORT is an acronym for the modules involved in the curriculum: **C**ommunication uses narrative clinical practices and person-centred messages to understand the patient's story and recognise task and relationship practices; **O**rientation and opportunity helps gauge health-literacy levels and gain an understanding of cultural humility to formulate a pathway of care; **M**indfulness involves remaining present in the moment so as to engage in active listening and understand nonverbal communication, as well as becoming culturally competent and adaptable to change; **F**amily helps to incorporate the family into care plans and recognise and understand the communication patterns and varying needs of family

caregivers; **O**penings improves the recognition of opportunities for discussions pivotal to the patient/family care, whilst being able to recognise and communicate in difficult/stressful moments; **R**elating explores uncertainty and the building of trust with patients/families to help realise their goals and link the care to QOL domains; **T**eam involves facilitating team meetings and improving communication and interdisciplinary collaboration (Wittenberg-Lyles, Goldsmith, & Ragan, 2010; Goldsmith, Wittenberg, & Ferrell, 2015). This curriculum has been shown to improve clinician self-efficacy, attitudes towards communication and reduced apprehension about communicating (Goldsmith & Wittenberg-Lyles, 2013; Goldsmith, Wittenberg-Lyles, Frisby, & Platt, 2015; Wittenberg-Lyles, Goldsmith, Richardson, Hallet, & Clark, 2013).

Banerjee et al. (2016) suggested that communication skills training should focus on being able to effectively communicate empathy and that when practicing these communication skills, nurses should do so in difficult or challenging interactions. Simulation training provides these difficult and challenging environments for nurses to refine their abilities to have emotional, sensitive and life-altering discussions (Tobler, Grant, & Maczinski, 2014). In fact, research has investigated the role of simulated patients or scenario-based training that focus on nurse-patient communication skills. A review of 19 studies (MacLean, Kelly, Geddes, & Della, 2017) found that the use of simulated patients was either in an active role where they were directly involved in the instruction of communication or in a passive role where they helped to evaluate the effectiveness of a communication skills programme. Simulated patients were used in these contexts to improve nurse-patient communication skills training and direct the focus towards these more challenging clinical interactions. Traditional classroom training/courses have been compared with scenario-based simulation training around the effect of these different formats on the improvement of nurses' communication competency, communication self-efficacy and communication performance (Hsu, Chang, & Hsieh, 2015). Nurses and independent raters found the scenario-based simulation training to be more effective, concluding therefore that scenario-based simulation training could increase the learner's/nurse's satisfaction and their communication performance. However, patients reported no

significant difference in communication performance between the two training formats, but should the scenario-based simulation course improve the perceived competence and self-efficacy of nurses, then it is likely a worthwhile inclusion in nurse communication skills training.

1.4.4. Therapeutic Relationships

Good communication is considered an inalienable right and prerequisite for building genuine and meaningful relationships between patients and nurses (Diamantopoulou, 2009). As a therapeutic relationship between the nurse and patient begins from first contact, it is important that conversations are held in appropriate conditions (Kourkouta & Papathanasiou, 2014). Providing a peaceful environment with no external distractions and appropriate confidentiality is a key element of a therapeutic relationship (Kourkouta & Papathanasiou, 2014). Courtesy and kindness are also requirements for the nurse in building a therapeutic relationship (Fakhr-Movelidi, Negarandeh, & Salsala, 2013). Therefore, good personal relationships are described as the ability of the nurse to ask questions with kindness and provide information in a way that doesn't scare, that demonstrates interest, creates feelings of acceptance, trust and harmonious relationship (Papadantonaki, 2012).

Oncology nurse managers (11) were asked during focus groups for their perspectives of palliative care/end-of-life (PC/EOL) communication (Sawin et al., 2019). Statements from these focus groups were analysed and they found that when "Fostering a Caring Climate" there were three core themes that nurses felt they should follow and be aware of: the imprinting of the initial grief experiences and emotions of the patient; being constantly vigilant by assessing and optimising family-centred care; and promoting a competent, thoughtful and caring workforce.

One theory of communication that has been developed within nursing is Peplau's (1991) Theory of Interpersonal Relationships (Fleischer et al., 2009). Peplau stated that nursing is a unique profession with major responsibilities to provide direct care and to assist patients in integrating their hospital experiences into their lives after discharge. Peplau's theory defines nursing as an interpersonal, therapeutic process

that takes place when professionals, specifically educated to be nurses, engage in therapeutic relationships with people who are in need of health services.

Nursing is a process that is “serial and goal-directed” and has “orderly steps” necessary for success (Peplau, 1991, p.5). Thus, according to Peplau’s theory, the nurse-patient relationship must pass through three phases to be successful: (a) orientation; (b) working; and (c) termination. The orientation phase is when the patient realises that they need help and adjustment to current or new experiences, consequently providing the nurse with essential information about the patient (i.e. their unique needs and priorities). To facilitate the patient’s awareness of their own feelings, nurses use “non-directive listening” which allows them to follow the patient’s lead, clarifying both the patient’s and their own thoughts through reflective and non-judgemental feedback. Peplau claimed that when initially meeting patients, nurses should greet them with the “respect and positive interest accorded a stranger” (p.44), continuing this professional courtesy throughout all phases. The aim is to have both nurse and patient pass quickly through this phase, so as to improve the relationship’s efficacy. Despite looking for a quick transition through this phase, it is also important that the patient be comfortable with their progress, as their experiences in this phase could impact perceptions through the other phases. The working phase accounts for the majority of the nurse’s time with the patient. Observations of the patient are made by the nurse to use during future advice for the patient and when providing physical care. Patients begin to assess their own situations and begin the process of recovery (although in the context of oncology, this recovery process may be longer or not possible at all). The nurses become more familiar to the patients, who no longer perceive them as strangers and begin to accept them as health educators, resource persons, counsellors and care providers. The working phase was originally divided into: identification, where the patient identifies the role of the nurse; and exploitation, when the patient starts to use/exploit the resources provided by the nurse. The final phase, termination, was previously referred to as the resolution stage and begins with planning the patient’s discharge. The success of this phase is dependent on how well patients and nurses navigate the orientation and working phases. A major part of this phase involves the nurse teaching the patient about symptom management and

recovery at home. Patients can then begin to integrate their hospital experiences with their everyday lives, a process that is assisted by a smooth transfer out of the hospital. This smooth transition is referred to as the “resolution” and occurs when the patient’s hospitalising issue is resolved to the point where they can be discharged. Again, when considering the application to oncology, there may not be a “resolution” for the patient and nurse; however, the education about symptom management and recovery from home is very important for oncology patients, as it provides them with a sense of autonomy and control that their illness may have stripped from them.

Once all of Peplau’s phases have been completed, including discharging the patient, there comes the integration. At the point of integration “the patient feels refreshed that in his time of troubles and helplessness, aid was actually forthcoming; this is a great fear of many people – that they may at some time be helpless and others will not care” (p.39). This integration has a summative characteristic as the nurses support the patient’s health integration through the skilful performances of their duties during the three phases of interpersonal relationships. Peplau’s theory has been successfully employed to guide nursing research (Forchuk, 1992; Peden, 1993; Stockmann, 2005), and was used to guide the current study.

1.5. Screening and Treatment of Psychological Distress

The NCCN and the guidelines that they produce are widely recognised as the criterion for clinical policy by clinicians in oncology in the US. The NCCN Clinical Practice Guidelines in Oncology: Distress Management recommend routine screening for psychological distress followed by assessment and/or referral to the appropriate services by those responsible for the cancer patients’ care (Adler & Page, 2008). Despite these evidence-based guidelines, screening and referral does not always routinely occur (Jacobsen & Ransom, 2007), another issue that needs to be rapidly addressed – this suggests that the lack of routine screening is a worldwide problem.

In 2015 the American College of Surgeons Commission on Cancer made it a compulsory criterion for accreditation for cancer centres to implement screening programmes for psychological distress. This has come after systematic reviews

conducted on the subject showed that distress screening and relevant referral improves recognition and management of psychosocial distress as well as reducing psychological morbidity in patients with cancer (McCarter et al, 2015).

Distress is considered the “Sixth Vital Sign” in cancer care, the others being measurements of pulse, respiration, blood pressure, temperature and pain (Bultz & Johansen, 2011). Distress is one part of the clinical significance criterion that is a qualifier for several mood disorders, including major depression and other adjustments disorders (Carlson, Waller, & Mitchell, 2012). The term distress is more easily understood, than other, more clinical terms, by patients and non-mental health clinicians, facilitating quick assessment through conversation or patient self-report. This less technical term carries less of the stigma that is so often associated with diagnostically clinical levels and is therefore more useful for cancer nurses and clinicians as it provides less of a barrier to communication (Carlson et al., 2012).

Consultations or clinical interviews would see a doctor or psychologist/psychiatrist using the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), which is considered the gold standard for assessing patients’ psychological distress (Thekkumpurath, Venkateswaran, Kumar, Newsham, & Bennett, 2009). The importance of these high-quality assessments is highlighted by the findings of one study: Mitchell et al. (2011) conducted a meta-analysis of 94 interview-based studies looking at the prevalence of mood disorders in oncological, haematological and palliative-care settings, and found that 30-40% of cancer patients suffer from a psychopathological condition, defined using the International Classification of Disease (ICD-10) or the DSM-IV. However, due to the time-consuming nature of interviews, it is not deemed feasible to implement this method routinely, hence the need for rapid and effective screening tools. It is, however, useful for research as it provides in-depth information/data to analyse against the results of the screening measures.

Despite organisations such as Macmillan and NICE recommending that screening for distress should be routine in all oncology units, it is often not commonplace. This is a familiar problem in the hospitals and oncology units around the Mid-Wales area. Current HDUHB operating procedures do not include routine,

standardised screening for psychological distress. As previously noted, cancer care professionals often have insufficient time to address the specific needs and issues of their patients, especially issues of distress, with one study finding that they actually tend to confuse clinical anxiety disorders (phobic avoidance, agitation, constant worry) with normal sadness and preoccupation, mistakenly believing it to be normal to feel sad or anxious because of cancer (Kissane, 2014). Unfortunately, this prevents proper identification of the emotional or psychological distress from which they may be suffering. A further finding of Kissane's (2014) showed that 30-40% of patients suffering psychological issues were not identified by their clinician and therefore not referred for onward clinical assessment. This can increase the risk of a shift towards more clinically "diagnosable" states (e.g. anxiety and depressive disorders), a risk that is already elevated by factors such as a previous history of psychiatric disorders and trauma, inadequate and poor social support, uncontrolled symptoms and gender (females are at greater risk; NCCN, 2017). Unidentified psychological disorders in cancer have also been associated with an increased risk of suicide (Anguiano, Mayer, Piven, & Rosenstein, 2012). If nurses have insufficient time or expertise to uncover these through their time-pressured conversations, then this indicates a need for either the use of tools that can identify these specifics or improved communication skills training.

Randomised studies have investigated the value of routine HRQOL assessments for patient management and outcomes and found that they have yielded less consistent and generally less favourable results than general practice (Kazis, Callahan, Meenan, & Pincus, 1990; Magruder-Habib, Zung, & Feussner, 1990; Taenzer et al., 2000; Wasson et al., 1992). However, improving patient outcomes is not always the only intention for many tools; another of the aims of many screening measures is to improve the quality of communication between the nurse and the patient. Several studies have reported improved detection of patients' problems (e.g. depression; Rubenstein et al., 1995) in comparison to standard practice – although other similar studies did not find any improvements (i.e. Dowrick & Buchan, 1995). However, the patients' responses to the measures have been shown to act as a prompt for nurses to broach particular areas of concern (Vachon, 2006). This is supported by findings

from one study where several physicians and/or patients reported that the availability of the HRQOL data facilitated communication (Mazonson et al., 1996). This could suggest that simply talking to the patients about their responses to screening tools could alleviate symptoms of worry and anxiety and potentially reduce rates of referral to clinical psychological services. A randomised trial found no difference in HRQOL when patient reports of HRQOL were just summarised and conveyed to the treating nurse compared with usual care (Rosenbloom, Victorson, Hahn, Peterman, & Cella, 2007), but other studies have suggested that if the information about elevated levels of distress provided to the clinician prompts them to make recommendations that lead to specific actions, then screening might make a difference (Boyes et al., 2006; McLachlan et al., 2001).

Detmar, Muller, Schornagel, Wever and Aaronson (2002) investigated the potential value of providing oncologists and their patients with timely, structured feedback on the patients' HRQOL during palliative chemotherapy treatment. The study had a longitudinal, randomised, crossover design with 10 oncologists (with a mean age of 44) and 237 patients receiving outpatient palliative chemotherapy. Patients in the intervention arm completed a standardised HRQOL questionnaire (specifically, the European Organisation for the Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core 30 (QLQ-C30)) immediately before each visit to the clinic. They were then provided with copies of the scores with an attached graphic summary profile. Significant increases in the frequency with which HRQOL issues were discussed occurred as a result of the intervention, with the most notable increase being in the discussion of less observable HRQOL issues (i.e. social functioning) or of a more diffuse, long-term nature (i.e. fatigue), likely alleviating worry and anxiety (Mazonson et al., 1996). Healthcare practitioners have been shown to often overlook these issues, leaving them unaddressed (Curt et al., 2000; Funch, 1988). The majority of patients and all the physicians involved in Detmar et al.'s (2002) study reported that the HRQOL summary profile was useful in facilitating communication and in enhancing physician awareness of patients' problems and favoured the continued use of the intervention as a standard part of the care they received or provided. These results support the use of standardised HRQOL

assessments in palliative cancer settings as a means of facilitating discussion of HRQOL issues and heightening physicians' awareness of their patients' problems. However, it seems that there needs to be some sort of structured feedback associated with the HRQOL summary for optimal responses to be seen.

Evidence would suggest that communication in cancer care may be suboptimal, in particular the empathy shown towards the emotional needs of the patients (Pollak et al., 2007) and the nurses' awareness of shifting communication needs and preferences across the cancer care trajectory (Thorne et al., 2014).

Screening is put in place to identify those who are distressed and those who are not. This is recommended to happen early in the treatment process and at regular stages throughout. However, as previously mentioned, literature still suggests that many patients are not receiving the psychosocial support services that they need (Zebrack et al., 2015). This could be due to oncologists and nurses lacking the skills to identify and discuss psychological issues (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001).

Using the NCCN's distress guidelines, Carlson et al. (2012) conducted a systematic review into the screening of distress and unmet needs in cancer patients, explaining that "distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears, to problems that can become disabling such as depression, anxiety, panic, social isolation and spiritual crisis" (NCCN, 2002, p.6). Carlson et al. (2012) also found that there are a number of promising new tools (e.g. Psychological Distress Inventory, Mood Thermometer and Emotion Thermometer) for assessing where a patient may be along this continuum but that they require independent validation to substantiate their clinical utility. A common theme amongst the distress screening questionnaires was a high negative predictive value (i.e. the tool is able to indicate those who are not distressed) but poor positive predictive value (i.e. not adequately indicating those who are distressed). Specifically, implementation of ultrashort screening measures is likely to result in many patients who are not distressed receiving inappropriate referrals (Mitchell, 2007). This means that currently, there is not a tool that is completely efficacious or that can be relied upon alone, and further follow-up is necessary. One of the main barriers that Carlson et al. found was concern that increased screening would lead to increased positive

screening cases which could overwhelm psychological services, as well as other necessary services.

Despite this, Hebert and Fillion (2011) found that nurses valued the training given to them prior to implementation. The training allowed them to have deeper conversations about problems that may not have been discussed otherwise. In the aforementioned systematic review, Carlson et al. (2012) concluded that the most successful studies include intensive staff training and suggested that non-specialist nurses must receive training prior to their involvement in the screening process. They also stated that if the barriers to implementation could be addressed there was the potential to improve identification of emotional disorders, facilitate communication and significantly improve QOL for cancer patients.

It is logical to assert that, for increased uptake of the screening tools to occur, it is important for the nurses to feel confident in their ability to communicate with their patients about the psychological issues they may be confronted with as a result (i.e. psychosocial support needs that may not have otherwise been disclosed by the patient).

1.6. Distress and QOL Screening Tools

Although there are a large number of distress and QOL screening tools and measures available, unfortunately the overall effectiveness of these tools remains unclear (McCarter et al., 2015). A few measures are favoured in research and clinical practice, e.g. the Distress Thermometer (DT), the Hospital Depression and Anxiety Scale (HADS) and the Functional Assessment of Cancer Therapy (FACT) (Vodermaier, Linden and Siu, 2009; Meijer et al., 2013). The tools come in different forms and are reported under different monikers – tools, instruments, measures, questionnaires, assessments, etc. Some come in questionnaire form and others, such as the DT, act as a visual analogue scale with an attached problem list. For instance, ‘needs assessment’ is defined by Carlson et al. (2012, p.1161) as “a strategy that focuses on identifying the unresolved concerns that patients are experiencing and determines if they require further assistance as well as the level of assistance they require.” Needs assessment

is a way of measuring the unmet needs of patients, providing a more comprehensive assessment of concerns and can be rather useful for high-risk patients in particular. It has also been suggested that supplementing regular distress measurements with needs assessment tools could have the potential to improve clinicians' ability to identify and manage the concerns of patients in a timely and appropriate manner (Sanson-Fisher, Carey, & Paul, 2009).

A number of these instruments are based on Patient Reported Outcomes (PROs) which are outcomes regarding the health of the patient and are directly reported by the patient (Strong, 2015); these instruments are known as PROMs. It is thought that they might contribute to a shift towards a more patient-centred care approach and improve the objective outcomes of the patients (Bouazza et al., 2017), such as better HRQOL, fewer emergency room visits and hospitalisations, longer duration of palliative chemotherapy, and improvements in both one-year survival and quality-adjusted survival (Basch et al., 2016). PROMs also appear to be a strong and independent factor in the prediction of survival from lung cancer by utilising them at the moment of diagnosis (Ediebah et al., 2014; Sloan et al., 2012). They are generally collected in the context of scientific research. However, to be considered acceptable scientific measures, PROMs must show good psychometric properties – they must be valid, reliable and responsive (FDA, 2009; Strong, 2015). The feasibility of these measures is also important (Bouazza et al., 2017) – there are practical aspects that affect this, such as cost and time, but also important to consider is the burden that the measures will place upon the patient and the staff implementing them. Bouazza et al. concluded that there was sufficient evidence to support the hypothesis that PROMs can play an important role as part of routine cancer care.

PROMs are rarely collected in clinical practice (Snyder et al., 2012) despite being considered essential tools for understanding the efficacy of a treatment and to serve as indicators of the impact of the disease and treatment on the patient (Acquadro et al., 2003). The poor uptake in the use of PROMs by clinicians has been found, in part, due to uncertainty over what they are assessing and low levels of self-efficacy about how they should be used (Norman, Dean, Hansford, & Ford, 2014). However, research has shown PROMs training programmes for child mental health

staff to improve their self-efficacy in using them, as it gave the staff members more time to practice and develop techniques for regular implementation (Edbrooke-Childs, Wolpert, & Deighton, 2014; Fullerton et al., 2018).

There is also convincing evidence for the improvement of communication between the patient and their healthcare professional, when PROMs are collected routinely (Chen, Ou, & Hollis, 2013). This systematic collection of PROMs also seemingly enhances the awareness of the physicians and shifts their focus more to the needs of the patient, resulting in better control of the symptoms (Basch et al., 2016). Previous studies also support this finding (Kotronoulas et al., 2014; Nicklasson, Elfstrom, Olofson, & Bergman, 2013). When PROMs are tailored for a specific patient population, the impact on patient outcomes is greatest. Conversely, the use of PROMs for screening unsuspected or unidentified problems is less effective in obtaining a positive impact on the outcome of care.

The length of the tool is another factor that can play a part in its acceptability. Ranging from ultrashort to long, healthcare professionals and researcher must make “a trade-off between a measure with adequate psychometric properties and one with a reasonable length” (Vodermaier et al., 2009 p.1484). Ultrashort and short tools (e.g. DT) are favoured in active oncology units where time is already limited, as assessment is rapid. However, this comes at a cost as whilst sensitivity to change in *levels* in distress is high they tend to have low to moderate specificity for the *actual degree* of distress the individual is experiencing. This means that patients that are experiencing high levels of distress may report similar results to patients with lower levels of distress, making it difficult to differentiate between the two, and therefore creating further challenges for healthcare professionals when it comes to ensuring appropriate referral to psychological (or other) services. To this end, shorter tools cannot be used alone to diagnose depression, anxiety or distress in cancer patients (Mitchell, 2010; Vodermaier et al., 2009). Therefore, high nurse self-efficacy is required to gain further understanding of the severity of the issue through effective communication. The nurse’s self-efficacy in this situation will be improved through previous mastery experiences of successfully identifying patient issues, as well as through vicariously observing colleagues being successful (Bandura, 1994). This is an important step when

moving from the orientation phase to the working phase of Peplau's Theory of Interpersonal Relations (1991) as it provides essential information and observations about unique patient needs and priorities that can aid the nurse in their interpersonal and therapeutic process, especially as they become more familiar to the patient.

The psychometric properties of longer tools are far superior to shorter tools – as a general rule they are considered valid and reliable measures. However, the time-consuming nature of these longer tools, particularly the scoring and interpretation of the results, increases the workload of already overworked healthcare professionals and is often a major reason for the lack of acceptance of these tools in a real-world oncology setting. That said, given, as mentioned earlier (Mitchell, 2007) that ultrashort measures are unlikely to possess the same accuracy as longer methods, it seems preferable to have more false-positive errors than false-negative errors come at the expense of brevity. The more time devoted by a nurse will help them to engage in a therapeutic relationship with their patient (Peplau, 1991). Heightened devotion through the use of longer tools also requires greater effort and perseverance from the nurse; however, this will improve their communication self-efficacy as they place greater emphasis on the motivational processes of their actions. Therefore, it is important for the nurse to have high expectations about the perception of their actions and the anticipated outcomes. The increased length of the tools could be seen as a barrier to effective and efficient nursing. However, nurses high in self-efficacy will see this as an opportunity and look to overcome the difficulty of the situation (Zhang et al., 2015; McLaughlin et al., 2008).

Preference tends to be given to disease-specific measures, as they are more sensitive to subtle changes (Patrick & Deyo, 1989; Pompili et al., 2011). The *European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire* (EORTC QLQ) – *Core 30*, and its modular supplement, *Lung Cancer 13* (C30 and QLQ-LC13), is considered the best tool for the measurement of HRQOL in lung cancer patients. This is due to the lack of criticism the tool attracts (Koller et al., 2015), and it is therefore generally recommended for use within research and more clinical settings (Damm, Roeske, & Jacob, 2013).

1.6.1. *Limitations of Screening Tools*

There is often controversy around the feasibility of implementing PROMs routinely. Some practical considerations act as pitfalls to implementation such as workload implications, the availability of training and support, as well as the potential price – some companies/organisations associate a charge with the use of the tools they develop (Bouazza et al., 2017). Unfortunately, despite the EORTC and FACT instruments being comprehensive, they may place a burden (e.g. time spent) on patients, especially those with advanced lung cancer. This issue of length has often meant that in many trials, only a minority of patients actually completed serial PRO assessments (Gralla, 2015). The strongest aspect of the LCSS is its brevity, which reduces the load on patients and staff alike (Hollen et al., 2013). However, this comes at a cost as the LCSS, similarly to the MDASI, does not encompass all aspects of HRQOL i.e. the psychological and social domains are not evaluated, two domains that it is essential to assess when considering the unmet support needs of the patient. LCSS also has no core module which means that the prevalence and severity of symptoms cannot be compared with other cancer types.

Despite this evidence, administration of self-reported HRQOL measures in outpatient clinic settings has been found to require only a modest investment in material and personnel and is acceptable to both patients and staff (Moore et al., 1997).

Assessment of a patient's QOL and identification of any psychological distress may not currently be up to the standards that patients require for benefits in their psychological well-being to be seen. This is despite previous research indicating that patients are significantly more likely to disclose information about their psychosocial functioning when their nurse or physician demonstrates more supportive behaviour (Levinson & Roter, 1995). Cancer patients suffer enough without their psychological needs being neglected, so it is the responsibility of us, as researchers, to improve the measures and services available to the people working on the 'front-line' of cancer care. This begins with correctly identifying any issues that the patients may experience throughout the treatment process. Once a reliable and accurate measure is in place, intervention methods can be designed and implemented to improve the QOL and

psychological well-being of the identified cancer patients. It would be hoped that this would also reduce the burden on other services outside the oncology unit, allowing for the whole system to benefit.

1.7. Aims and Research Questions

The overall aim of this thesis is to explore nurse perceptions of the relationship between their self-efficacy and the quality of communication had with cancer patients. The subsequent aims were: to learn from oncology nurse experiences, thus helping inexperienced nurses to develop their communication skills more efficiently; understand the barriers and facilitators of effective communication in oncology nursing, focusing on self-efficacy, competence and positive and negative patient outcomes; whether QOL measures could be perceived as facilitators to improved self-efficacy/communication; and to explore the hypothetical application of these measures to routine care. Therefore, the research questions were as follows:

Primary Research Question

1. What is the perceived relationship between nurse self-efficacy and the quality of communication had with their patient?

Secondary Research Questions

2. How does the nurses' perceived competence influence their self-efficacy in good communication?
3. What are the barriers and facilitators towards high perceived competence/self-efficacy?
4. Can the use of QOL measures aid nurse-patient communication via an enhanced sense of competence/self-efficacy for the precise task?

Chapter Two

Method

2.1. Methodological Stance: Epistemology and Ontology

Rather than using questionnaires, surveys, or other reductionist/positivist methods (Guba & Lincoln, 1998), the present investigation used one-to-one semi-structured interviews to gain a deep, rich, insightful understanding of the perceived role a nurse plays in a cancer patient's experience, particularly through the lens of their self-efficacy and perceived competence when communicating with the patient. The researcher took a phenomenological approach to this qualitative study because it aligns with his philosophical stance (interpretive epistemology and subjectivist ontology), the individualised nature of nurse experience to be explored during the interviews, and his corresponding research aims and questions.

Considered the 'fore-father' of phenomenology, Edmund Husserl (*Logical Investigations*, 1901; *Ideas*, 1913) was a mathematician-turned-philosopher whose main issue with philosophy and science was the uncertainties surrounding their observations and findings, with a strong epistemological belief that a person's experience was their fundamental source of knowledge. Husserl believed that to give science an absolute foundation we must first drive out all uncertainties that arise due to 'experience.' Experience forms the basis for scientific theory; however, experience is full of different types of assumptions, biases and misconceptions (Davidsen, 2013). So, how can we be certain about science when the scientific observations are based on such uncertain experiences? Husserl turned to the philosophy of René Descartes (e.g. *Meditations on First Philosophy*, 1641), who wanted to free philosophy and science of all bias and assumptions. From this, Husserl developed the idea of "bracketing out", where scientists and philosophers alike should lay aside all preconceptions and assumptions. Then philosophy and science can begin anew, with a clean slate. This approach became known as Phenomenology: the belief that our understanding and knowledge are grounded in the *manner in which we make sense* of our lived experience. The aim of this approach was to provide a rigorous and

unbiased study of *things* as they appear in the human consciousness and experience, affording the researchers an essential understanding of these phenomena (Sadala & Adorno, 2003). Hence, the use of interviews in the present study enabled the researcher to gain information on the participant's own experiences as this, as Husserl believed, is their fundamental source of knowledge and guide for their actions. How people perceive their experiences is, therefore, fundamental to how they make meaning of their truths, realities, and essentially their lives as a whole (Guenther, 2014).

Husserl's ideas about phenomenology were based upon exploring perceptions of the human experience. However, one of his most successful students – Martin Heidegger (*Being and Time*, 1927; *Contributions to Philosophy*, 1989) – believed that we must look beyond what is merely perceived as the human experience, concerning himself with how we might go about analysing what it is to be human. He rejected epistemology – the nature and scope of knowledge and justification and the rationality of belief (Turri, 2013) – and instead adopted ontology – the science of *being* (Reiners, 2012). Heidegger stated that “We are ourselves the entities to be analysed” (*Being and Time*, 1927, p.42). If we are to explore questions of *being* then we must start with ourselves, by looking at what it means “for us to exist.” He also stated that “the furthest horizon of our being is death,” meaning that everything we can do, see, or think takes place within this horizon and we cannot see beyond it. The aim of the interviews conducted for the present study was to gain an understanding of oncology nurse self-efficacy and the quality of communication had with patients, with a specific focus on QOL issues. The researcher believes that to achieve the best understanding we must delve beyond the surface meanings (without writing them off) of what has been said to fully interpret the words and beliefs of those interviewed to discover the underlying meanings behind them – going beyond the individual's own “horizon.”

A student of Heidegger's – one Hans-Georg Gadamer (*Truth and Method*, 1960) – based his philosophy on the Hermeneutic approach, which drew comparisons with phenomenology. Groundwork for Hermeneutics was laid by German philosopher Friedrich Schleiermacher (*On Religion: Speeches to Its Cultured Despisers*, 1799), but it was another German philosopher, Wilhelm Dilthey (*Introduction to the Human*

Sciences, 1883), who described interpretation of the individual's experience as taking place within the "Hermeneutic Circle." This interpretive approach seems to be an important factor in the differentiation of Husserl's Phenomenology and Heidegger's, with Husserl focusing on *descriptions* of individual experience whereas Heidegger was interested in *understanding* the experiences of the individual. The only way to fully understand individual experiences is to interpret the deeper meanings or reasons behind certain behaviours and social interactions. By delving deeper into the meaning of certain aspects of life and being, and as we reach deeper levels of understanding in this area, our sense of life and being may also change. Changes in how we make sense of the world (life and being) can then lead to changes in how we understand the initial aspects that were explored. Indeed, the present researcher's perception of the "life world" of the study's participants naturally evolved during the research process, and he was able to use this learning to his analytical advantage when re-reading through earlier interview transcripts having already completed their initial analysis. Heidegger was a great proponent of the interpretation process beginning with what we know. Thus, changing our initial thoughts alters what we know and from where we begin the process of interpretation – this is the "Hermeneutic Circle."

As beings we exist in particular historical eras or, as Heidegger says, we are "temporal beings." This means that we understand the world through interpretation and any particular interpretation occurs during 'your' particular historical era. Thus, anyone making interpretations brings biases and prejudices with them – they are influenced by the historical era. These prejudices and biases prevent understanding of things outside that individual's history and culture. So, we can never reach an absolutely objective perspective. These prejudices and biases do act as our starting points however, which as Heidegger explained was integral to interpretation of the world. Through the "Hermeneutic Circle" we attempt to understand these particular prejudices and biases so our overall understanding can deepen and eventually our prejudices/biases can be altered or removed. Hence, when analysing the acquired interview data the present qualitative researcher (a) sought to question his own "sense of life and being" and the meanings he attaches to the nurse role, so that he could more clearly interpret the surface *and* deeper meanings that nurses' stories

depicted, and (b) equally, attuned himself to the sense-making opportunities that the nurses took advantage of when telling him their stories.

2.2. Procedure

2.2.1. Study Design

The research project included a preparation stage which involved the development of the line of questioning for the interviews exploring nurse perceptions of the relationship between their support self-efficacy and the quality of communication had with cancer patients (i.e. the primary research question). This process followed the five phases that Kallio, Pietila, Johnson and Kangasniemi (2016) outlined for design of a semi-structured interview guide: (1) identifying the prerequisites for using semi-structured interviews (e.g. when interested in studying “people’s perceptions and opinions or complex...or emotionally sensitive issues,” p. 2959); (2) retrieving and using previous knowledge (i.e. a conceptual basis for the interviews was created via a critical appraisal of previous knowledge located in the relevant literature); (3) formulating the preliminary semi-structured interview guide; (4) pilot testing; and (5) presenting the complete semi-structured interview guides to the nurse participants (see Appendices 1 and 2). From a practical point of view, this involved separating the interview into two sections: nurse experience (research questions 1,2 and 3); and QOL measures (research question 4).

Step 3 followed Spradley’s (1979) guidance on descriptive questioning. He outlines the use of ‘Grand-Tour’ questions as a good starting point for interviews. Grand-Tour questions ask the participant to give a verbal tour or “voyage” of something that they know well – in this case, their career in nursing and what led them to work in oncology, helping to explore and answer research questions 1, 2 and 3. Grand-Tour questions are useful for building rapport and gradually encouraging individuals to talk in a relatively focused manner. Some of the comments participants make offer the opportunity for further exploration on a specific topic – these are known as ‘Mini-Tour’ questions. Similarly, ‘Example’ questions take a single act or event that the individual has identified and ask them to give a detailed example of

this. The examples they give can lead to interesting and note-worthy stories that may not have been discovered otherwise. 'Experience' questions were also utilised, asking the participants for any experiences they have had in a particular setting. They are inclined to be open-ended and often slightly more difficult to answer, and tend to elicit uncommon events rather than recurrent, routine ones. This means they are best used after a number of 'Grand-Tour' and 'Mini-Tour' questions, as the participant is likely to feel more at ease by this point. This form of questioning was particularly pertinent to this study as focus moved towards the nurses' experience of communicating with patients about their QOL issues (including psychological distress), QOL assessment and subsequent actions taken by the nurse to address the identified issues (research question 4). The present investigator attempted to establish a rapport with the individual at the beginning of the process by introducing themselves and showing appreciation and empathy for the nurse taking time out of their busy schedule to participate in the study.

Finally, Spradley suggested the use of 'Native-Language' questions which allow the investigator to understand the common words and phrases used by the individuals immersed in a specific setting/environment – in this case a Lung Cancer clinic. These are also useful for developing rapport with the participants, as the investigator can ask questions in their "language." With the assistance of gatekeepers within Hywel Dda University Health Board and Tenovus Cancer Care, the primary researcher visited lung cancer clinics and chatted informally to lung cancer care providers to learn this native language (e.g. Ty Geraint and Meurig Ward at Bronglais Hospital in Aberystwyth). Following guidance from a member of Tenovus Cancer Care, the investigator concluded the interview by asking the participant to sum up which aspect of the discussion was most important to them, and then how and why they reached this conclusion.

By conducting a pilot study of the topic guide, the researcher was able to ensure that the most appropriate questions were included, and any inappropriate or unnecessary questions were removed (Galleta & Cross, 2013). This process also identified any researcher effects or bias (e.g. leading questions) that might have influenced the interviewees' responses, so that they could be addressed, perhaps

simply by modifying the wording of certain questions. Participants were only required to attend one interview, which lasted 45 minutes to an hour and was audio-taped to ensure no useful information was missed in the quest to answer the research questions.

2.2.2. *Quality of Life Measures*

The purpose of the QOL measures in this study was to act as a reference that stimulated and focused further discussion with participants about QOL assessment, needs support, and communication with cancer patients. Therefore, a review of the relevant literature allowed the two most validated tools for assessing psychological distress and the QOL of lung cancer patients to be selected. The two tools that were selected were the *European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire – Lung Cancer 13* (EORTC QLQ-LC13; Bergman et al., 1994) (see Appendices 3 and 4) and the *Functional Assessment of Cancer Therapy – Lung* (FACT-L; Cella et al., 1995) (see Appendix 5). Patient Reported Outcome Measurements (PROMs) Group Oxford (2010, p.18) concluded that there was “a more robust body of evidence” for the EORTC QLQ-LC13, followed by the FACT-L, than any of the other lung cancer-specific instruments.

EORTC QLQ-C30. A project was launched in 1986 by the European Organisation for the Research and Treatment of Cancer (EORTC) to develop an instrument that evaluated all aspects of HRQOL (Aaronson et al., 1993). A 30-item, cancer-specific questionnaire was designed that is divided into four domains: functional scale (physical, role, emotional, social and cognitive), symptom scale (fatigue, pain and nausea/vomiting), single items (dyspnea, insomnia, appetite loss, diarrhoea, constipation and financial difficulties) and overall QOL. This is known as the EORTC Quality of Life Questionnaire Core 30 (QLQ-C30; Aaronson et al., 1993). Disease-specific modules were designed to complement the core module. The lung cancer module (QLQ-LC13) was developed in 1994 with extensive field testing conducted for validity, reliability and responsiveness (Bergman et al., 1994).

Item generation was based upon three criteria: assessing items that are specific to lung cancer and its standard treatment, which are insufficiently covered by the core questionnaire; having the same format and employing the same time frame as the core questionnaire; be reliable, valid and responsive to clinical status and change over time. Thus, 13 lung cancer-specific symptoms were identified, and items were developed: coughing, haemoptysis, dyspnea, treatment side-effects, pain and pain medication.

The EORTC tools were also designed so that content validity is based on the combination of the QLQ-C30 and QLQ-LC13 (Bergman et al., 1994); the same goes for all other disease-specific modules. Nicklasson and Bergman (2007) conducted a study of 112 patients with advanced lung cancer or pleural mesothelioma with the aim of evaluating the validity, reliability and clinical relevance of the EORTC QLQ-C30 and LC13 in a palliative setting. Results found that internal consistency (measured with Cronbach's alpha) for all scales, except cognitive functioning (0.57), was above 0.70 or higher which is generally accepted as the minimum reliability for group comparisons, giving support to the reliability of this chosen tool. Various checks were performed and they supported the scale's validity: *construct validity* with a multitrait analysis; *criterion validity* using variables such as gender and age; *clinical validity* with measures such as performance status, a walk test and tumour stage; *concurrent validity* measured by correlations with ratings from a clinical social worker and other screening tools including the Health Anxiety and Depression Scales (HADS); and finally a *multivariate analysis* with physical functioning, emotional functioning, and global QOL as the dependent variables, and performance status, walking distance, physiological measurements, HADS-A (anxiety), and HADS-D (depression) as the independent variables. The validity of the QLQ-LC13 has been extensively proven through field studies by evaluating validity with an ANOVA by disease stage and by performance status. Results also demonstrated good reliability on the multi-item dyspnea scale (Koller et al., 2015). Bezjak et al., (2008) also illustrated validity for the QLQ-C30, as well as showing the responsiveness of the tool via its ability to detect statistically significant improvements in physical, emotional, social, and roles functioning (also supported by O'Brien, 2004). Lis, Rodeghier, Grutsch, & Gupta (2009) used a univariate

analysis to show that the Function and Symptom scales were predictive of overall patient satisfaction, thus supporting the predictive validity of the QLQ-C30. For the LC13 specifically, responsiveness was shown through a number of studies (Booton et al., 2006; Lee et al., 2009a, Sarna et al., 2008a), with predictive validity also being further supported (overall survival and disease-free survival; Movsas et al., 2009).

FACT-L. The Functional Assessment of Cancer Treatment – General (FACT-G) was developed in 1993, including four domains: physical well-being, social/family well-being, emotional well-being and functional well-being (Cella et al., 1995a). As the name suggests, this was created for use within a number of different cancer settings. However, much like the EORTC, a lung cancer subscale (LCS) was introduced to the FACT-G to make up the Functional Assessment of Cancer Treatment – Lung (FACT-L; Cella et al., 1995b). Items for the FACT-L were generated via open-ended interviews with lung cancer patients who then ranked them for importance, thus the LCS consists of items that include the specific concerns of lung cancer and its treatment from a patient-centred point of view (Bouazza et al., 2017).

When using this scale for assessment in a clinic, specific subscales can be isolated to create outcome indices such as the Trial Outcome Index (TOI) which combines the physical subscale, functional subscale and LCS (Cella et al., 2002). In a study with 116 lung cancer patients Cella et al. (1995) found the internal consistency (Cronbach's Alpha) of the LCS to be slightly low at 0.53 for all nine items. However, this went up to 0.68 with the removal of two uncorrelated items – hair loss and regret about smoking. The seven items that did correlate with each other were also the seven that asked about disease symptoms. This demonstrates that reliability is sound when using the 7-item symptom-specific subscale compared to the 9-item subscale. Therefore, a 21-item Trial Outcome Index (TOI) was created from the physical well-being (PWB) subscale, the functional well-being (FWB) subscale and the LCS, with 7-items per subscale. The TOI was highly reliable (Cronbach's Alpha = 0.89) and showed good sensitivity to change when 41 patients were tested again, two months later, using the performance status rating (PSR). Correlations between the TOI subscales ranged from 0.66 to 0.68 which suggests that very little information or data is lost through the combination of the three subscales. Construct validity was assessed by

calculating correlations between FACT-G and FLIC (Functional Living Index – Cancer) (0.58) and FACT-L and FLIC (0.60). The emotional well-being (EWB) subscale also correlated highly with a Brief Profile of Mood States (POMS), showing good convergent validity. Cella et al. (1995) concluded that, whilst the FACT-L was a relatively brief assessment of QOL, it was comprehensive, valid and reliable.

FACT-L is a well-validated and feasible tool, performing consistently with good psychometric properties (Butt et al., 2005) and has been extensively used in clinical research as a key patient-reported outcome (Bouazza et al., 2017). Factor analysis has confirmed the hypothesised multidimensional structure of the instrument, demonstrating good construct validity. Patterns of correlation coefficients, such as those with Functional Living Index – Cancer (FLIC), further support the validity of FACT-L. The LCS has also been shown to discriminate between patients of differing clinical status before treatment, and good responsiveness was found in 41 patients tested for sensitivity to change in performance status (Cella et al., 1995). This finding has been supported in several clinical trials (Butt et al., 2005). FACT-L has been extensively validated and appears to be psychometrically robust, and is therefore, the most preferred instrument for use in clinical research after the EORTC QLQ-LC13.

Other Instruments. The Lung Cancer Symptom Scale (LCSS) was developed in 1985 (Burke, Gralla, Kris, Howard, & Monras, 1985) with the aim of providing clinical trials with a specific instrument for measuring HRQOL. It does not have a general cancer component, making it completely lung cancer-specific. The instrument analyses the physical and functional aspects of the HRQOL by measuring severe symptoms of lung cancer and how they impact everyday life. The psychometric properties have been extensively investigated and demonstrated, showing the LCSS to be a valid and reliable measure (Hollen et al., 1994).

Another instrument, the MD Anderson Symptom Inventory (MDASI; Cleeland et al., 2000) was developed to assess the severity of cancer symptoms or its treatment, and is considered a symptom assessment tool (Bouazza et al., 2017). It is made up of 13 items that question the symptoms experienced most frequently by all types of cancer patients. Six interference items are also included – general activity, mood,

walking ability, normal work, relations with others, and enjoyment of life (Cleeland et al., 2000). Similar to previously discussed tools, the core module can be supplemented with a disease-specific module. The MDASI-LC module was developed in 2011 (Mendoza et al., 2011), through the selection of lung cancer-specific items that were distinguished after a literature review and input from relevant oncology clinicians. Mendoza et al's (2011) study also showed strong psychometric evidence for the MDASI-LC. It is considered a concise yet comprehensive instrument that requires minimal effort from the patients (Wang et al., 2016). As it is a relatively "new" instrument, it is often less utilised than other, more well-established tools.

Despite the selected tools not being used for their intended purpose, which is to assess various aspects of the patient's QOL in situ (i.e. physical, social/family, emotional, and functional well-being), it was still important to ensure that the QOL tools selected had sound psychometric properties. The possibility of the hypothetical usefulness of these tools and their potential to be incorporated into standard care make it essential that they are the best tools available.

2.2.3. Sampling and Recruitment

A "request for research participants" (see Appendix 6) was sent to Tenovus – the project sponsor – for approval. Once an expression of interest had been received from potential participants, a letter (see Appendix 7) was sent to Tenovus' support-line nurses, as well as nurses from other cancer organisations around the Hywel Dda University Health Board area, outlining the specific inclusion criteria of the study.

Inclusion Criteria

- Male or female
- 18+
- Currently working as an oncology nurse
- Experience in a clinical oncology setting

Exclusion Criteria

- Under 18

- Unable or unwilling to provide informed consent

The need for these criteria is self-explanatory and those who met them and were willing to participate then contacted the Investigator or their Supervisor directly, or Tenovus (acting as the gatekeeper) – who then passed on their information and expression of interest to the Investigator. Participants indicated their informed consent by reading the Participant Information Sheet (PIS) (see Appendix 8) and completing the Informed Consent Form (ICF) (see Appendix 9).

2.2.4. *Sample Population and Sampling Technique*

Initially, the target population was Lung Cancer Nurses. However, it quickly became apparent that the availability of these nurses would be limited, which led to a broadening of the selected population and recruitment of oncology nurses from various specialties (Support-Line Nurses, Clinical Nurse Specialists and Research/Trial Nurses). Therefore, purposive sampling was used as all of the selected participants shared the same characteristic in that they are all nurses working with cancer patients, making this sampling technique non-random (Robinson, 2014). Due to these defining characteristics, this purposive sampling was homogeneous in nature as the participants share similar backgrounds in terms of age, occupation, socio-economic status and geography (Mid-Wales). This homogenous sample has a unique, different or important perspective on the phenomenon in question (Mason, 2002) – oncology nurse self-belief, quality of nurse-patient communication and barriers and facilitators to communication and addressing QOL issues. The homogeneous nature of the sample allowed for a more in-depth analysis and better-informed recommendations for these particular areas.

In this current study, eight oncology nurses were recruited for interview. They varied in their roles (support-line nurses, CNSs and a trial nurse) and the types of cancers that they treated and supported. Their post-qualification experience ranged from 11 years to 27 years. Recruitment finished once the researcher felt that they had reached 'saturation', as no new information was being collected and further data collection would have been unnecessary (Saunders et al., 2018). Of course, it is

recognised that in a different geographical region, different nursing specialism, different target age range, and more, it might have taken less or more time to reach saturation, as this concept is unique to each sample. The minimum number of participants recommended for qualitative research is five, “this is because qualitative research methods are often concerned with garnering an in-depth understanding of a phenomenon or are focused on *meaning (and heterogeneities in meaning)*—which are often centred on the *how* and *why* of a particular issue, process, situation, subculture, scene or set of social interactions” (Dworkin, 2012, p.1). However, this is generally only recommended for phenomenological studies following Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2015). When following thematic analysis guidelines, Braun and Clarke (2013, p.50) recommend 6-10 participants for “small projects” when analysing interview data. Saturation occurred at eight participants, in line with Braun and Clarke’s guidelines.

2.2.5. *Study Setting*

As study partners, Tenovus Cancer Care made their premises available for interviews. The participants were interviewed either at Tenovus’ offices in Gleider House, Llanishen or at their place of work if this was more appropriate. This provided them with a safe, secure and convenient environment for the discussions to take place.

2.3. Ethical Considerations

These ethical considerations are based upon guidance from the British Psychological Society (BPS; 2018) and the Health and Care Professions Council (HCPC).

2.3.1. *Consent and Right to Withdraw*

PIS provided participants with the information they needed (any questions they had could be raised via the contact information given in the PIS). An informed

consent form was then signed that indicated participants had: confirmed that they had read and understood the PIS; understood that participation was voluntary and they were free to withdraw at any time; and understood that certain individuals would have access to their data. They also agreed to: the interview being recorded for transcription; direct quotes being used (under pseudonyms); and to take part in the study. Participants were assured that any identifiable information would be redacted from the transcripts. There was also a section on the informed consent form where they could indicate whether they would like to receive a summary of the findings at the completion of the study.

Participants were asked to give informed consent prior to the interviews. To achieve this, they received an information sheet (PIS) that expressed the purpose and nature of the research, the prospective benefits and potential risks/burdens associated with participation, and how their information was going to be used. The benefits of this study were communicated as the opportunity to learn from the introspection that is prompted by being interviewed on a topic, the chance to verbalise any previously unspoken thoughts and feelings on the topic and in that sense “work through them,” and from an external perspective, contribute to knowledge that could improve nurse-patient communication and provide a better understanding of the role that QOL measures might play in improving efficiency and effectiveness of consultations/support-line conversations. Following BPS and HCPC guidance, and due to the sensitive nature of the topic, it was necessary for the investigator to show empathy and respect with the participants and approach certain issues cautiously. All information and questions provided were sensitive and considerate to the needs of the participants and the experiences they have had, whilst also allowing for the necessary information to be collected. If patients experienced fatigue or anxiety, they were offered a break, or the option to stop entirely if they wished. An opportunity for a debrief at the end of the process was provided.

Participants also had the right to withdraw from the study at any point. Data collected from and about the participants was and is stored securely in password protected files and computers and any data used in the final project will be done so anonymously, following the “Caldicott Principles” (Caldicott, 2013) justification for

obtaining the data; not using person-identifiable information unless absolutely necessary; if necessary, using as little person-identifiable information as possible; access to person-identifiable information will remain between the investigator and supervisors; all of these individuals are aware of their responsibilities; and everyone involved will comply with the law at all times.

2.3.2. Anonymisation/Pseudonymisation

Ensuring that all participants' information – particularly personal data – remained anonymous or unidentifiable has become particularly pertinent this year following the Facebook/Cambridge Analytica scandal and the introduction of the new General Data Protection Regulation (GDPR; implemented on 25th May, 2018). Therefore, all data that was presented or available for others (e.g. Tenovus Cancer Care and the external examiners) besides the Investigator and their Supervisor was anonymised so that no participants could be identified.

2.3.3. Assessment and Management of Risk

All elements of this project were supervised by Drs Payne, Keenan, and Wallace, who all have a background of successful supervision and research within this field. In addition, Dr. Payne has clinical experience in acute mental health and residential supported housing. Representatives from the project sponsors, Tenovus Cancer Care, also supported the project, and they had clinical experience too. Moreover, the Chief Investigator (MPhil student) has undertaken Health and Care Research Wales (HCRW) Good Clinical Practice training and has also successfully completed postgraduate modules on qualitative research. In-depth personal training was given to the MPhil student by Dr Keenan, who has extensive experience interviewing cancer patients. This training equipped the student with the skills to handle any distress or anxiety that participants might experience during the interviews.

The nature of the discussions could have led to emotions and memories being brought back to the surface that could cause the participant(s) to feel distressed. So, in terms of managing distress, a modified version of Draucker, Martsof and Poole's (2009) distress protocol for research on sensitive topics was put in place (see Appendix 14). However, the protocol was not needed during this study as no participants experienced distress, but it was important to have the protocol available.

2.4. Data Analysis

After each interview had been conducted the investigator transcribed the audio recordings, and annotated, coded, and provisionally categorised the transcripts. A theoretical thematic content analysis at the latent level was used to identify patterns and themes within the data that were most useful in answering the central research question and sub-questions (Braun & Clarke, 2006). Attention was paid to detect and interpret potential meanings that underpinned the participants' stories. Via this process a number of themes and sub-themes were identified and analysed for their utility in helping to improve the self-efficacy and perceived competence of oncology nurses when communicating with patients.

A theoretical approach here means that data is identified in a deductive or 'top-down' way (Boyatzis, 1998), driven by the researcher's theoretical interest and understanding in the area. It is more of a detailed analysis of some aspects of the data, tending to provide a less rich description of the overall data. It is a more explicitly analyst-driven approach, meaning the researcher coded around the specific research questions. However, the analysis was a combination of top-down and bottom-up approaches, because although theoretical concepts were assumed to emerge and were to be identified to help answer certain research questions, the researcher was equally sensitive to idiosyncratic ideas and meanings to be voiced by participants and was thus equally looking for data that did not fit with theoretical expectations. Although a phenomenological approach was taken, with Husserl suggesting "bracketing out" be used by scientists to lay aside their preconceptions and assumptions and begin with a clean slate, it is important to note that the data was not

coded in an epistemological vacuum as no researcher can completely free themselves from their theoretical and epistemological commitments (Braun & Clarke, 2006). This research, therefore, was more in line with Heidegger's "Hermeneutic Circle" in terms of accepting and understanding our preconceptions and biases. Thematic content analysis at the latent level goes beyond the semantic content of the data and starts to ascertain and study the underlying ideas, assumptions and conceptualisations that the researcher has theorised could be informing the semantic content. Hence, this research followed a deductive thematic analysis at the latent level to interpret the data. However, the initial analysis – during phases 1 and 2 – was conducted inductively to allow for themes to emerge that may have otherwise been overlooked. The deductive approach was later employed to filter out the initial themes that did not fit within the theoretical framework of self-efficacy.

The present researcher followed Braun and Clarke's (2006) step-by-step guide, which is informative whilst retaining the flexibility that is consistent with thematic analysis:

Phase 1 is the data familiarisation stage, where the researcher transcribed the data, reading and re-reading it and noting down any initial ideas that were formed. Transcription is considered an excellent way to begin familiarising oneself with the data (Riessman, 1993) and is "a key phase of data analysis within interpretative qualitative methodology" (Bird, 2005, p.227). Rather than simply an act of putting someone else's words onto paper, transcription is recognised as an interpretative act, where meanings are created (Lapadat & Lindsay, 1999). An active engagement during the transcription informed the early stages of analysis and helped the researcher gain a far more thorough understanding of the data than would be attained through a passive transcription technique.

Phase 2 involved the production of initial codes from the data that were interesting to the analyst/researcher – whether theoretically anticipated or unanticipated; 'codes' refer to "the most basic segment or element, of raw data or information that can be assessed in a meaningful way regarding the phenomenon" (Boyatzis, 1998, p.63). The process of coding the data items begins the organisation of the data into meaningful groups as part of the analysis (Tuckett, 2005). The researcher

worked systematically, giving full and equal attention to each data item, and identifying interesting aspects in those data items that seemed to form the basis of repeated patterns (themes) across the data set and which were to some extent related to the initial research questions. However, as previously mentioned, these first two phases generally followed an inductive approach, focusing on all aspects of the data to create an initial pool of codes that were not necessarily all theoretically relevant.

Phase 3 involved the search for themes by sorting the different codes into potential themes and collating all relevant coded data extracts – which refers to “an individual coded chunk of data, which has been identified within, and extracted from, a data item” (Braun & Clarke, 2006, p.6) – within the identified themes. This required the researcher to be more critical of the initial codes, applying a more deductive approach and considering which aspects of the data would help answer the research questions. The researcher started to consider how different codes might combine to create an overarching theme. It was important to consider the relationship between codes, between themes, and between different levels of themes (e.g. main themes and sub-themes). This phase ended with a collection of candidate themes and sub-themes as well as all the data extracts that were coded in relation to them, the coding tables (see Appendices 11 and 12). In addition, two coding tables were developed based on the separate aspects of the interview process: nurse experience and QOL measures.

Phase 4 involved reviewing the themes in relation to the coded extracts – did they form coherent patterns? – and the entire data set, and vice-versa in a form of doubled quality-assurance check. Consideration of the validity of individual themes and refining them was necessary, helping to generate a thematic ‘map’ of the analysis. The candidate thematic map needed to ‘accurately’ reflect the meaning evident in the data set as a whole. ‘Accurate representation’ very much depends on the theoretical and analytical approach taken and in this sense is rather subjective, but in essence it was the ability to ascertain whether the themes worked in relation to the data set. This required further critique of the codes and themes to merge those that could come under a wider umbrella term and eliminate those that did not fully encapsulate the theoretical framework of the study, helping answer the research questions.

Phase 5 was when the themes were defined and named. Defining and further refining the themes that were presented for analysis helped identify the 'essence' of what each theme was about, and helped determine what aspect of the data each theme captured. The themes needed organising into coherent and internally consistent accounts, with their accompanying narrative which required the researcher to conduct and write a detailed analysis of each individual theme. It was necessary to consider the themes individually as well as each theme in relation to the others. By the end of this phase the researcher was clearly able to define what the themes were and what they were not.

Lincoln and Guba (1985) developed oft-cited evaluative criteria to ensure that a study has good rigour and trustworthiness when using a naturalistic inquiry approach, where participants' "social realities are social constructions, selected, built, and embellished by social actors (individuals) from among the situations, stimuli, and events of their experience" (Lincoln & Guba, 1989, p.227).

This involves the establishment of credibility (confidence in the 'truth' of the findings), transferability (applicability to other contexts), dependability (ensuring the process is logical, traceable and clearly documented) and confirmability (extent to which the findings are shaped by the respondents, not bias, motivation or interest). There are several techniques that Lincoln and Guba described for establishing credibility, including:

- **prolonged engagement** involves spending sufficient time in a specific environment to understand the setting and cultural/environmental differences – providing context for the study. This was achieved through visits by the researcher to lung cancer clinics with members from the Health Board, attendance at nursing conferences and time spent at Tenovus Cancer Care's offices;
- **persistent observation** during prolonged engagement identifies characteristics and elements that are most relevant to a situation or problem – providing depth. Again, this was achieved through attendance of clinics, conferences and Tenovus' offices;

- **member checking** involves testing the data, analytic categories, interpretations and conclusions of the findings with the participants from whom the data was originally obtained. Participants involved in this study were given the chance to question the findings and interpretations of what they said to ensure they were as accurate as possible. This was achieved during the interviews themselves through probing and paraphrasing, and via the opportunity for participants to read and comment on transcripts and the analysis;
- **deviant case analysis** uses elements of data that do not support the findings/explanations or seem to contradict these explanations or patterns that have emerged – by implementing this technique into this study, revision, broadening and confirmation of emerging patterns was able to occur.

Transferability was ensured through a **thick description** of the phenomenon by describing it in sufficient detail so that the conclusions drawn would be applicable to other oncology/nursing settings, people, situations and times should other researchers wish to transfer methods and findings to their own studies. In terms of dependability, an **inquiry audit** is suggested to assess the reliability of the study. This required the investigator to keep a detailed audit trail of data collection methods, derivation of categories, and the decision-making process throughout (Merriam, 1995). Confirmability was achieved through the use of **reflexivity** (see Appendix 15), whereby the researcher systematically attends to the context of knowledge construction, at every step of the process, so that it is clear how the researcher's own preconceptions, beliefs, values and assumptions influence the outcome of the research. This, and other techniques, helped the researcher to situate themselves in the "Hermeneutic Circle" to understand their own prejudices and biases as well gaining new information for restarting the interpretation process, i.e. through prolonged engagement and persistent observation.

Chapter 3

Results and Discussion

Chapter 3 will present a discussion of the interview data alongside the thematic content analysis, structured to follow the primary and secondary aims of the present study (higher order themes: sub-headings in bold and italic; corresponding sub-themes: sub-headings in just italic). These depict the five phases outlined by Braun and Clarke (2006), providing theoretical interpretations of the data with supporting quotes from the interviews to illustrate the practicalities and answer the study's research questions. Should the reader wish to see a complete theme table with *all* the relevant quotes, they are referred to Appendices 10 and 11, and Appendices 12 and 13 for a list of theme definitions and descriptions. Table 1 provides details of the study's informants, including their role as a nurse and their years of nursing experience.

Table 1: Participant Characteristics

Participant number	Pseudonym	Job title	Years of experience	Gender
1	Angela	Support-line Nurse	20	Female
2	Lisa	Support-line Nurse	21	Female
3	Imogen	Support-line Nurse	20	Female
4	Ethan	Support-line Nurse	23	Male
5	Anita	Support-line Nurse	22	Female
6	Rachel	Clinical Nurse Specialist	11	Female
7	Orla	Trial Nurse	25	Female
8	Irene	Clinical Nurse Specialist	27	Female

3.1. Perceived Relationship Between Nurse Self-Efficacy and the Quality of Their Communication

3.1.1. Importance of High Self-Efficacy

Previous research has shown that self-efficacy in nurses can act as a positive resistance against stress (Bisschop et al., 2004), mediating the relationship between stressful situation and depressive symptoms (Maciejewski et al., 2000). The moderating effects of self-efficacy on stress also reduce the likelihood of burnout (Yao et al., 2018). Nurses told various stories which attest to the general importance of belief in themselves and their ability to succeed and the crucial part that high self-efficacy, specifically when communicating in tough situations, plays in their role.

The nurses in this study described the need to be confident enough to know where their limits lay and to express to patients/clients these limits. This can be quite a difficult thing to do as it opens the nurse up to a sense of vulnerability, but they spoke clearly about the need for honesty with patients/clients – an important requirement for nurses, alongside frankness (Kourkouta & Papathanasiou, 2014) – which they believed would instill in the patients/clients more confidence with respect to how they felt about the communication and care they were receiving: *“it’s very honest to say ‘I really don’t know, you’re talking about something now that I have no experience of, but I know a person who does’, and I think that gives them more confidence in the service, as well, that they’re saying ‘Ok, well I can ring them and if they don’t know, they will be truthful.’”* (Angela, support-line nurse). Kraus and DuBois (2017) found, when speaking to nurses and physicians about their attitudes towards giving more independence to nurses, that the theme ‘knowing your limits’ emerged as crucial to the nurses’ ability to provide quality care. The nurses interviewed by Kraus and DuBois felt that they knew their limits and would stop and seek further help if they thought they reached their limit, ensuring the safety and quality of care for their patients/clients. The nurses and physicians often mentioned having never come across a nurse who did not know their limit and, therefore, there is no mention of the consequences of this behaviour. Despite this, one nurse warned against those who think they know more than they do as they will avoid seeking help from a consultant or physician, possibly causing further harm. A physician in this study also used the

term 'overconfident' in this context, suggesting a possible link between optimum self-efficacy and 'knowing your limits'. However, there is no other research that looks into 'knowing your limits' in nursing, which, therefore, means that there is also no support for the link this might have with self-efficacy.

High self-efficacy also provides nurses with the confidence to ask difficult questions of their patients or clients, which may be avoided otherwise. Nurses' with high self-efficacy see these challenges as opportunities not threats to their practice (Zhang et al., 2015), looking to overcome these difficulties rather than showing task avoidance behaviours (McLaughlin et al., 2008). It is especially important during PC/EOL care discussions (Hendricks-Ferguson et al., 2015). These difficult questions are generally important to ask as they cover aspects of the patient/client experience that often have a significant impact on the individual and their QOL and if missed could further worsen the patient's/client's experience with their cancer (Fallowfield et al., 1990). Rachel, a CNS, said: *"I think just learning to be brave enough to ask the questions like 'what's important to you?', that kind of question, and that's quite hard to ask sometimes."* This suggests that not being scared to approach these topics is a principle element in successful oncology nurse practice and requires the nurse to have high levels of self-efficacy. Baer and Weinstein (2013) conducted a successful educational programme aimed at improving oncology nurse therapeutic communication skills by engaging the nurses in a communication programme and promoting self-efficacy. Following the general trend of communication skills training for nurses (Pehrson et al., 2016; Coyle et al., 2015; Banerjee et al., 2017), Baer and Weinstein's main focus was on the importance of self-efficacy for effective communication in difficult conversations, such as end-of-life discussions. Should the training improve the communication skills and effectiveness of the nurse (Reed et al., 2015), it is likely that nurse-patient/client communication will also benefit (Kourkouta & Papathanasiou, 2014).

It is also important to consider the patient's/client's own psychological state at that time so as not to distress them further. Rachel's quote continued: *"it's crucial that we do ask that at appropriate times"*, thus illustrating her awareness of timing. This supports the suggestion that nurses with strong communication self-efficacy will

know when to time the introduction of difficult content to the conversation (Barclay & Maher, 2010). So, developing high self-efficacy in communication of bad news is essential as nurses have been shown to sometimes be unaware that they lack the knowledge or expertise to deliver such news effectively (Adebayo et al., 2013).

Therefore, it can be argued that self-efficacy is an important factor for nurses when communicating with their patients/clients. This is because the nurse must be able to know when to time the introduction of certain distressing or sensitive topics, as well as having the confidence to approach such topics in an empathetic, caring yet informative manner. The nurse must also be aware of where their own limits lie so as not to provide misinformation or unwarranted hope to the patient/client. Hence, there is a general trend for communication skills training to focus on the promotion of self-efficacy.

3.1.2. *Mastery Experience*

'Mastery Experiences' are based on individual experiences that raise efficacy expectations through the repeated perception of success (Bandura, 1994). Providing opportunities for mastery experiences has been suggested to enhance leadership self-efficacy in a study of 727 nurses, which had a significant influence upon their motivation and aspirations to lead (Cziraki, Read, Spence-Laschinger, & Wong, 2018). While general self-efficacy has been suggested to be an important predictor in job-related burnout (Perrewe et al., 2002), another study found that specifically mastery experiences were the only recovery strategy that significantly predicted burnout (Els, Mostert, & De Beer, 2015). This is likely explained by the similarity between mastery experiences (self-efficacy) and personal accomplishments – one of the main factors in burnout (Maslach, 1998) and therefore means that providing opportunities for mastery experiences could mitigate the effect of burnout. For the oncology nurses in this study, mastery perceptions were generally based on feedback from patients/clients about the benefit of their care or their own perceptions of success. Angela spoke about "*when people say little things like 'I feel a lot better now I've spoken to you', simple little phrases but it boosts your confidence, that yeah, I'm doing the right thing*", highlighting the role of feedback from those they are caring for in the

nurses' perceptions of success. However, she also said *"the more experience you get, the better you get at dealing with different situations and hopefully remembering situations that were similar in the past."* This seems to emphasise a need for internal perceptions of success and gives an indication of the role of repeated success. Bandura (1982) stated that self-appraisal (i.e. internal perceptions) of the individual's operative capabilities acts as one method for closely determining people's behaviours, thought patterns and emotional reactions experienced in challenging situations. Similar influences on thoughts and emotions also come from other people's judgements (i.e. external perceptions) of the individual's capabilities. These factors fall into two categories (Stajkovic & Luthans, 1998): situational factors (external perceptions) and conception of ability (internal perceptions). Situational factors describe environmental influences such as the availability of resources, physical distractions, help received and type of supervision. Conception of ability is described in terms of whether it is perceived as a given entity – which can cause a perceived lack of control, anxiety and diminished learning if mistakes occur – or an acquirable skill – which helps maintain high levels of personal efficacy and means an individual is less prone to mistakes and failures having negative outcomes. A nurse's achievements should not just be seen as a normal part of their role but something to be proud of, otherwise successes are less likely to act as a source of self-efficacy.

When considering the sources of perceived mastery, researchers have developed a form of performance evaluation, multi-source feedback (Latham & Wexley, 1994; Nadler, 1977), which involves feedback and evaluation of an individual from multiple sources around them (e.g. peers/colleagues, supervisors, customers), and which has gained some traction as a method of quality improvement in health systems (Lockyer, 2003). It is thought that feedback from multiple sources will provide those rating the individual with information that would have been otherwise unavailable (Ashford, 1993). It could be argued that the individual being assessed would not have this information available to them either and could therefore benefit from also seeing the feedback, as it could act as a collective external perception, potentially identifying examples of mastery experiences that they had not recognised or considered themselves.

Another support-line nurse, Anita, spoke specifically about her experience of dealing with emotional issues: “*I had seen people from lots of walks of life, so seeing lots of different reactions, so that wasn’t a problem for me in terms of the emotion of the client.*” This suggests that the nurses become used to communicating with patients/clients about issues of varying magnitude (self-efficacy expectancy), requiring the ability to generalise (self-efficacy expectancy) their skills across different roles and situations. It also illustrates how *repeated* experience increases the strength (self-efficacy expectancy) in a nurse’s belief that they can deal with a patient’s/client’s problems – supporting the relationship between their mastery experiences and overall efficacy beliefs (Bandura, 1994). This also supports Dunn et al’s (2005) and Mischelmovich et al.’s (2016) findings that confidence in communication improves through practice and rehearsal over time.

The importance of mastery experiences in developing an individual’s self-efficacy is well-documented (e.g. Bandura, 1994). Therefore, it is crucial that nurses can perceive moments of success or good performance as mastery experiences. This requires a level of self-awareness to be able to conceptualise one’s own ability as well as recognising situational factors that allow feedback from external sources (i.e. colleagues) to help identify moments of mastery (Stajkovic & Luthans, 1998). The awareness of mastery experiences has also shown to improve the nurse’s self-efficacy expectancies, as repeated perception of success increases (Bandura, 1994) the magnitude or difficulty level they believe they can perform at, their ability to generalise experiences, and the strength of their belief that they can perform successfully.

3.1.3. *Vicarious Experience*

Another of Bandura’s (1994) sources of self-efficacy that emerged in the nurses’ stories is *vicarious experience*, which refers to the knowledge, skills or efficacy information gained from visualising yourself completing a task or hearing about or observing the completion of a task by another individual. This was illustrated in its simplest form by Angela who stated, “*you just pick up things off other people over the*

years.” The benefit of vicarious experience seems to require some level of respect towards the experience, knowledge and competency of the colleague who is modelling the behaviour and the little tricks and nuances learnt from their years of practice (Bandura, 1971b). Observers of modelled behaviour tend to seek out individuals who they see as intelligent, talented or popular which suggests a level of respect, often perceived as mutual, for the chosen modeller. This was indicated by support-line nurse, Imogen, who said, *“you learn from your peers as well, because they know things that you don’t, and you can give them back something.”* Lisa also stated: *“just be like a sponge and absorb everything around you and see the way that other people work but be yourself and adapt that to something that works for you.”* The respect will likely come from an awareness and acceptance of their own limitations so that they are open to taking on new information or improving upon a certain area. Stajkovich & Luthans (1998) spoke about the greater influence of having perceived similarities between the observer and model and stated that “employees may turn to competent colleagues or mentors for knowledge of the task, needed skills, or development of effective strategies for successful performance” (p.71). These characteristics will likely mean the model is held in higher esteem by the observer.

Whilst observing experienced individuals does appear to be of value, the nurse acting as the observer needs to attempt the observed behaviour themselves to be able to adapt it to their own personality, or a different situation, to increase the likelihood of success when interacting with patients/clients, as the end of Lisa’s quote states: *“find what works for you from that.”* This is supported by support-line nurse, Ethan’s quote: *“So, picking up bits and pieces down the line, which is good practice and using it again, and trying it out for yourself, and you might get it wrong, you might not get it wrong, but hopefully if you’ve seen it work before, it’ll work in your situation.”* Therefore, the value and benefit of vicarious experience is more likely to become apparent if the observing nurse is open and willing to learn from those around them. This could be facilitated by having respect for their colleagues, as having this characteristic makes the nurse more likely to see others as valid models of behaviour and thus more open to emulating them. This would improve the observer’s attention and retention of the behaviour being observed – two of the main components of Social

Cognitive Theory in the acquisition or learning of the model's behaviour – thus improving the influence of this observational learning (Bandura, 2017). Vicarious experience also requires the individual to test or practice the observed behaviour so they can shape it around their own nursing techniques and behaviours to fit naturally with their personal approach to oncology nursing. Should the nurse be able to properly assimilate, apply and ultimately benefit from the use of vicarious experience, they will see an increase in their self-efficacy when communicating with their patients/clients.

3.1.4. *Persuasion from Significant Others*

This theme can be described as a source of belief for an individual or nurse in their capability to master certain activities, through verbal persuasion that increases their effort to succeed (Bandura, 1994). This verbal persuasion often comes from those whom the nurses perceive as holding credibility, prestige and expertise in their role. In the present study, a lot of the nurses' persuasion from those around them came in the form of positive reinforcement and emotional support from their colleagues, which gave them the confidence to discuss the issues and difficulties they were experiencing, potentially unburdening themselves in the process (Robb, 2012). Developing these strong interpersonal relationships with their colleagues and subsequent improvements in self-confidence has been associated with successful nurse-patient communication (Hsu et al., 2015). Angela spoke about the support-line team and how they help each other: *"it's not very often that things fester. We do have clinical supervision which we can access, but as a team we're also really good. If we've come off the phone and it's been a particularly bad call, then we'll talk about it straight away."* All within the team hold a high level of trust between each other due to consistently demonstrating credibility, prestige and expertise throughout their nursing career, therefore feeling comfortable to unburden themselves in this environment. Again, this could come back to the individual nurse's need for respect for those around them, offering persuasion, advice and support.

Whilst the colleagues or other significant others around the nurses offer praise and positive reinforcement, they can also offer constructive criticism in an effort to improve the nurse's practice. This can help to "focus on the individual's appraisal of self-efficacy so as to enhance the person's beliefs that he or she 'has what it takes'" (Stajkovic & Luthans, 1998, p.72). This is especially important after a bad experience, but should be done with empathy – something unlikely to be an issue for individuals whose chosen career revolves around caring for vulnerable people (Kesbakhi, Rohani, Mohtashami, & Nasiri, 2017). This was shown through another quote from Angela:

It's also having people around you saying 'oh, you handled that call really well', and we try and do a lot of, you know, when we're talking about calls, we try and do a lot of positive reinforcement with people, and if they say it's rubbish you, you know, I would always say to my team 'well that bit wasn't very good, but actually that bit was really good, so, you know, carry on doing that'.

This form of persuasion gives the nurse a balance between positive reinforcement for behaviours that they are exhibiting well when communicating with patients/clients, but also – through constructive criticism/feedback – offers advice for areas that require some improvement. The quality of communication that nurses demonstrate will likely improve as their self-efficacy benefits from the persuasion and support they receive. This requires trust between the nurses and their colleagues and allows the nurse to unburden themselves through this emotional support.

3.1.5. *Nurse Experience/Continuous Learning*

The Oxford English Dictionary defines experience as either the knowledge or skills acquired by a period of practical experience of something or an event which leaves an impression. In this instance, the knowledge, skills and practical experience relate to that gained through experiences in nursing (including training, post-qualification practice and Continuing Professional Development (CPD)) and communicating in difficult situations. Therefore, this theme emerged as participants described long careers which had provided multiple opportunities for them to continue learning, developing and reflecting on previous situations. Support-line nurse Ethan said: *"it is an art but it's learning as well, because you learnt these situations before and now you're drawing on all those experiences. They may not be*

the same experiences but they're very similar experiences." This includes any courses or training that the nurses completed, as "learning plays a key role in their development, job satisfaction and the continuous improvement of patient care" (Skar, 2010, p.2), as well as the vicarious experience gained from these courses and from those around them (previously discussed).

Significant nursing experience seemed to benefit nurses' transition into oncology as they were able to transfer their existing skills and knowledge to this new, different environment. This was illustrated by support-line nurse, Lisa, who spoke about her time as a sister on a Special Care Baby Unit: *"I've got that experience even if I didn't have, urmm, the precise experience, I've got the communication experience that I've had for like 30 years, in an extreme environment."* Successful transitions into oncology nursing are incredibly important as this area is considered one of the most stressful specialties in nursing as a whole (Naholi, Nosek, & Somayaji, 2015). Lisa's experience in an *"extreme environment"* gave her the tools to understand what the potential stressors might be and potentially how to protect herself from these. Therefore, nurses considering a move to oncology should look to develop mastery of their role and maintain/develop relationships that will contribute to good well-being (Schumacher & Meleis, 1994).

In terms of communication courses and training, there was a varied response, with some participants having had limited training or not seeing the benefit of their training, whereas others believed them to be of great help. Nurses have previously stated a definite need for further communication skills training (Jors et al., 2016) as formal training may still not be commonplace (Newman, 2016) and where there is communication training offered, the options are often limited (Wittenberg et al., 2018). The present study's findings also support Al-Mohaimed and Sharaf's (2013) finding that nurses perceive communication training for delivering bad news as inadequate. The lack of benefit could be due to a lack of willingness to engage fully with a course, which could be a result of failures to adapt the teaching to the learning style or academic ability of the students/nurses (Chant, Jenkinson, Randle, & Russell, 2002). This lack of benefit could also be related to high existing confidence in their ability that has come about through experience; this is despite Cantwell and Ramirez'

(1997) claim that communication skills training (CST) should be mandatory due to nurse communication not reliably improving with experience. For example, Lisa stated that *"I did do a counselling course many, many years ago but I couldn't say 'and how does that make you feel?' with any kind of sincerity because I can see it written on people, I can hear it in their voices."* An early literature review (Kruijver, Kerkstra, Francke, Bensing, & van de Wiel, 2000) found CST to show limited or no effect on a nurse's skills and behavioural changes in practice or on patient/client outcomes, although, the majority of the studies reviewed had weak designs which possibly contributed to the poor outcomes. However, a systematic review that focused on CST courses in oncology found them to be a promising approach to communication behaviour and attitude change – though once again, there was a lack of strong study design (Barth & Lannen, 2011). Since these reviews, Banerjee et al. (2017) and Wittenberg and Goldsmith (2016) have developed successful communication programmes. Banerjee et al. developed the Comskil Training Programme that focuses on: communication of empathy with patients/clients and families; discussions of death, dying and EOL goals of care; and navigating through difficult family interactions. Nurse self-efficacy improved through the training and good increases in empathic skills were also identified – which Banerjee et al. (2016) previously stated should be the focus for effective communication. Just one empathetic response from oncologists has been shown to significantly improve patient/client perceptions of the communication they receive (Malhotra et al., 2018). Wittenberg and Goldsmith's COMFORT communication curriculum improved the self-efficacy of clinicians and their attitudes towards communication, reducing their apprehension during this process (Goldsmith & Wittenberg-Lyles, 2013; Goldsmith et al., 2015; Wittenberg-Lyles et al., 2013). Despite the promising findings of these studies, it is still difficult to determine the prolonged effect of CST for oncology-based healthcare professionals (Moore et al., 2018), an important consideration if Cantwell's statement holds true.

Conversely, training perceived as beneficial was often focused around some sort of role-play or simulation training which supports Hsu et al.'s (2015) findings that scenario-based simulation training was more effective than traditional classroom training and would improve nurse competence, self-efficacy, satisfaction and

communication performance. This is indicated by CNS, Irene, who spoke about the benefit of role-play and verbal and visual feedback in her training:

The Advanced Communication course was really good because you had to think of a scenario and then you had an actor and then you had to act out the scenario, and then it was videoed. So they video you and you have a group of your peers and they give you feedback, so that's really helpful because you don't ever get the opportunity to actually watch yourself and to hear, sort of, comments, not negative necessarily, but just comments about, you know, it makes you think a little bit more about how you communicate and what you communicate.

Irene's quote clearly demonstrates the impact of effective communication training on her own self-efficacy. She verbalised this by describing sources of self-efficacy, these being mastery experience, vicarious experience and verbal persuasion. This benefit has likely occurred due to the focus on more challenging clinical interactions (MacLean et al., 2017) which Banerjee et al. (2016) stated as an important consideration for nurses practicing their communication skills. Simulation training provides these interactions in challenging environments for the nurses to refine their skills (Tobler et al., 2014).

A large and vital aspect of 'experience' is the learning process itself; Kolb's (1984) experiential learning theory states that "learning is the process whereby knowledge is created through the transformation of experience" (p.38). Kolb's model is cyclical in nature and begins with the 'Concrete Experience' stage which is where the occurrence of practical experience or an impressionable event happens. The next stage is 'Reflective Observation' and involves active reflection of the experience, followed by 'Abstract Conceptualisation' where the nurse would seek to conceptualise what they observed into a theory or model, in this case based around appropriate behavioural responses to various stimuli (i.e. responding empathetically to distressed patients/clients: "*it makes you think a little bit more about how you communicate and what you communicate*" (Irene)). The final stage is 'Active Experimentation' which is the practical application of the theory or model or the testing of the theory in practice, with appropriate reflection and modifications based on experience. A prime example of this comes from Ethan's earlier quote: "*it is an art but it's learning as well, because you learnt these situations before and now you're drawing on all those experiences.*"

They may not be the same experiences but they're very similar experiences." The end of Irene's quote can be used again to support this by noting the importance of relevant reflection: *"it makes you think a little bit more about how you communicate and what you communicate."* Ethan's quote is suggestive of the benefit of drawing on mastery experiences and vicarious learning, either through training or through practical experiences and Irene's quote indicates that more control could be had over the nurses' psychological and emotional states through training.

The term 'lifelong learning' has also been used to describe the active process that nurses engage with in the search for knowledge and understanding (Nayda & Rankin, 2008). Lifelong learning is recognised as a crucial aspect of the nursing profession (NLN, 2011). In fact, over time, nurses' confidence in communication has been shown to improve with practice (Dunn et al., 2005), preparation, education and rehearsal (Mischelmovich et al. 2016). In line with the findings of the present study, lifelong learning can be either official (training/courses) or unofficial (working experience; Tan & Morris, 2005), and the autonomy and proactiveness of the nurse in their learning has been shown to be a key characteristic of lifelong learning (O'Shea, 2003). The Royal College of Nursing (RCN) provide guidelines for CPD for nurses which they are responsible for 'revalidating' every three years, so that those from the top of the chain of command to the bottom know that the patients/clients will be cared for safely and competently (RCN, 2018). Therefore, this would ultimately lead to improved self-efficacy and competence in the various aspects of their role (Bhatnagar & Srivastava, 2012).

Nurses must look to continually learn and develop themselves in order to stay up to date and relevant in an ever-changing profession. Having significant communication experience in nursing prior to working in oncology will be beneficial to nurses' self-efficacy in their transition to this area. The resultant preparation for the stressors they will experience will give them the tools to be able to cope with, and protect themselves from, the burden that this line of work can often bring. However, for the nurse to benefit from their experience, oncology nurses must make a personal commitment to continue their pursuit of learning throughout their professional career (Rishel, 2013) – as demonstrated through the above quotes. Opportunities for training

and development also come in the form of communication skills training as part of nurses' CPD. Simulation training has had positive results and feedback (e.g. Hsu et al., 2015), due in part to the opportunities it provides for mastery experiences, vicarious experience and persuasion from others in an unpressured and safe environment, without the possibility of causing harm to anyone. Other training programmes which have focused on the role of self-efficacy in communication have also shown success (e.g. Banerjee et al., 2016; Goldsmith & Wittenberg-Lyles, 2013). However, the nurses in the present study were not enamoured with the training they had received (with the exception of simulation-based training) and this supports findings from previous studies showing communication skills training to be inadequate (e.g. Al-Mohaimeed & Sharaf, 2013; Jors et al. 2016; Newman, 2016; Wittenberg et al., 2018). Poor training could ultimately be detrimental to a nurse's self-efficacy when communicating with their patients/clients as they lack confidence in the skills they have been taught.

3.1.6. *Strong Nursing Identity*

Nurses in the present study demonstrated a strong professional nursing identity, defined as consisting of "the person's feeling and experience of her/himself as a nurse, the subjective part, and other people's image of the person as a nurse, the objective part" (Öhlen & Segesten, 1998, p.725). The qualities, beliefs, values and personality that the nurse holds contribute to or characterise their nursing identity. Lisa embodies the nurse identity and experienced its powerful influence when taking time away from nursing: *"I volunteered to be that welcome desk person and very slowly I realised that that let me get back to having a purpose, helping people again, doing something useful, which is all I've ever wanted to do, doing something useful."* Specifically, Lisa talks about *"having a purpose"* and *"doing something useful,"* the purpose being to help people ("the subjective part") and the usefulness coming through her role as a nurse which is, in its very nature, a profession that helps people ("the objective part"). This allowed her to re-establish a crucial identity that she had previously thought was lost, likely contributing to her self-efficacy and essentially

providing her with the foundation for which to build or re-build her self-efficacy beliefs.

Other nurses spoke of the value they feel they have in their role as they see differences in the nurse-patient interactions compared to patient-doctor interactions. It was the participants' perception that patients/clients tend to appear more willing to discuss personal/emotional issues with them than their clinician counterparts. Trial nurse, Orla, said that she thinks that *"there is a very big difference in the way patients communicate with nurses as they do with doctors as well, I think they tell us a bit more"* and that *"you have that barrier, I suppose, between a doctor and a patient"* but for nurses *"those barriers tend to be a little lifted."* This suggests that nurses can be instilled with confidence through the recognition of the importance and qualities of their role, which links back to nurses' perceived mastery experiences and their internal and external perceptions of success (Bandura, 1982).

3.1.7. Reflection

Reflection can be defined as the cognitive process of making sense of events, situations and actions that occur in the workplace (Oelofsen, 2012). Edwards (2017) expanded on Schön's (1991) Theory of Reflective Practice in Nursing which originally identified two types of reflection: reflection-in-action, which describes reflective thinking that occurs whilst still immersed in a clinical situation, allowing the nurse to make moment-to-moment decision making; and reflection-on-action which involves a retroactive critical analysis of incidents that have occurred (Bulman & Schutz, 2013). Edwards (2017) added two further reflection types: reflection-before-action which requires the nurse to reflect on previous, similar experiences before they go into a clinical environment; and reflection-beyond-action which involves critical thought about the experiences of the nurses, allowing them to look into the past, inward at the present and forward to the future. Self-efficacy has been shown to have a direct causal relationship on the stages of reflection (Phan, 2007) and is further enhanced in education/learning contexts by successful prior academic performance (i.e. mastery experiences) (Phan, 2013). Reflection is an important process for nurses to follow as

some nurses may not be aware that they lack the knowledge and expertise to communicate in certain situations (Adebayo et al., 2013), requiring introspection to increase their self-awareness and thus allowing them to identify areas for improvement.

Lisa spoke about how nurses *“always do a reflective practice”* and how it is *“it is good practice to always reflect on what happened and what you can do better.”* Lisa later spoke about the importance of self-awareness: *“it’s all about learning about you [emphasis on you] as a person and, you know, being quite self-aware of what you can do and then developing that.”* Eckroth-Bucher’s (2010) definition of self-awareness shows the clear link between this concept and reflection as *“self-awareness involves the cerebral exercise of introspection. This attribute reflects the cognitive exploration of own thoughts, feelings, beliefs, values, behaviours, and the feedback from others”* (p.297). Increases in self-awareness allow nurses to be more effective in their personal and professional lives (McCabe, 2000). Ahmed and Elmasri (2011) conducted a study on the effect of self-awareness education on the self-efficacy and sociotropy-autonomy (this describes the contrast between beliefs, behavioural dispositions, and attitudes that either draw an individual to attend to and depend on others or to invest in themselves) in psychiatric nurses. 19 nurses were assessed repeatedly throughout the study using a self-efficacy and sociotropy-autonomy scale. They found significant increases in the nurses’ self-efficacy and a highly significant correlation between self-efficacy and sociotropic-autonomy, thus concluding their self-awareness education programme to be positive and successful. This supported the findings of Engin and Cam (2009) who conducted an almost identical study on self-efficacy and sociotropy-autonomy. Ahmed and Elmasri’s study did not include a control group. However, this was mitigated through the use of pre- and post-tests to determine a baseline for later comparison. In addition, despite referencing various theories or concepts (e.g. Beck’s [1987] cognitive theory and Rohrer’s [2002] ABC of awareness), their study was not framed within one. Therefore, future research in this area should look for it to be framed within or around a theory or concept that could help to explain the consequent findings.

Lisa's quote also highlights the need for reflective practices in nursing so that nurses can continually improve in their approach to care and also links back to Rishel (2013) who spoke about the need for oncology nurses to commit to lifelong or continued learning throughout their career. However, for the reflection to be of use to the nurse, they must actively engage with activities or behaviour changes and fully immerse themselves in different situations that will improve the identified area of weakness. Kolb's (1984) experiential learning theory has been considered as a useful model for reflection in nursing (Oluwatoyin, 2015) and, importantly, includes the 'Abstract Conceptualisation' phase where the nurse seeks to conceptualise their reflection into a theory or model that can be practically introduced to improve their practice. There must be 'action-based-on-reflection', otherwise the reflection becomes inane. In terms of "Fostering a Caring Climate" (Sawin et al., 2019), one of the themes that emerged from discussions with nurse managers on their PC/EOL communication perspectives, identified the need to be constantly vigilant by assessing and optimising family-centred care. This supports the need for 'action-based-on-reflection' as nurses begin by initially assessing (reflecting upon) their care provision and consequently optimising the care based on the assessment (the action). Blatt, Plack, Maring, Mintz, and Simmens (2007) found that giving medical students the chance to reflect on encounters with patients/clients and then revisit that individual increased the patient's/client's ratings on satisfaction and the students' medical skills. This demonstrates the benefit of 'action-based-on-reflection'.

Unfortunately, nurses aren't always going to be at their most confident, illustrated by this quote from Orla: *"There's definitely days where you feel less confident, yes. I mean, especially if you have dealt with very tricky patients which on reflection could've gone better or perhaps you didn't make quite the right decision or the best decision for the patient at the time."* Despite findings showing that nurses subconsciously allude to positive aspects of their communication with patients/clients, they can often be quite critical of their communication abilities (Bumb et al., 2017). This is perhaps due to the nurses lacking the confidence to communicate effectively on that particular day, as Orla describes. Therefore, whilst it is crucial that oncology nurses look to overcome or mitigate any weaknesses they

might have, they should not overlook the strengths they bring to their practice and the positive experiences they have had. These strengths are what they can fall back on during periods of reduced confidence, acting as a form of protection against issues such as burnout or compassion fatigue. This comes back to acknowledgement and appraisal of mastery experiences (Bandura, 1982) which provides the nurse with examples that upon reflection show their abilities and remind the nurse that they are capable of performing competently, thus improving their confidence/self-efficacy. In regards to the Theory of Reflective Practice in Nursing (Edwards, 2017), this acknowledgement of what went well, and not just negative experiences, would be useful at all four stages.

“While confidence is not a substitute for competency, it creates trusting relationships, empowerment, and resiliency to persevere when challenges arise” (Owens & Keller, 2018, p.97); the following quote from Angela illustrates the importance of reflecting on positive experiences too:

Nurses are quite bad at recognising when they've done something good, I've found, as a ward nurse. So, if something nice has happened I acknowledge that thing, and that I think would be another thing to say to younger people trying to deal with it, if you do something good, don't shy away from recognising that and taking that on, because that's brilliant, because you're going to have enough crap times where things aren't going to go right, that you're going to need all of those good times. So, if you don't actually acknowledge them, you don't remember them, so, remember the nice times, remember the funny times ... and all the strange things, because they're the things that will remind you why the job is worth having, and they will help to, being in your 'happy bank,' so, they'll help to deal with all of the shit that happens as well.

Angela uses the word “*acknowledge*” twice in this quote, demonstrating the role of reflection, as it is unlikely for the nurse to see much benefit without first recognising that a situation has gone well and then accepting that it was a positive experience. Furthermore, in the quest for stress and burnout prevention strategies amongst oncology nurses, reflection should work as an active coping tool – whether before, during, or after a stressful scenario at work (reflection-in-action, reflection-on-action, reflection-before-action, reflection-beyond-action; Edwards, 2017; Schön, 1991) – or as Angela stated: “*the things that will remind you why the job is worth having... in your 'happy bank.'*”

Increased self-awareness is beneficial in reflective practice and has shown links with self-efficacy (e.g. Ahmed & Elmasri, 2011; Engin & Cam, 2009). Having high self-awareness will allow the nurse to identify the areas of their communication which require improvement – which once acted upon will increase their confidence in their abilities. However, it also helps to identify the nurse’s strengths in this area of their practice as acknowledgement and appraisal of their mastery experiences could provide confidence to the nurse in negative situations. Therefore, reflection is a useful tool for nurses to use when looking to increase their self-efficacy surrounding the quality of their communication with patients/clients.

3.2. Influence of Perceived Competence on Self-Efficacy in Communication

3.2.1. *Self-Determination Theory*

This theory suggests that people/nurses are motivated to grow and change by innate BPNs: autonomy; competence; and relatedness (Ryan & Deci, 2000) with fulfilment of these BPNs (or ‘needs satisfaction’) coming through their nursing behaviours (Deci & Vansteenkiste, 2004). Satisfying one’s needs is hugely beneficial to all walks of life as it provides the individual with the motivation they need to continue forward in whatever they are doing. Lisa spoke about how she had felt “*extraordinarily low*” and “*very depressed*” when she was forced to take time away from nursing – these feelings were in part due to her own cancer diagnosis – but after volunteering to work on Tenovus’ welcome desk said that “*very slowly I realised that that let me get back to having a purpose, helping people again, doing something useful, which is all I’ve ever wanted to do, doing something useful.*” The use of the terms “*having a purpose*”, “*helping people*” and “*doing something useful*” suggest that Lisa was able to begin fulfilling or satisfying her BPNs as they respectively relate to her being autonomous, feeling a sense of relatedness and a sense of competency.

Autonomy describes the nurses’ need for control over their own lives and the decisions they make (Deci & Ryan, 1985): “*you just need to find what works for you and do it your way*” (Lisa). The nurses in the present study spoke about autonomous behaviours concerning their practical nursing role and improving their practice

through independent learning. Rachel and Irene (respectively) spoke about the increasing responsibilities they are trusted with:

Nursing has changed quite a bit in that we've taken on a lot of roles that were traditionally seen as medical roles, and there's good and bad to that. Ummm, for me it was a way of furthering my education and doing something new.

We're now their Specialist Nurse and, sort of, key worker right through their treatment journey, right the way through. So, it gives a better continuity, for us as nurses and for the patients as well, ummm, and they've got direct contact to us at any point across their treatment.

Increasing the responsibilities and roles of the nurse gives them more control of their care, in part due to the “better continuity” they are able to provide to their patient/client. Whilst added responsibilities may increase the nurses’ workload, it also shows a perceived level of trust from those higher up in the organisation which increases self-efficacy (Attiq, Rasool, & Iqbal, 2017). Nurses willing and capable of handling increased workloads show high levels of self-efficacy by overcoming these more challenging situations and seeing them as opportunities to “further [their] education and doing something new” (McLaughlin et al., 2008; Zhang et al., 2015). Furthermore, this additional level of goal-setting potentially leads to higher commitment to goals, improving the cognitive processes within the nurses’ self-efficacy (Bandura, 1994). It is also possible that the trust they receive will increase their perceived competence as it confirms that they have gained mastery over their nursing skills and tasks (Ryan & Deci, 2000).

Relatedness describes the nurses’ want or need to interact, be connected to and experience caring for others (Ryan, 1995). Naturally, within nursing, the staff want to interact with and experience caring for the patients/clients, otherwise it is unlikely they would have pursued such a career in the first place (Mooney, Glacken, & O’Brien, 2008). The nurses, therefore, show this through their communication with their patients/clients. Angela said:

You have got a professional relationship but there's nothing wrong with that gentleness that you use when you talk to your friends, to talk to somebody on the phone.

This is an important consideration for nurses as research has found complaints from patients/clients to focus around perceived communication failures and an inability to convey a sense of care (Moore, et al. 2018; Lussier & Richard, 2005). If the nurse is aware that the patient/client is perceiving communication to be ineffective this could increase the nurse's stress levels, lower their job satisfaction and increase their risk of burnout (Emold et al., 2011). This is likely to impact their perceived competence around their communication skills and could also reduce the nurse's self-efficacy due to its negative relationship with stress and burnout (Yao et al., 2018).

Relatedness is also important between colleagues as *"they can talk to somebody, even somebody to bounce off, that understands what you're going through"* (Angela). This means that they are receiving support from people who can fully empathise with their situation and the challenges they face. Rachel said:

We talk to each other if we've had difficult days because there's only so much your family can understand about what you go through, unless they're working in it as well. So, talking to each other does help, urmm, because everyone has good and bad days, so you do know what it's like, so I think yeah we do support each other quite well, yeah.

The relatable support allows nurses to reflect on the motivational and affective self-efficacy processes of their communication which guide their actions and determine how well they regulate their emotional states and subsequent reactions. (Bandura, 1993; Flannery, 2017).

3.2.2. Competence

This BPN refers to the need for nurses to gain mastery of their nursing tasks whilst also learning new skills, capable of achieving their goals by successfully navigating their nursing environment (White, 1959). Therefore, competence shares links with self-efficacy as strong performance accomplishments or mastery experiences demonstrate mastery of a nurse's tasks with encouragement and persuasion from significant others (i.e. colleagues and supervisors), adding to their sense of achievement (Bandura, 1993). In terms of communicating with cancer patients, the expertise of the nurse is an important requirement (Davison et al., 2004),

as Orla describes in her experience of working in the different areas of oncology and how this variety has benefitted her expertise:

I think that my experience of working everywhere in the hospital has actually given me a good knowledge of what the patient experiences throughout their whole journey, through the hospital, through their diagnosis, through their treatments, because I know about the treatments they're having and what experiences they have when they're actually sat in the treatment unit and that type of thing. So, when I see the patients, I can quite comfortably talk about what's going to happen when they have their chemotherapy, cos I've actually given it.

Orla feels competent in her ability to talk to patients/clients about their journey as she has experienced all the aspects of oncology, which also suggests that she has some level of mastery experience in each area (Bandura, 1994). If this is the case, then Orla's perceived competence in communicating with her patients/clients likely stems from her mastery of all the tasks she has experienced (Dunn et al., 2005; Mischelmovich et al., 2016), leading to an overall sense of competence in oncology nursing.

The importance of this competence is highlighted by Irene, who states: *"we should come across that we know exactly where we started, what information we've got and where we're going with it before we go in and speak to people. It's important that you know what you're going to be talking about when you're there, because I think if you lose somebody's confidence early on, as a clinician you're going to be in trouble really."* This supports the claim that a nurse's communication-related confidence and competence will improve with preparation (Dunn et al., 2005). It also demonstrates that a nurse's perceived competence has an impact on the patient's/client's confidence regarding their nurse's ability to provide them with adequate care (Fosbmdr, 1994). If the patient's/client's confidence, or lack of, is identified by the nurse, this will also potentially impact the nurse's perception of their competence, either positively or negatively depending on the patient's/client's reaction.

For the nurses to recognise their mastery of certain tasks, it is important for their colleagues and others around them to give them praise should they do something well or, if they have not mastered the task yet, to provide constructive criticism that will allow the nurse to develop and improve and, therefore, master the

task in the future (Laskowski-Jones, 2018). This is an important consideration as nurses may not always be aware that they are doing a good job (Bumb et al., 2017) or may be unaware that their knowledge or expertise when communicating is lacking (Adebayo et al., 2013). Angela spoke about the benefit of *“having people around you saying ‘oh, you handled that call really well’”* as well as the role of encouragement and persuasion within her support-line team:

When we’re talking about calls, we try and do a lot of positive reinforcement with people, and if they say it’s rubbish, you know, I would always say to my team ‘well that bit wasn’t very good, but actually that bit was really good, so, you know, carry on doing that.’

Without people giving the nurses indications of what they have done well and where and how they could improve, individuals may miss out on opportunities to perceive themselves as competent. This links back to the nurses’ perceptions of their mastery experiences and how they are unlikely to gain a benefit to their self-efficacy (and, in this case, their self-determination or needs satisfaction) unless they perceive the situation as successful (Bandura, 1984). This perception of success can either be gained through internal awareness or from external sources, such as the encouragement and persuasion that the nurse’s colleagues can provide.

3.2.3. *Communication Skills*

Communication skills can be defined as the ability to convey and share information effectively and efficiently (Oxford English Dictionary). Good communication is considered an inalienable right and the foundation for developing a genuine and meaningful relationship between the patients/clients and nurses (Diamantopoulou, 2009). Therefore, in a specialism such as oncology, with such a wide range of potential issues that may be brought up for discussion by patients/clients (Macmillan, 2017; NICE, 2004, 2016), and typically under time pressures, nurses must be effective and efficient when conveying information. Nurses are required to understand specific patient/client experiences, concerns and how the patient/client receives the information, conveying an understanding of the patient’s/client’s message and providing clarification when necessary (Aungst, 2009; Papadantonaki,

2006). This means that they need to consider how they can adjust to new or changing events and issues to provide the most appropriate service in an effort to achieve maximum productivity with minimum wasted effort when communicating, all while being well-organised and demonstrating competence (Kourkouta & Papathanasiou, 2014). To achieve these aims, CNS, Irene, spoke about preparing for a consultation by *“making sure we’ve got the environment right, we’ve got the information and that we’re prepared for what we’re going to encounter, what we’re going to deal with really.”* Research has previously found that appropriate settings are crucial when communicating with patients/clients, and that they require quiet, private areas, free from interruptions, which will help the nurse convey a sense of respect and also maintain the dignity of the patient/client (Fujimori et al., 2005; Kaplan, 2010). Providing this peaceful environment for the patient/client is also a key element to the development and maintenance of a therapeutic relationship (Kourkouta & Papathanasiou, 2014). However, a lack of privacy or time can hinder nurse-patient communication (VandeKieft, 2001).

Support-line nurse Imogen alluded to the range of issues they have to deal with as they *“could be anything from wanting to donate something to the shop, to a pervert calling, to somebody who wants to take their own life, so, the variation is enormous,”* highlighting the need for nurses to be prepared but adaptable when it comes to communication with their patients/clients; indeed, across a range of workplaces, important outcomes are associated with being *“prepared and/but adaptable”* (Davlin-Pater & Rosencrum, 2019; Lent, 2013; Scannapieco, Hegar, & Connell-Carrick, 2012). This is further supported by Mischelmovich et al. (2016) who showed that good preparation can help improve nurses’ confidence in communication

Patients/clients can often react to bad news in anger, disbelief, moaning, aggression and denial as defence mechanisms (Panagopoulou & Benos, 2004). The benefit of transferability and development of communication skills was demonstrated by Angela when discussing her time with the support-line:

A lot of people come on the phone either very distressed or quite angry, and although it’s a very basic communication skill, it’s about bringing that person down to a place where you can have a decent conversation with them, so if you

learn that on the phone you can definitely transfer that to a clinical setting where somebody comes at you very angry.

Angela's skills appear to have developed and improved through the varied challenges that support-line nurses face when working on the support-line (e.g. lack of physical cues and longer, more emotionally charged conversations). She has an increased sense of self-efficacy when it comes to dealing with emotional patients/clients – due to previous mastery experiences – and, therefore, perceives that her competence would be high when communicating with such individuals in a clinical setting (see Banerjee et al., 2016, for a discussion of how anger from one side of a discussion or consultation puts the conversation members in 'dialectical tension' and precludes desirable outcomes being achieved, hence the importance of nurse self-efficacy to diffuse patient/client anger; Smith & Hart, 1994). Effective communication by the nurse can help reduce cancer patients'/clients' high prevalence of affective and psychological disorders and problems (Banerjee et al., 2016; Breaking Bad News Foundation, 2016). However, certain behaviours (e.g. distancing and avoidance) can inhibit a nurse's communication practices which are linked to factors such as skill deficits and anxiety about negative consequences (Parle, Maguire, & Heaven, 1997; Davies et al., 2008; Al-Mohaimed & Sharaf, 2013; VandeKieft, 2001).

Therefore, whilst 'communication skills' can be considered a vital tool for nurses in any area, it is even more pertinent that they be employed competently in an area such as oncology, due to the increased levels and range of distress that patients/clients experience and the heightened communication skills nurses need to address these levels of distress. In order to properly demonstrate competency in this area, nurses must be 'prepared but adaptable' during interactions with patients, allowing them to feel confident that they can deal with the majority of situations or issues that may arise. This can be aided by their ability to transfer the skills they have learnt from previous nursing experiences, thus providing them with some level of mastery experience and allowing them to generalise their self-efficacy to the new situation. Having these communication skills thus ensures the satisfaction of the patient/client and the protection of the nurse (Kourkouta & Papathanasiou, 2014), allowing the nurse to be competent and consistent in the care they provide.

3.2.4. *Counselling Skills*

Counselling skills are the necessary behaviours for giving advice to, assisting and guiding patients/clients throughout their cancer experience. This means that the counsellor – or nurse – needs to be in a state of mind that allows reasonable conversation and a willingness to be open, as does the patient/client (research has shown that increased levels of distress can prevent patients/client being open and reasonable; Street, Makoul, Akora, & Epstein, 2009). In the present study, when nurses broadly described the use of counselling skills they often referred to situations where the patient/client was in a heightened state of distress and the nurse was required to calm the individual down. Imogen, talking about how the skills she developed had helped through her time on the support-line, said *“I think another thing is getting the level of how you speak to people at different levels and how to perhaps calm a person down, how to rationale perhaps bad news that they’ve been given.”* This would allow the nurse to bring the individual down *“to a place where you can have a decent conversation with them”* (Angela) and potentially get a better understanding of why they were distressed. In the present study and the extant literature, nurses often admit that patients’/client’s emotional support needs are the most difficult for them to meet (Bumb et al., 2017; Adams et al., 2012) and patient/client complaints often focus on poor communication and not conveying a sense of care (Lussier & Richard, 2005; Moore et al., 2018). These needs require the use of counselling skills to be sensitive to patient’s/client’s verbal, physical and emotional cues, which will improve the nurse support and care provided (Ptacek & Ellison, 2000). This is supported by Malhotra et al. (2018), whose findings showed that just one empathetic response from an oncologist could significantly improve patient/client perceptions of the communication and care they receive. This further highlights the importance of counselling skills to overall communication self-efficacy in oncology nursing.

Also emerging from the discussions was the use of specific skills to help when a more counselling-style approach was needed. These were: the identification of verbal and non-verbal cues (e.g. Ptacek & Ellison, 2000); probing to gain a better understanding (e.g. Aungst, 2009; Papadantonaki, 2006); building rapport with the patient/client (e.g. Papadantonaki, 2012; Chan et al., 2018); and authenticity (e.g.

Kourkouta & Papathanasiou, 2014; Fakhr-Movahedi et al., 2013). These skills and behaviours bear some similarities with established counselling micro-skills (Ivey & Ivey, 2003) which include ‘client observation’ skills to help identify discrepancies in the patient’s/client’s communication or their own communication and is done through observation of body language, tone of voice and facial expressions – similar to cue identification. Furthermore, ‘questioning’, which helps guide the conversation and enrich the story, ‘responding’, to confirm that the counsellor/nurse understands what has been said, and ‘focusing’ which enables direction of the conversation towards certain areas, all share similarities with probing. Lastly, ‘attending behaviours’ relate to the building of rapport and the need for authenticity as this demonstrates that the nurse is engaged and interested in what is being said, but in a genuine manner. For instance, oncology nurses consider being comforting, supportive, empathetic and the use of appropriate touch to be facilitative behaviour for the affective side of their communication (Kruijver et al., 2000). Therefore, competent use of these counselling-related skills will improve the nurse’s belief (self-efficacy) that they can communicate effectively with patients/clients who are in a distressed state.

However, effective use of the skills identified in the present study and/or the counselling micro-skills (Ivey & Ivey, 2003) first requires the effective use of listening skills.

3.2.5. *Listening Skills*

Listening skills refer to the nurse’s ability to pay attention and effectively interpret what is being said by the patient/client – or even their colleagues (Ivey & Ivey, 2003), helping to assess the patient/client situation and possibly enhancing the nurse’s own self-esteem (Papadantonaki, 2006). This was demonstrated simply by Irene (CNS): *“what we tend to do is listen to them really and then quite often there’s key points coming out.”* It is a crucial skill for properly perceiving a patient’s/client’s verbal and non-verbal messages (Kourkouta & Papathanasiou, 2014) as individual interpretations mean that the message delivered by the patient/client may not always be the one received and vice versa (Arapakis, 2006). Naturally, the support-line nurses

have to utilise their listening skills even more so due to the lack of visual cues. This was described by Imogen:

Your listening skills are heightened because you haven't got those visual skills to depend on, so then you've got to – I suppose it's like being blind and you're, you know, you're hearing becomes more sensitive or something.

This suggests that experience on the support-line or with conversations over the phone will benefit the nurses' listening skills, making them more attuned to the emotions and subtle cues that a patient/client may express (Choudhari, 2006). Therefore, this would aid their ability to correctly interpret the information they are receiving, thus further enhancing their counselling and overall communication skills (Greenberg, 2000). This is supported by findings which show nurse support and care to improve with higher sensitivity to the patient's/client's verbal, physical and emotional cues (Ptacek & Ellison, 2000). As Angela's earlier quote about dealing with distressed patients/clients stated: *"if you learn that on the phone you can definitely transfer that to a clinical setting."* So, this could be of value to more clinical nurses, especially with the time constraints they are often under which require them to be incredibly efficient and effective with their communication, something these improved listening skills would certainly benefit.

The support-line nurses in the present study perceived their listening skills to be *"heightened"*, which increased their sensitivity to the patient's/client's verbal cues. By identifying these cues earlier or more effectively, they believe their overall competence – and consequently their self-efficacy – to be improved, as they perceive their communication to have been successful or beneficial to the patient/client.

3.2.6. Cue Identification

Cue identification can be described as the prompts and informative behaviours that are conveyed from the patient/client, either verbally or non-verbally and has similarities with 'client observation' (counselling micro-skills; Ivey & Ivey, 2003) as the counsellor, or in this case – the nurse, would look for changes in body language, tone of voice or facial expressions. Patients'/clients' expressions of negative emotions are

not always frequently responded to by oncologists (Adams et al., 2012; Morse et al., 2008). Therefore, a nurse's sensitivity to their patient's/client's cues and responding empathetically will improve the supportive nature of their care (Ptacek & Ellison, 2000) and significantly improve the patient's/client's perception of the communication they are receiving (Malhotra et al., 2018). Due to the varied roles of the nurses in the present study, there was a divide between the focus on tone of voice (due to the nature of support-line nursing this is naturally more of a concern for these nurses) and body language and facial expressions (the clinical and trial nurses have the benefit of face-to-face contact with their patients/clients). This is demonstrated by the stark contrast of these two quotes from support-line nurse, Angela, who said *"because you haven't got any visual cues, you have to be much more conscious of tone of voice and language used"* compared with this quote from CNS, Rachel, who said *"you can read people's body language, you can provide reassurance a lot more easily, because you can see expression changes."*

The experience of the nurses in the present study has also increased their confidence surrounding their intuition for identifying verbal and non-verbal cues. Angela spoke about her intuition and judgement for both verbal and non-verbal cues:

You get tuned into hearing if somebody is, even if somebody says they're really, really good, they're not actually really good, you can hear things in their voices. So, you learn how to gauge the way you talk to people from what you hear.

I think with my past experience as well, I've got now, after 30 years, generally if I can see somebody and they tell me they're fine I know when that's an absolute load of rubbish because I can see it, I can read people really, really well.

Angela uses the term *"tuned into"* when referring to verbal cues over the phone which suggests that she has developed a skill that helps her to identify the nuances and incongruencies in her patient's/client's speech (Jansen et al., 2010; Purc-Stephenson & Thrasher, 2010; Uitterhoeve et al., 2009). This allows Angela to adapt and tailor her style of communication for the most effective and efficient outcome. When comparing the phone conversations with face-to-face interactions, Angela's second quote referring to non-verbal cues includes the phrase *"I can read people"*, which offers a similar benefit in terms of identification of nuances and incongruencies and

consequent adaptations to her style when interacting with a patient/client. This suggests, therefore, that previous success and mastery of cue identification is indicative of a positive relationship between nurses' perceived cue identification competence and their self-efficacy. Previous findings support this, as nurses with high confidence are more likely to trust and act swiftly on their instincts (Burke & Mancuso, 2012; McMurray, 1992).

3.2.7. *Probing*

This emerged as the nurses described using closer inquiry and deeper exploration of certain aspects of the patient's/client's situation. Nurse-patient communication includes encouraging the sharing of feelings and fears as this helps the patient/client find a sense of control, meaning and purpose in life (Ragan et al., 2008). This means that when probing, the nurse is required to withhold judgement and never assume that they know exactly what the problem is based on a short conversation with somebody ("*never assume, always investigate*"; Angela). Individual interpretations can lead to miscommunication between the nurse and patient/client (Arapakis, 2006). Therefore, nurses must look to understand specific patient/client experiences and concerns, being wary of how their information is received (Aungst, 2009), whilst also conveying an understanding of the patient's/client's message (Papadantonaki, 2006). This was expanded upon by Irene (CNS):

When you delve a bit, especially with peoples' symptoms you tend to find, in your mind you're thinking one thing but you mustn't make assumptions, you've really got to go back to the person and get a clear history or a clear idea of exactly what is going on before you make a decision, because you can make a wrong decision, you can bring somebody into hospital that doesn't need to be there, or you can leave somebody at home that needs to be here. So, it's really important that you listen and that you ask the right questions.

This demonstrates the importance of exploring the issue as in-depth as possible to mitigate any further harm to the patient/client (McCormack et al., 2011). So, whilst it is important to trust one's instincts when first identifying an issue or underlying problem, further investigation of the problem is crucial before any major action is taken.

The last line of Irene's quote ("*it's really important that you listen and that you ask the right questions*") also provides a link between having competent listening skills and successful cue identification and subsequent probing. The listening skills will help the nurse recognise the subtleties and nuances that will likely influence the direction of their probing and their decision-making (Rosenzweig, Clifton, & Arnold, 2007). Irene's quote also demonstrates that a nurse's perception that they are probing competently requires them to have confidence that they are asking the right questions and probing the right areas, as the nurse lacking confidence could have negative consequences for the patient/client. Therefore, a nurse's self-efficacy surrounding probing will improve should they perceive themselves to have shown competence/success in previous communications with patients/clients (i.e. mastery experiences), watched similarly matched nurses and colleagues – in terms of skill and knowledge level – probe effectively (i.e. vicarious experience), and received and acted upon constructive feedback (i.e. persuasion from others).

3.2.8. *Building Rapport*

Building rapport can be described as developing mutual trust, friendship and affinity with a patient/client and the ability to identify and initiate working, therapeutic relationships, maintaining them in a way that is mutually beneficial to both parties (O'Toole, 2016). CNS, Rachel described how this helped in her role: "*as soon as you've built that rapport with people they are willing to give you that bit more insight into what's important to them.*" That added level of insight could be the difference between identifying the cause of an underlying QOL issue or missing it and it being allowed to manifest into something worse. Trial nurse, Orla, expressed the mutually beneficial nurse-patient relationship when saying "*it is just communicating with them and being completely honest and open and knowing that it is a two-way thing and that they've got somebody that they can phone if they need to.*" This could suggest that something as simple as the *availability* of the nurses' support could be as important as anything more complex in the development of rapport with the patient/client (Schluter, Seaton, & Chaboyer, 2011; Shin, 2013). Other factors that emerged from the present study that encapsulate the nurses' attempts to build

rapport included: 'breaking the ice', which involves doing or saying something when the nurse first interacts with the patient/client that makes them feel more comfortable; the use of language familiar to the patient/client (e.g. Kidd et al., 2005; Papagiannis, 2003); awareness and acceptance of limitations; providing ongoing support by maintaining the relationship through continued monitoring and assistance of the patient/client; having discussions in a conversational or less formal manner; and showing empathy and respect for the patient's/client's situation. Participant tactics in this respect broadly mirror advice that is freely available in the nursing press (Price, 2017), as well as those that previous research has uncovered (e.g. Lang, 2012).

Due to the nature of cancer, many of the patients/clients that the nurses meet are going to be present for a prolonged period of time. Therefore, as Angela states "*if you're going to have on-going support for somebody, you do need to develop some kind of relationship between you.*" So, for mutual trust to be gained in this relationship, both parties involved must be honest with each other (Kourkouta & Papathanasiou, 2014), and for the nurses this means being aware of and accepting limitations they have in their practice (Smith, 2012; Ünal, 2012). Ethan said that "*if I don't know what somebody's talking about, you know, 'I'm sorry could you explain that to me?', I'm not afraid to say 'I don't understand what that means.'*" This can also help the patient/client to recognise the nurse as a person themselves who isn't always going to be perfect, thus increasing the authenticity of the nurse (which will be further discussed later). The development of these good personal relationships requires the nurse to ask questions with kindness and provide information in a way that doesn't scare the patient/client but demonstrates interest, creates feelings of acceptance, trust and a harmonious relationship (Papadantonaki, 2012).

Building rapport is also necessary to develop a therapeutic relationship with the patient/client as the nurse would then be more sensitive to the individual's needs, whilst maintaining clear boundaries that keep the patient/client – and the nurses themselves – safe (Price, 2017). Effective communication is considered essential for establishing a therapeutic relationship with the patient/client (Angelini, 2011). Irene spoke about her realisation of the need for some level of professional distance:

When I first started I very much, I wouldn't say I was getting too involved, I think the term I mean is I was getting down there with people a little bit too much, you know, and then you have to learn a level of staying up a little bit, not because you don't feel for them but because you're the person who's got to help them. That doesn't mean you don't have every empathy and every sympathy and every care for them, but you just keep yourself slightly distanced.

To provide the best possible care for their patients/clients, the nurses need to protect themselves so that they continue to perform at a high level with each patient/client that they interact with (Stenbock-Hult & Sarvimaki, 2011). Good communication has been shown to ensure the protection of the nurse as well as ensuring the satisfaction of the patient/client (Kourkouta & Papathanasiou, 2014). Ethan demonstrated this by saying *"they all have that perception that you're giving them the time, and that's a real skill to be able to do that, whether you're interested in them or not, and it sounds really cold but I've got to protect me, to do it the next day as well."* If a nurse were to have a bad day in which the patients/clients perceive their care to not be up to usual standards, this could be taken personally, thus reducing the patient's/client's trust in the nurse. Therefore, nurses are under pressure to maintain a consistent high standard that extends to the relationships they will form, or have formed, with patients/clients.

Perceiving the development of rapport to be successful will increase the nurse's perceived competence and thus their self-efficacy when attempting to build rapport. The nurse will be able to approach the discussion confident that they can initially break the ice between themselves and the patient/client before using less formal conversational styles, whilst still showing empathy and respect, to be able to provide ongoing support and maintain the relationships they have developed. Conversely, they must also have the awareness and confidence to stop if they believe that they have reached their skill/knowledge limit, looking to find alternate care styles or another nurse more suited to the individual. This shows that self-efficacy is also important when nurses perceive their communication skills and knowledge to be incompetent or lacking so as not to cause further harm to the patient/client.

3.2.9. Authenticity

Authenticity describes how the nurses feel the need to avoid deceiving the patient/client by being sincere, genuine and honest in nature (Starr, 2008). Acting authentically means that the patient/client is more likely to have trust in the nurse and therefore listen to their advice and guidance. This was demonstrated by Lisa, who said *“I think the main thing is to be yourself, so, [slight pause] people respond to genuine people better, even over the phone.”* However, to *“be yourself”/authentic* in high pressure/high stress situations and environments requires a strong sense of self-efficacy that this is the best action to take (Pike & O’Donnell, 2010) – therefore, necessitating high self-esteem as well. However, if, as Lisa says, *“people respond to genuine people better”* then they are likely to be more accepting and forgiving of any mistakes or gaps in the nurse’s knowledge. Lisa went on to explain how this genuine attitude can facilitate better acceptance as the patient/client then identifies them as a *“human”* rather than just a nurse:

If you don’t understand something, or you confess a little bit of, not ignorance, but perhaps you’re not sure, ‘ooh, I dunno, right hang on a minute, let’s have a little look’, if you show them your human side and that you’re not some kind of automaton, they’re more happy to sit there for 5 minutes.

Therefore, this sub-theme links well with having awareness and acceptance of the nurse’s limitations as they both require the nurse to act in a sincere, genuine and honest (e.g. Kourkouta & Papathanasiou, 2014) manner and authenticity could, thus, also be seen as a facilitator for building rapport. This is beneficial for the patient/client as well as it often means that the nurse – or someone they can refer to – can provide the patient/client with a better service, as Angela summed up in this quote:

If there’s somebody else in the team that we know is far more skilled then we will always say ‘look my skills are limited but I do know somebody who could probably answer all these questions without even thinking about it’, and that comes down to confidence.

Another quote from Lisa supports this idea as it states that *“admitting you don’t know things is not a vulnerability, it’s not a lack, it’s actually a strength.”* This is an important consideration because less experienced nurses may come away from situations where

they felt they were lacking in knowledge and feel disheartened (e.g. Adebayo et al., 2013). However, what Angela's and Lisa's quotes show are that to be honest and accept when you've reached your limit is actually a virtue for nurses which ultimately "*comes down to confidence.*" So, less experienced nurses should be taking confidence from situations when they've recognised their limit and taken a step back before causing any damage or harm by pursuing the wrong course of action (Henderson, Cooke, Creedy, & Walker, 2012). Similarly, to building rapport, the nurses' ability to be authentic, and their perceived competence in this area, will help protect them from causing further harm or distress to their patient/client as they recognise and accept their limitations. Once again, should this action be considered beneficial to patients/clients and the nurse has had repeated successful communications along this vein of authenticity, they will likely perceive such events as mastery experiences.

As well as this link with awareness and acceptance of limitations, authenticity appears to play a role in counselling micro-skills (Ivey & Ivey, 2003) as 'attending behaviour' could come across as insincere and potentially patronising if not expressed in an authentic and genuine way. Therefore, the nurse must be confident that they are approaching this communication behaviour in an appropriate manner, highlighting another link between their perceived competency in their authentic behaviours and the self-efficacy required to perform them successfully.

3.2.10. *Increased Confidence through Experience*

This theme emerged as it became apparent that the participants' experience had allowed them to build belief in themselves and their ability to succeed, and that it was integral in improving their confidence (e.g. Dunn et al., 2005; Mischelmovich et al., 2016). Therefore, this subtheme links particularly closely with mastery experiences (Bandura, 1994). Ethan stated that he thinks "*the confidence takes experience, and I think it's a combination of the art of nursing and the academia side of it: I was trained, but after that I got educated.*" This has, also, likely led to improved self-efficacy and perceived competency. Continuing to learn through working experience in oncology, whether through their training or through clinical/on-the-job experience, accumulates knowledge and skill which ultimately equips the nurses with the tools they need to be

competent and comfortable with any future experiences in their role (Lucas, 2014). So, building confidence and competence through experience will naturally take time and could be considered somewhat of a process, expressed by support-line nurse, Angela, who stated, when discussing nurse-patient communication, that *“you can hear things in their voices ... you learn how to sort of gauge the way you talk to people from what you hear, urmm, and you go quietly to start with but then perhaps you, you’re sort of a bit more confident in the best way for people.”* A study of 264 nurses investigating the factors that predict nurses’ self-efficacy found a significant difference in self-efficacy beliefs between nurses with more than 16 years working experience and nurses with less than five years (Soudagar, Rambod, & Beheshtipour, 2015). The number of years of experience working as a qualified nurse was the biggest predictor of self-efficacy. Previous research has also suggested that clinical experience is an important factor in the development of a nurse’s clinical confidence (Boi, 2000) and self-efficacy beliefs have been linked with years as a functioning nurse in a mental health capacity (Gloude-mans, Schalk, & Reynaert, 2013).

It is self-evident that self-efficacy is a natural by-product of experience, but equally, less experienced nurses should not be robbed of strong self-efficacy if ways can be found to fast-track its development. Supervision and reflection are useful tools in this pursuit, but nurses working in pressured environments are typically time-poor and may not have the quality of support or time needed to fully develop these tools (Sarre et al., 2018). Upcoming sections of this discussion will evaluate nurse perceptions of the potential usefulness of QOL measures to augment their communication self-efficacy and confidence to meet patients’/client’s most pressing support needs.

Therefore, regarding the present study’s research questions, it could be suggested that greater nursing experience positively impacts the development and improvement of the quality of nurse-patient communication, leading to increased levels of confidence in perceptions of the nurse’s own competence and self-efficacy beliefs in this area. These improvements seem to be facilitated by a willingness to continue learning, whether that be through specific courses and training (e.g. Jors et al., 2016) or through actual working experience (e.g. Dunn et al., 2005), dealing with

real patients/clients and real situations/issues (e.g. Tobler et al., 2014; MacLean et al., 2017) and being able to transfer the knowledge and skills learnt from these.

3.3. Facilitators and Barriers of Perceived Competence and Self-Efficacy

3.3.1. Facilitators

This refers to the factors that promote or benefit the nurse's perceived competence and/or self-efficacy.

3.3.1.1. Importance of Coping

This emerged as participants spoke about the need for, or significance of, coping mechanisms. When the nurse perceives their communication to be ineffective this can cause them to experience higher stress levels, lower job satisfaction and increase their risk of burnout (Emold et al., 2011). Therefore, the nurses must have consideration for their own well-being so that they are able to perform consistently at a high standard for each of their patients/clients, but also to protect themselves from issues such as compassion fatigue and burnout (Todaro-Franceschi, 2019). Irene summed this up by saying: *"if you don't look after yourself then how can you look after other people, you can't function at your best if you don't look after yourself."* Previous research has linked difficulties with keeping work and personal life separate with a lack of training, putting the nurse at risk of transferring their own problems to the patient/client (Panagopoulou & Benos, 2004). A quote from Lisa expands on the need for nurses to keep their work and personal life separate:

Everybody [nurses] has good days and bad days but everyone [patients/clients] deserves a minimum amount, a minimum amount of service, so, even if you're having a stressy day, the person on the end of the phone, or the person that you're having a face to face with, is dealing with you, they have a right to the minimum goodness of you, and that still needs to be really high. So, it doesn't matter what shit you're going through, you have to park that.

These quotes are concerned with coping efficiently for the benefit of the patient/client – the patient/client, of course, being the main concern for oncology nurses. However,

it is also important for nurses to realise the importance of maintaining their own mental health and well-being, not just for the benefit of their patients/client, otherwise, as Rachel said, *“some nights you can just be up all night worrying about patients and families.”* Nurses need support to be able to discuss their own issues so that they don’t fester and manifest into something worse and more long-term (Teasdale, Brocklehurst, & Thom, 2008). However, this support isn’t always there, as shown by Irene who said: *“we haven’t got enough support from our employers, certainly here, because I think it’s underestimated the impact of the role and the impact of giving bad news and the impact that has on us.”* By ignoring this *“impact”* organisations run the risk of isolating their nurses and increase the likelihood of mental health and well-being issues developing (Catt et al., 2005). Irene continued, saying: *“I think it’s really important to talk to people, I think it’s really important to say how you’re feeling, to be able to say if you’re having a bad day, to be upset if something’s upset you.”*

For oncology nurses to communicate with high self-efficacy they must be able to protect themselves from the burden that their job can often bring. The individual coping mechanisms that the nurses choose to deploy provide this protection, allowing them to continuously communicate competently and with confidence. However, organisations as a whole need to consider how their lack of organisational support impacts the nurses and potentially creates a barrier to the nurse performing competently on a regular basis. Fortunately, the nurses in the present study also discussed the role that their peers and colleagues have in providing support, which will be discussed in further detail later on.

3.3.1.2. *Coping Resources*

Coping resources can be defined as the nurses’ efforts in thought and action to manage specific demands, responsibilities, problems, or difficulties in a calm or adequate manner (Lazarus, 1993). The resources that emerged in the present study included: humour; self-talk; reflection; compartmentalising; rationalising; formal and informal supervision; and different types of support (i.e. emotional, esteem, tangible

and informational). The informal supervision and support the nurses receive from colleagues seems to be one of the biggest sources for coping, as Lisa stated:

It's not very often that things fester, we do have clinical supervision which we can access, but as a team we're also really good, if we've come off the phone and it's been a particularly bad call, then we'll talk about it straight away. We do instant supervision, if you like, so then you can almost put it to one side because, you know, you've managed to have that conversation with somebody, ... so instead of that festering 'til the next day, they can talk to somebody, even somebody to bounce off, that understands what you're going through, and I think that's probably one of our biggest assets for how we deal with things that we understand what's going on and we can talk to somebody else about it.

Lisa's quote also alludes to relatedness when she discusses talking to someone that “understands what you're going through.” This aspect of the support, the relatedness they feel towards their colleagues, might play a crucial role in the benefit they feel from it (Hoeve, Kunnen, Brouwer, & Roodbol, 2018), so should be an important consideration amongst all oncology nurse teams. This mutual understanding helps the whole team be more willing to discuss issues that they have had during the day, thus unburdening themselves. Having these strong interpersonal relationships with colleagues has been associated with successful communication (Hsu et al., 2015), therefore making this pivotal for maintaining high self-efficacy and for the nurses' ability to continue performing at high levels (Sweet, Fortier, Strachan, & Blanchard, 2012) without the occurrence of issues such as burnout and compassion fatigue (Todaro-Franceschi, 2019). The coping resources identified in the present study act as a source of protection for the nurse and, therefore, facilitate high self-efficacy.

3.3.1.3. *Positive Environment*

This theme relates to settings and situations that make nurses feel worthwhile and valued. Oncology nurses work in an acute setting that unfortunately requires them to deal with a high level of distress and loss (Ameri, Safavibayatneed, & Kavousi, 2016; Saifan, Al Zoubi, Alrimawi, & Melhem, 2018). However, Angela said “*if you're going to be in a dark place, then you've got look at the way some people manage it*

and try and find the positives in that as well.” Therefore, oncology nurses need to have an optimistic approach to their roles to maintain self-efficacy and this can be facilitated by a commitment from all members of the nursing staff to cultivate a positive environment.

This is often achieved using humour *“because sometimes things are so horrific that the only way that you can get through it is to make a joke of it”* (Angela). This seems to help patients/clients and their families as Lisa spoke about her time working in Velindre and how *“although you think it’s quite a depressing place to work it is actually quite an upbeat place to work and I think patients find that when they go there is that as well. They always think it’s going to be all doom and gloom but it’s not.”* This positive environment doesn’t necessarily foster hope in the patients/clients but it does provide a positive experience for them in an otherwise solely negative situation. Lisa continued by saying:

Some of these people are very, very strong, their families are very, very strong, urmm, and they come in with a sense of humour, so there is a lot of laughter in a place where you wouldn’t expect there to be any and I think that’s lovely for other people coming in as well, that, you know, the nurses and the patients have banter with each other and some laughter.

Humour has the ability to alleviate or distract from stress and anxiety and provides the patients/clients and nurses with some respite from the morbid prognosis that they have to deal with on a day-to-day basis (Joshua, Cotroneo, & Clarke, 2005) – a positive experience in a negative situation. As shown in Lisa’s quote, by alleviating some of this stress and anxiety, nurses are better able to positively approach their day’s tasks and, therefore, provide the most competent care possible for their patients/clients. This positive approach will be noticed in the way that the nurse communicates and potentially impacts the mood or emotional state of the patient/client (e.g. Malhotra et al., 2018).

3.3.1.4. *Learning from Weaknesses*

This theme emerged as nurses described identifying areas of reduced experience, skills or knowledge and then acting to develop and improve on this area.

This requires a high level of self-awareness from the nurse (Smith, 2007). As Angela discussed, these include recognition of the nurse's triggers: *"knowing what your triggers are as well, I think that's important for people because we all have different triggers, you know, what winds us up. Sometimes I don't think you know what they are, but if you can identify them as you come across them you think 'ok, next time I won't fall into that trap and I know what my triggers are'."* This will allow the nurse to remain consistently professional despite situations or patients/clients which may cause frustration, anger or annoyance. Early identification of the nurse's own feelings gives them the opportunity to act in order to prevent any negative outcomes, such as the nurse getting angry with the patient/client (Zander, Hutton, & King, 2013). This was further illustrated by Ethan, when discussing his *"inadequacies"* and the importance of confidence in effective communication: *"recognising that, and facing it and doing something about it, rather than cowering away in your inadequacies and making an arse of the whole thing."* This also highlights the importance of being proactive when learning and developing from the identified weaknesses, and, slightly crudely, alludes to the potential for negative outcomes if these *"inadequacies"* aren't addressed.

This theme also has links with 'Authenticity', as to learn from a weakness the nurse must first acknowledge it as such, which requires the nurse to be honest with themselves (Shirey, 2006). As well as honesty with one's self, the nurse must be honest with the patient/client too so that they have the best care and best experience possible (Smith et al., 2010). Lisa said:

You're not going to be universally liked by everybody, but reassure them that look 'I'm not sure that I'm the right person to talk to at the moment but I'll get one of my colleagues and perhaps you'll be better talking to them, I think their experience will be better for you', nothing wrong in doing that [slight whisper].

This was followed up by a later quote of Lisa's stating that *"I'm not too proud to find out and go and read, so, yeah, if I don't know it, I'll tell people I don't know it."* Identifying and addressing a weakness, overcoming pride and putting the patient's/client's needs before your own could also be perceived as mastery experiences, should this approach consistently provide successful outcomes for the patient/client. This provides a link between 'Learning from Weaknesses' and improved

self-efficacy and perceived competence as the more weaknesses or “inadequacies” are overcome, the higher the likelihood of improved belief and mastery in the nurse’s own ability for future similar situations.

3.3.1.5. *Faux Confidence*

This describes projections of confidence that mask the nurse’s insecurities and instill confidence in those receiving their care (Haavardsholm & Naden, 2009), illustrated simply by Orla: “*You have to show that you’re confident and you know what you’re talking about.*” In general, this theme was discussed in the sense that nurses are playing a role or acting. This was explained in detail by Lisa when discussing her experience of teaching people about using, what she termed as, “a ‘bullshit hat’”:

Nurses are performing a role, it’s like any other role, it’s an act. With people who don’t have a lot of confidence, provided they’re not arrogantly thinking they know everything, I used to have a ‘bullshit hat’. They wear the ‘bullshit hat’, which means that they are pretending in their own minds that they know exactly what they’re doing ... they’re doing it with confidence, they’re taking on this role of somebody who knows what they’re doing, so they’re being confident in their actions.

By putting on this ‘hat’, nurses can act in a manner that exudes confidence. For oncology patients/clients, having confidence in your nurse is incredibly important as without this there is often a lack of trust (Dinc & Gastmans, 2011). Therefore, any suggestions, advice or information gained from the nurse would not be received fully by the patient/client, potentially leading to a lack of improvement or even a reduction in aspects of their QOL.

From the perspective of the nurses in the current study, projections of confidence could result in having genuine belief in a certain area of their role (i.e. communication), especially if they have repeated success or view other colleagues being successful with this approach (Bandura, 1994). Ultimately, this could lead to an improved sense of competency and self-efficacy. Even if this is not the case, it will at least give the patient/client the perception that the nurse is competent and has high self-efficacy. This is especially important when considering findings that show patient

complaints about nurses and other healthcare professionals to often focus around poor communication and an inability to convey a sense of care (Lussier & Richard, 2005; Moore et al., 2018).

3.3.2. **Barriers**

This theme emerged as the nurses referred to experiences/events that created mental or physical effort and obstructed or impeded the nurse's perceived competence and/or self-efficacy when communicating with their patients/clients. Heightened stress levels, lower job satisfaction and increased risk of burnout (Emold et al., 2011), can result when the nurse perceives their communication with the patient or family to be ineffective.

3.3.2.1. *Lack of Experience*

This can be defined as a lack of nursing experience that impedes the development and use of knowledge and skills. This is in part due to confidence improving through practice over time (Dunn et al., 2005). Speaking about how this impacted them, Rachel and Angela (respectively) said:

It's really nerve-wracking when you don't know. It's probably just age as well, the older you get, it does get easier, but yeah, it's harder when you're in a new situation and you're not quite sure how to say it or is this the right thing to say, what if I upset somebody.

If you get something you don't know much about, urmm, your listening skills go out the window for a start, because you're too busy thinking 'how am I going to do this, I really don't know what to do.'

Rachel's quote supports findings that nurses can feel uncomfortable and inadequate when communicating in difficult situations (Davies et al., 2008), and that they may look to protect patients/clients and families to avoid upsetting them – which can lead to hesitancy when disclosing bad news (Al-Mohaimed & Sharaf, 2013; VandeKieft, 2001). This uncertainty around the best course of action and the detriment to their required skill-set (“*your listening skills go out the window for a start*”) will impede the

nurse's self-efficacy in this situation due to not having the opportunity to develop any specific mastery experiences that they can refer back to. This will also leave them feeling as if they have not successfully navigated their nursing environment in order to achieve their goals, therefore perceiving their competence to be low (White, 1959).

By not being confident in what they need to tell the patient/client, the nurses will be distracted from making the necessary observations during the working phase of Peplau's Theory of Interpersonal Relations. As a result, they will not have these observations to refer to when providing physical care or teaching about self-management/care.

3.3.2.2. *Challenging Conversations*

Challenging conversations can be defined, based on the results of the present study, as conversations that are repetitive, spontaneous or that provide more challenges to overcome, whether tangibly, mentally or emotionally. Patients/clients usually expect full and accurate disclosure of their prognosis and diagnosis (Repetto et al., 2009; Rao et al., 2016), even when the information is negative or stressful (Tuckett, 2004). Despite this, Chan et al., (2018) found that psychosocial care was not always expected, although it was appreciated. Ineffective communication during these challenging conversations can cause unnecessary distress to the patient/client, causing them to doubt their nurse's competence (Brock & Allen, 2000) and potentially having lasting effects on all those involved (Bumb et al., 2017). Patients/clients and family members can often have angry or distressed reactions to bad news as defence mechanisms (Panagopoulou & Benos, 2004). Banerjee et al. (2016) found that nurses struggled to deal with these angry or upset patients/clients or family members during the delivery of bad news. The nurse's confidence may be impeded if they worry about losing control during these difficult discussions (Friedrichsen & Milberg, 2006). In these situations, they felt uncomfortable and often unprepared (e.g. Davies et al., 2008), creating barriers to successful communication within the working phase of the interpersonal relationship between patient/client and nurse (Peplau, 1991), which in turn prevents the patient/client from exploiting the resources provided by the nurse.

These challenges have also been shown to interfere with delivery of effective psychosocial care (Traeger et al., 2013). This is in line with findings from the present study. The nature of oncology is unfortunately a distressing and morbid one and many of the conversations that the nurses described followed this tone. This has been shown to cause difficulties in a nurse's communication abilities (Banerjee et al., 2016), acting as a barrier to effective communication (Kruijver et al., 2000). Irene spoke about the difficulties of giving information: *"we have huge challenges really, because the information that we're giving is difficult information, it's complex information, it's life-changing information, it's distressing information."* Imogen spoke about those patients/clients who are already in a distressed state:

When you've got a very anxious patient, or, urmm, suicidal patient, urmm, I think that can be quite a challenge, but sort of, the inappropriate callers you can put the phone down on them, that's not an issue at all, but the ones that are in a very bad state, that is something that, urmm, can be quite difficult.

Speaking to distressed and potentially suicidal individuals and trying to *"bring them down to a decent level so you can, hopefully, have a valid conversation"* (Angela), is going to take a great deal of emotional effort from the nurse. This was demonstrated by Imogen: *"It can affect me"*, said prior to referencing an experience of dealing with a suicidal patient/client. Research has referred to the term 'emotional labour' (Hochschild, 1983), which is the process of managing feelings and expressions to match the emotional requirements of a job. Emotional labour has links with self-efficacy and burnout (Yang, 2011; Oz, 2017).

The nurses from the present study spoke about either the tedium of repeated conversations over the course of a day: *"I may have the same story a dozen times that day, kind of thing, and I'm trying not to glaze over but I've learned when to say the 'mmm's', so, they still believe I'm interested"* (Ethan), or similar conversations that are had regularly with the same patient/client, as illustrated by Lisa:

We've had regular callers who literally phone us every 3 days, the same thing again and again and again and again [clicking], and that can be really difficult because you start off trying to help them, all bright and sparkly, and by the 50th time you've spoken to them and said all the same things to them, it can be really, really, difficult to have that same kind of interaction with them.

This tedium can begin to affect the nurse's self-efficacy if they believe that the frustration experienced from repeated conversations is going to impair their ability to help their patient/client. The repetitive and tedious conversations will increase feelings of incompetence due to a lack of perceived success, and the feelings of discomfort or ill-preparedness caused by spontaneous or more challenging conversations will result in a lack of confidence for communicating effectively for the patient's/client's benefit. The nurse may experience a reduction in their mastery experiences i.e. feeling that they have failed to have an impact on the patient/client, reducing their perceived competence for that situation. This could also be indicative of the symptoms of compassion fatigue (i.e. diminished performance; Cross, 2019). The mental and emotional toll of these challenging conversations will cause barriers to the nurses' communication if they allow feelings of incompetence and low self-efficacy to manifest into more serious issues.

3.3.2.3. *Individual Differences/Needs*

Individual differences/needs refer to the enduring psychological characteristics and needs that differentiate patients/clients from each other (Baumeister & Vohs, 2007). Lisa illustrated this by saying: *"you can get people with all kinds of personality and mental health issues ringing you, so it can be difficult."* She also said:

Unfortunately, we deal with everybody in this service, so we may deal with somebody who's not the brightest bear in the forest to somebody that's really, really intelligent, and you have to be able to make the information available for all.

This highlights the variation in patients/clients and the challenges that this can cause as the nurse attempts to adapt their communication style and information-giving to the individual (Teutsch, 2003). Individual differences in interpretation mean that the message delivered by the nurse may not always be the one received by the patient/client – and vice versa (Arapkis, 2006). The language used by the nurse is, therefore, very important (Kidd et al., 2005) so that it is at the patient's/client's level, ensuring they understand what they're being told (Papagiannis, 2003). This is often an

issue nurses deal with when faced with cultural differences, such as: the absence of translated written material for the patients/clients; the absence of a shared language; and approaching sensitive topics (Weber et al., 2016). Across most cultures, patient/client preferences are for experienced nurses with empathy and caring, offering hope with appropriate wording (Martins & Carvalho, 2013). However, preferences for how the illness information is disclosed vary across cultures (Tse et al., 2003; Abazari et al., 2016). This is something that the nurses must be sensitive to, although Weber et al. (2016) has shown that nurses felt a need for improved and more frequent cross-cultural training.

Nurses may feel more confident with one patient/client but less confident with the next, due to personality and cultural differences that require a separate approach. Perceiving their competence to be lower with certain types of people could impact their future belief (self-efficacy) that their behavioural capabilities (Bandura, 1977) can successfully provide care to patients/clients with specific personality types, issues and needs. This lack of perceived competence and self-efficacy is indicated by Angela, who said *“I think you start off quite tentatively, urmm, and test the waters, and see what you get a response to.”* The use of the word *“tentatively”* indicates a lack of confidence and uncertainty from the nurse. However, it could be argued that being tentative is important in the orientation phase (Peplau, 1991) as the nurse looks to gain essential information about the patient/client, including their unique needs and priorities.

3.3.2.4. *Phone Conversations*

Phone conversations, in the present study, refers to nurse-patient communication and relationships that are initiated and developed over the phone, with no physical contact. This provides challenges through the loss of the physical feedback that nurses would ordinarily incorporate into their assessment of a patient or client (Huibers, Keizer, Giesen, Grol, & Wensing, 2012). Therefore, Kourkouta and Papathanasiou's (2014) suggestion that listening is crucial for properly perceiving a patient's/client's verbal and non-verbal messages becomes even more pertinent

when communicating over the phone. Imogen spoke about how on the phone “*you haven’t got those visual skills*” and that “*it’s like being blind.*” These are obvious barriers to communication when we consider observations of body language and facial expressions in face-to-face communication. Rachel described this by saying: “*I’d much rather see somebody to talk to them, it’s a lot easier ... you can read people’s body language, you can provide reassurance a lot more easily, because you can see expression changes, whereas you can’t see that over the phone.*”

There was a clear and expected contrast between the participants when describing over-the-phone communication had with patients/clients. The support-line nurses only communicate with patients/clients over the phone, so, as they get more experienced, this form of communication becomes more natural and instinctive as their confidence improves (Dunn et al., 2005; Mischelmovich et al., 2016), Ethan said:

How do you respond when you’ve got one part of the verbal stuff taken away from you, you pick up on other bits, you do, you end up tuning in on various bits that you, and it comes naturally, I think, as well, because, again, you’re still trying to give the best service that you can, despite being limited.

Working within these limitations forces the nurse to fall back on other skills and senses (i.e. listening skills) thus providing more of an opportunity to develop these skills (Choudhari, 2006). In contrast, as with Rachel’s quote, we can see that clinical or trial nurses, who are more used to face-to-face communication and who haven’t developed such instinctive listening skills, will have more challenges when having phone conversations with their patient/client (Roberts, 2007). When experiencing these situations, the support-line nurses’ behaviour towards their patient/client is impacted by their restricted environment, showing elements of reciprocal determinism (Bandura, 1977).

The support-line nurses are able to develop mastery over their listening and communication skills over the phone due to their repeated use and, hopefully, success. However, prior to them gaining this experience, they would have initially lacked competence and self-efficacy in this domain. This is mirrored in how the other nurses in the study (i.e. clinical and trial nurses) feel, as they lack the experience to have developed mastery over phone conversations and, therefore, perceive

themselves to be less competent and confident when communicating this way. Clearly, lack of experience in communicating with patients/clients via phone is a barrier to nurses' self-efficacy in this area.

3.3.2.5. *Lack of Closure*

Lack of closure can be described as the ambiguity and uncertainty around the fate or outcome of patients/clients, including feelings of loss. Lisa said: *"we don't get that closure, and sometimes when you've built up quite a relationship with somebody that's a difficult thing."* This was expanded upon by Angela and Irene (respectively) who stated:

Obviously if you've been supporting somebody for quite a long time, and then the phone just rings, because that's all we can do, we just ring that number, and if that number just rings and rings every time you call and there's nobody on the end of the phone and then one day you just get beep [dead dial tone], that person's probably passed away, and that can be quite difficult because you don't get that, sort of, closure with them, they're just suddenly, the interaction just suddenly stops, so that can be quite difficult.

We spend a lot of time with people and prognosis for our cancer is bad. I've had patients die, so, you've built a relationship with someone who is ultimately, a few months down the road or who 6 months down the line is going to die, that has an impact so it's, sort of, dealing with that and knowing how to deal with it and looking after yourself really.

For the nurse to know that potentially the interaction and relationship they've had with a patient/client might end suddenly is a major barrier to perceived competence and self-efficacy as the nurse could view their care as unsuccessful if the patient/client moves on (e.g. to palliative care) or passes away without the nurse knowing. Aside from potentially feeling 'unsuccessful' – quite a cynical view – the nurses also form an emotional attachment to the patient/client through their developed relationship. Therefore, when a patient/client moves on or passes away this could impact the nurse's affective process (Bandura, 1994) leading to feelings of grief. Bereavement can cause emotional upset and contribute to learned helplessness, ultimately reducing the confidence of the nurse in their ability to successfully perform specific behaviours (Lev & Owen, 1996). However, Bauer and Bonanno (2001) suggest that greater perceptions

of self-efficacy predict less grief over time, indicating the mediating role of self-efficacy in grief management. Previous research has shown oncology nurses to be at an increased risk of psychological distress due to the morbid nature of their role (Moya del Pino, 2012), as well as being at an increased risk of burnout, compassion fatigue and moral and occupational distress (Wahlberg et al., 2016). Grief and lack of closure are likely to facilitate increases in the nurse's risk of developing symptoms of these issues (Houck, 2014). This is borne out by the nurses in the present study.

In terms of Peplau's Interpersonal Relations theory and the final termination phase, lack of closure and the potential death of the patient/client is clearly a major barrier to completing this phase as there is no "resolution" to the care. It has also been found to act as a barrier to effective nurse-patient communication (Kruijver et al., 2000). Lack of closure can cause further barriers to self-efficacy and perceived competence as the nurse aims to successfully transition through the phases of Peplau's theory to the point where the patient/client can be discharged. This is due to a lack of mastery experience specific to the termination phase, as well as greater emphasis on and difficulty in controlling their emotional and psychological states (Bandura, 1994; Maddux & Gosselin, 2003).

3.4. Perceived Facilitators and Barriers of Communication, Self-Efficacy and Competence when using QOL Measures

3.4.1. *Facilitators*

This theme describes the factors of QOL measures that benefit the nurse in terms of their self-efficacy, competence and the quality of communication with the patient/client.

3.4.1.1. *Identification of Cues/Issues*

Nurses must understand the precise concerns and experiences of the patient/client (Aungst, 2009; Papadantonaki, 2006). Therefore, identification of cues/issues describes how the EORTC-QLQ LC13 and FACT-L measures can aid the

nurse in recognising signals or areas for concern from the patient/client, that may previously have been overlooked (Rubenstein et al., 1995). Previous studies have shown oncologists and nurses to infrequently respond to patients'/clients' expressions of negative emotions (Adams et al., 2012; Morse et al., 2008). Anita said: *"as a tool for somebody new, maybe it would act as a guide and perhaps stop people then saying "well, nobody asked about my financial situation.""* Therefore, the nurse's self-efficacy in terms of cue identification when communicating with the patient/client should be improved through the use of these measures, as the nurse would have a higher sense of belief that they can identify the most pertinent areas for exploration. Irene said: *"I do find it opens up a lot of things"* and in terms of less experienced nurses, Angela said:

I think it does gives you a sense of reminding you, and I think especially for maybe less experienced nurses, who are not used to doing that kind of thing, it gives them a structure for what they need to do.

New or less experienced nurses may be less confident than their more experienced counterparts when assessing a patient's/client's needs and QOL issues and as Lisa stated: *"if there were people that were new to Lung Cancer, as well, it could be a really good prompt."* Therefore, QOL measures offer a good resource for these less experienced nurses. The term *"prompt"* is important within this sub-theme as it describes how the nurses may be encouraged to seek certain courses of action and behaviour that would ultimately benefit each specific patient/client. The use of these tools could, therefore, increase the nurse's sensitivity to a patient's/client's verbal, physical and emotional cues, thus improving the support and care they provide (Ptacek & Ellison, 2000). This has clear links with self-efficacy which describes important determinants for how we think, feel and motivate ourselves and the consequent actions and/or behaviours (Bandura, 1994). In terms of the Social Cognitive Theory, positive patient/client responses would reinforce nurse behaviours and confidence in the use of QOL measures, therefore developing the individual's behavioural capability when identifying patient/client needs and concerns (Bandura, 1977). This is likely achieved as the measures will facilitate opportunities for the nurse to achieve mastery experiences.

This identification of issues also encourages the nurse and the patient/client to prioritise the most pertinent concerns so that they can be addressed first: “it [Distress Thermometer] *had its uses, so, you got the patient to prioritise*” (Ethan). Anita said: “*especially for inexperienced nurses this is a great way to help get them focused on perhaps important things.*” Considering findings that showed healthcare professionals can be unsure about how best to establish individual information needs of patients/clients (Maguire & Faulkner, 1988), the QOL measures offer an important resource to support nurses in this pursuit. This again ties in with facilitating the nurses’ opportunities for mastery experiences.

If a nurse believes that the cues identified through these measures, and the prompts they offer for further investigation, improve the care that they provide for their patient/client, it is likely that they will also see improvements in their communication self-efficacy and perceived competence.

3.4.1.2. *Measurable Nature of EORTC-QLQ LC13 and FACT-L*

The measurable nature of the EORTC-QLQ LC13 and FACT-L describes how they quantify the QOL issues that patients/clients experience. The use of these measures standardises the approach and collective vocabulary in communication used by oncology nurses, acting as a source of collective self-efficacy. All the nurses working in a team can be confident that the same approach is being followed: “*it standardises responses and things, so you’d get less experienced people being able to respond to that*” (Ethan). Angela supports this quote by saying:

Because they’re standardised there will be questions that sometimes you may not ask, but if you knew you had to cover those questions, I think you’d get a more standardised approach to be able to measure what was going on.

Both Ethan and Angela’s quotes show that having a standardised approach will act as a facilitator to enhanced self-efficacy and competence when identifying patient/client concerns, especially for those nurses with less communication experience.

At an organisational level, these measures can also be used to assess the effectiveness of the care that is being provided, as continued use can identify improvements or reductions in the patient's/client's QOL concerns that may be linked to the care they are receiving (Detmar et al., 2002). This supports Sawin et al.'s (2019) findings that when "Fostering a Caring Climate", nurse managers look to be constantly vigilant through assessment and optimisation, a process that could be improved or supported through the use of the QOL measures. Angela described this by saying:

If you're looking ongoing and somebody says, "well how do you prove the benefit of what you do?", having something like this that you could say "well, when people first started calling they scored all 4s, and the last call they scored all 2s", then we can say "that's a measure of our successes" in a way, or how our supporters assisted those people. Ummm, from our point of view, again, you could say "well, we know this works because, you know, the way we're approaching it is the right approach", and if it's not working then we can say "well, what do we need to do different?", so as a team it could help us to develop, maybe, the way we approach different things, even if it's just specifically lung cancer patients, whose outcomes might not be that good.

Therefore, this demonstrates that the use of QOL measures could increase self-efficacy in the nurses if they are able to see that the care they are providing is worthwhile and effective, acting as an indication of their mastery experiences (Bandura, 1994). Identifying these mastery experiences shows the nurse examples of effective communication between themselves and the patient/client, which Banerjee et al. (2016) showed to increase the overall well-being of both the patient/client and nurse, improving treatment adherence, psychological functioning and patient/client recovery. In addition, vicarious experience and persuasion could act as sources of self-efficacy at the individual level (Bandura, 1994), as the nurses see others using these measures and are informally persuaded by feedback from others on the usefulness of the measures. This would then contribute to the wider, collective self-efficacy (Lee & Ko, 2010).

When considering Peplau's theory (1991), nursing is described as a process that is "serial and goal-directed" and has "orderly steps" necessary for success (p.5). The use of these measures provides orderly steps for the nurse to follow and opportunities to develop pertinent goals for the nurse and patient/client to work through. The benefit of this systematic approach was shown by Anita:

I suppose in terms of being able to sort of recall that you've touched base on these kind of things, if that's the way you want to use this tool, urmm, you would have some record of that and you could reference back.

The measures can then also facilitate observations made by the nurses about patients/clients to use during teaching of self-care and when providing physical care, allowing the patients/clients to assess their own situations and begin the process of recovery (Peplau, 1991). Unfortunately, this is a longer process in oncology and may not occur at all. Nurses become more familiar to patients/clients, who are no longer perceived as strangers, accepting the nurses as health educators, resource persons, counsellors and care providers. This helps to develop good personal relationships (Papadantonaki, 2012). The patients/clients are, therefore, able to exploit the resources provided by the nurse i.e. actions taken based on the responses to the measures (Peplau, 1991). Exploitation of these resources should suggest to the nurse that they are performing and communicating competently, facilitating a sense of enhanced self-efficacy.

3.4.2. **Barriers**

This theme describes the factors of QOL measures that create challenges or obstacles to their use.

3.4.2.1. *Subjectivity*

The subjectivity of the QOL measures (Lindley & Hirsch, 1994; Velikova, Stark, & Selby, 1999) refers to how responses can be influenced by individual opinions, biases or fluctuating feelings and cannot therefore be interpreted in the same way. For the nurse, this can reduce their confidence in the measures due to the uncertainty the questions and/or responses could cause. Angela said:

It gives you a good basis for what exactly people are dealing with, as long as they answer them realistically, and I think that's the problem. For instance, this question "a long walk", what does that mean to somebody? For somebody who's never done any exercise, a long walk might be to the end of the street, but for somebody who walks 3 miles a day, a long walk might be 10 miles. So,

it's qualifying, really, the questions, isn't it? Ummm, and sometimes it's quite subjective.

This could negatively impact the nurse's perceived competence, as they cannot be certain that they have gained mastery over the use of the QOL measures. This lack of mastery experience could also be detrimental to the nurse's self-efficacy (Bandura, 1994).

"I think it still comes back to the skills of the individual nurse in interpreting what these all mean" (Anita). Hagerty et al. (2005) stated that ineffective nurse-patient communication would lead to increased patient/client uncertainty and dissatisfaction with care. The subjective nature of these measures could cause a breakdown in communication if the nurse interprets the patient's/client's response incorrectly: therefore, the use of these measures could also cause the nurse to feel uncertain and dissatisfied with the care that they are providing. This could prevent a successful transition into and then through the termination phase (Peplau, 1991) as the success of this phase is dependent on how well the patients/clients and nurses have navigated the orientation and working phases. This could cause problems for the nurse when communicating with the patient/client in the final phase, especially if they perceive their care to be incompetent.

A further example of the potential lack of consistency in responses comes from changes and fluctuations in the patient's/client's emotions. This was illustrated by Angela and Anita (respectively):

For some people, it depends how they feel when they fill it out. If they're having a good day, sometimes their answers are better than they actually are: if they're having a bad day then sometimes they're worse than things actually are.

It's going to change, it's a dynamic thing because clients will change their focus of what's important as they do that journey through what's going on with them in terms of treatment and in terms of their mental health because that's going to change as well.

This can challenge the strength of the nurse's self-efficacy expectancies (Bandura, 1994) as they would be uncertain of the applicability of previous patient/client responses to the QOL measures. It may be difficult, therefore, for the nurse to

perceive their care provision as competent because they are constantly having to adapt their approach to the fluctuating emotions of their patient/client. This was further demonstrated by Irene:

Patient's problems change from week to week and it doesn't matter how many times we feel like we've addressed everything, we haven't. Or it feels like no matter how many times we ask cos people will only tell you what they want you to know at that point in time and 3 weeks later they'll be like "well, nobody asked me about such and such."

The feelings Irene describes could potentially cause a sense of hopelessness and frustration in the nurse as repeated changes and fluctuations could cause them to see the use of the QOL measures as futile. Nurse confidence has been shown to be affected by patient/client unpredictability and emotional fluctuation, as they are led to feel insecure, worthless, threatened, powerless and ashamed (Vatne & Fagermoen, 2007). This could lead to the nurse acting in a non-caring way as their self-efficacy and perceived competence take a significant knock. However, it should be mentioned that the unpredictability of patient/client responses and needs and the nurses' need to be adaptable to these is not unique to situations involving QOL measures (e.g. Arapakis, 2006). Therefore, it is arguably not unreasonable to expect nurses to be prepared or experienced in responding to the huge variety of individual patient/client needs and concerns. Despite this, adding to the uncertainty that nurses face (Hagerty et al., 2005) may be seen as excessive and the added burden that this causes will be detrimental to their perceived competence and self-efficacy related to patient/client communication. Certainly, in the present study nurses concerns around subjectivity were perceived as a barrier to their competence and self-efficacy.

3.4.2.2. *Organisational Issues/Concerns*

Organisational issues/concerns describe the organisational level factors that limit the use of these QOL measures and may cause a lack of clarity for their purpose. The main issue that came up was that of time, as well as the added workload in the nurses' already busy schedule: *"Time... time, another bit of paper ... it's time, it's time, it's always time, time and people, I'm afraid"* (Lisa). This is largely due to the length of

these measures which, unfortunately, is necessary to increase their accuracy (Mitchell, 2007). This can lead to the measures being used and assessed incorrectly, poorly or not at all. Angela described how this burden prevents the measures being used properly:

Nurses in a unit have so limited time to sit down with people, that they might just hand them it, very often, and it's a tick box exercise then, they know it needs to be done so they just fill it, to do it. So, it then becomes a waste of time and eventually fades into the background instead of being used as a tool to develop themselves and to help them develop services that the patients might need. I don't think, it's not done maliciously, it's just literally another piece of paperwork and, you know, the NHS is drowning in paperwork, bless them. So, it just, it's something that's put to one side probably, it's a "oh, that's something else I need to do later", and then just gets forgotten.

As mentioned previously, should nurses perceive the implementation or use of these measures as futile – Angela's quote illustrates how they could be "a waste of time" – this could impair their confidence (Vatne & Fagermoen, 2007). The nurses' belief that they are providing the most effective care they can will be lost, therefore reducing their self-efficacy when communicating with their patient/client. This could also prevent the patient/client being able to exploit the resources provided by the nurse (Peplau, 1991) as the nurse may come across as unconfident, likely instilling the patient/client with a lower belief in the nurse's ability. If the nurse perceives the patient/client to have low confidence in them, this could cause a reduction in their own self-efficacy as they will not perceive themselves to be competent at mastering the QOL assessment, whether through the use of the tools or simply through a therapeutic conversation (Bandura, 1994).

Nurses in the present study also described how they were unclear about the reasons and motivations for using these QOL measures: "generally, we use them because we're told to use them" (Orla). This was expanded upon by Rachel: "you're just doing it because you've been told to do it, and then the people who've told you to do it don't even know why they've been told to do it, when you actually look at where it's come from, there's not much there [slight laugh]." This lack of clarity for the purpose of these measures impacts the expectancies of the nurse (SCT; Bandura, 1977) causing uncertainty in their beliefs about how their actions are perceived (e.g.

how the patient/client will respond to the QOL measures) and the anticipated outcomes of these (e.g. what do the nurses then do with the information gained from responses to the QOL measures?). As the uncertainty also comes from those in higher positions, this is likely to be a perceived institutional barrier (Banerjee et al., 2016). Irene went on to say: *“When do we do it? How often do we do it? It’s not clear cut, so I do think that does impact on us.”* This could cause ineffective communication between the nurse and the patient/client as the uncertainty of the nurse may come across as, or lead to, low confidence. Ineffective communication has been shown to increase nurse stress levels, lower job satisfaction and increase their risk of burnout (Emold et al., 2011).

3.4.2.3. *Impediment to Conversational Flow*

This describes how the structured nature of the QOL measures can be a barrier to conversational flow, as the knowledge and skills acquired through practical experience already equip the nurse to deal sufficiently with the patient’s/client’s QOL issues. Anita said: *“I’d hope that a more experienced nurse would not need this, that it would come up in general conversation.”* This is because, as Imogen stated: *“you can learn so much from a general conversation with a person that you can answer most of these questions [referring to QOL measures].”* In addition, as Angela said:

If you focus too much on just answering the questions, there might be things that you miss because, you’re like “I know I need to fit all these bits in” but then they’re telling you something maybe about a family member that doesn’t come into this, that’s having a major impact on them, urmm, but you’re too concentrated on what you need to complete.

This could cause a breakdown in the therapeutic relationship between the nurse and patient/client (Peplau, 1991) *“because it felt so cold and just not right somehow, just to ask a list of questions”* (Imogen). This is rather far removed, for instance, from Papadantonaki’s (2012) description of good personal relationships, which requires the nurse to ask questions with kindness and provide information in a non-intimidating manner and that demonstrates interest and creates feelings of acceptance and trust. If the nurses feel that they are utilising the measures ineffectively, this could lead to

barriers developing in their communication and ultimately result in poor psychosocial care for the patient/client (Chen & Raingruber, 2014). The nurses in the present study indicate low strength in the self-efficacy expectancies around the use of the QOL measures as they seem unconvinced that this particular behaviour will result in successful performance (Bandura, 1994). The nurses also lose a sense of autonomy when using these measures as they perceive themselves to have reduced control over their actions and the decisions they make (Ryan & Deci, 2000). Worry over the lack of control they have in the conversation can be an impediment to their confidence (Friedrichsen & Milberg, 2006). In addition, as shown through Angela's and Imogen's quotes, the nurses may perceive their care to not be meeting the supportive care needs of their patient's/client's, as to them the QOL measures appear to be a barrier to the highest level of service or support the nurse can provide (Carey et al., 2012).

By reducing the autonomy of the nurses to react to changes in the conversation and address the most pertinent concerns of the patient/client, they are reducing the nurses' belief/self-efficacy that they are providing the most effective care, thus reducing their perceived competence for patient/client communication.

3.5. Considerations for Practical Application of QOL Measures

This theme describes the factors that require thought and deliberation when considering the practical application of the QOL measures.

3.5.1. *Timing*

Timing refers to the nurse's judgement over when to deliver/use the QOL measures. Irene said: "*When do you use them? Because things are going to change weekly*" and as Lisa said:

You might not even get them to fill that one in, or some of the really hairy ones, because they won't want to go there, they've got enough on their plate, they're not going to deal with that.

The nurses must ensure that the behaviours and actions they implement into their care do not increase the distress of the patient/client. So, the nurses do have to be wary of the patient's/client's emotional state when considering the use of the measures. Incorrect timing could be considered ineffective communication, leading to increased patient/client uncertainty, dissatisfaction with care and increased rates of anxiety and depression (Hagerty et al., 2005; Donovan-Kicken & Caughlin, 2011). Other research has found patient/client complaints about their healthcare professionals to be focused on perceived communication failures and an inability to convey a sense of care (Moore et al., 2018; Lussier & Richard, 2005) and a pessimistic or unsympathetic approach from the nurse is associated with patient/client dissatisfaction (Martins & Carvalho, 2013). This could occur due to a nurse's poor timing and lack of understanding of the patient's/client's emotional state when delivering these measures. Not only would this be of detriment to the patient/client but could also cause discomfort in the nurse and the fear that they may remove the patient's/client's hope (Newman, 2016). If the nurse perceives their communication alongside the QOL measures to be ineffective this could also lead to the negative outcomes described by Emold et al. (2011).

For the nurses to understand their patient/client and identify the most appropriate time to deliver the QOL measures, they need to have developed a good rapport with the patient/client (O'Toole, 2016). The importance of a good, harmonious relationship between the nurse and the patient/client was highlighted by Lisa:

It may be something that you could introduce after you'd built a little bit of a relationship with them, urmm, because if you are going to be asking them about whether they worry about dying, that's a hell of a whack, you have to have a whole phone call on that, not answer that and we'll move onto this one. So, it's just, yeah, these could be something that over a series of calls you could work through as well, perhaps, you know, deal with the things that are more immediate.

Within Peplau's Theory of Interpersonal Relations (1991), the working phase is when the nurse begins to become more familiar to the patient/client, indicating the development of the therapeutic relationship that is at the core of this theory. This is likely to be the most appropriate phase to implement QOL measures into the care as

some level of rapport will have been established. So, *“once you get that rapport with a patient, and that trust built up, you can ask them, ‘listen, you know, would you mind filling in, have a look and see if you’re happy to do it and would you then fill it in?’”* (Imogen).

The timing and delivery of QOL measures can act either as a barrier or facilitator to good nurse-patient communication. As shown in the present study, finding the most appropriate time and approach requires high levels of competence and self-efficacy from the nurse to be able to recognise this opening and have confidence in their decision. Lacking in competence and self-efficacy in this situation could lead to negative outcomes for the patient/client and is likely to reduce their confidence in the nurse’s capabilities.

3.5.2. *Conversational Prompts*

QOL measures can be used as conversational prompts or guides to assist the content and direction of the discussions between the nurse and their patient/client. This is crucial for understanding the patient’s/client’s specific concerns and experiences (Aungst, 2009; Papadantonaki, 2006). This is highlighted by two quotes from Lisa:

If you’re using this then to guide people towards the questions that they should be asking, I think they’re an excellent memory jogger. They’re an ideal prompt if they’re used as that, urmm, towards people that have not got the experience, you don’t forget the important things that you need to ask. Then everybody finds their own flow, and obviously you’re talking to somebody you have no idea what they’re going to say to you, so they may stick something in half way through the conversation that is not in the order, for that.

It’s a useful tool, but it shouldn’t be the be all and end all, but it’s something you can work with the patient with, and not instead of conversation.

This illustrates the importance that nurses place on the role of the conversation and maintaining the conversational flow. It is crucial, therefore, to prevent anything from creating a barrier and stunting the conversation. Lisa describes these measures as *“excellent memory joggers”* which is clearly important for ensuring that all necessary

topics are explored. The nurses in the present study describe doing this in a less formal way, naturally introducing topics, which overcomes the issue of the measure being too structured: *“for me personally I find the best way is to use them alongside the consultation”* (Irene). Irene went on to speak about how she benefitted from a self-made guide: *“when I first started, I actually made my own little forms like that to remind myself about nausea and to ask about this and to ask about that, to prompt myself.”*

Nurses’ confidence can be impeded should they worry about losing control during difficult patient/client interactions (Friedrichsen and Milberg, 2006). For the nurse to have a say in how they utilise this resource (QOL measures) will promote autonomy in their care, giving them more control over how and when these measures are used (Ryan & Deci, 2000). This also demonstrates competence as they show mastery of their communication skills and ability to uncover QOL issues (Bandura, 1994). Furthermore, by adapting the QOL measures to fit the individual nurse’s style of communication, they are identifying ways of overcoming the barriers that these measures may bring. This demonstrates high levels of self-efficacy as they see obstacles as an opportunity and look to overcome these difficult situations (McLaughlin et al., 2008; Zhang et al., 2015). Nurses in the present study clearly valued the use of the measures as a prompt, displaying confidence over their use in this way.

In terms of Peplau’s Theory of Interpersonal Relations (1991), using the QOL measures as conversational prompts and guides will facilitate non-directive listening in the nurse and help them to provide reflective and non-judgemental feedback, thus further engaging the patient/client.

3.5.3. *Further Exploration of Identified Issues*

The answers or responses to QOL measures require thorough examination and investigation by the nurse, including proper reflection and record-keeping of the patient/client information gained, to develop a full understanding of the issue. By themselves, the QOL measures only identify the issues that a patient/client has, and further follow-up is required: *“it’s something that needs to be further explored, but as*

a stand-alone question, I don't think it really covers ... it gives them a basis for taking things further" (Angela). If nothing is done following the responses to these measures then they become futile, which only goes to further the burden they place on the nurse's and patient's/client's time. This was indicated by Anita:

It might be seen as a really positive tool, you know, as long as then you don't think ticking a box isn't the end of what you do with Quality of Life information and I think there's an inherent risk in that.

Nurses provide direct care within their therapeutic process but without further exploration of the identified issue there will be a lack of direct care, preventing patients/clients being able to exploit the resources that the nurse provides (Peplau, 1991). Imogen demonstrated this by saying:

It's brilliant that people come up with these ideas to evaluate and to think of a holistic approach, and I know holistic care and, urmm, patient's individual rights and doing what's best for the patient has been sort of the crux of nursing in all time but on a hospital ward, urmm, you've got to have structure and they can clash.

To facilitate a "holistic approach" the nurses emphasised the use of these QOL measures alongside their note-taking practices. Lisa stated:

It's about getting that as part of the general reporting of how the patient is, part of the note-taking rather than having to fill this in [referring to QOL measures] and then write more notes ... making it user friendly in a way that it's something they find easy to incorporate into the note-taking, into the recording that they already do.

Feedback from these experienced nurses clearly indicates their understanding of the need to follow through on any data collected, otherwise they perceive the process as purely academic. Nurses are open to using new techniques, such as these QOL measures, however, they will only have a high sense of self-efficacy around their use if they believe the consequent actions and behaviours to be beneficial to the patient/client. This requires them to adapt the use of the measures to ensure that they are responding effectively to the patient's/client's issues. A nurse who lacks self-efficacy and perceives themselves to be lacking competence in this domain, may struggle to have the belief and confidence to properly explore the identified issues further. This could lead to a breakdown in nurse-patient communication and stunt the

care that the patient/client receives, whilst further reducing the self-efficacy and perceived competence the nurse has surrounding the use of QOL measures. If the measures are used in a manner that promotes further exploration and complements their note-taking practices, the observations that the nurses make in the working phase (Peplau, 1991) will be more beneficial when providing subsequent care.

3.5.4. *Implementation Strategies*

Implementation strategies describe the application and execution of specific action plans for delivering QOL measures. Nurses in the present study described the need for further consideration for how these measures can be assimilated into their practice. For example, Lisa said:

It's about getting that as part of the general reporting of how the patient is, part of the note-taking rather than having to fill this in [referring to QOL measures] and then write more notes ... making it user friendly in a way that it's something they find easy to incorporate into the note-taking, into the recording that they already do.

Lisa's quote indicates a need to normalise the use of the measures whilst again alluding to using them in a less formal way than their structure was originally intended for. Improved implementation will improve the motivation of the nurses to use these measures in a way that suits their practice. This will provide more opportunities for the nurse to gain mastery over their use of the measures, therefore improving their perceived competence and self-efficacy for communicating with patients/clients, aided by the measures (Bandura, 1994; Ryan & Deci, 2000). One nurse (Rachel) suggested changing the whole model of consultation *"rather than just adding something on to it all the time"*, which would allow the measures to be incorporated more easily and naturally into nurses' practice – although, this clearly comes with its limitations.

One technique that has already received some traction with other measures is the use of online versions. In today's day and age where technology is controlling our lives more and more, why not exploit its reach and ease of use? Angela said:

If they could do it online or something, something that flags the areas, in some kind of way, that, you know, might be of concern, so they can concentrate on those but being aware of the others as well. Ummm, I think the less the nurses have to do any paperwork and the more intuitive a system could be to say they talked about staying in bed all day, as a red flag.

Not only does this make life easier for the nurse in terms of it *“not being another piece of paper”* (Lisa), but it potentially provides easier access for the patient/client too. The easier it is to use and to incorporate into their practice, the less burden the nurses will feel from its use. Online versions also have the advantage, as Angela’s quote alludes to, of being able to immediately identify issues (*“a red flag”*), bringing them to the attention of the nurse. This also allows the patient’s/client’s progress to be easily tracked and monitored, potentially leading to more efficient identification of problems by the nurse in the working phase of their therapeutic relationship (Peplau, 1991). One limitation to the use of online versions in oncology is the fact that many patients/clients are elderly and it is assumed that they are less technologically savvy, but as Lisa states: *“that’s one restriction, although, that’s going to change, in your lifetime, that will change, because people will be more technically aware.”*

By considering best implication practices for the QOL measures, the nurses and those involved at a management level will ensure that they are being constantly vigilant by assessing and optimising their care whilst also promoting a competent, thoughtful and caring workforce. These are themes which will help to foster a caring climate for the patient/client (Sawin et al., 2019). These implementation considerations will also imbue greater belief in the nurses that these measures are feasible and useful, rather than seeing them as a burden to their practice. It is possible that this will increase the nurses’ self-efficacy for the use of these tools – as well as their competence – as they become more willing to engage in their use.

Chapter Four

General Discussion

As holistic care of a patient/client, especially in oncology, continues to grow as a necessary approach to nursing, the findings from this study demonstrate the various types and levels of perceived self-efficacy and competence concerning a nurse's role, specifically regarding the quality of their communication through all aspects of their care. The data also explores the factors that promote and those that restrict perceived self-efficacy and competence in communication. Previous research demonstrates that QOL measures are a well-established, if slightly underused, communication aid – therefore this study also considered the perceived utility of the measures to improve the self-efficacy and competence of a nurse's communication.

4.1. Implications and New Research Possibilities

This section is a discussion of the key findings from the present study and the theoretical and practical implications of these findings. Opportunities for further research and interventions will also be considered.

4.1.1. Theoretical Implications

The importance of self-efficacy for nurses' communication was shown through the data in the present study, descriptions of which tended to focus around difficult conversations that the nurses have with their patients/clients and an awareness of their own limitations when communicating. This adds to the knowledge available on the relationship between self-efficacy and nursing, particularly in communication (e.g. McLaughlin et al., 2008; Pehrson et al., 2016). Principles from self-efficacy theory were, therefore, supported by the nurse participants as they specifically spoke about the impact of mastery experiences, vicarious experiences, and persuasion from others – three sources of self-efficacy. In terms of mastery experience, it appeared that the

nurses' perception of whether their communication with a patient/client had been successful was based on their own internal perceptions (self-appraisal) and external perceptions from those around them (other people's judgements) (Bandura, 1982). The concept that repeated successes benefit mastery experiences (Bandura, 1994) was also supported through this study as the repetition of success solidifies the magnitude, strength and generality of the nurse's experience. Therefore, mastery experience stood out as the most beneficial source for the nurses when improving their self-efficacy as they indicated the benefit of repeated experience and success in certain situations, increasing their belief that they can recreate these successful performances. Research should consider how best to promote an individual's internal perceptions of their performances (self-appraisal) and how best to promote the use of external perceptions (other people's judgements) within the nursing team. This could potentially highlight the role of supervision in recognition of success.

Conversely, if nurses are given more and more to do within their role and they are unable to do it all they may feel like a failure. Should this failure continue or be repeated the nurse will suffer from poor self-efficacy as a consequence. They may not have the time, training or experience to effectively implement these new tasks. Therefore, this increased workload will lead to feelings of failure and consequently poor self-efficacy. This makes the finding that self-efficacy is crucial to a nurse 'knowing their limits' even more pertinent, as nurses look to avoid failure. It is crucial that nurses 'know their limits' (Kraus & DuBois, 2017) so as not to exaggerate their competencies, overstep boundaries in their care, and potentially cause unnecessary damage to the nurse-patient relationship and the patient/client's QOL. By being aware of their own limits, the nurse will avoid putting themselves in situations where they are likely to fail, thus reducing feelings of failure. Not only will this benefit the self-efficacy of the nurse but ensures that the patient/client is receiving the best care possible (e.g. Banerjee et al., 2016). Of course, nurses should equally be encouraged to avoid downplaying their competencies, and this highlights the need for strong self-efficacy (e.g. Zhang et al., 2015; McLaughlin et al., 2008). Future research should investigate how nurses recognise their limits and how this awareness and recognition can be taught or developed - and indeed communicated, so that the nurse's

peers/colleagues, and their organisation as a whole, can be confident that they will not take unnecessary or miscalculated risks (i.e. beyond their capabilities). Recognising limitations, or 'knowing your limits,' is useful when seeking help with issues such as not having the right expertise for that particular patient/client, and there are aspects of the nurse's role that should be addressed if they are considered a limitation. Low self-efficacy seems to affect the nurses' willingness to address sensitive subjects and have 'the difficult conversation' and vice versa (Zhang et al., 2015). When considering the holistic approach to nursing, avoidance of difficult or challenging conversations could have a detrimental effect on the patient/client (Chen & Raingruber, 2014). As such, future research should focus on improving nurses' self-efficacy in difficult conversations by providing opportunities: for mastery experiences; learning through observation of a modelled behaviour; persuasion from colleagues; and techniques to control their emotional and psychological states in the build-up and during those scenarios. Research needs to consider the most efficacious strategies for promoting sources of self-efficacy, as well as how they can potentially be combined to reduce the risk of overburdening the nurses and organisations with a multitude of different training courses.

Principles of self-determination theory were also supported through this study as nurses must satisfy their BPNs to be able to work effectively. Specifically, the positive relationship between perceived competence and mastery experiences (and, therefore, self-efficacy) was supported (e.g. Yoo et al., 2006; Mohamadirizi et al., 2015). Perceptions of competence are crucial to maintaining high levels of nursing and communication as the more confidence the patient/client has in the nurse, the better the patient/client outcomes. A crucial aspect of a nurse demonstrating competent communication skills is their ability to be 'prepared but adaptable' in consultations with patients/clients. This requires the nurse to prepare for each patient/client prior to their consultation to ensure that they go in at least with a base level of knowledge about the patient/client and their situation (e.g. Mischelovich et al., 2016). This not only demonstrates a level of caring and interest towards the patient/client but allows the nurse to understand and address their patient's/client's needs sooner (e.g. Aungst, 2009; Papadantonaki, 2006). However, the initial preparation is unlikely to

provide all the relevant information about the patient/client which requires the nurse to be able to adapt to each individual in an attempt to gain and impart as much useful information as possible. Due to the links with mastery experiences, similar future research – in terms of promoting perceptions (internal and external) of success – should also be useful in the endeavor to improve oncology nurse competence.

In terms of maintaining and protecting their self-efficacy and perceived competence, the nurses in the present study alluded to the use of coping resources – the most commonly discussed being the use of humour, self-talk, reflection, compartmentalising, formal and informal supervision, and different forms of support). These resources or techniques help the nurse maintain their own well-being through specific efforts to manage the demands, responsibilities, problems and difficulties they experience in an appropriate manner. This means the nurses can continuously perform to high standards and protect against issues such as burnout and compassion fatigue (e.g. Wahlberg et al., 2016). Informal colleague/peer support appeared to be one of the most beneficial coping resources for nurses. Therefore, can training be developed that facilitates and promotes emotional support and appropriate constructive criticism for colleagues?

However, there were barriers to self-efficacy and perceived competence that were also identified in this study (e.g. lack of experience, challenging conversations, phone conversations, individual differences, and lack of closure). These can cause a lack of belief in the nurses and feelings of failure. The identification and confirmation (e.g. Wilkinson, 1991; Banerjee et al., 2016) of these barriers offers opportunities for future research to test these assertions and ultimately develop techniques or interventions aimed at overcoming them. These techniques and interventions could focus on progressing the coping resources identified in the present study, as well as focusing on cultivating a positive environment and ensuring that nurses are able to learn from their weaknesses.

4.1.2. *Practical Implications*

The main aspect of QOL measures presented in this study that appears to be of benefit is their ability to identify patient/client cues and issues, supporting previous findings (e.g. McCarter et al., 2015; Carlson et al., 2012; Vachon, 2006). This is ideal for prompting less experienced nurses and helps to prioritise the most pertinent issues. Research should compare and contrast the measures' perceived usefulness between less experienced and more experienced nurses, and test the impact they have on self-efficacy, competence and communication. Can they be used until the nurse is confident/certain enough to identify issues without them? As well as looking at the nurse perspective, it is important to consider how the patients/clients feel about QOL measures – do they perceive them to be a useful resource in identifying their own problems? The measurable nature of the tools allows the patient experience to be quantified and standardises the nurses' approach to the care given (e.g. Carlson et al., 2012; Detmar et al., 2002). However, research should further investigate whether this standardisation is necessary and whether giving the nurse autonomy over their delivery of care has a greater impact. Moreover, organisations could use the measurable nature of the tools to test and monitor the effectiveness of the care provided. Future research should, therefore, show how the data gained from this can be of benefit to the organisation and the individual nurses.

However, these QOL measures can be overly structured and subjective (e.g. Lindley & Hirsch, 1994; Velikova et al., 1999), impeding the nurse's conversational flow and impacting their perceived communication competence. The forced use of inappropriate tools by organisations, and the uncertainty around their purpose, will undermine nurses' self-efficacy (Norman et al., 2014) due to the reduced control and autonomy they have in their care. The structure of these QOL measures can be a barrier to conversational flow that experienced nurses have developed for their practice over the years (e.g. Friedrichsen & Milberg, 2006). This in turn can act as a barrier to the nurses' sense of autonomy in their practice (Ryan & Deci, 2000), leading to the suggestion that research look to remove the structure of the tools and develop a more informal approach – a conversational prompt. Can research overcome the requirement for psychometrically sound instruments for QOL assessment, creating a

more user-friendly tool that is easier to implement into routine care and providing less experienced nurses with a guide to use alongside their care? The subjective nature of the tools occurs as the responses and interpretations of these responses will be influenced by the individual opinions, biases or emotional fluctuations in the nurse and the patient/client (e.g. Lindley & Hirsch, 1994; Velikova et al., 1999). Does this require the questions to be even more specific? Or are more general measures, such as the Holistic Needs Assessment (HNA), more appropriate in clinical/consultation settings as they embrace the subjectivity and allow the nurse the freedom to have a conversation? This supports the idea that these measures should be used as conversational prompts rather than using them as the sole or main technique for identifying issues – an idea that requires more in-depth exploration to understand its utility and benefit in nursing.

Nurses must be open to continuing to develop and improve their practice consistently throughout their career. However, in terms of the communication skills training that oncology nurses receive, there were mixed feelings about their usefulness. The general finding was that they are inadequate and result in limited improvement to experienced nurses' communication skills (e.g. Al-Mohaimeed & Sharaf, 2013). This could be due the courses/programmes being too generalized and not accounting for the individual communication styles and approaches that nurses have, as well as the individual differences and needs of the patients/clients with whom they are communicating. This leads to the suggestion that there is a need for a systematic, critical evaluation of existing CSTs used by health boards, exploring such things as the most appropriate theoretical underpinnings, best design, their practical utility, and the transference and use of the training in the nurses' everyday practice. Despite the mixed responses regarding CSTs, simulation training consistently received positive feedback (e.g. Hsu et al., 2015), and should, therefore be considered a promising tool to incorporate into CPD. Further validation of this form of training is first required and it would also be worth exploring how video recording, watching it back and receiving feedback would benefit the nurse and whether the nurses can be primed/educated to make the most of such training opportunities – the same goes for the individual delivering the training, as intervention fidelity should be included in its

design. Within this nurse experience and continuous learning theme, previous non-oncology nursing experience – especially in an extreme environment – helped with the transition into oncology. This suggests a need to prepare nurses for their transition into the distress-laden area of oncology. Experimental research could, therefore, look at normalising the context of oncology at an earlier stage in the nurse training process so that it is seen not only as something for the especially experienced and/or brave.

4.2. Study Limitations

The present study requires replication to other areas of oncology so that the findings can be generalised across different contexts with a broader demographic (Chuah et al., 2017). There was an issue around the sample that was not thoroughly explored as the setting, context and experiences of the support-line nurses differs from that of the more clinically-based nurse participants. There is “an added level of complexity associated with telephone-based communication not present in face-to-face interactions” (Shaw et al., 2013, p.444). The support-line nurses are in an environment which requires a high level of communication skills to compensate for the lack of visual cues (Car, Freeman, Partridge & Sheikh, 2004; Souza-Junior, Mendes, Mazzo & Goday, 2016), due to the high impact attributed to visual and non-verbal communications in face-to-face interactions (Car & Sheikh, 2003). Studies have also found the competency of nurses in telehealth to be an issue (Ariens et al., 2017; Kort & van Hoof, 2012). The support-line role can differ as patients are often already well-informed about treatment options due to previous clinical interactions, but can be unsure of what is best for them personally (Choudhari, 2006). Therefore – as the findings of an Australian study, which described the communication behaviours in supportive care telephone calls, suggests – support-line nurses need to be able to: identify and respond verbally to underlying emotional needs/cues; use more open directive questions and empathetic statements to facilitate patient understanding; and clarify patient understanding (Shaw et al., 2013). Many of the skills that a support-line nurse requires are still common to that of all areas of nursing. However, for instance, the use of the nurse’s voice to enhance contact is a distinctive competency to telehealth (van Houwelingen et al., 2016). There are also many opportunities to

learn on the job and from colleagues in the support-line context (Choudhari, 2006), which could have an impact on the nurses self-efficacy as their experiences of mastery and learning vicariously may differ significantly. Therefore, further research is needed to comprehensively understand the differences in experience, skills and knowledge of support-line and telehealth nurses so that specific issues around competency and communication can be addressed.

Another issue around the sample was that there were notably more females than males (seven to one), which could have led to a gender bias in the results. Gender bias is an issue that has been seen throughout the vast majority of nursing research and is a type of sampling bias which systematically underrepresents one of the sexes in a particular field of research (Polit & Beck, 2013). Nursing is a female-dominated profession (Meadus & Twomey, 2011; Barrett-Landau & Henle, 2014) and this is largely mirrored in research studies. A review of nursing studies between 2005 and 2006 showed that in 181 UK-based studies nearly 75% of participants were female (Polit & Beck, 2009). Similar findings were shown in a review of 86 studies where 19 studies had all-female samples, compared to only 4 all-male studies (Geller, Koch, Pellettieri & Carnes, 2011).

Gender bias is an issue that needs consideration when conducting nursing research to ensure that male nurses are not underrepresented, as it is possible that some findings may be gender-specific and, therefore, not generalisable to male nurses. For instance, the gender differences among nurses' stress perception and coping are unclear (Gemmell et al., 2016) as studies have shown female nurses to perceive more stress from certain situations than male nurses (Caruso et al., 2017). Male nurses have also been found to be more resilient, possibly due to differences in coping strategies (Naz, Saeed & Muhammad, 2019). This could have impacts on the findings of the present study as the nursing experiences of male nurses may differ significantly from that of the female nurses. They may also perceive different barriers and facilitators to their roles and use different coping resources to manage the burden of their job. Therefore, studies that have only female participants or which have a significantly larger female sample than male, should be recreated with either all-male samples or more balanced samples in order to compare the similarities and

differences in the experiences and perceptions of these different groups. However, the use of the term gender bias may be becoming outdated within today's society as we become more aware and accepting of the diversity of different genders that people identify with. It may be pertinent to move towards the use of a term such as 'identity bias' when describing this form of sampling bias within research to promote and ensure inclusivity and representation of all groups.

The QOL measures used for reference in this study were Lung Cancer specific – therefore other cancer specific measures should be explored as the findings are difficult to generalise in this particular context. Both the EORTC QLQ-LC13 and the FACT-L have specific Lung Cancer aspects that enquire, for example, about coughing, shortness of breath and chest pain. However, due to the study having to move away from Lung Cancer specific nurses, the perceptions the participants gave on the tools were largely based on their own personal experiences and not always specific to the QOL measures referred to in the present study. The Lung Cancer specific aspects of these tools were consequently not useful as prompts for the participants in the present study. Therefore, it is reasonable to conclude that the findings and interpretations gained from this study are based both on perceptions of the EORTC QLQ-LC13 and FACT-L and previous experiences. Future research should either look to match the specialty of the nurse with the appropriate QOL measure or consider how more general measures are perceived throughout different areas of oncology. Also, whilst the most psychometrically sound tools were selected, offering use in research settings, their length was a significant barrier when considering the practical application of these tools. Therefore, as shorter tools are more practically feasible for nurses to implement into their care, nurse perceptions of these tools may offer more useful and applicable findings.

Following the initial interview and analysis of particular codes, the pertinent words and phrases could have been collated into a further interview guide for secondary interviews to help to clarify the initial data interpretations. This is because "by asking participants to group their responses under headings they chose themselves, the meanings were confirmed and verified by the participants and not by the interpretations of the researcher" (Wilson, 2014, p.44). This would have avoided

the issue of anecdotalism (Green & Thorogood, 2014). However, the time constraints on this particular research negated this possibility – therefore future research could look to employ this technique when conducting a similar study to the present one, helping to validate or elaborate on the initial interpretations.

There is also the issue of recall and response bias, which has been flagged as a concern in other research (i.e. Bracher, Corner, & Wagland, 2016). This is because participants may not accurately remember prior events/experiences or they may omit various details which could be of importance, whether intentional or not (Sedgwick, 2014). The distressing and morbid nature of oncology means that these nurses often experience professional bereavement and they may look to cope with that through denial (da Luz et al., 2016). Therefore, they may block out and omit specific detail or memories about their feelings and emotions during such experiences.

In agreement with an eloquent summary by Thornton, et al. (2015, p.551), the present study's qualitative methods were "well-matched to the task of discovery where little or no information exists on a topic. The data it produces are observational, not quantitative, and are intended to generate information for subsequent studies in which statistical significance can be ascertained". As with all research, this study has limitations, but its findings provide a useful stimulus for future research, highlighting specific areas for exploration and rigorously designed interventions to be tested.

4.3. Conclusion

This study aimed to explore oncology nurses' perceptions of: their approach to communication with patients; their self-efficacy for different types of communication and meeting the various associated support needs of their patients; the consequences they associate with their communication approach; and the relationships therein.

Based on the analysis of qualitative interview data, it can be concluded that nurses who have strong self-efficacy beliefs for the task of patient communication are more likely to perceive positive outcomes of their communication with patients and be satisfied with their "performance" (perceived competence) when supporting

patient QOL needs. Certain crucial factors emerged that contributed to these conclusions. The most pertinent sources of self-efficacy were the nurses' mastery experiences, vicarious experiences and experiences of persuasion from others. Perceptions of success are crucial to a nurse's awareness of their mastery of the task. For vicarious experiences and persuasion from others to be successful, the nurse must view colleagues with respect, trust and credibility.

Highlighted by the findings was the role of a strong nurse identity and the drive for the nurses to continue learning through experience and further/advanced training opportunities, whilst effectively reflecting on their experiences. These factors, if approached successfully, could contribute to the nurse's self-efficacy when communicating with patients/clients.

The nurses' perception of their competence is important for maintaining effective communication and has links with internal and external perceptions of mastery experiences. The higher the confidence and belief the patient has towards their nurse, the better the patient outcomes. Perceived competence improves the motivation of the nurses but it is supported by providing opportunities for autonomy and relatedness to satisfy all BPNs. Increased responsibilities and perceived organisational trust will facilitate feelings of autonomy. The interactions the nurses have with those around them are important to their feelings of relatedness and have links with authenticity when caring for patients.

There are specific communication skills that the nurses utilise in their practice. Heightened listening skills, the ability to identify patient/client cues, then probe and explore the identified concerns, are crucial for the nurse when communicating with their patient/client and they require the nurse to be confident and competent.

The nurses' coping resources, their working environment and how they responded to identified areas of weaknesses appeared to facilitate their perceived competence and self-efficacy, helping them to project confidence to their patient/client despite not having high levels of confidence themselves, i.e. 'faux confidence'. However, barriers to self-efficacy and perceived competence also emerged. The conversations nurses have with the patients/clients require them to be

'prepared but adaptable' when dealing with patients' individual differences, needs and challenges. This is only exacerbated when considering over-the-phone conversations had by support-line nurses. The participants also described how lack of experience and the lack of closure that they regularly experience both play a large role in obstructing self-efficacy, competency and communication.

The results also indicated the potential usefulness of QOL measures for facilitating communication, self-efficacy and competence as they offer the user a tool for identifying a patient's/client's issues or cues and they are also measurable so, therefore, quantifiable. However, there are aspects of the QOL measures that were considered barriers by the nurses. The measures can be subjective and there are certain organisational concerns around their implementation that can cause uncertainty when using them. The experience of the nurses provided them with the skills and intuition to identify patient's/client's QOL concerns and, therefore, the structured nature of the tools can impede the conversational flow between the nurse and patient/client. The findings also indicated that less formal uses of QOL measures or heightened emphasis on using them *alongside* a nurse's care as a conversational prompt could improve the usefulness of these tools. The nurse administering the measure should consider the timing of delivery so as not to further distress their patient/client and once completed, there needs to be further exploration of the identified issues. In addition, there should be further consideration for how these tools are implemented – possibly through the use of implementation sciences – to minimise disruption of the other tasks and responsibilities held by the nurses.

This study demonstrates the importance of high levels of self-efficacy and perceived competence in oncology nurse communication. Further experimental research is required, alongside observational research, with the aim of uncovering and confirming the precise mechanisms that relate to this study's findings.

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Appendices

Appendix One: Clinical Nurse Topic Guide

Introductory Paragraph

Good afternoon, firstly I'd like to say thank you for agreeing to help with this study – your insights will be incredibly useful and hopefully we can develop important and relevant recommendations based on them. My name is Patrick and I'm a postgraduate researcher at Aberystwyth University; specifically this research will be looking into nurse perceptions of the relationship between their own self-efficacy and the quality of communication with patients. We will be discussing the role you play in the patients' experience, also the impact that Quality of Life assessment measures could have in their treatment and how all of this can relate specifically to Lung Cancer.

This is completely voluntary, and you are free to withdraw at any time (without having to give a reason), just let me know if you would like to do so. We will ask, however, to keep the audio that you have provided us with up to the point. The transcripts will also be completely confidential and anonymous.

Any questions before we get started?

Nurse Experience

Q. Could you tell me a bit about yourself and your background?

p. How long have you been in nursing and how did you first get into cancer nursing?

p. What was your motivation for going into oncology?

p. What experience have you got in oncology clinics?

Q Could you describe what your role entails on a day-to-day basis?

p. What sort of issues do you deal with?

p. How do you help individuals overcome these issues? / Typically, how would you address these issues?

Q. What are the main issues to do with Quality of Life that you tend to experience?

p. When there are Health-Related QOL issues, how much of a role do you feel that unmet support needs have on this? (*psychological, interpersonal, emotional, financial, spiritual issues and health policy and system difficulties*)

p. How are patient needs met or not?

p. What would be the process to help these unmet support needs be met?

Q. What sort of challenges come with speaking to these cancer patients?

p. How do you cope with these challenges?

p. Do they ever significantly impact how you go about your role? / Do they ever get in the way of performing your role effectively? In what sort of way?

p. How do your confidence levels effect how you deal with these challenges?

p. What training/support do you receive to deal with arising issues?

p. How often are you required to deal with issues through on-the-spot intervention?

Q. What sort of skills have you learned in this role?

p. How have they helped you perform your role effectively?

p. How confident are you when utilising these skills?

p. How much of an impact has experience played in the development of these skills?

Q. What sort of relationship do you develop with the patients?

p. How important is this relationship? To yourself and the patient?

p. How long does a relationship take to develop?

p. Have you got any recommendations/tips for developing a relationship with the patients?

Q. Are there any protocols that you would routinely follow in certain situations? E.g. a patient indicates that they are having issues at home/ with family.

p. If so, how do these help you in your role?

p. Are they feasible? Is this important?

QOL Assessment Measures

Q. What are your thoughts on these QOL assessment tools?

p. Does it assess all the necessary symptoms?

p. Which aspects would you consider the most relevant/important?

p. Which aspects would you consider irrelevant and/or unnecessary?

Q. How would you feel about these tools as more of a conversation-prompt?

p. Would they be useful in identifying individuals who require onward referral?

p. Are there any benefits you can see from their use?

p. How would their use impact your role?

Q. Why do you think these kinds of tools are not regularly used in cancer units?

p. How useful would these be in routine clinical care?

p. How would you suggest we overcome these barriers/obstacles? Can we?

p. How, when and why would they work?

Q. Which of these two tools would you recommend for use in a clinical setting and why?

p. If neither is applicable, could you explain why?

Q. What do you think about the possibility of having a QOL tool online for self-assessment to act as a prompt for conversations in the clinic?

Q. If you could sum up your experience as a cancer phone-line nurse in 3/5 words, what would they be and why?

Appendix Two: Support-Line Nurse Topic Guide

Introductory Paragraph

Good afternoon, firstly I'd like to say thank you for agreeing to help with this study – your insights will be incredibly useful and hopefully we can develop important and relevant recommendations based on them. My name is Patrick and I'm a postgraduate researcher at Aberystwyth University, specifically this research will be looking into nurse perceptions of the relationship between their own self-efficacy and the quality of communication with patients. We will be discussing the role you play in the patients' experience, also the impact that Quality of Life assessment measures could have in their treatment and how all of this can relate specifically to Lung Cancer.

This is completely voluntary, and you are free to withdraw at any time (without having to give a reason), just let me know if you would like to do so. We will ask, however, to keep the audio that you have provided us with up to the point. The transcripts will also be completely confidential and anonymous.

Any questions before we get started?

Nurse Experience

Q. Could you tell me a bit about yourself and your background?

p. How did you first get into cancer nursing?

p. What was your motivation for going into oncology?

p. What experience have you got in oncology clinics?

Q. Could you describe what your role entails on a day-to-day basis?

p. What sort of issues do you deal with?

p. How do you help individuals overcome these issues? / Typically, how would you address these issues?

Q. What are the main issues to do with Quality of Life that you tend to experience?

p. When there are Health-Related QOL issues, how much of a role do you feel that unmet support needs have on this?

p. How are patient needs met or not?

p. What would the process to help these unmet support needs be met?

Q. What sort of challenges come with speaking to these cancer patients?

p. How do you cope with these challenges?

p. Do they ever significantly impact you go about your role? / Do they ever get in the way of performing your role effectively?

p. In what sort of way?

p. What training/support do you receive to deal with arising issues?

p. How often are you required to deal with issues through on-the-spot intervention?

Q. What sort of skills have you learned in this role?

p. Do you think that they could be transferred into a clinical setting?

p. How could they help in routine cancer care within in a clinic?

p. How would you recommend they be introduced into routine care? (if you do recommend them)

Q. What sort of relationship do you develop with the patients?

p. How important is this relationship? To yourself and the patient?

p. How long does a relationship take to develop?

p. Have you got any recommendations/tips for developing a relationship with the patients?

Q. Are there any protocols that you would routinely follow in certain situations? E.g. a patient indicates that they are having issues at home/ with family.

p. If so, how do these help you in your role?

p. Are they feasible? Is this important?

QOL Assessment Measures

Q. What are your thoughts on these QOL assessment tools?

p. Does it assess all the necessary symptoms?

p. Which aspects would you consider the most relevant/important?

p. Which aspects would you consider irrelevant and/or unnecessary?

Q. How do you feel about these tools as a conversation-prompt over the phone?

p. Would they be useful in identifying individuals who require onward referral?

p. Are there any benefits you can see from their use?

p. How would their use impact your role?

p. If they were to be introduced for phone conversations, how would change/adapt them?

Q. Why do you think these kinds of tools are not regularly used in cancer units?

p. How useful would these be in routine clinical care?

p. How would you suggest we overcome these barriers/obstacles? Can we?

p. How, when and why would they work?

Q. Which of these two tools would you recommend for use in a clinical setting and why?

p. If neither is applicable, could you explain why?

Q. What do you think about the possibility of having a QOL tool on the Tenovus website for self-assessment to act as a prompt for their conversations?

Q. If you could sum up your experience as a cancer phone-line nurse in 3/5 words, what would they be and why?

Appendix Three: EORTC QLQ-C30

ENGLISH



EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year):

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

Please go on to the next page

During the past week:	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

Appendix Four: EORTC QLQ-LC13

ENGLISH



EORTC QLQ - LC13

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week :		Not at All	A Little	Quite a Bit	Very Much
31.	How much did you cough?	1	2	3	4
32.	Did you cough up blood?	1	2	3	4
33.	Were you short of breath when you rested?	1	2	3	4
34.	Were you short of breath when you walked?	1	2	3	4
35.	Were you short of breath when you climbed stairs?	1	2	3	4
36.	Have you had a sore mouth or tongue?	1	2	3	4
37.	Have you had trouble swallowing?	1	2	3	4
38.	Have you had tingling hands or feet?	1	2	3	4
39.	Have you had hair loss?	1	2	3	4
40.	Have you had pain in your chest?	1	2	3	4
41.	Have you had pain in your arm or shoulder?	1	2	3	4
42.	Have you had pain in other parts of your body?	1	2	3	4
	If yes, where _____				
43.	Did you take any medicine for pain?				
	1 No 2 Yes				
	If yes, how much did it help?	1	2	3	4

Appendix Five: FACT-L

FACT-L (Version 4)

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<u>PHYSICAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed.....	0	1	2	3	4

<u>SOCIAL/FAMILY WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends.....	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness.....	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i>					
GS7	I am satisfied with my sex life	0	1	2	3	4

FACT-L (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

EMOTIONAL WELL-BEING

		Not at all	A little bit	Some- what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
GE3	I am losing hope in the fight against my illness.....	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

FUNCTIONAL WELL-BEING

		Not at all	A little bit	Some- what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling.....	0	1	2	3	4
GF3	I am able to enjoy life.....	0	1	2	3	4
GF4	I have accepted my illness.....	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now.....	0	1	2	3	4

FACT-L (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<u>ADDITIONAL CONCERNS</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
B1	I have been short of breath.....	0	1	2	3	4
C2	I am losing weight.....	0	1	2	3	4
L1	My thinking is clear	0	1	2	3	4
L2	I have been coughing	0	1	2	3	4
B5	I am bothered by hair loss	0	1	2	3	4
C6	I have a good appetite	0	1	2	3	4
L3	I feel tightness in my chest.....	0	1	2	3	4
L4	Breathing is easy for me.....	0	1	2	3	4
Q3	Have you ever smoked? No ___ Yes ___ If yes:					
L5	I regret my smoking	0	1	2	3	4

Appendix Six: Recruitment Email



Exploring Nurse Perceptions of the Relationship Between their Support Self-Efficacy and the Quality of Communication with Cancer Patients

Aberystwyth University are looking for nurses working within cancer units and organisations.

As the title suggests, this research will use semi-structured discussions to explore nurse perceptions of their self-belief in delivering support and the quality of communication they share with cancer patients.

Through the discussions, we hope to learn from experienced nurses, understand barriers and facilitators to effective communication, including the role of self-belief, and to gather perceptions on the potential usefulness of Quality-of-Life assessment tools as prompts during conversations with cancer patients. The overall findings from the study – nothing identifiable to any single participant – will be shared with key cancer stakeholders in Wales.

The discussions will last for about an hour and will take place either at the Tenovus Cancer Care offices in Llanishen, or at your workplace, at a time that is convenient to yourself.

If you are interested in taking part in these discussions and contributing to nurse development, and would like further information, please contact either:

Patrick Cronin – pjc7@aber.ac.uk, 07900540377

or

Dr. Simon Payne – smp14@aber.ac.uk, 01970628629

Many thanks for your time,

Patrick Cronin



Appendix Seven: Cover Letter



IBERS
Athrofa y Gwyddorau Biolegol, Amgylcheddol a Gwledig
Institute of Biological, Environmental and Rural Sciences

**Athrofa y Gwyddorau Biolegol,
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www.aber.ac.uk/en/ibers**

Dear Potential Participant,

Thank you for showing interest in participating in this research. I am a postgraduate student at Aberystwyth University and, with cooperation and support from Tenovus Cancer Care and Hywel Dda University Health Board, we are looking to explore nurse perceptions of the relationship between their perceived self-efficacy and the quality of communication provided to cancer patients. This will involve the use of one-to-one interviews so that the nurses can have an open and in-depth conversation about their experiences with cancer patients.

If you are willing to volunteer in this study or would like more information, please read the enclosed 'Participant Information Sheet'. If you do decide to take part, please also complete the Informed Consent Form (as required by Aberystwyth University's Ethics Board).

Also enclosed is a copy of the questionnaires that will be the focus of some of the discussion.

Should you have any queries, please do not hesitate to contact me via the details provided at the end of the Information Sheet. Should you decide to take part, I will contact you to discuss where and when the interview will take place.

Thank you in advance for your help.

Yours faithfully,

Patrick Cronin



Yn ôl y polisi dwyieithol o'r Prifysgol, mae chi'n gael hysbysu'n rhedeg yn Gymraeg neu yn Saesneg.
In accordance with the bilingual policy of the University, you are welcome to correspond with the University in Welsh or in English.



Version 7.0, 29/08/18

Appendix Eight: Participant Information Sheet



Exploring Nurse Perceptions of the Relationship Between Their Support Self-Efficacy and the Quality of Communication with Cancer Patients

Participant Information Sheet

We would like to invite you to take part in an interview as part of a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

PLEASE ASK US IF YOU WOULD LIKE THIS PARTICIPANT INFORMATION SHEET IN WELSH.

A major part of an oncology nurse's role is to provide information and support to their patients. This requires effective communication between the patient and nurse to ensure that issues are not overlooked. Nurses receive training in communication and then develop their skills further through extensive experience talking to patients.

What is the purpose of the study?

Communication is a key ingredient of a cancer patient's treatment. It is vital that the information they receive from health care professionals matches their needs (physically, emotionally, socially, spiritually, etc.), as not meeting these needs can be problematic. Thus, it is important that the nurse providing this information is confident that their knowledge and experience will allow them to understand and match the patient's needs.



Version 10.0, Submitted 15/01/19

The aims of this study are: to learn from experienced nurses to give recommendations for newer, less experienced nurses who lack the necessary communication skills; understand barriers and facilitators to effective communication, including the role of self-efficacy – a nurse’s belief in their ability to deal with prospective situations; and to gather perceptions on the potential of Quality-of-Life assessment tools to act as a prompt for effective and efficient communication during nurse-patient discussions. These tools will be specific to Lung Cancer, one of the most prominent cancers in Wales, and could potentially act as an important aid for non-specialist nurses. From this we can make specific recommendations for assessing Quality-of-Life in Lung Cancer patients.

Participation

We are looking for nurses currently working within cancer units or organisations in Wales and who have regular communication with patients. These discussions will be in a one-to-one interview format. Participants will also be shown questionnaire-based measures of quality of life which will be the focus of some of the questions and themes explored, these will simply be used as a reference during the discussions.

The interview will take place at a convenient time and place for yourself. You can expect the interview to last for around an hour and for it to be audio-taped. The data collected will not be able to be traced back to you, as we will remove or anonymise any identifiable information. Your confidentiality is our utmost priority.

Participation in this study is completely voluntary. Should you choose to take part you will be asked to sign a consent form to indicate that you have understood the project’s purpose and what your role will be, and that you are willing to participate. You will be given a signed copy of this form as well as this participant information sheet. Withdrawal from the study is acceptable at any point; however, if you decide that you no longer wish to continue after the interview has started, then we will ask

to use the recorded data collected up to the time of your withdrawal. Of course, you can choose not to allow this without giving a reason.

Possible disadvantages and risks

Part of the discussion will include asking participants to describe if they have had any experiences of patients showing signs of distress. This may bring back memories or emotions that the individual finds upsetting. The researcher will be available to offer advice on ways of coping. If the participant feels that this is insufficient, they can ask for referral to the most appropriate service within their organisation or the NHS.

Possible benefits

Taking part in the study will not benefit you directly but insights gained through the study will be shared and may help nurses, future patients and the general public. Please refer back to the purposes of the study, above, for more on the benefits we anticipate.

Confidentiality

If you consent to take part in the research any relevant data collected during the study may be inspected by the regulatory authorities to check that the study is being carried out ethically. Any data you provide will be treated in accordance with the General Data Protection Regulation (2018). The interview will be recorded and transcribed; however, you will not be identifiable in the transcripts as we will replace your name with a pseudonym (a fictitious name) and carefully mask any identifying information. Once transcribed, the interview audio recording will be deleted. Your name will not be disclosed outside the interview or appear on any reports or publications resulting from the study.

The data generated from this research will be stored on a secure university server and will be anonymous, with no indication of the identity of individuals involved. The data will be kept for 5 years or up to 1 year after the findings are published in the scientific literature.

Results of the research study

The study may be published in a scientific journal, usually within three years after completion of the study. If results are published, this will be done without revealing your identity, which will remain confidential. We may also wish to use a direct quote from the answers given in the interview; this will be done anonymously and will not be able to be traced back to you. At the end of the study you will be sent a summary of the findings, if you have indicated on the consent form that this is your wish.

Organisation and review of the study

The research is sponsored by ~~U.S.O.W.S.~~ Tenovus Cancer Care (charity number 1054015) and funded by the Knowledge Economy Skills Scholarships (KES2). The staff conducting the study will receive no personal payment resulting from this study.

The Research Governance aspects of this study have been reviewed and approved by Aberystwyth University. All research is assessed by the university's ethics committee to protect your safety, rights, wellbeing and dignity.

Should you require any more information or if you have any concerns about the study, please contact:

Patrick Cronin BSc(Hons) – Chief Investigator
KES2 Funded Postgraduate Researcher

Institute of Biological, Environmental and Rural Sciences (IBERS)
F21 Carwyn James Building
Aberystwyth University, SY23 3FD
+44 (0)7900 540377
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Dr. Simon Payne BA(Hons), MSc, PhD, PGCTHE, FHEA - **Supervisor**
Lecturer in Sport, Exercise and Health Psychology
Institute of Biological, Environmental and Rural Sciences (IBERS)
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Research Ethics Office
Research, Business and Innovation
Visualisation Centre
Penglais
Aberystwyth University
SY23 3GN
+44 (0)1970 621694
ethics@aber.ac.uk

Appendix Nine: Informed Consent Form



Ynghyd â'r Eiddoedd Cymorth Eiddoedd
Knowledge Economy Skills Scholarship



Crefft Cymdeithasol Ewrop
European Social Fund

IBERS

Athrofa y Gwyddorau Biolegol, Amgylcheddol a Gwledig
Institute of Biological, Environmental and Rural Sciences

**Athrofa y Gwyddorau Biolegol,
Amgylcheddol a Gwledig**

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Email: pjc7@aber.ac.uk

www.aber.ac.uk/en/ibers

Informed Consent Form

Participant identification number for this trial (to be completed by researcher).....

Project Title: **Exploring Nurse Perceptions of the Relationship Between Their Support Self-Efficacy and the Quality of Communication with Cancer Patients**

Name of Researchers: **Patrick Cronin** (Chief Investigator) and **Dr. Simon Payne** (Supervisor)

Contact Number: **+44 (0)7900 540377**

**Please initial box
if you agree with
the statement**

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions
2. I understand that my participation in the one-to-one interview is voluntary and that I am free to withdraw at any time, without giving any reason
3. I understand that sections of any of the data collected may be looked at by the responsible researcher and academic supervisors or other authorised individuals (i.e. **Tenovus Cancer Care**), where relevant within the research whilst ensuring anonymity. I give permission for these individuals to have access to my data
4. I agree for the interview to be audiotaped and I understand that such information will be handled in accordance with the terms of the General Data Protection Regulation (GDPR) 2018
5. I agree for anonymised/pseudonymised direct quotes from the interview to be used
6. I understand that if I disclose anything criminal or that indicates my own or others' safety is at risk, the researcher will have to contact the relevant authorities
7. I agree to take part in the above study involving my participation in a one-to-one interview discussion

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

Name of Participant	Date	Signature
Name of Researcher	Date	Signature
If you would like to receive a summary of the findings from this study please indicate yes with a tick in the adjoining box (leave blank if you would not like to receive this):		



**Ynghyd â'r Eiddoedd Cymorth Eiddoedd
Cymorth Cefnogaeth Cymorth Eiddoedd
Cymorth Cefnogaeth Cymorth Eiddoedd
Cymorth Cefnogaeth Cymorth Eiddoedd**

In accordance with the bilingual policy of the University, you are welcome to correspond with the University in Welsh or in English.



Version 7.0, 15/01/19

Appendix Ten: Nurse Experience Coding Table

Quote	Theme/Sub-Theme	Participant/Page No.
	<i>Nurse Self-Efficacy</i>	
“very often you get people who you might never be able to develop that relationship with and sometimes you’ve got to accept that you’re just not the right person to for them to talk to”	<i>Importance</i>	1 – p.4
“something you don’t know much about, urmm, your listening skills go out the window for a start, because you’re too busy thinking ‘how am I going to do this, I really don’t know what to do’”		1 – p.8
“if there’s somebody else in the team that we know is far more skilled then we will always say ‘look my skills are limited but I do know somebody who could probably answer all these questions without even thinking about it’, and that comes down to confidence”		1 – p.8
“it’s very honest to say ‘I really don’t know, you’re talking about something now that I have no experience of, but I know a person who does’, and I think that gives them more confidence in the service, as well, that they’re saying ‘Ok, well I can ring them and if they don’t know, they will be truthful’”		1 – p.8
[referring to patients] “you just have to follow their lead really and not be afraid to say the words that most people are too scared to discuss. You have to talk about death and funerals and things like that and ask questions and just not be afraid to take that extra step, and I think my previous experience probably helps me with that”		2 – p.3
[referring to own cancer diagnosis] “I wasn’t the least bit surprised really, because something had caused that, it wasn’t normal, so, for me for somebody to say ‘actually you’ve got cancer’, that wasn’t too much of a problem, and then when I had all my planning and I spoke to my consultant, he said “ ‘well, I’m confident that I can cure you’, not a problem”		2 – p.6
[referring to patients] “they’re having confidence in you, so, you need to have confidence in yourself”		2 – p.11
“it’s getting information off them so you can give information back, it’s getting the facts ... one of the most important things is we haven’t got any medical, urmm, any medical details at all, we’ve only got what the patient is telling us, so we’ve got to give that, the feedback on what you’re having”		3 – p.4/5
“I think it changes as you get more experienced probably. I think you did always have some patients that are more difficult to communicate with than others, but as you get more confident, I suppose you get a bit more used to trying to get people to talk and getting more out of them”		6 – p.3
“I think just learning to be brave enough to ask the questions like ‘what’s important to you?’, that kind of question, and that’s quite hard to ask sometimes, but,		6 – p.3

<p>you know, it's crucial that we do ask that, at appropriate times"</p> <p>"It's really nerve-racking when you don't know. It's probably just age as well, the older you get, it does get easier, but yeah, it's harder when you're in a new situation and you're not quite sure how to say it or is this the right thing to say, what if I upset somebody. There's all those kinds of things that when you've, sort of, done it more often it gets a little bit easier to do"</p> <p>"there's a lot of emotional needs as well that our patients have when they come and see us for the first time and again when they're trying to make decisions as well, when they've got a decision, you know, they need to make decisions, so giving them a lot of information about what happens if I don't go into a trial, what happens if I do"</p> <p>"There's definitely days where you feel less confident, yes. I mean, especially if you have dealt with very tricky patients which on reflection could've gone better or perhaps you didn't make quite the right decision or the best decision for the patient at the time. I think it does knock your confidence a little bit"</p> <p>"So, we tend to build up a relationship, not just with the patient but with their families because they're waiting, with our staging process sometimes it can go on for quite a number of weeks, so families then are very anxious because they're a little bit in limbo and they're not sure what's coming next and so we get a lot of calls from family members, you know, questions really about what's going to happen next, who are they going to see next and when are we going to know about this, and, cos obviously people are trying to plan their lives and things around it. It's not just about the cancer care it's about life, work, holidays that they've booked, family weddings, urmm, all the things that life involves, trying to fit that in to suddenly having this devastating diagnosis and a treatment of, we're talking months and months and months, you know, for some people it's going to be sorted in a week or 2, a lot of them can go on for months, years, you know, and it's really difficult for people to manage. So, they tend to build up that relationship with us and everybody's very different, we'll have people who'll ring us every day, we'll have people who maybe have 1 or 2 contacts and then won't need our contact again, so it's very individual, urmm, as to the sort of access that people need, or the things that people need from us really, but they know we are if they want us, if they need us"</p> <p>"I think for me when I'm thinking about communicating with patients, and we always prepare very well, whether we're talking to them or over the phone, or when we're going into clinic, it's to make sure we've got all the information upfront before we go into a consultation, which is very important to make sure that we have a clear plan of action of what we're gonna do, sometimes that means not answering all the questions, it just means that actually we've got to this and we've got to do that, but it's being clear about what we're going to do and not have unanswered questions in our head. I think the worst thing, and as I say I've been in nursing for many, many years and I've worked a lot on the wards, and the worst things about going into a consultation, sometimes,</p>		<p>6 – p.4</p> <p>7 – p.3</p> <p>7 – p.5</p> <p>8 – p.2/3</p> <p>8 – p.4</p>
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<p>was the other members of staff who were giving information who were flicking through books and trying to work out what's going on and I was sort of thinking 'oh, for goodness sake'. We should know all that, we should come across that we know exactly where we started, what information we've got and where we're going with it before we go in and speak to people"</p> <p>"It's important that you know what you're going to be talking about when you're there, because I think if you lose somebody's confidence early on, as a clinician you're going to be in trouble really, urmm, so I think it's really about being prepared for the clinic"</p> <p>"If you don't look after yourself then how can you look after other people, you can't function at your best if you don't look after yourself"</p>		<p>8 – p.4</p> <p>8 – p.7/8</p>
<p>"it fulfils a need for them that, you know, you're doing like a two-pronged job really, you know, you're supporting them in a psychosocial way but you're also having that chit chat, if you like, with them that helps to make it feel as if it's not as formal, as formal as counselling or something like that"</p> <p>"the more experience you get, the better you get at dealing with different situations and hopefully remembering situations that were similar in the past"</p> <p>"I think confidence just comes with experience of knowing that you can do it"</p> <p>"it's trying to get some positive reinforcement from them, but also when people say little things like 'I feel a lot better now I've spoken to you', simple little phrase but it boosts your confidence, that yeah, I'm doing the right thing"</p> <p>"So, it's all about learning about you [<i>emphasis on you</i>] as a person and, you know, being quite self-aware of what you can do and then developing that"</p> <p>"What I do have is 30-mm years of communicating with people in distress, people that are grieving, people whose worlds have been taken, you know, their worlds have gone and their knees have been taken out from underneath them, so, I've got that experience even if I didn't have, urmm, the precise experience, I've got the communication experience that I've had for like 30 years, in an extreme environment, another extreme environment"</p> <p>[referring to patients] "you just have to follow their lead really and not be afraid to say the words that most people are too scared to discuss, you have to talk about death and funerals and things like that and ask questions and just not be afraid to take that extra step, and I think my previous experience probably helps me with that"</p> <p>"I always try and put things in my happy bank, a bit like the nice/nasty thing, so, urmm, nurses are quite bad at recognising when they've done something good, I've found, as a ward nurse. So, if something nice has happened I acknowledge that thing, and that I think would be another thing to say to younger people trying to deal with it, if you do something good, don't shy away from recognising that and taking that on, because that's brilliant, because you're going to have enough crap</p>	<p><i>Mastery Experience</i></p>	<p>1 – p.4</p> <p>1 – p.6</p> <p>1 – p.8</p> <p>1 – p.9</p> <p>1 – p.9</p> <p>2 – p.2</p> <p>2 – p.3</p> <p>2 – p.10</p>

<p>times where things aren't going to go right, that you're going to need all of those good times"</p> <p>"They're the things that will remind you why the job is worth having, and they will help to, being in your happy bank, so, they'll help to deal with all of the shit that happens as well. But if you don't acknowledge them, if you don't take them on board, if you just think that that's the way things are supposed to be, then you've got no armour, you've got nothing to protect you from the bad times"</p> <p>"I just became a bit more Velindre-centric, if you like, did my, started my Masters, did my prescribing and then last year, I was, sort of, doing a bit more management and stuff and wanted a change. So, I'm now out of clinical trials and I'm just a nurse specialist and, urmm, a prescriber for two teams – urology and breast team here"</p>		<p>2 – p.10</p> <p>6 – p.1/2</p>
<p>"you just pick up things off other people over the years"</p> <p>"I've been fortunate enough to work very closely with our counselling team and listening to them talk about some of their counselling skills and getting information on them, we very often used to have good chats about counselling skills and things. So, I picked up tips along the way I guess"</p> <p>"work very closely with our counselling team and listening to them talk about some of their counselling skills and getting information on them"</p> <p>"just be like a sponge and absorb everything around you, and see the way that other people work but be yourself and adapt that to something that works for you"</p> <p>"take yourself to the job but then get hints and tips and find, everything that other people do, but find what works for you from that"</p> <p>[referring to man-van] "it was in conjunction with Prostate Cancer UK and Movember and it was a male cancer, urmm awareness, one stop van which travelled all over Wales to support men and their families who've got Prostate Cancer. So, that involved basically, urmm, being outside the hospitals, working closely with the consultants, the urology consultants"</p> <p>"I went to work with oncology nurses, ... , I went to spend a day with a consultant in Morrision, who dealt with Prostate Cancer, and that's where my, sort of, interest in male cancers developed from"</p> <p>"learning from patients, I think that's such a valuable lesson, urmm, every patient is different, but every patient has, perhaps, tried something different to see if it works"</p> <p>"you learn these little things from other people that you pass on and it, and it helps"</p> <p>"you learn from your peers as well, because they know things that you don't, and you can give them back something"</p> <p>"So, picking up bits and pieces down the line is, which is good practice and using it again, and trying it out for yourself, and you might get it wrong, you might not get</p>	<p><i>Vicarious Experience</i></p>	<p>1 – p.6</p> <p>1 – p.6</p> <p>2 – p.12</p> <p>2 – p.12</p> <p>3 – p.1</p> <p>3 – p.2</p> <p>3 – p.7</p> <p>3 – p.7</p> <p>3 – p.7</p> <p>3 – p.8</p> <p>4 – p.13</p>

<p>it wrong, but hopefully if you've seen it work before, it'll work in your situation"</p> <p>"you use colleagues who are experienced as well, urmm, you know, who've maybe been on the support-line for some time, you can tap into that as a support system"</p> <p>"we've got benefit advisors here with a wealth of knowledge, so you learn from them, we used to have counsellors"</p> <p>"you learn stuff off other people"</p> <p>"The Advanced Communication course was really good because you had to think of a scenario and then you had an actor and then you had to act out the scenario, and then it was videoed, so they video you and you have a group of your peers and they give you feedback, so that's really helpful because you don't ever get the opportunity to actually watch yourself and to hear, sort of, comments, not negative necessarily, but just comments about, you know, it makes you think a little bit more about how you communicate and what you communicate"</p>		<p>5 – p.5</p> <p>5 – p.5</p> <p>5 – p.5</p> <p>8 – p.10</p>
<p>"it's not very often that things fester, we do have clinical supervision which we can access, but as a team we're also really good, if we've come off the phone and it's been a particularly bad call, then we'll talk about it straight away"</p> <p>"we do instant supervision, if you like, so then you can almost put it to one side because, you know, you've managed to have that conversation with somebody. And because we do work late as well, urmm, as a team, if we have a particularly bad call, say at 7 o'clock at night, urmm, one of us is always open to the other ringing them and saying 'oh you won't believe what's just happened', so instead of that festering 'til the next day, they can talk to somebody, even somebody to bounce off, that understands what you're going through, and I think that's probably one of our biggest assets for how we deal with things that we understand what's going on and we can talk to somebody else about it"</p> <p>"I've been fortunate enough to work very closely with our counselling team and listening to them talk about some of their counselling skills and getting information on them, we very often used to have good chats about counselling skills and thing"</p> <p>"if it's something we know nothing about, we don't try and blag because that gets nobody anywhere, and if there's somebody else in the team that we know is far more skilled then we will always say 'look my skills are limited but I do know somebody who could probably answer all these questions without even thinking about it', so it's good to- and that comes down to confidence. Probably when I was first qualified, I would've tried to blag it because you just assume then that you need to know everything, but I think as you get more experienced, and as time goes by, you realise you can't be all things to all people and you're doing them a disservice by not giving them the information that they need or maybe even giving them misinformation, whereas, you know, it's very honest to say 'I really don't know, you're talking about something now that I have no experience of, but I know a person who does', and I</p>	<p><i>Persuasion from Significant Others</i></p>	<p>1 – p.5</p> <p>1 – p.5</p> <p>1 – p.6</p> <p>1 – p.8</p>

<p>think that gives them more confidence in the service, as well, that they're saying 'Ok, well I can ring them and if they don't know, they will be truthful'"</p> <p>"talking to people, just, you know, with your friends and stuff, just the way you speak to them, and transferring those skills to people that you're on the phone with, there's nothing, you know, yes you have got a professional relationship but there's nothing wrong with that gentleness that you use when you talk to your friends, to talk to somebody on the phone"</p> <p>"like I said you can get people with all kinds of personality and mental health issues ringing you, so it can be difficult, but that's where your team comes in as well, that, 'oh my god, we've had so and so on the phone again', you know, you share, always share, and that makes it a bit easier then. You can talk them down, because they'll do the same to you, it doesn't matter who you are in the team, someone will talk you down"</p> <p>"I suppose we talk to each other if we've had difficult days because there's only so much your family can understand about what you go through, unless they're working in it as well. So, talking to each other does help, urmm, because everyone has good and bad days so you do know what it's like, so I think yeah we do support each other quite well, yeah"</p> <p>"we've got a really good peer-group support around us as well so, you know, you can bounce ideas off, or, urmm, if you are dealing with someone who's quite tricky or there's quite a lot of emotional needs or whatever, we've got people we can talk to about what to do and stuff"</p> <p>"We're very good as a team, as I said there's 3 of us in the team now, at looking at self-care and obviously we're MacMillan funded now, so we do a lot of MacMillan courses with them where we go off on these days and it's all about supporting ourselves and looking after ourselves"</p> <p>"I think as a team we've got that, we work, we spend a lot of time reflecting, analysing, thinking about what we're doing, and talking it through"</p> <p>"We've got a really good consultant team and they're very good for, in fact when I was lacking in nursing support, they were the people I could talk to and run by problems and if there were issues in the working day. So, I think it's really important to talk to people, I think it's really important to say how you're feeling, to be able to say if you're having a bad day, to be upset if something's upset you"</p>		<p>1 – p.9</p> <p>2 – p.9</p> <p>6 – p.5</p> <p>7 – p.5</p> <p>8 – p.6</p> <p>8 – p.6</p> <p>8 – p.7</p>
<p>"we've done quite a few communications courses"</p> <p>"basic courses for helpline workers"</p> <p>"I also went on and did a lot of communication skills courses within nursing"</p> <p>"I've known people who've had training on training on training, their communication skills are terrible, but if you have got a skill that you can develop then it seems to work"</p>	<p><i>Nurse Experience/ Continuous Learning</i></p>	<p>1 – p.6</p> <p>2 – p.10</p> <p>2 – p.10</p> <p>2 – p.10</p>

<p>“absolutely none”</p>		2 – p.10
<p>“I did do a counselling course many, many years ago but I couldn’t say ‘and how does that make you feel?’ with any kind of sincerity because I can see it written on people, I can hear it in their voices”</p>		2 – p.10
<p>“it literally has come with experience”</p>		4 – p.2
<p>“I did a diploma in nursing, postgrad training diploma, I also trained, was educated up to masters level, didn’t complete the masters”</p>		4 – p.2
<p>“I did 3 communication skills courses at advanced level as well, so that’s where I feel, that was the best benefit for me in my whole career, communication skills training at an advanced level”</p>		4 – p.2
<p>“that was done with actors and I love stuff like that, I mean I love role play and stuff, so I mean that, well it’s the only way to learn, I think, communication skills is to experience it”</p>		4 – p.2
<p>“experiential learning”</p>		4 – p.2
<p>“I learnt something different every single time”</p>		4 – p.2
<p>“THAT’S what gives you the confidence to deal with those, I used to always think that it would take away your, urmm skills, like the listening skills and all that, it would take away from the spontaneity with patients, it just enhanced it so much, unbelievably so, you know”</p>		4 – p.2
<p>“it gives you the skills to, urmm, it makes you much more aware of people that get buried in their own stuff and ask some of the difficult questions and relay it back to the patient, how to conduct interviews but with patients”</p>		4 – p.9
<p>“I learnt it on the Manchester course that I did, was when a patient’s giving you verbal, they’ll give you cues of what they want you to ask, so I won’t hear it lots of times, but you have to be astute enough to pick them up, pick up on those cues”</p>		4 – p.9
<p>“but having those communication skills, and the communication skills courses, again, it enables you in how to speak to people who are in a perceived higher position than you in the hierarchy”</p>		4 – p.9
<p>“I’ve worked in cancer care for 20 years”</p>		1 – p.1
<p>“my background is actually as, for 20-mmm years as a sister on the special care baby unit”</p>		2 – p.1
<p>“what I do have is 30-mmm years of communicating with people in distress, people that are grieving, people whose worlds have been taken, you know, their worlds have gone and their knees have been taken out from underneath them”</p>		2 – p.2
<p>“I’ve got that experience even if I didn’t have, urmm, the precise experience, I’ve got the communication experience that I’ve had for like 30 years, in an extreme environment”</p>		2 – p.2

<p>“that’s something that’s come from my previous job, you never lie to people, you never fudge answers”</p>	2 – p.4
<p>“you just have to follow their lead really and not be afraid to say the words that most people are too scared to discuss, you have to talk about death and funerals and things like that and ask questions and just not be afraid to take that extra step, and I think my previous experience probably helps me with that”</p>	2 – p.3
<p>“if you can acknowledge to people how hideous the situation is and quite frankly how shit it is, you can tell them that you know it’s really rubbish and crap, but that they can get through it, there is ways of doing it”</p>	2 – p.8
<p>“I’ve always worked with giving the ‘right, let me just give you the benefit of my experience and see if that’s any good for you””</p>	2 – p.8
<p>[referring to communications training] “mine has come with, basically, too many years of experience of dealing with people, as I said, in distress”</p>	2 – p.10
<p>“I’ve come out of an acute, sort of, crisis led environment, I think that has been invaluable to everything that I’ve done”</p>	2 – p.10
<p>“I’ve worked with Tenovus as a support-line nurse for the last 6 years, urmm, included in that time, I’ve worked as a nurse advisor on the man-van”</p>	3 – p.1
<p>“I do another part-time job, because I’m only part-time at Tenovus, and that job involves working with young adults with spinal or acquired head injury, urmm, and that can be anything from failed hangings to, urmm, car accidents, drug overdoses, which can leave them vegetative states”</p>	3 – p.1
<p>“my knowledge of oncology was very little apart from having cancer”</p>	3 – p.2
<p>“I started training in 1982, qualified in 85”</p>	4 – p.1
<p>“I worked in an acute surgery and acute medicine, and then I moved onto oncology”</p>	4 – p.1
<p>“I worked in oncology for about a year, and then came down to Cardiff to do an oncology course”</p>	4 – p.1
<p>“I worked in Velindre hospital for 15 years, urmm, as a charge-nurse on night duty, and then in charge of a ward on day duty”</p>	4 – p.1
<p>“then I worked, developed a post as a specialist post in male neurological cancers”</p>	4 – p.1
<p>“my main background in cancer care, looking after patients, was a specialist Breast Cancer nurse, which I did for almost 20 years”</p>	4 – p.1
<p>“I came here [Tenovus] after I retired and moved on to the support-line, probably for about 18 months”</p>	5 – p.1
<p>“I still work here but in a health and well-being role”</p>	5 – p.1
<p>“I was very used to speaking with patients, my background was specifically breast cancer but, you</p>	5 – p.1

<p>know, I had a broader knowledge having been a general nurse for cancer”</p>		
<p>“the other half of my job was health and well-being and I’d been a health visitor for about 5 years”</p>		5 – p.1
<p>“I had lots of experience in both those sides of things, more so in cancer care, but certainly my health visiting training equipped me to health promotion which is focused on, urmm, cancer risk”</p>		5 – p.1
<p>“originally I got a degree in Biology, got that and then thought what am I going to do? [laughter], so I did a degree in nursing. So, then I started working in Swansea in the burns unit in their high dependency and then I went to intensive, neuro ICU in Swansea, and then did a lot of agency work and travelled for year, including New Zealand and worked over there in their ICU in Auckland. Then I came back and did a bit more critical care, had children, had 8 years off, cos of looking after the children. Then I did a ‘Return to Practice’ course, urmm, that’s about 11 years ago now, and, urmm, initially went back on a medical ward but I couldn’t sustain the shift work because my husband was still working away all the time and I didn’t have childcare. So, I had to find something that was 9-5, so I got into research! So, gradually worked my way up as a research nurse and came to Velindre, and worked, part of it was in our outreach unit”</p>		6 – p.1
<p>“Then I just became a bit more Velindre-centric, if you like, did my, started my Masters, did my prescribing and then last year, I was, sort of, doing a bit more management and stuff and wanted a change. So, I’m now out of clinical trials and I’m just a nurse specialist and, urmm, a prescriber for two teams – urology and breast team here”</p>		6 – p.1/2
<p>“Nursing has changed quite a bit in that we’ve taken on a lot of roles that were traditionally seen as medical roles, and there’s good and bad to that. Urmm, for me it was a way of furthering my education and doing something new”</p>		6 – p.2
<p>“when I first started clinical trials they did a ... it was some kind of communication skills session and they had some videos doing some role play, urmm, that was once about 8 years ago probably [laughter], I’ve not had anything else ... I don’t think there was anything from that that had a huge impact”</p>		6 – p.5/6
<p>“I qualified in 94, so a little while ago, urmm, trained in Cardiff, my first job was in Intensive Care Unit in UHW, I worked there for about 10 or so years, and then came to Velindre, urmm, years and years ago [slight laugh]. So, basically I’ve done every job you can be a nurse in Velindre, I’ve done it, so, palliative care, chemotherapy, day-case units, research nursing, I suppose the only one I haven’t done is outpatient care, but I do, I’m based in outpatient for the trials. So, quite a lot of experience in Velindre anyway”</p>		7 – p.1
<p>“I think that my experience of working everywhere in the hospital has actually given me the experience of, or a good knowledge of what the patient experiences throughout their whole journey, through the hospital, through their diagnosis, through their treatments,</p>		7 – p.2

<p>because I know about the treatments they're having and what experiences they have when they're actually sat in the treatment unit and that type of thing. So, I can talk, sort of, when I see the patients, I can quite comfortably talk about what's going to happen when they have their chemotherapy, cos I've actually given it"</p> <p>"I've worked in all the different places, I think, obviously me being able give information on places where perhaps other nurses haven't actually worked, haven't experienced, so they can't give their personal experience of what will happen too the patients, to what they're going to go through"</p> <p>"the whole experience that I've got is quite an advantage, that I can talk more confidently because I've actually done it, seen it and seen all the different roles as well"</p> <p>"I suppose apart from a general, sort of, communication training in my general nursing training, I have done a couple of communication courses a really long time ago, but I have done a couple. One particularly, for trials communication, because obviously we've got issues around consent, ethics and the GCP and stuff like that"</p> <p>"I trained in 1992, so I've been in the NHS since then, I've worked in a number of different areas – too many to go in to"</p> <p>"I moved to Wales, 22 years ago, I worked as a District Nurse and then I came back to the hospital as a Surgical Nurse, and did surgical work mainly around Colorectal cancer and that sort of thing, urmm, then went on to become a Colorectal Nurse Specialist and then this post came up, a new post setting up the service basically, then moved over, set up the Upper GI Specialist Nurse, it was just me for a number of years doing this, looking after Pancreatic cancer, Stomach cancer, Soft-tissue cancer and Liver cancer, so that's our remit"</p> <p>"When I think now on what I did 10 years ago, I think 'oh my goodness, how?', but I just think that I was 10 years younger and jumped into it with lots of enthusiasm and lots of research, went all around Wales to find out what other people were doing, urmm, and basically, just set up the service as it was needed"</p> <p>"I think at first, when I first started I very much, I wouldn't say I was getting too involved, I think the term I mean is I was getting down there with people a little bit too much, you know, and then you have to learn a level of staying up a little bit, not because you don't feel for them but because you're the person who's got to help them"</p> <p>"I think it's about being sensible really and trying to clock off when it's your time to clock off, and again when I was on my own I didn't do that because the workload was so busy I couldn't get out of the door a lot of the time and then you felt like you were letting people down, so you stayed an extra hour or extra 2 hours, and it's very easy then to clock up a working week and I suspect that's very normal in the NHS, to clock up a working week that's, you know, above what you should be doing"</p>		<p>7 – p.4</p> <p>7 – p.4</p> <p>7 – p.7</p> <p>8 – p.1</p> <p>8 – p.1</p> <p>8 – p.1</p> <p>8 – p.7</p> <p>8 – p.8</p>
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<p>“Well, I coped but it was hard going and, urmm, it, some days it would cause me to feel very, at the end of the day, very tired, and not able really to do anything other than work, because by the time I got home from work, there was no energy left for anything else. So, it used to just, it took over my life a bit really, to be honest with you, I mean a job like this will take over your life, there’s no getting away from it, but it completely took over my life because there wasn’t, there was no energy left really, or very little energy left to give to anything outside work, urmm, and I think when you get to that point you are reaching a bit of a crisis. I don’t think anyone should have to work like that, where they’ve got nothing to give, you know, to their family and relationships and that can start cause a real problem as well. It can lead to burnout, compassion fatigue, all those sorts of things that we hear”</p>		8 – p.9
<p>[referring to courses] “One of them was called ‘Know Your Own Mind’ and the other one was called ‘Living in Alignment’. That was really good for me actually the ‘Living in Alignment’ because that looked at all your, sort of, core values and working within your core values, and that really helped me because I realised I was shifted, you know, what I was doing was away from them and I needed to pull back and that was purely of trying to manage a service on my own really. Ummm, so, that we did and I’ve done communication courses and things like that with MacMillan, so, I’ve done Advanced Communication, Motivational Interviewing, urmm, Managing Your Impact, so, a number of, sort of, different day things”</p>		8 – p.9
<p>“The Advanced Communication course was really good because you had to think of a scenario and then you had an actor and then you had to act out the scenario, and then it was videoed, so they video you and you have a group of your peers and they give you feedback, so that’s really helpful because you don’t ever get the opportunity to actually watch yourself and to hear, sort of, comments, not negative necessarily, but just comments about, you know, it makes you think a little bit more about how you communicate and what you communicate”</p>		8 – p.10
<p>“So, that was quite important for me because it made me think about the ways we were giving clinical information and whether we should be using more than just the verbal, you know, whether we should be using diagrams and pictures and all the different, sort of, forms of communication, urmm, that people might need”</p>		8 – p.10
<p>“Motivational Interviewing, that was very good, that’s more about the listening as well isn’t it? Which, you know, that’s helpful because sometimes listening is more important than talking, but again for us as clinicians, we’ve got maybe a 20 minute clinic slot, we’ve got certain things that we need address, so it’s getting a balance of, I suppose the thing is, having a consultation where the patient feels that their needs are being met and that it’s all about them but also us making sure our agenda is put across, whatever that is, you know, explaining this procedure or telling them about this report, so it’s making sure we’ve got the two happening alongside really”</p>		8 – p.10
<p>“I’ve been a nurse for many, many, many years”</p>	<p><i>Strong Nurse Identity</i></p>	1 – p.1

<p>“A lot of people say to me ‘well you used to be a nurse’, well I’m still a nurse, I’m still registered, and I’m still using all the skills that I’ve developed over the years but in a different way”</p>		1 – p.7
<p>“just because I don’t wipe your bottom doesn’t mean I’m not nursing people”</p>		1 – p.7
<p>“I volunteered to be that welcome desk person and very slowly I realised that that let me get back to having a purpose, helping people again, doing something useful, which is all I’ve ever wanted to do, doing something useful”</p>		2 – p.2
<p>“in some strange way, if I hadn’t had cancer, I wouldn’t have come here, so I wouldn’t have been able to carry on doing the thing that I ‘it’s not a job, it’s what I am’ kind of thing”</p>		2 – p.6
<p>“I was born wonky, it’s not stopped me doing the job I wanted to do, I was only ever going to be a nurse, there was never any discussion in my family, I didn’t have careers talks, I didn’t need it, because there was nothing else I was going to do”</p>		2 – p.7
<p>“I wanted to work and I wanted to get into it”</p>		2 – p.7
<p>“uniform’s really helpful actually, by putting on the uniform you become somebody else, or something else, and that, sort of, that imbues you with a certain amount of confidence within a situation”</p>		2 – p.11
<p>“I developed Breast Cancer about 12 years ago, urmm, and I was, I actually was retired from the NHS because of my illness, because I didn’t think I would be fit enough to go back to work. So, of course, once you retire you get better somehow, and after a little while I felt that I needed to go back to work, so, I looked for another post, because I couldn’t go back to the NHS within a certain limit of time, urmm, and a job came up with Tenovus and I applied for and I got the job”</p>		3 – p.2
<p>“So, it’s the nurses face that comes, so it’s urmm, I mean there’s some days where you’re more tired or whatever and you have a moan, but you have that with your colleagues and as soon as you pick up the phone you’re back to that role, and it is, it is a role, the phone rings and [<i>finger snap</i>] you set”</p>		3 – p.6
<p>“Patients often will respond differently to a nurse than they do a Doctor. I’m usually in uniform but today I do telephone clinic on a Wednesday, so, I’m not in uniform today. As soon as they see that uniform it is a different response, some patients are ‘oh, why aren’t I seeing the Doctor today?’, but as soon as you’ve built that rapport with people they are willing to give you that bit more insight into what’s important to them”</p>		6 – p.3
<p>“I wish I could do a lot more than I do do because these guys are living with this disease for a long time, which is fantastic, but you want them to live well, and I know that’s all you hear ‘oh, well there are people living well with it’, it’s hard to actually achieve sometimes with the resources that we actually have and given a chance I’d do it every day of the week just looking after them because I just think they really need it”</p>		6 – p.7

<p>“So, basically I’ve done every job you can be a nurse in Velindre, I’ve done it, so, palliative care, chemotherapy, day-case units, research nursing, I suppose the only one I haven’t done is outpatient care, but I do, I’m based in outpatient for the trials. So, quite a lot of experience in Velindre anyway”</p> <p>“I’ve worked in all the different places, I think, obviously me being able give information on places where perhaps other nurses haven’t actually worked, haven’t experienced, so they can’t give their personal experience of what will happen too the patients, to what they’re going to go through ... the whole experience that I’ve got is quite an advantage, that I can talk more confidently because I’ve actually done it, seen it and seen all the different roles as well”</p> <p>“Generally, people are ok seeing a nurse and they’re actually reassured. I think that they can talk, I think that there is a very big difference in the way patients communicate with nurses as they do with doctors as well, I think they tell us a bit more”</p> <p>“It may come across as very, very old fashioned, but the doctors do, sort of, command more respect from, because I deal with more elderly patients, they’re older gentlemen, and as I say, it might be very old fashioned, they generally do. You have that barrier, I suppose, between a doctor and a patient, the nurse does tend to, you know, those barriers do tend to be a little lifted, I think anyway”</p> <p>“I’m one of these people who can’t leave the building if there’s something outstanding, I’m a little bit, I need to make sure I’ve done everything I can before I leave on a Friday and then when I leave I can, the minute I’m out the door I can shut it down. But if I don’t make that phone call or answer that, or don’t do that then at the weekend people will be popping into my brain in the middle of the night, you know, ‘what happened with that?’, that does happen”</p>		<p>7 – p.1</p> <p>7 – p.4</p> <p>7 – p.8</p> <p>7 – p.8</p> <p>8 – p.8</p>
<p>“I won’t say it never happens, that, you know, you get things that you think about but as nurses we always do a reflective practice, and you know, it is good practice to always reflect on what happened and what you can do better, so you can use that as well”</p> <p>“We need to write reflections for our registration so if you have something you’ve handled particularly badly you can reflect on it and, you know, even by writing it down sometimes, you think ‘oh, Lord that was rubbish, but what can I do better next time?’”</p> <p>“it’s a learning experience, because, you know, if anybody ever tells you they don’t need to learn anything else, they’re fooling themselves [<i>slight laugh</i>]”</p> <p>“knowing what your triggers are as well, I think that’s important for people because we all have different triggers, you know, what winds us up. And until you come across them, sometimes I don’t think you know what they are, but if you can identify them as you come across them you think ‘ok, next time I won’t fall into that trap and I know what my triggers are’”</p>	<p><i>Reflection</i></p>	<p>1 – p.6</p> <p>1 – p.6</p> <p>1 – p.6</p> <p>1 – p.6/7</p>

<p>“I think confidence just comes with experience of knowing that you can do it, and your confidence will always get knocked, you know, you will have a call where you think ‘yeah, that was rubbish’, urmm, but again it goes back to being able to reflect on it and saying ‘well, I was rubbish that time but I can be better next time’, and just building that confidence back up, and the next time if it does go better that’s a confidence boost”</p>		1 – p.8
<p>“it’s all about being willing to talk about what you do and, you know, being able to say ‘I did this bit well but I didn’t do this bit very well’, urmm, and accepting that some people are always going to be better at things than you, but not necessarily better, we all have different styles”</p>		1 – p.9
<p>“I always try and put things in my happy bank, a bit like the nice/nasty thing, so, urmm, nurses are quite bad at recognising when they’ve done something good, I’ve found, as a ward nurse. So, if something nice has happened I acknowledge that thing, and that I think would be another thing to say to younger people trying to deal with it, if you do something good, don’t shy away from recognising that and taking that on, because that’s brilliant, because you’re going to have enough crap times where things aren’t going to go right, that you’re going to need all of those good times”</p>		2 – p.9/10
<p>“So, if you don’t actually acknowledge them, you don’t remember them, so, remember the nice times, remember the funny times ... and all the strange things, because they’re the things that will remind you why the job is worth having, and they will help to, being in your happy bank, so, they’ll help to deal with all of the shit that happens as well”</p>		2 – p.10
<p>“There’s definitely days where you feel less confident, yes. I mean, especially if you have dealt with very tricky patients which on reflection could’ve gone better or perhaps you didn’t make quite the right decision or the best decision for the patient at the time”</p>		7 – p.5
<p>“I think as a team we’ve got that, we work, we spend a lot of time reflecting, analysing, thinking about what we’re doing, and talking it through”</p>		8 – p.6
<p>“So, you have to find another way of dealing with that and, as I say, reflection and talking and supervision if that’s what you need, I think”</p>		8 – p.9
<p>“I know a lot nurses do telephone call-backs, especially the specialist nurses, but even for those that don’t, it would be nice almost to have this sort of thing included as part of training. Probably never going to happen, but, urmm, we have had some students do even a week’s placement, and when they see the kinds of things that go on, hopefully it helps their communication skills then, because they can understand more about what you need that’s different. Ummm,<i>[slight pause]</i> it’s not for everyone, because some people miss that clinical interaction so much but I think a taste of it would be a good thing for people to see, where there is something different, in medicine, it’s not all about hands-on face-to-face, you know”</p>		1 – p.7

<p>“So, it’s all about learning about you [<i>emphasis on you</i>] as a person and, you know, being quite self-aware of what you can do and then developing that”</p>		1 – p.9
<p>“they needed somebody on the welcome desk, they needed somebody to volunteer and at that time I was extraordinarily low, very depressed and about this big [<i>holds fingers up and apart</i>] - that’s about an inch for the transcript – because, urmm, I literally lost everything – you’ve asked the question how did I get here – everything, my whole self, I didn’t know who I was anymore. Urmm, so, I volunteered to be that welcome desk person and very slowly I realised that that let me get back to having a purpose, helping people again, doing something useful, which is all I’ve ever wanted to do, doing something useful”</p>		2 – p.2
<p>“I developed Breast Cancer about 12 years ago, urmm, and I was, I actually was retired from the NHS because of my illness, because I didn’t think I would be fit enough to go back to work. So, of course, once you retire you get better somehow, and after a little while I felt that I needed to go back to work, so, I looked for another post, because I couldn’t go back to the NHS within a certain limit of time, urmm, and a job came up with Tenovus and I applied for and I got the job. Although, then my knowledge of oncology was very little really apart from having cancer, but, urmm, it seemed to work quite well, and that was it, yeah”</p>		3 – p.2
<p>“I think another thing is getting the level of, urmm, of how you speak to people at different levels, you know, urmm, I think that’s, but mainly it’s the communication skills and how to perhaps calm a person down, how to, urmm, not, not, but rationale perhaps bad news that they’ve been givens, so, or interpret the medical jargon that they have, ‘well, what does it mean?’, and this, I can relate that in a simpler form perhaps to some people”</p>		3 – p.5
<p>“A lot of people say to me ‘well you used to be a nurse’, well I’m still a nurse, I’m still registered, and I’m still using all the skills that I’ve developed over the years but in a different way, and they say ‘oh yeah, I didn’t think about it like that’, yeah just because I don’t wipe your bottom doesn’t mean I’m not nursing people, so yeah I think it would be nice for them to be able come and just sit and watch and see what we do”</p>		1 – p.7
<p>“So, I think, my own confidence, I hope, is a help not an arrogance, so, yeah, I’m not too proud to find out and go and read, so, yeah, if I don’t know it I’ll tell people I don’t know it”</p>		2 – p.10
<p>“I see them more often than the doctors do, cos it’s a nurse-led clinic and I’m the one who sees them on regular basis, you know, if they’re on chemo on three-weekly basis, even in-between they have my number and they can ring me, so I suppose it’s, urmm, I don’t know, and they don’t see the doctors that often, unless there’s a real problem we can’t deal with”</p>		7 – p.8
<p>“It may come across as very, very old fashioned, but the doctors do, sort of, command more respect from, because I deal with more elderly patients, they’re older gentlemen, and as I say, it might be very old fashioned, they generally do. You have that barrier, I suppose,</p>		7 – p.8

<p>between a doctor and a patient, the nurse does tend to, you know, those barriers to tend to be a little lifted, I think anyway”</p> <p>“if you don’t look after yourself then how can you look after other people, you can’t function at you’re best if you don’t look after yourself”</p> <p>“I think the relationships, because I think people, once they get to know you, will be more open with you, and because they come into a clinic room with us and they don’t gave to re-hash everything because we know what’s happened to them, they can sit down and it’s about that moment and what’s going on this week and how they’re feeling at the point in time, and, you know, people will feel comfortable, more comfortable to tell us, more so than telling the Doctor or telling the GP, because it might, they might turn up at the GPs and it’s somebody they don’t know, or a Doctor, they quite often feel with Doctors that they’re too busy and they don’t want to bother them with the more trivial aspects of their life or in general. Sometimes they feel a little bit like that with us as well but I think after time that that’s what we’re there for, we’re there to listen and so they will, on the whole, communicate with us if there is a problem”</p>		<p>8 – p.7</p> <p>8 – p.10/11</p>
	<p><i>Quality of Communication, Self-Efficacy and Perceived Competence</i></p>	
<p>“You can have all the training in the world but unless you’re [<i>slight pause</i>], not talented but have a skill in that, you know, I’ve known people who’ve had training on training on training, their communication skills are terrible, urmm, but if you have got a skill that you can develop then it seems to work”</p> <p>“I think it is transferrable, in that you might be more probing in what you ask and not making any assumptions, because I think sometimes when we do see people we do make assumptions from what they look like, whereas on the phone you can’t do that so you have to ask questions to be able to get to the right answers, never assume, always investigate”</p> <p>“A lot of people say to me ‘well you used to be a nurse’, well I’m still a nurse, I’m still registered, and I’m still using all the skills that I’ve developed over the years but in a different way”</p> <p>“a lot of people come on the phone either very distressed or quite angry, and although it’s a very basic communication skill, it’s about bringing that person down to a place where you can have a decent conversation with them, so if you learn that on the phone you can definitely transfer that to a clinical setting where somebody comes at you very angry”</p> <p>“What I do have is 30-mm years of communicating with people in distress, people that are grieving, people whose worlds have been taken, you know, their worlds have gone and their knees have been taken out from underneath them, so, I’ve got that experience even if I didn’t have, urmm, the precise experience, I’ve got the communication experience that I’ve had for like 30 years, in an extreme environment, another extreme environment”</p>	<p><i>Communication Skills</i></p>	<p>1 – p.6</p> <p>1 – p.7</p> <p>1 – p.7</p> <p>1 – p.7</p> <p>2 – p.2</p>

<p>“I did a lot communication skills courses within nursing”</p>		1 – p.6
<p>“you just pick up things off other people over the years”</p>		1 – p.6
<p>“I’ve been fortunate enough to work very closely with our counselling team and listening to them talk about some of their counselling skills and getting information on them, we very often used to have good chats about counselling skills and things”</p>		1 – p.6
<p>“we have had some students do even a week’s placement, and when they see the kinds of things that go on, hopefully it helps their communication skills then, because they can understand more about what you need that’s different. Ummm, [<i>slight pause</i>] it’s not for everyone, because some people miss that clinical interaction so much but I think a taste of it would be a good thing for people to see, where there is something different, in medicine, it’s not all about hands-on face-to-face, you know”</p>		1 – p.7
<p>“I know for a fact that until I went to, urmm, Tenovus, if somebody had asked me to do interviews, or do presentations, I would’ve run a mile. Ummm, but through, perhaps, the confidence, and the knowledge I’ve gained, urmm, doing this, I would be, I’ve done quite a few interviews for radio, for TV, I do presentations, or I used to do presentations, on, on Prostate, on male cancers, and, urmm, I’ve done sort of GP training days where we’ve talked about, sort of, the man van and what we do, and urmm, give them a bit more awareness of what Prostate Cancer is, you know. So, yes, it has given me confidence in my field of expertise”</p>		3 – p.7
<p>“the whole experience that I’ve got is quite an advantage, that I can talk more confidently because I’ve actually done it, seen it and seen all the different roles as well”</p>		7 – p.4
<p>[referring to comms. skills courses] “One of them was called ‘Know Your Own Mind’ and the other one was called ‘Living in Alignment’. That was really good for me actually the ‘Living in Alignment’ because that looked at all your, sort of, core values and working within your core values, and that really helped me because I realised I was shifted, you know, what I was doing was away from them and I needed to pull back and that was purely of trying to manage a service on my own really. Ummm, so, that we did and I’ve done communication courses and things like that with MacMillan, so, I’ve done Advanced Communication, Motivational Interviewing, urmm, Managing Your Impact, so, a number of, sort of, different day things”</p>		8 – p.9
<p>“The Advanced Communication course was really good because you had to think of a scenario and then you had an actor and then you had to act out the scenario, and then it was videoed, so they video you and you have a group of your peers and they give you feedback, so that’s really helpful because you don’t ever get the opportunity to actually watch yourself and to hear, sort of, comments, not negative necessarily, but just comments about, you know, it makes you think a little</p>		8 – p.10

<p>bit more about how you communicate and what you communicate”</p> <p>“So, that was quite important for me because it made me think about the ways we were giving clinical information and whether we should be using more than just the verbal, you know, whether we should be using diagrams and pictures and all the different, sort of, forms of communication, urmm, that people might need”</p> <p>“Motivational Interviewing, again that was very good, that’s more about the listening as well isn’t it? Which, you know, that’s helpful because sometimes listening is more important than talking”</p>		<p>8 – p.10</p> <p>8 – p.10</p>
<p>“So, it’s using some counselling skills, but we’re not trained counsellors”</p> <p>“I’ve been fortunate enough to work very closely with our counselling team and listening to them talk about some of their counselling skills and getting information on them, we very often used to have good chats about counselling skills and things”</p> <p>“a lot of people come on the phone either very distressed or quite angry, and although it’s a very basic communication skill, it’s about bringing that person down to a place where you can have a decent conversation with them”</p> <p>“using tone of voice and slowing your speech down and things like that, that we use a lot of so that you can have a decent conversation with somebody”</p> <p>“I did do a counselling course many, many years ago but I couldn’t say ‘and how does that make you feel?’ with any kind of sincerity because I can see it written on people, I can hear it in their voices, so, I was a bit crap at that, I’ll leave that to the counsellors. Urmm, I, no nothing formal, it literally has come with experience, but like I said, if I had been, urmm, I think if I’d been in a ward based environment, I think, it would be different but because I’ve come out of an acute, sort of, crisis led environment, I think that has been invaluable to everything that I’ve done, and I’m a big mouth and I’m not frightened to say things, so, urmm, yeah, I, I’m very rarely lost for words [<i>slight laugh</i>]. And I listen, I’m just very rarely lost for words”</p> <p>“just give them a little bit of support, make sure they’re not worried about anything and making sure that they’re aware of, urmm, I suppose, the side-effects or what to expect or what not to expect, put them at ease”</p> <p>“I think another thing is getting the level of, urmm, of how you speak to people at different levels, you know, urmm, I think that’s, but mainly it’s the communication skills and how to perhaps calm a person down, how to rationale perhaps bad news that they’ve been given, so, or interpret the medical jargon that they have, ‘well, what does it mean?’, and this, I can relate that in a simpler form perhaps to some people”</p> <p>“Being a nurse you’ve got leave any worries or woes that you’ve had, you leave them at the front door, you just can’t, urmm, and you just can’t talk to somebody who’s had so many problems themselves in a tone that makes them feel worse than they already are, so,</p>	<p>- <i>Counselling Skills</i></p>	<p>1 – p.5</p> <p>1 – p.6</p> <p>1 – p.7</p> <p>1 – p.7/8</p> <p>2 – p.10</p> <p>3 – p.2</p> <p>3 – p.5</p> <p>3 – p.6</p>

<p>basically, when I open that door to work, or close my front door, everything is left behind. So, it's the nurse's face that comes, so it's urmm, I mean there's some days where you're more tired or whatever and you have a moan, but you have that with your colleagues and as soon as you pick up the phone you're back to that role, and it is, it is a role, the phone rings and [<i>finger snap</i>] you set"</p> <p>"You need, you just need to stay calm yourself and realise that it's not you they're angry with it's actually what's happening to them and, urmm, just answer as many questions as they can, if they've got questions or try to be reassuring that, you know, this is the right way that things are done, that this is what happens. Urmm, I think, it's just a lot to do with your attitude as well, it's not panicking, not reacting to them, just, sort of, try and calm things down, be reassuring, and I'd say just put their minds at rest that this is, you know, it's a lot of information giving basically"</p> <p>"you've just got to reassure them and give them as much information as you can, and I find, just be honest with patients as well. If you're honest with them and give them the information that they need, then they tend to come round and calm down, and as I said, usually it takes maybe two or three visits as well before a patient will actually start to trust you, urmm, start to, so you build a rapport with the patients"</p> <p>"I think it's just communicating with the patient everything you're doing, and making sure it's a two-way communication with them as well"</p> <p>"it is just communicating with them and being completely honest and open and knowing that it is a two-way thing and that they've got somebody that they can phone if they need to"</p> <p>"Be calm, try and go into the consultation, sort of, fully aware, so you know exactly who the patient is and what's wrong with them, know a bit about their history, so make sure you've read their notes before you go and see them. It goes a long way I think, when the patient feels like you already know them before you've actually met, so they know you've actually read-up and discussed things"</p>		<p>7 – p.3</p> <p>7 – p.3</p> <p>7 – p.4</p> <p>7 – p.4</p> <p>7 – p.8</p>
<p>"But it's just judging the situation as it goes along because you haven't got any visual cues either, you have to be much more conscious of tone of voice and language used, and what's not said as well as what's said, because that can give you more idea of what's going on"</p> <p>"we have had some students do even a week's placement, and when they see the kinds of things that go on, hopefully it helps their communication skills then, because they can understand more about what you need that's different. Urmm, [<i>slight pause</i>] it's not for everyone, because some people miss that clinical interaction so much but I think a taste of it would be a good thing for people to see, where there is something different, in medicine, it's not all about hands-on face-to-face, you know"</p> <p>"it does involve listening skills as well, you have to be able to listen and pick out sometimes the things that</p>	<p>- <i>Listening Skills</i></p>	<p>1 – p.3</p> <p>1 – p.7</p> <p>2 – p.3</p>

<p>people aren't saying, urmm, to be able to help them and to answer questions, or to just be somebody who listens on the end of the phone"</p> <p>"I listen, I'm just very rarely lost for words"</p> <p>"I think my main skills are communication skills, listening, listening to, urmm, what the patient is trying to tell you in not so many words, the undertones, urmm, you get, you get knowledge just by the tone of voice, the loudness of the voice, you learn so much when they first open "hello, who's there?", you know straight away if they're not well, you can see by the tone, the, sort of, demeanour of the voice, so that's, sort of, a good start and then you start talking"</p> <p>"Listening skills, urmm, and, listening skills more for the support-line because I don't physically see them, but I do visual communication, you know, the way they move, the way the turn. So, you know, your listening skills are heightened because you haven't got those visual skills to depend on, so then you've got to – I suppose it's like being blind and you're, you know, your hearing becomes more sensitive or something"</p> <p>"so we do get a lot of distressed calls, urmm, and that's just really being, listening, we do a lot of listening, and then just identifying what's the most important thing for that person at that time and then just trying to support them with that need, whatever that might be"</p> <p>"what we tend to do is listen to them really and then quite often there's key points coming out"</p> <p>"When you delve a bit, especially with people's symptoms you tend to find, in your mind you're thinking one thing but you mustn't make assumptions, you've really got to go back to the person and get a clear history or a clear idea of exactly what is going on before you make a decision, because you can make a wrong decision, you can bring somebody into hospital that doesn't need to be there, or you can leave somebody at home that needs to be here. So, it's really important that you listen, 1, and that you ask the right questions"</p> <p>"Motivational Interviewing, that was very good, that's more about the listening as well isn't it? Which, you know, that's helpful because sometimes listening is more important than talking"</p>		<p>2 – p.3</p> <p>3 – p.4</p> <p>3 – p.8</p> <p>8 – p.4</p> <p>8 – p.5</p> <p>8 – p.5</p> <p>8 – p.10</p>
<p>"But it's just judging the situation as it goes along because you haven't got any visual cues either, you have to be much more conscious of tone of voice and language used"</p> <p>"what's not said as well as what's said, because that can give you more idea of what's going on"</p> <p>"you get tuned into, hearing if somebody is, even if somebody says they're really, really good, they're not actually really good, you can hear things in their voices. So, you learn how to, you learn how to sort of gauge the way you talk to people from what you hear"</p> <p>"I think with my past experience as well, you have to be really good at, I've got this, I've got now, after 30 years, that if somebody, generally if I can see somebody and they tell me they're fine I know when that's an</p>	<p>- <i>Cue Identification</i></p>	<p>1 – p.3</p> <p>1 – p.3</p> <p>2 – p.3</p> <p>2 – p.3</p>

<p>absolute load of rubbish because I can see it, I can read people really, really well”</p> <p>“I think my main skills are communication skills, listening, listening to, urmm, what the patient is trying to tell you in not so many words, the undertones, urmm, you get, you get knowledge just by the tone of voice, the loudness of the voice, you learn so much when they first open “hello, who’s there?”, you know straight away if they’re not well, you can see by the tone, the, sort of, demeanour of the voice, so that’s, sort of, a good start and then you start talking”</p> <p>“you can read people’s body language, you can provide reassurance a lot more easily, because you can see expression changes”</p>		<p>3 – p.4</p> <p>6 – p.4</p>
<p>“people will say to you ‘how are you?’, ‘ooh I’m fine, I’m fine’, ‘are you sure because you don’t sound very fine?’ and, you know, you’ve got to give them permission to open up because we all do that ‘how are you today?’, ‘I’m good, how are you?’, and close it down”</p> <p>“it’s trying to open it for them then to know that, to give them permission to talk to you”</p> <p>“you do often ask them probing questions, urmm, but then sometimes you step back very quickly because they just don’t want to go there, and you know that”</p> <p>[referring to Support-Line role] “I think you learn a lot more, I don’t know if it’s patience, but you ask a lot more questions because you need to”</p> <p>“if you are face-to-face with somebody and they look ill you can see it, whereas, when you’re on the phone you don’t know that so you ask the questions you need to ask to get to the answers you need”</p> <p>“you might be more probing in what you ask and not making any assumptions, because I think sometimes when we do see people we do make assumptions from what they look like, whereas on the phone you can’t do that so you have to ask questions to be able to get to the right answers”</p> <p>“never assume, always investigate”</p> <p>[referring to patient] “you just have to follow their lead really and not be afraid to say the words that most people are too scared to discuss, you have to talk about death and funerals and things like that and ask questions and just not be afraid to take that extra step, and I think my previous experience probably helps me with that”</p> <p>“it’s getting information off them so you can give information back ... we’ve only got what the patient is telling us, so we’ve got to give that, the feedback on what you’re getting”</p> <p>“I think something I’ve learned over the years is, I will often get information second-hand, for instance my support-worker tells me that someone’s rung in and this is the problem and quite often when I dig a little bit deeper and have a full conversation and ask them some questions, that actually it’s a different story, so it’s about asking the right questions really, isn’t it? And asking</p>	<p>- <i>Probing</i></p>	<p>1 – p.3</p> <p>1 – p.3</p> <p>1 – p.4</p> <p>1 – p.7</p> <p>1 – p.7</p> <p>1 – p.7</p> <p>1 – p.7</p> <p>2 – p.3</p> <p>3 – p.4/5</p> <p>8 – p.5</p>

<p>them, sort of, open questions and allowing them to give you the information that you need”</p> <p>“When you delve a bit, especially with people’s symptoms you tend to find, in your mind you’re thinking one thing but you mustn’t make assumptions, you’ve really got to go back to the person and get a clear history or a clear idea of exactly what is going on before you make a decision, because you can make a wrong decision, you can bring somebody into hospital that doesn’t need to be there, or you can leave somebody at home that needs to be here. So, it’s really important that you listen, I, and that you ask the right questions”</p>		8 – p.5
<p>“going on different communication courses, urmm, talking to people, just, you know, with your friends and stuff, just the way you speak to them, and transferring those skills to people that you’re on the phone with”</p> <p>“you learn how to sort of gauge the way you talk to people from what you hear, urmm, and you go quietly to start with but then perhaps you, you’re sort of a bit more confident in the best way for people, it is very much about adapting things and being able to respond to the person because not everyone can cope with the same amount of information, or the same way of speaking to them”</p> <p>“My role on the support-line, a typical day would mean that first of all we’d contact primary call-backs, and this is where we work in conjunction with the all of the chemo units that we work with, where we contact patients who are going through chemotherapy, usually contact these patients on a day 3 and a day 7 post-chemotherapy, on cycle 1 and cycle 2, just to ensure, I suppose, just give them a little bit of support, make sure they’re not worried about anything and making sure that they’re aware of, urmm, I suppose, the side-effects or what to expect or what not to expect, put them at ease. So, that will be, sort of, the first part of the day, then I have a case-load of roughly 50/60 patients which want to continue the calls, so, they want the support either throughout their chemotherapy or even after. I’ve got a lot of patients which are 2 or 3 years down the line, perhaps still receiving treatment, some are palliative, some are end-of-life stage, so all different patients”</p> <p>“I have the support-line, so the phone’s appointed to my phone, so, any incoming calls that are coming through the system, I would be the one, perhaps, taking them. And that could be anything from wanting to donate something to the shop, to a pervert calling, to somebody who wants to take their own life, urmm, so, the variation is enormous”</p> <p>“I think another thing is getting the level of, urmm, of how you speak to people at different levels, you know, urmm, I think that’s, but mainly it’s the communication skills and how to perhaps calm a person down, how to, urmm, not, not, but rationale perhaps bad news that they’ve been givens, so, or interpret the medical jargon that they have, ‘well, what does it mean?’, and this, I can relate that in a simpler form perhaps to some people”</p> <p>“A huge role of a nurse is an interpreter, so, we interpret all that jargon and crap that they hear and they don’t understand, they use these big words but don’t even</p>	<p><i>Adaptability</i></p>	<p>1 – p.9</p> <p>2 – p.3</p> <p>3 – p.2</p> <p>3 – p.2</p> <p>3 – p.5</p> <p>4 – p.3/4</p>

<p>know what they're, a lot of people don't even know what they're, what they're actually saying. So, as an interpreter then, so, you go through the article, or Dr. Google – save us from Dr. Google – urmm, because there's so much misinformation, so, it just, it creates anxiety, it creates uncertainty, and all sorts of stuff like that, rather than, so that's why you need people with special skills, perhaps, to be around for that”</p> <p>“A crew I was training, many, many years ago now, we used to have a wheel, urmm, a diagram wheel, where the patient was in the middle, and we had all the arrows coming off to the occupational therapist, and urmm, doctors and physios, and all those people around them that affected the patient. I would always, I would put a Specialist Nurse alongside the patient, you're there to direct the traffic, you're there to say ‘I think we should think about this, and I'll get you in touch with them and I'll get you in touch with that one”</p> <p>“You're there to, urmm, interpret, you're to allay fears by your knowledge and your skills, and your communication skills, if you're a good communicator, that's your job, half your job's there, you know, and it's being able to, and it can be a challenge. It's being able to look at all the vulnerable leakage and understanding that, and understanding maybe that certain cancer patients that their emotions are usually much more heightened, so, they'll pick up anything from you that you let leak because they're so emotionally, their emotions are so heightened from the situation they're in”</p> <p>“I do try to find out a bit more about how it's impacting on their day-to-day living and whether this is what's right for them at this time. Trying to make it a bit more shared, shared decision making, that's the, sort of, word they use now but, I mean, that really is what it should be about rather than a, sort of, paternalistic attitude, which is often what you get”</p> <p>“I think that my experience of working everywhere in the hospital has actually given me the experience of, or a good knowledge of what the patient experiences throughout their whole journey ... So, I can talk, sort of, when I see the patients, I can quite comfortably talk about what's going to happen when they have their chemotherapy, cos I've actually given it”</p> <p>“I see a lot of my patients when they're first diagnosed so they're highly anxious and, urmm, and sometimes very upset and still, sort of, getting their way, feeling their way around what is happening to them, without, you know, me bombarding them with treatment options, and then we throw a trial in to the mix as well. So, you know, when they come to clinic, some people are very laid back and quite, sort of, with it and have looked up the trial previously, you know, quite in control, other patients are really, urmm, they can be, not aggressive I wouldn't say, they can be quite angry and, you know, sort of confrontational and have a lot of questions. Ummm, so, yeah, there's a lot of emotional needs as well that our patients have when they come and see us for the first time and again when they're trying to make decisions as well, when they've got a decision, you know, they need to make decisions, so giving them a lot of information about what happens if I don't go into a trial, what happens if I do, urmm, yeah”</p>		<p>4 – p.4</p> <p>4 – p.5</p> <p>6 – p.3</p> <p>7 – p.2</p> <p>7 – p.3</p>
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<p>“You just need to stay calm yourself and realise that it’s not you they’re angry with it’s actually what’s happening to them and, urmm, just answer as many questions as you can, if they’ve got questions or try to be reassuring that, you know, this is the right way that things are done, that this is what happens. Ummm, I think, it’s just a lot to do with your attitude as well, it’s not panicking, not reacting to them, just, sort of, try and calm things down, be reassuring, and I’d say just put their minds at rest that this is, you know, it’s a lot of information giving basically”</p>		7 – p.3
<p>[referring to trial situation] “We have to treat them quite sensitively and I think having the confidence to, urmm, to say to a patient ‘well, this is what is expected of you, you don’t have to come in, you don’t have to take part in the trial but if you are taking part then we do need to see you because it could be for your own safety’, you have to have quite a bit of confidence to say that with some patients”</p>		7 – p.6
<p>“they tend to build up that relationship with us and everybody’s very different. We’ll have people who’ll ring us every day, we’ll have people who maybe have 1 or 2 contacts and then won’t need our contact again, so it’s very individual, urmm, as to the sort of access that people need, or the things that people need from us really, but they know where we are if they want us, if they need us”</p>		8 – p.3
<p>“I think sometimes the family wonder why they can’t talk to them, and we do have that conversation as well with the family members”</p>		1 – p.4
<p>“you’re doing like a two-pronged job really, you know, you’re supporting them in a psychosocial way but you’re also having that chit chat, if you like, with them that helps to make it feel as if it’s not as formal, as formal as counselling or something like that”</p>		1 – p.4
<p>“So, it’s using some counselling skills, but we’re not trained counsellors”</p>		1 – p.5
<p>“A lot of people say to me ‘well you used to be a nurse’, well I’m still a nurse, I’m still registered, and I’m still using all the skills that I’ve developed over the years but in a different way”</p>		1 – p.7
<p>“it is very much about adapting things and being able to respond to the person because not everyone can cope with the same amount of information, or the same way of speaking to them”</p>		2 – p.3
<p>“I think it changes as you get more experienced probably, I think you did always have some patients that are more difficult to communicate with than others, but as you get more confident, I suppose you get a bit more used to trying to get people to talk and getting more out of them”</p>		6 – p.3
<p>“some visits they will need more time than others and it’s not until that visit that you know that that’s going to happen”</p>		6 – p.4
<p>“So, you know, when they come to clinic, some people are very laid back and quite, sort of, with it and have</p>		7 – p.3

<p>looked up the trial previously, you know, quite in control, other patients are really, urmm, they can be, not aggressive I wouldn't say, they can be quite angry and, you know, sort of confrontational and have a lot of questions. Urmm, so, yeah, there's a lot of emotional needs as well that our patients have when they come and see us for the first time and again when they're trying to make decisions as well, when they've got a decision, you know, they need to make decisions"</p> <p>[referring to drug trial patient phone conversations] "generally those conversations happen over the phone, which is not great for communicating because, you know, they need, sometimes they don't want to come in to hospital to see us, so we just have to explain that it is really important that they come and see us, urmm, you know, we can't force them, and if they don't want to come they won't come but, you know, you just try to be as encouraging as you can really"</p> <p>"it's very individual, urmm, as to the sort of access that people need, or the things that people need from us really, but they know we are here if they want us, if they need us"</p>		<p>7 – p.7</p> <p>8 – p.3</p>
<p>"Just read people, and if it's going wrong, if it's going wrong and they're really are not getting you, that's fine, that's also fine, if they don't like you, that's fine. You're not going to be universally liked by everybody, but reassure them that look 'I'm not sure that I'm the right person to talk to at the moment but I'll get one of my colleagues and perhaps you'll be better talking to them, I think their experience will be better for you', nothing wrong in doing that [<i>slight whisper</i>]. Because we can't like everybody, and there's always somebody else that they might get on better with and, urmm, what you've done is made sure that they've had a better experience, you've not, you've not sort of, you've not locked them into this relationship with you, you've offered them somebody else that they might get on with better"</p> <p>"Everybody has good days and bad days but everyone deserves a minimum amount, a minimum amount of service, so, even if you're having a stressy day, the person on the end of the phone, or the person that you're having a face to face with, is dealing with you, they have a right to the minimum goodness of you, and that still needs to be really high. So, it doesn't matter what shit you're going through, you have to park that, urmm, but obviously there will be days that are better and worse than others, and there will be days where you get on better or worse with others, but again, there's nothing wrong with saying 'I'm not the right person to for this - I'll get my colleague, hang on a minute, I'll get someone else to talk to you', because they might interact better with them"</p> <p>"it's all in the moment, it depends on, it's very dependent on who's calling you, what they want to know, and why"</p> <p>"I can't emphasise this enough, I think communication is the key to everything really, but especially with nurses, the way the nurses communicate with the patient, and with the doctor, and it's, and sometimes the nurse is the interpreter, you know, there to focus the conversation, I think for nurses, more than anything else, communication is the key"</p>	<p><i>Efficiency</i></p>	<p>2 – p.3</p> <p>2 – p.11</p> <p>3 – p.3</p> <p>3 – p.8</p>

<p>“interestingly I’ve had a lot more telephone conversations of recent, that’s becoming more common, urmm, also, as well, with the logistics of where we are, because we are quite a rural health board, so a lot of our patients are a long way from us, they aren’t like 5 minutes away, a lot of them are coming quite distances to come up to the clinic to see us, so phone conversations are actually really good”</p> <p>“Working with whatever, urmm, suits the patient and at the moment it’s phone but I suspect in the future it will be other forms of WhatsApp and Skype and whatever and, you know, they’ve been doing tele-linking or something, tele-health aren’t they? We’re not using that but I suspect in the future that will be the way we’re communicating more, especially in these rural communities because as I say some patients are driving an hour to get here so, urmm, and we are, the team is here, so anybody, they’ve got to come from all directions to come here, basically”</p> <p>“making sure we’ve got the environment right, we’ve got the information and that we’re prepared for what we’re going to encounter, what we’re going to deal with really”</p>		<p>8 – p.3</p> <p>8 – p.3</p> <p>8 – p.4</p>
<p>“I thought ok, oncology, I can do this and started working and thought why haven’t I done this years before”</p> <p>“the opportunity came up to do something very, very different, which is working on what was then the helpline, and I thought yeah let’s give it a go”</p> <p>“the reason for moving into oncology was because I worked on wards with patients with cancer, didn’t know how to deal with it, so, I thought, well let’s face it straight on”</p> <p>“I’ve always been interested in real difficult questions, in difficult subjects, like death and dying and all that sort of stuff”</p> <p>“Then I just became a bit more Velindre-centric, if you like, did my, started my Masters, did my prescribing and then last year, I was, sort of, doing a bit more management and stuff and wanted a change”</p> <p>“Nursing has changed quite a bit in that we’ve taken on a lot of roles that were traditionally seen as medical roles, and there’s good and bad to that. Ummm, for me it was a way of furthering my education and doing something new”</p> <p>“I started here so long ago that I’ve just moved around, you know, I did palliative care for a few years decided then to get some experience then with chemotherapy, which is very different. So, you know, you have to apply for the jobs, applied for them, got the jobs and moved over there, urmm, then did, urmm, the day-case units just for, to get more experience with different kinds of chemotherapy and then in, urmm, I think I’ve been here about 10 years, doing trials 10 years, so, that was a movement away from the clinical area I suppose, urmm, to do the, sort of, cancer research side of things”</p>	<p><i>Challenge-Approach Mindset</i></p>	<p>1 – p.1</p> <p>1 – p.2</p> <p>4 – p.1</p> <p>4 – p.1</p> <p>6 – p.1/2</p> <p>6 – p.2</p> <p>7 – p.1</p>

<p>“then this post came up, a new post setting up the service basically, then moved over, set up the Upper GI Specialist Nurse, it was just me for a number of years doing this, looking after Pancreatic cancer, Stomach cancer, Soft-tissue cancer and Liver cancer, so that’s our remit”</p> <p>“When I think now on what I did 10 years ago, I think “oh my goodness, how?”, but I just think that I was 10 years younger and jumped into it with lots of enthusiasm and lots of research, went all around Wales to find out what other people were doing, urmm, and basically, just set up the service as it was needed. The thing was, there was nothing before, so anything was an improvement, urmm, and as I say I did that for about 9 years”</p>		<p>8 – p.1</p> <p>8 – p.1</p>
<p>“I think you start off quite tentatively, urmm, and test the waters, and see what you get a response to”</p> <p>“I think my main skills are communication skills, listening, listening to, urmm, what the patient is trying to tell you in not so many words, the undertones, urmm, you get, you get knowledge just by the tone of voice, the loudness of the voice, you learn so much when they first open ‘hello, who’s there?’, you know straight away if they’re not well, you can see by the tone, the, sort of, demeanour of the voice, so that’s, sort of, a good start and then you start talking and, urmm, you can, I suppose, squeeze things out of people”</p> <p>“I suppose it starts when you start to see a patient, straight away you just introduce yourself, make sure they know who you are, make sure they know how the clinic is run, because we run our clinics quite differently as we’re a nurse-led clinic, sometimes they’re expecting to see a doctor so you explain how the clinic works, urmm, obviously we talk a lot about the trial, say that the, you know, we do give them our contact details as reassurance that they’ve actually got somebody that they can phone and they’ve got a number to take away with them”</p> <p>“what we do to start it, it is just communicating with them and being completely honest and open and knowing that it is a two-way thing and that they’ve got somebody that they can phone if they need to”</p> <p>“Be calm, try and go into the consultation, sort of, fully aware, so you know exactly who the patient is and what’s wrong with them, know a bit about their history, so make sure you’ve read their notes before you go and see them. It goes a long way I think, when the patient feels like you already know them before you’ve actually met, so they know you’ve actually read-up and discussed things, so you’re read-up about them”</p> <p>“consent from the patient first but then working with whatever, urmm, suits the patient”</p> <p>“you’re just led by them, you know, we tend to use the language they use”</p> <p>“we have got a short time span to do that, and sometimes we get it wrong, and I think, and if you deny that you do get it wrong then you’re not doing your best practice, because you’ve got to learn from your mistakes to move on”</p>	<p><i>Building Rapport</i></p>	<p>1 – p.3</p> <p>3 – p.4/5</p> <p>7 – p.4</p> <p>7 – p.4</p> <p>7 – p.8</p> <p>8 – p.3</p> <p>1 – p.3</p> <p>1 – p.3</p>

<p>“very often you get people who you might never be able to develop that relationship with and sometimes you’ve got to accept that you’re just not the right person to for them to talk to”</p>		1 – p.4
<p>“you’ve got to think whether you’re right person for them to talk to, and maybe signpost them, even to other organisations that maybe fit their needs better”</p>		1 – p.4
<p>“the difficulty you get when you talk to one person is that you don’t get a rounded view ... that’s only that person’s opinion so you’ve got to be mindful of that”</p>		1 – p.5
<p>“So, it’s using some counselling skills, but we’re not trained counsellors”</p>		1 – p.5
<p>“Probably when I was first qualified, I would’ve tried to blag it because you just assume then that you need to know everything, but I think as you get more experienced, and as time goes by, you realise you can’t be all things to all people and you’re doing them a disservice by not giving them the information that they need or maybe even giving them misinformation”</p>		1 – p.8
<p>“we all have different styles, and it’s no good saying ‘I want to be like Angela’ because if your personality is very different, you’re never going to achieve that, so, it’s working with what you’ve got to be the best that you can with the style that you use, you know, if you listen, there’s 4 of us on the support-line and we’re all very different in the way we approach things but all get the job done in a different way. And it’s accepting that you can’t be what you’re not, you know, you can learn – yes, you can learn some skills but you’re still going to use them in a way that’s right for you. You know, some people are very loud when they talk, urmm, I’m much more, I’m much quieter when I speak, urmm, and there’s nothing wrong with either, it’s just whatever suits”</p>		1 – p.9
<p>“there’s no set rule for how to deal with each patient, urmm, basically, if I’m confident enough to give them a straight answer I will, if I don’t know I’ll just say ‘I’m sorry this isn’t my field, I recommend you to contact, you know, your team in the hospital, or you need to go to A&E if it’s urgent”</p>		3 – p.2
<p>“I think if I didn’t have the confidence, I think more than anything the confidence to say ‘I’m sorry, I don’t know much about this”</p>		3 – p.6
<p>“you can’t be all things to all men, but, you know, you know a man that has, you know a man that can, and that’s what it’s all about as well, knowing your limitations and unfortunately a lot of nurses think they can do everything, and you can’t, and I think sometimes that’s a barrier, and so patients don’t get the best care that they should have, because of people’s need to be needed as well sometimes”</p>		4 – p.4
<p>“Very important because of my inadequacies, anyone in my career, but recognising that, and facing it and doing something about it, rather than cowering away in your inadequacies and making an arse of the whole thing. There’s difficult questions, I’ve felt, urmm, so I’ve experienced that, and realised I wasn’t being fair in my nursing care and, you know, did something about it, and</p>		4 – p.8

<p>took it head on and tried to get help, and I think it took me a while to realise that that's what I needed to do but I got there in the end [<i>slight laugh</i>]"</p> <p>"I could talk to anybody now about, my speciality is neurological cancers, so if I get a women with breast cancer my knowledge is not as great but other stuff that I've learned in the past, on how to speak to people for example, if I don't know what somebody's talking about, you know, 'I'm sorry could you explain that to me?', I'm not afraid to say 'I don't understand what that means'"</p> <p>"some days it doesn't go the way you want it, and some days you've got to admit, 'well, actually I don't know that fact', but I am going to get it wrong sometimes but it's about accepting that and holding your hands up and saying 'sorry, I got that wrong, I shouldn't have said that to them', or 'I hope I didn't upset you by saying that', it's having the confidence to that as well, and again, the ability and the confidence to say 'I don't know'"</p> <p>"In the end if you don't get it right, you don't get it right, and if people don't phone back or whatever, ok, you've done what you could at the time and you can't do any more than that, you can't beat yourself up about it, because such and such happened, they never rung back or whatever, you know. It's accepting the limitations of what you're working with, I think that, that's, not accepting the status quo"</p> <p>"I met a medic in Velindre hospital, long gone, long retired, urmm, but he said that he struggled with difficult questions, he always found it really hard to go into them and stuff, he was a consultant for 30-odd years, why not go and get some education in that area and help yourself to bloody deal with them? You bloody eejit, because it's not about you, it's about the body in the bed, you know, it's terrible, I mean it's about the person in the bed, it's about them, it's not about you. But anyway, so, a lot of people missed out because of his inadequacies and inability, or not inability, but unwillingness to do something about it"</p> <p>"If I went back to the wards to work, because currently I'm working in trials, you know, I work in the outpatients, I see patients in the outpatient clinic, but I don't give them treatments anymore or treat patients, so, urmm, I probably think that if I went back to those places I'd need an awful lot of re-learning shall we say. Urmm, so in some respects I've lost a lot of your clinical skills by doing, urmm, trials, at least I'm still up to date and aware of the new treatments and the process of what happens on the ward, what happens to the patients when they actually go through the ward, and I think that experience of working everywhere in the hospital has actually given me the experience of, or a good knowledge of what the patient experiences throughout their whole journey, through the hospital, through their diagnosis, through their treatments, because I know about the treatments they're having and what experiences they have when they're actually sat in the treatment unit and that type of thing"</p> <p>"if you're going to have on-going support for somebody, you do need to develop some kind of relationship between you, whether it's strictly medical,</p>		<p>4 – p.9</p> <p>4 – p.12</p> <p>4 – p.15</p> <p>4 – p.16</p> <p>7 – p.2</p> <p>1 – p.4</p>
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<p>that you just ring up and talk about the medical stuff or whether sometimes it expands past that and you get to talk more about holidays and things like that”</p> <p>“I’ve found that as my role with my male patients from the man-van, I still have, probably, 20 patients, male patients, from there that I regularly contact, and probably then a further 10 that will call in and ask me questions when and if they need to, so, urmm, they sort of use me as, I suppose, a stopping point, you know, ‘they want me to have this, or they want me to have that, what do you think?’, urmm, or ‘I’ve got a problem with this, is there anything else I can use instead of this?’, and with those patients, because we’ve met face-to-face in a lot of these cases, they seem to know me very well and we can talk about anything, and the men bring these subjects up; erectile dysfunction, continence care, all of these things are open, not with everybody but some people are more reluctant to speak about things than others”</p> <p>“the thing of it was that you see patients and yet you have your own clinics and then you can’t actually complete the process and you’ve actually got to go to the Doctor and say I’ve seen the patient, can you prescribe for them and that doesn’t really make sense, but if you can do the whole process it makes a lot more sense, and it’s continuity of care, and you get to know your own patients, and it should be better for the patients and better for the system”</p> <p>“We’re now their Specialist Nurse and, sort of, key worker right through their treatment journey, right the way through. So, it gives a better continuity, for us as Nurses and for the patients as well, urmm, and they’ve got direct contact to us at any point across their treatment”</p> <p>“I think it helps them in the respect that they’ve got one person that they’ve met or 1 or 2 people, they get to know us, they get to know us quite well at the start with their diagnosis and their treatment plan, and we’re there as they’re going through treatment”</p> <p>“it just gives them somebody that they know, they know us, they’ve got a face to the name, it’s not like they’ve got somebody that they don’t know, who’s not going to know their story or their treatment plan. They can ring us and we know what’s going on with them, so we can help support them then to whatever services they need, whatever problem they’ve got, whatever crisis they’re in”</p> <p>“because often we’re with them at their diagnosis and often we’re with them going through their staging, so we do see a lot of them during that time, during the staging process, so we tend to build up a relationship, not just with the patient but with their families”</p> <p>“they tend to build up that relationship with us and everybody’s very different, we’ll have people who’ll ring us every day, we’ll have people who maybe have 1 or 2 contacts and then won’t need our contact again, so it’s very individual”</p> <p>“you’re doing like a two-pronged job really, you know, you’re supporting them in a psychosocial way but you’re also having that chit chat, if you like, with them that</p>		<p>3 – p.3</p> <p>6 – p.2</p> <p>8 – p.2</p> <p>8 – p.2</p> <p>8 – p.2</p> <p>8 – p.2</p> <p>8 – p.3</p> <p>1 – p.4</p>
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<p>helps to make it feel as if it's not as formal, as formal as counselling or something like that"</p>		
<p>"yes, you have got a professional relationship but there's nothing wrong with that gentleness that you use when you talk to your friends, to talk to somebody on the phone"</p>		1 – p.9
<p>"So, we do the sort of formal bits and then it tends to become a bit more of a discussion, and sometimes people even won't mention the most difficult thing to talk about until they're almost going out of the room and then they need to sit down again then, they spend the whole time working up the nerve to actually say what it is, and other people, it comes out the moment you sit down. And I think the relationships, because I think people, once they get to know you, will be more open with you, and because they come into a clinic room with us and they don't have to re-hash everything because we know what's happened to them, they can sit down and it's about that moment and what's going on this week and how they're feeling at the point in time, and, you know, people will feel comfortable, more comfortable to tell us, more so than telling the Doctor or telling the GP"</p>		8 – p.10
<p>"Sometimes people come on the phone and they're crying, when they come on the phone, and they say sorry to you constantly, but you've got to remind them that actually I'm here for as long as you need me so take your time, or, if you'd rather ring me back in 10 minutes when you feel that you're more settled yourself"</p>		1 – p.4
<p>"You do often ask them probing questions, urmm, but then sometimes you step back very quickly because they just don't want to go there, and you know that"</p>		1 – p.4
<p>"I could bring with that my own experience of having cancer, luckily very successful treatment, but all of those things that to me are really important, so when you're talking about, urmm, their quality of life things, urmm, you know, the little things that are actually the important things, the things that aren't perhaps immediately obvious but they're the things that really matter to people, so that I could bring my own experience of that into the job, and that's what I've been doing ever since"</p>		2 – p.2
<p>"I try not to make it about me, but obviously there are things that I have experienced, or little hints and tricks, perhaps on the lifestyle bits, that I know are very relevant to people, so I can bring those up that might not be so obvious to the other members of staff, so, I hope that I've brought something rather unique to the team"</p>		2 – p.7
<p>"People can't say to me in anyway whatsoever 'you don't know how I feel', because I damn well do"</p>		2 – p.7
<p>"I think my cancer, having been a patient has helped me greatly and I think every nurse and doctor should be a patient before they become a doctor or a nurse because then they know what it's like"</p>		3 – p.3
<p>"They've more of an insight, not even empathy, an insight to what the problems are, and, urmm, perhaps how difficult it is to sometimes live with those problems. So, yes, I think it's helped me in my role, not so much in my knowledge of different cancers, because, you know,</p>		3 – p.3

<p>it's more about the patient experience than anything else"</p>		
<p>"Some people still get to you, and they always will, and if you don't get upset every now and then by some people then it's time to pack it in, you know, it's time to just give it in ... I think that's something that every nurse needs to have, and I don't think there's enough emphasis played on it during training"</p>		4 – p.2/3
<p>"So, it's that, kind of, it's going that extra step, if it takes all morning for them to have a wash, that's fine, let them take their time to get it done, but I'll come and freshen up the water, rather than me doing, I can do it in 5 minutes. It's giving them that respect, as a human-being you know, respecting a grown-up person"</p>		4 – p.8
<p>"So, you do tend to transpose yourself a wee bit into their lives as well, how would I do that? That gives you empathy that you can be effective and have compassion, urmm, I think compassion's a really underused word as well, and some people think it's a bit, sort of, over the top, but having compassion is a, but not, being effective, having that empathy and avoiding sympathy, because sympathy doesn't work, it does on some occasions but, you know, about acknowledging that it's ok to feel that way"</p>		4 – p.16
<p>"it's having that empathy and that understanding of what maybe people are having to through, and sometimes, sometimes you don't care because that's how it is on that day, sometimes you think 'I couldn't care less, could you just shut up and give me some peace', but that's a human response, but the professional response is to say 'oh, I'm really interested in what you're telling me', and that's the difference"</p>		4 – p.17
<p>"You need, you just need to stay calm yourself and realise that it's not you they're angry with it's actually what's happening to them and, urmm, just answer as many questions as they can, if they've got questions or try to be reassuring that, you know, this is the right way that things are done, that this is what happens"</p>		7 – p.3
<p>"I've worked in all the different places, I think, obviously me being able give information on places where perhaps other nurses haven't actually worked, haven't experienced, so they can't give their personal experience of what will happen too the patients, to what they're going to go through"</p>		7 – p.4
<p>"you get others that you develop a very, urr, deep relationship with but in a, it's weird because it's in a distance way"</p>		1 – p.4
<p>"it has to be a therapeutic relationship, not a 'let's be chums', I'm not your chum, I'm not your friend and they're not your friend, they're your patient"</p>		4 – p.5
<p>"you can be friendly and have, I think that humour is a wonderful, wonderful tool to use, appropriately, urmm, but I think that that relationship, that therapeutic relationship between nurse and patient is vital to the recovery, absolutely essential to the recovery"</p>		4 – p.5
<p>"that therapeutic relationship between the nurse and the patient is vital"</p>		4 – p.5

<p>“it is a learning process and you will get on better with some people than others, urmm, but it’s more in the boundaries and realising your own boundaries and where the boundaries, and the patient’s boundaries are, and managing their expectations”</p> <p>“So, it’s about keeping that distance, you’ve got to keep that professional distance”</p> <p>“everybody’s needs are different in many ways. So, particularly when you look at touch, people are, health professionals who touch patients are seen as more caring and knowledgeable, and that sort of stuff, than people who don’t touch, because we’re beings that need touch, but that’s appropriate touch”</p> <p>“they all have that perception that you’re giving them the time, and that’s a real skill to be able to do that, whether you’re interested in them or not, and it sounds really cold but I’ve got to protect me, to do it the next day as well”</p> <p>“when I first started I very much, I wouldn’t say I was getting too involved, I think the term I mean is I was getting down there with people a little bit too much, you know, and then you have to learn a level of staying up a little bit, not because you don’t feel for them but because you’re the person who’s got to help them”</p> <p>“that doesn’t mean you don’t have every empathy and every sympathy and every care for them, but you just keep yourself slightly distanced”</p>		<p>4 – p.5</p> <p>4 – p.5</p> <p>4 – p.5</p> <p>4 – p.17</p> <p>8 – p.7</p> <p>8 – p.7</p>
<p>“sometimes we get it wrong, and I think, and if you deny that you do get it wrong then you’re not doing your best practice, because you’ve got to learn from your mistakes to move on”</p> <p>“if you get something you don’t know much about, urmm, your listening skills go out the window for a start, because you’re too busy thinking ‘how am I going to do this, I really don’t know what to do’. Ummm, then you’re scrabbling around trying to think of answers but we try and be very honest, urmm, if it’s something we know nothing about, we don’t try and blag because that gets nobody anywhere”</p> <p>“if there’s somebody else in the team that we know is far more skilled then we will always say ‘look my skills are limited but I do know somebody who could probably answer all these questions without even thinking about it’, and that comes down to confidence”</p> <p>“Probably when I was first qualified, I would’ve tried to blag it because you just assume then that you need to know everything, but I think as you get more experienced, and as time goes by, you realise you can’t be all things to all people and you’re doing them a disservice by not giving them the information that they need or maybe even giving them misinformation, whereas, you know, it’s very honest to say ‘I really don’t know, you’re talking about something now that I have no experience of, but I know a person who does’, and I think that gives them more confidence in the service, as well, that they’re saying ‘Ok, well I can ring them and if they don’t know, they will be truthful”</p>	<p><i>Authenticity</i></p>	<p>1 – p.3</p> <p>1 – p.8</p> <p>1 – p.8</p> <p>1 – p.8</p>

<p>“being willing to talk about what you do and, you know, being able to say ‘I did this bit well but I didn’t do this bit very well””</p>		1 – p.9
<p>“I think the main thing is to be yourself, so, [<i>slight pause</i>] people respond to genuine people better, even over the phone”</p>		2 – p.4
<p>“if you don’t understand something, or you confess a little bit of, not ignorance, but perhaps you’re not sure, ‘ooh, I dunno, right hang on a minute, let’s have a little look’, if you show them your human side and that you’re not some kind of automaton, they’re more happy to sit there for 5 minutes”</p>		2 – p.4
<p>“so, you never, I mean that’s something that’s come from my previous job, you never lie to people, you never fudge answers”</p>		2 – p.4
<p>“Be yourself, admit if you don’t know what they’re talking about, try and reassure them that you will go and find out for them, from a responsible source, urmm, and that, and that that’s the best thing to do. Admitting you don’t know things is not a vulnerability, it’s not a lack, it’s actually a strength”</p>		2 – p.4
<p>“You’re not going to be universally liked by everybody, but reassure them that look ‘I’m not sure that I’m the right person to talk to at the moment but I’ll get one of my colleagues and perhaps you’ll be better talking to them, I think their experience will be better for you’, nothing wrong in doing that [<i>slight whisper</i>]. Because we can’t like everybody, and there’s always somebody else that they might get on better with and, urmm, what you’ve done is made sure that they’ve had a better experience, you’ve not, you’ve not sort of, you’ve not locked them into this relationship with you, you’ve offered them somebody else that they might get on with better”</p>		2 – p.4
<p>“if you can acknowledge to people how hideous the situation is and quite frankly how shit it is, you can tell them that you know it’s really rubbish and crap, but that they can get through it, there is ways of doing it, and if I, like I said, handy hints and tips”</p>		2 – p.8
<p>“bring yourself, I think the best people that communicate bring themselves, urmm, because people can sense a liar a long way away”</p>		2 – p.12
<p>“We’re all different, Angela’s really quiet, as you’ve probably heard, and a lot of her clients that is absolutely marvellous for them. Ethan, if you meet Ethan, is loud, Scottish and mad, that’s really good and he’ll talk to the men about prostate things with complete confidence, you just need to find what works for you and do it your way”</p>		2 – p.12
<p>“you do develop a good relationship with the ones you constantly, the ones you call on a regular basis, to the point where, urmm, they will phone up and ask for you specifically, which is fine because that’s what, urmm, that’s what the aim is, that you build a rapport, and they can ask you questions that perhaps they wouldn’t dream of asking anyone else”</p>		3 – p.3
<p>“I’ve found that as my role with my male patients from the man-van, I still have, probably, 20 patients, male</p>		3 – p.3

<p>patients, from there that I regularly contact, and probably then a further 10 that will call in and ask me questions when and if they need to ... and with those patients, because we've met face-to-face in a lot of these cases, they seem to know me very well and we can talk about anything, and the men bring these subjects up; erectile dysfunction, continence care, all of these things are open, not with everybody but some people are more reluctant to speak about things than others"</p> <p>"as soon as you've built that rapport with people they are willing to give you that bit more insight into what's important to them"</p> <p>"you've just got to reassure them and give them as much information as you can, and I find, just be honest with patients as well, if you're honest with them and give them the information that they need, that they tend to come round and calm down, and as I said, usually it takes maybe two or three visits as well before a patient will actually start to trust you, urmm, start to, so you build a rapport with the patients, once they get to know you"</p> <p>"what we do to start it, it is just communicating with them and being completely honest and open and knowing that it is a two-way thing and that they've got somebody that they can phone if they need to"</p> <p>"There's nothing wrong with saying to the patient 'I don't know that, let me find out and I will get back to you', it shows them that you're human as well, and I think sometimes that helps a little bit with the rapport and the communication with the patient as well"</p>		<p>6 – p.2</p> <p>7 – p.3</p> <p>7 – p.4</p> <p>7 – p.5/6</p>
	<i>Self-Determination Theory</i>	
<p>"if you have got a skill that you can develop then it seems to work"</p> <p>"I must say the first 6 months I thought I'm not going to be able to do this and although I'd been a nurse for many, many years, talking to people on the phone was quite scary ... I wasn't 100% confident that I'd be able to do it and hadn't developed enough communication skills to be able to talk to people competently on the phone"</p> <p>"the more experience you get, the better you get at dealing with different situations and hopefully remembering situations that were similar in the past"</p> <p>"One of the things I think we're very good at, hopefully, is, urmm, a lot of people come on the phone either very distressed or quite angry, and although it's a very basic communication skill, it's about bringing that person down to a place where you can have a decent conversation with them, so if you learn that on the phone you can definitely transfer that to a clinical setting where somebody comes at you very angry, and you just learn those kinds of, you know, using tone of voice and slowing your speech down and things like that, that we use a lot of so that you can have a decent conversation with somebody"</p> <p>"Everybody has good days and bad days but everyone deserves a minimum amount, a minimum amount of service, so, even if you're having a stressy day, the person on the end of the phone, or the person that you're</p>	<p>- <i>Competence</i></p>	<p>1 – p.6</p> <p>1 – p.6</p> <p>1 – p.6</p> <p>1 – p.7</p> <p>2 – p.11</p>

<p>having a face to face with, is dealing with you, they have a right to the minimum goodness of you, and that still needs to be really high”</p> <p>“I know for a fact that until I went to, urmm, Tenovus, if somebody had asked me to do interviews, or do presentations, I would’ve run a mile. Ummm, but through, perhaps, the confidence, and the knowledge I’ve gained, urmm, doing this, I would be, I’ve done quite a few interviews for radio, for TV, I do presentations, or I used to do presentations, on, on Prostate, on male cancers, and, urmm, I’ve done sort of GP training days where we’ve talked about, sort of, the man van and what we do, and urmm, give them a bit more awareness of what Prostate Cancer is, you know. So, yes, it has given me confidence in my field of expertise”</p> <p>“learning from the patients, I think that’s such a valuable lesson, urmm, every patient is different, but every patient has, perhaps, tried something different to see if it works ... you learn these little things from other people that you pass on and it, and it helps”</p> <p>“I think confidence just comes with experience of knowing that you can do it”</p> <p>“you will have a call where you think ‘yeah, that was rubbish’, urmm, but again it goes back to being able to reflect on it and saying ‘well, I was rubbish that time but I can be better next time’, and just building that confidence back up, and the next time if it does go better that’s a confidence boost”</p> <p>“if you can make things a little bit better, and they leave, at the end of the call they’re happier than when you first spoke to them”</p> <p>“if something nice has happened I acknowledge that thing, and that I think would be another thing to say to younger people trying to deal with it, if you do something good, don’t shy away from recognising that and taking that on, because that’s brilliant, because you’re going to have enough crap times where things aren’t going to go right, that you’re going to need all of those good times”</p> <p>“they’re the things that will remind you why the job is worth having”</p> <p>“having people around you saying ‘oh, you handled that call really well””</p> <p>“we try and do a lot of, you know, when we’re talking about calls, we try and do a lot of positive reinforcement with people, and if they say it’s rubbish you, you know, I would always say to my team ‘well that bit wasn’t very good, but actually that bit was really good, so, you know, carry on doing that””</p> <p>“when people say little things like ‘I feel a lot better now I’ve spoken to you’, a simple little phrase but it boosts your confidence, that yeah, I’m doing the right thing”</p> <p>“Don’t go blowing your own trumpet, but why not go and tell somebody that somebody said thank you to you for everything that you’ve done. Ummm, I, you know, I</p>		<p>3 – p.7</p> <p>3 – p.7</p> <p>1 – p.8</p> <p>1 – p.8</p> <p>2 – p.8</p> <p>2 – p.10</p> <p>2 – p.10</p> <p>1 – p.8</p> <p>1 – p.8/9</p> <p>1 – p.9</p> <p>2 – p.10</p>
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<p>would do that in my previous job, you know, ‘we’ve had a really crap day today but everybody’s done really well’, or ‘god, that was really good, we’ve worked so well as a team’, because then when the day is bad you can look back on those ones and it just helps a bit”</p> <p>[referring to suicidal client]“ in that case then I phoned a colleague afterwards to discuss it with her to get it, urmm, but that’s the only time I’d say that I felt, it was more feeling upset because I had to put the phone down, rather than the call itself because that’s the only way I feel I could’ve handled it, so ... it’s like supervision really, like ‘what would you have done?’, we discussed it and in fact we realised that this caller had called previously in, urmm, in a very similar, not quite as bad situation, and she has called again since, which makes me feel better [<i>slight laugh</i>], but, yeah”</p> <p>“I just became a bit more Velindre-centric, if you like, did my, started my Masters, did my prescribing and then last year, I was, sort of, doing a bit more management and stuff and wanted a change. So, I’m now out of clinical trials and I’m just a nurse specialist and, urmm, a prescriber for two teams – urology and breast team here”</p> <p>“I think that my experience of working everywhere in the hospital has actually given me the experience of, or a good knowledge of what the patient experiences throughout their whole journey, through the hospital, through their diagnosis, through their treatments, because I know about the treatments they’re having and what experiences they have when they’re actually sat in the treatment unit and that type of thing. So, I can talk, sort of, when I see the patients, I can quite comfortably talk about what’s going to happen when they have their chemotherapy, cos I’ve actually given it”</p> <p>“I’ve worked in all the different places, I think, obviously me being able give information on places where perhaps other nurses haven’t actually worked, haven’t experienced, so they can’t give their personal experience of what will happen too the patients, to what they’re going to go through”</p> <p>“the whole experience that I’ve got is quite an advantage, that I can talk more confidently because I’ve actually done it, seen it and seen all the different roles as well”</p> <p>“the worst things about going into a consultation, sometimes, was the other members of staff who were giving information who were flicking through books and trying to work out what’s going on and I was sort of thinking ‘oh, for goodness sake’. We should know all that, we should come across that we know exactly where we started, what information we’ve got and where we’re going with it before we go in and speak to people”</p> <p>“It’s important that you know what you’re going to be talking about when you’re there, because I think if you lose somebody’s confidence early on, as a clinician you’re going to be in trouble really, urmm, so I think it’s really about being prepared for the clinic ... making sure we’ve got the environment right, we’ve got the information and that we’re prepared for what we’re going to encounter, what we’re going to deal with really”</p>		<p>3 – p.4</p> <p>6 – p.1/2</p> <p>7 – p.2</p> <p>7 – p.4</p> <p>7 – p.4</p> <p>8 – p.4</p> <p>8 – p.4</p>
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<p>“The Advanced Communication course was really good because you had to think of a scenario and then you had an actor and then you had to act out the scenario, and then it was videoed, so they video you and you have a group of your peers and they give you feedback, so that’s really helpful because you don’t ever get the opportunity to actually watch yourself and to hear, sort of, comments, not negative necessarily, but just comments about, you know, it makes you think a little bit more about how you communicate and what you communicate”</p> <p>“So, that was quite important for me because it made me think about the ways we were giving clinical information and whether we should be using more than just the verbal, you know, whether we should be using diagrams and pictures and all the different, sort of, forms of communication, urmm, that people might need”</p>		<p>8 – p.10</p> <p>8 – p.10</p>
<p>“you just need to find what works for you and do it your way ... and take yourself to the job but then get hints and tips and find, everything that other people do, but find what works for you from that”</p> <p>“You learn, oh right, well that worked this time so I’m going to try that next time. So, you are, it’s continuous learning, you know, whether it’s from a book or from a person, it’s, urmm, you know, if you go to a conference regarding anything about Lung Cancer, or anything, you learn from your peers as well, because they know things that you don’t, and you can give them back something”</p> <p>“So, it’s constant, you know, your head is like a sponge really and you try to gather as much, or retain as much knowledge as you’ve been given because you can’t always retain everything”</p> <p>“the more experience you get, the better you get at dealing with different situations and hopefully remembering situations that were similar in the past”</p> <p>“you learn how to sort of gauge the way you talk to people from what you hear, urmm, and you go quietly to start with but then perhaps you, you’re sort of a bit more confident in the best way for people, it is very much about adapting things and being able to respond to the person because not everyone can cope with the same amount of information, or the same way of speaking to them”</p> <p>“in some strange way, if I hadn’t had cancer, I wouldn’t have come here, so I wouldn’t have been able to carry on doing the thing that I ‘it’s not a job, it’s what I am’ kind of thing”</p> <p>“we are constantly learning, for the benefit of the people who call us”</p> <p>“you learn how to, you learn how to sort of gauge the way you talk to people from what you hear”</p> <p>“I’m not too proud to find out and go and read”</p> <p>“the most challenging thing is trying to keep updated with all the technology and new information, the new treatments, we have such a variety of cancer, urmm, and trying to keep up with that knowledge and training,</p>	<p>- <i>Autonomy</i></p>	<p>2 – p.12</p> <p>3 – p.8</p> <p>3 – p.8</p> <p>1 – p.6</p> <p>2 – p.3</p> <p>2 – p.6</p> <p>1 – p.8</p> <p>2 – p.3</p> <p>2 – p.10</p> <p>3 – p.4</p>

<p>especially when there's no training fund available, so, urmm, either you have to self-fund your training or get a lot of, urmm, of the knowledge Google or, you know, research papers, but which again is time consuming, which, urmm, again, takes up a time factor as well"</p> <p>"I just became a bit more Velindre-centric, if you like, did my, started my Masters, did my prescribing and then last year, I was, sort of, doing a bit more management and stuff and wanted a change"</p> <p>"Nursing has changed quite a bit in that we've taken on a lot of roles that were traditionally seen as medical roles, and there's good and bad to that. Ummm, for me it was a way of furthering my education and doing something new"</p> <p>"So, basically I've done every job you can as a nurse in Velindre, I've done it, so, palliative care, chemotherapy, day-case units, research nursing, I suppose the only one I haven't done is outpatient care, but I do, I'm based in outpatient for the trials. So, quite a lot of experience in Velindre anyway"</p> <p>"I started here so long ago that I've just moved around, you know, I did palliative care for a few years decided then to get some experience then with chemotherapy, which is very different"</p> <p>"I'd done about 10 years of ITU and felt that a little bit of that, sort of, burning out, it's sort of quite intense"</p> <p>"Read a lot [<i>laughter</i>], make sure you're, for me reading the protocol quite a lot, checking with the doctors that that is what's happening, especially with new drugs coming along which have new pathways of working, so learning how the drugs work gives you a bit more confidence with learning about the side-effects of the drugs, and what to happen and what to expect from the trial, if you know how the drug works... Yeah, it's a lot of learning again, learning from the doctors, from the trial company themselves, they can actually give you a lot of information, so if there's something in the protocol you're not sure of or if the patient asks you something you're not sure of, you can ask the trial company about what they found, because a lot of the time they've had the same questions as well"</p> <p>"I suppose apart from a general, sort of, communication training in my general nursing training, I have done a couple of communication courses a really long time ago, but I have done a couple. One particularly, for trials communication, because obviously we've got issues around consent, ethics and the GCP and stuff like that"</p> <p>"this post came up, a new post setting up the service basically, then moved over, set up the Upper GI Specialist Nurse, it was just me for a number of years doing this, looking after Pancreatic cancer, Stomach cancer, Soft-tissue cancer and Liver cancer, so that's our remit"</p> <p>"well originally, as I say, I was doing surgery – Colorectal – and then Upper GI because there was a gap here and they needed an upper GI, so I started with small</p>		<p>6 – p.1/2</p> <p>6 – p.2</p> <p>7 – p.1</p> <p>7 – p.1</p> <p>7 – p.2</p> <p>7 – p.5</p> <p>7 – p.7</p> <p>8 – p.1</p> <p>8 – p.2</p>
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<p>surgical, I was employed with surgery, but then there was a gap with Oncology”</p> <p>“We’re now their Specialist Nurse and, sort of, key worker right through their treatment journey, right the way through. So, it gives a better continuity, for us as Nurses and for the patients as well, urmm, and they’ve got direct contact to us at any point across their treatment”</p> <p>“I think for me when I’m thinking about communicating with patients, and we always prepare very well, whether we’re talking to them or over the phone, or when we’re going into clinic, it’s to make sure we’ve got all the information upfront before we go into a consultation, which is very important to make sure that we have a clear plan of action of what we’re gonna do”</p> <p>“As I was saying, it’s important that you know what you’re going to be talking about when you’re there, because I think if you lose somebody’s confidence early on, as a clinician you’re going to be in trouble really. Ummm, so I think it’s really about being prepared for the clinic, the environment is very important to me, I’ve had a lot of problems over the years with clinics that weren’t particularly suitable for the types of consultation I was trying to have, so I’ve actually, I’ve identified that and I’ve moved clinic rooms now, because the last thing you want is to have a lot of noise or have people laughing outside the clinic room, or just other things going on when you’re telling somebody some bad news or you’re relaying a treatment plan where people are likely to be upset and distressed. You know, I know life goes on in those clinic rooms but we have to be aware of those sorts of things, making sure we’ve got the environment right, we’ve got the information and that we’re prepared for what we’re going to encounter, what we’re going to deal with really”</p> <p>“When you delve a bit, especially with people’s symptoms you tend to find, in your mind you’re thinking one thing but you mustn’t make assumptions, you’ve really got to go back to the person and get a clear history or a clear idea of exactly what is going on before you make a decision, because you can make a wrong decision, you can bring somebody into hospital that doesn’t need to be there, or you can leave somebody at home that needs to be here. So, it’s really important that you listen, I, and that you ask the right questions”</p> <p>“Self-care, we go to Tai Chi classes, we do Tai Chi here in the hospital on a Thursday morning before work. Ummm, we’re good at, you know, the pace of the work during the day, some days become really mad and hectic, but we’re very good at having a cup of tea, taking 5 minutes out, we always have a lunch break, I say always, don’t always quite make it, but most days we have a lunch break, we go and we have lunch with other people, we sit down, we have the opportunity to talk, it’s not a very long lunch break but again going without food and drink and all those things, it affects you”</p> <p>“I try now to prepare for the clinic, whereas before I might not have had the opportunity to do that because I was on my own, now I look at the list and I prepare, so</p>		<p>8 – p.2</p> <p>8 – p.4</p> <p>8 – p.4</p> <p>8 – p.5</p> <p>8 – p.7</p> <p>8 – p.9</p>
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<p>I think ‘ooh, have I got anything difficult there?’, so that I can, I think that preparation is important”</p> <p>“Yeah, urmm, one of them was called ‘Know Your Own Mind’ and the other one was called ‘Living in Alignment’. That was really good for me actually the ‘Living in Alignment’ because that looked at all your, sort of, core values and working within your core values, and that really helped me because I realised I was shifted, you know, what I was doing was away from them and I needed to pull back and that was purely of trying to manage a service on my own really. Ummm, so, that we did and I’ve done communication courses and things like that with MacMillan, so, I’ve done Advanced Communication, Motivational Interviewing, urmm, Managing Your Impact, so, a number of, sort of, different day things”</p>		8 – p.9
<p>[referring to colleagues/herself] “they can talk to somebody, even somebody to bounce off, that understands what you’re going through”</p> <p>“you have got a professional relationship but there’s nothing wrong with that gentleness that you use when you talk to your friends, to talk to somebody on the phone”</p> <p>“you always let people know how it’s been and that, that makes it easier”</p> <p>[referring to own cancer] “I think it’s helped me in my role, not so much in my knowledge of different cancers, because, you know, it’s more about the patient experience than anything else”</p> <p>“We talk to each other if we’ve had difficult days because there’s only so much your family can understand about what you go through, unless they’re working in it as well. So, talking to each other does help, urmm, because everyone has good and bad days so you do know what it’s like, so I think yeah we do support each other quite well, yeah”</p> <p>[referring to other nurses] “it’s just looking out for each other”</p> <p>“we’ve got a really good peer-group support around us as well so, you know, you can bounce ideas off, or, urmm, if you are dealing with someone who’s quite tricky or there’s quite a lot of emotional needs or whatever, we’ve got people we can talk to about what to do and stuff”</p> <p>“When I first started I had a line manager at the time who worked in cancer herself and so that was very supportive to have somebody I could go to but then she moved on and after that I had management support which wasn’t, they weren’t working in cancer care so didn’t really understand the impact on the job and the impact of needing some type of clinical supervision really. So, over time I have had clinical supervision, I went and sought that out myself because at that time I was struggling and needed it”</p> <p>“We’re very good as team, as I said there’s 3 of us in the team now, at looking at self-care and obviously we’re MacMillan funded now, so we do a lot of MacMillan courses with them where we go off on these days and it’s</p>	<p>- <i>Relatedness</i></p>	<p>1 – p.5/6</p> <p>1 – p.9</p> <p>2 – p.9</p> <p>3 – p.3</p> <p>6 – p.5</p> <p>6 – p.6</p> <p>7 – p.5</p> <p>8 – p.6</p> <p>8 – p.6</p>

<p>all about supporting ourselves and looking after ourselves”</p> <p>“There is very much a culture now of well-being in the workplace, it’s there but, and as I say for me because I’ve had 6 line managers since I’ve been in post, and for me because my line managers don’t work in the same field, don’t understand, I don’t feel like if I’m having a bad day I can just knock on their door, like I used to be able to with my previous line manager, and say ‘look, this has happened to me today’, and she’d say ‘come in, sit down and let’s talk about this’. It’s having that support system isn’t it? And I think as a team we’ve got that, we work, we spend a lot of time reflecting, analysing, thinking about what we’re doing, and talking it through, but when I worked on my own it was extremely difficult, and I got to an extremely difficult - to a bad place, in all honesty, where I literally went and sought the supervision myself”</p> <p>“I am a great believer in, I think these things that are, sort of, group supervisions, groups where people get together, are necessary for health professionals but again, it’s not happening, it’s not happening as it should. Ummm, so I think in the future these sorts of things should be compulsory. I’m not saying you have to go every week or every month but every couple of months just to check-in with your peers and just be able to say ‘such and such happened to me the other week’ or if it’s a difficult case, and they might say ‘oh, yes I’ve had that happen or I had similar happen’. Sharing the experiences, because if you don’t share the experiences with people how do you learn really”</p> <p>“We’ve got a very good clinical team, so we’ve got a really good consultant team and they’re very good for, in fact when I was lacking in nursing support, they were the people I could talk to and run by problems and if there were issues in the working day. So, I think it’s really important to talk to people, I think it’s really important to say how you’re feeling, to be able to say if you’re having a bad day, to be upset if something’s upset you”</p> <p>“it’s important to talk in work because you cannot take this work home with you, you can’t take this home and talk to your family members and relatives and talk to them about it, you can’t do that”</p>		<p>8 – p.6</p> <p>8 – p.7</p> <p>8 – p.7</p> <p>8 – p.9</p>
<p>[referring to support-line] “I found that actually I had time to talk [<i>emphasis on talk</i>] to patients which on a ward you don’t get time to”</p> <p>[referring to Tenovus] “they needed somebody on the welcome desk, they needed somebody to volunteer and at that time I was extraordinarily low, very depressed and about this big [<i>holds fingers up and apart</i>] - that’s about an inch for the transcript – because, ummm, I literally lost everything – you’ve asked the question how did I get here – everything, my whole self, I didn’t know who I was anymore. Ummm, so, I volunteered to be that welcome desk person and very slowly I realised that that let me get back to having a purpose, helping people again, doing something useful, which is all I’ve ever wanted to do, doing something useful”</p> <p>“I developed Breast Cancer about 12 years ago, ummm, and I was, I actually was retired from the NHS because of my illness, because I didn’t think I would be fit</p>	<p>- <i>Needs Satisfaction</i></p>	<p>1 – p.2</p> <p>2 – p.2</p> <p>3 – p.2</p>

<p>enough to go back to work. So, of course, once you retire you get better somehow, and after a little while I felt that I needed to go back to work, so, I looked for another post, because I couldn't go back to the NHS within a certain limit of time, urmm, and a job came up with Tenovus and I applied for and I got the job"</p> <p>"For us as clinicians, we've got maybe a 20 minute clinic slot, we've got certain things that we need to address, so it's getting a balance of, I suppose the thing is, having a consultation where the patient feels that their needs are being met and that it's all about them but also us making sure our agenda is put across, whatever that is, you know, explaining this procedure or telling them about this report, so it's making sure we've got the two happening alongside really"</p>		8 – p.10
<p>"I think my first 6 months on the job was a massive learning curve and all I thought I knew about cancer after 5 years in Velindre was nothing [<i>slight laugh</i>]"</p> <p>"the more experience you get, the better you get at dealing with different situations and hopefully remembering situations that were similar in the past"</p> <p>"you have to be really good at, I've got this, I've got now, after 30 years, that if somebody, generally if I can see somebody and they tell me they're fine I know when that's an absolute load of rubbish because I can see it"</p> <p>"you can hear things in their voices ... you learn how to sort of gauge the way you talk to people from what you hear, urmm, and you go quietly to start with but then perhaps you, you're sort of a bit more confident in the best way for people"</p> <p>"Experience really, but be yourself, admit if you don't know what they're talking about, try and reassure them that you will go and find out for them, from a responsible source"</p> <p>"perhaps, from experience from, urmm, my ward days, because once you walked in you didn't have time to have, urmm, those, sort of, negative, you know, it was right ok"</p> <p>"I suppose it's the same as an actor, it's like people acting, it just, urmm, it just develops over years"</p> <p>"in general nursing as the guys you were seen as gay, nothing wrong with that, it's fine, you know, but that was always the perception and that outside perception is, sort of, coming into nursing as well so you've got, you know, sort of, be who you are"</p> <p>"it takes a long time to learn as well, because it is a learning process and you will get on better with some people than others, urmm, but it's more in the boundaries and realising your own boundaries, and the patient's boundaries, and managing their expectations"</p> <p>"Very important because of my inadequacies, any one in my career, but recognising that, and facing it and doing something about it, rather than cowering away in your inadequacies and making an arse out of the whole thing"</p> <p>"There's difficult questions, I've felt, urmm, so I've experienced that, and realised I wasn't being fair in my</p>	<p><i>Increased Confidence through Experience</i></p>	<p>1 – p.6</p> <p>1 – p.6</p> <p>2 – p.2</p> <p>2 – p.3</p> <p>2 – p.4</p> <p>3 – p.7</p> <p>3 – p.7</p> <p>4 – p.4</p> <p>4 – p.5</p> <p>4 – p.8</p> <p>4 – p.8</p>

<p>nursing care and, you know, did something about it, and took it head on and tried to get help”</p>		
<p>“I think the confidence takes, it takes experience, and it takes both a, urmm, the academic side of it plus the art, and I think it’s a combination of the art of nursing and the academia side of it, I was trained, but after that I got educated”</p>		4 – p.10
<p>“We learned by task”</p>		4 – p.10
<p>“it is an art but it’s learning as well, because you learnt these situations before and now you’re drawing on all those experiences, they may not be the same experiences but they’re very similar experiences”</p>		4 – p.10
<p>“I had lots of experience, like I said, nearly 20 years of experience talking to cancer patients, I didn’t have problems on the level of talking”</p>		5 – p.3
<p>“I had seen people from lots of walks of life, so seeing lots of different reactions, so that wasn’t a problem for me in terms of the emotion of the client, it was more a sort of an academic learning to make sure that what I was telling these clients was accurate”</p>		5 – p.3
<p>[referring to communication challenges]</p>		
<p>“I think it changes as you get more experienced probably, I think you did always have some patients that are more difficult to communicate with than others, but as you get more confident, I suppose you get a bit more used to trying to get people to talk and getting more out of them”</p>		6 – p.3
<p>“It’s really nerve-wracking when you don’t know. It’s probably just age as well, the older you get, it does get easier, but yeah, it’s harder when you’re in a new situation and you’re not quite sure how to say it or is this the right thing to say, what if I upset somebody. There’s all those kinds of things that when you’ve, sort of, done it more often it gets a little bit easier to do”</p>		6 – p.4
<p>“I think because, as you noted earlier, I’ve worked in all the different places, I think, obviously me being able give information on places where perhaps other nurses haven’t actually worked, haven’t experienced, so they can’t give their personal experience of what will happen to the patients, to what they’re going to go through. I think that comes with time as well, because obviously, if we have, if there’s a member of staff who’s not quite as confident and that, then perhaps actually they could spend a day over there, looking and seeing how that works out. But, yeah, I think it, the whole experience that I’ve got is quite an advantage, that I can talk more confidently because I’ve actually done it, seen it and seen all the different roles as well”</p>		7 – p.4
<p>“I thought ok oncology, I can do this, and started working and thought why haven’t I done this years before”</p>		1 – p.1
<p>“I must say the first 6 months I thought I’m not going to be able to do this ... I wasn’t 100% confident that I’d be able to do it and hadn’t developed enough communication skills to be able to talk to people competently on the phone”</p>		1 – p.6

<p>“the more experience you get, the better you get at dealing with different situations and hopefully remembering situations that were similar in the past”</p> <p>“I think confidence just comes with experience of knowing that you can do it”</p> <p>“your confidence will always get knocked ... it goes back to being able to reflect on it and saying ‘well, I was rubbish that time but I can be better next time’, and just building that confidence back up, and the next time if it does go better that’s a confidence boost”</p> <p>“when people say little things like ‘I feel a lot better now I’ve spoken to you’, a simple little phrase but it boosts your confidence, that yeah, I’m doing the right thing”</p> <p>“the thing is that I think with my past experience as well, you have to be really good at, I’ve got this, I’ve got now, after 30 years, that if somebody, generally if I can see somebody and they tell me they’re fine I know when that’s an absolute load of rubbish because I can see it, I can read people really, really well”</p> <p>“I’ve come out of an acute, sort of, crisis led environment, I think that has been invaluable to everything that I’ve done, and I’m a big mouth and I’m not frightened to say things, so, urmm, yeah, I, I’m very rarely lost for words [<i>slight laugh</i>]. And I listen, I’m just very rarely lost for words”</p> <p>“if I’m confident enough to give them a straight answer I will, if I don’t know I’ll just say ‘I’m sorry this isn’t my field, I recommend you to contact, you know, your team in the hospital, or you need to go to A&E if it’s urgent””</p> <p>“I think another thing is getting the level of, urmm, of how you speak to people at different levels, you know, urmm, I think that’s, but mainly it’s the communication skills and how to perhaps calm a person down, how to, urmm, not, not, but rationale perhaps bad news that they’ve been givens, so, or interpret the medical jargon that they have, ‘well, what does it mean?’, and this, I can relate that in a simpler form perhaps to some people”</p> <p>“I have found in my role with the support-line, urmm, the medical part of it is dealt in the hospital, so, you know, I can give a little advice on the side-effects and I can give advice on what I’m confident on giving advice which is general side-effects of chemotherapy or all of that knowledge that I’ve got, but I wouldn’t dream of giving them medical advice, I would automatically push them back to the team in the hospital. So, that takes away some of the worry, so, that gives you the confidence”</p> <p>“Patients often will respond differently to a nurse than they do a Doctor. I’m usually in uniform but today I do telephone clinic on a Wednesday, so, I’m not in uniform today. As soon as they see that uniform it is a different response, some patients are ‘oh, why aren’t I seeing the Doctor today?’, but as soon as you’ve built that rapport with people they are willing to give you that bit more insight into what’s important to them”</p>		<p>1 – p.6</p> <p>1 – p.8</p> <p>1 – p.8</p> <p>1 – p.9</p> <p>2 – p.3</p> <p>2 – p.10</p> <p>3 – p.3</p> <p>3 – p.5</p> <p>3 – p.6</p> <p>6 – p.2</p>
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<p>“In some respects I’ve lost a lot of my clinical skills by doing, urmm, trials, at least I’m still up to date and aware of the new treatments and the process of what happens on the ward, what happens to the patients when they actually go through the ward, and I think that my experience of working everywhere in the hospital has actually given me the experience of, or a good knowledge of what the patient experiences throughout their whole journey, through the hospital, through their diagnosis, through their treatments, because I know about the treatments they’re having and what experiences they have when they’re actually sat in the treatment unit and that type of thing. So, I can talk, sort of, when I see the patients, I can quite comfortably talk about what’s going to happen when they have their chemotherapy, cos I’ve actually given it”</p>		7 – p.2
<p>“I’ve worked in all the different places, I think, obviously me being able give information on places where perhaps other nurses haven’t actually worked, haven’t experienced, so they can’t give their personal experience of what will happen too the patients, to what they’re going to go through”</p>		7 – p.4
<p>“the whole experience that I’ve got is quite an advantage, that I can talk more confidently because I’ve actually done it, seen it and seen all the different roles as well”</p>		7 – p.4
<p>“we have to treat them quite sensitively and I think having the confidence to, urmm, to say to a patient ‘well, this is what is expected of you, you don’t have to come in, you don’t have to take part in the trial but if you are taking part then we do need to see you because it could be for your own safety’, you have to have quite a bit of confidence to say that with some patients”</p>		7 – p.6
<p>“I think that there is a very big difference in the way patients communicate with nurses as they do with doctors as well, I think they tell us a bit more ... I think from my point of view it’s because I see them more often than the doctors do, cos it’s a nurse-led clinic and I’m the one who sees them on regular basis, you know, if they’re on chemo on three-weekly basis, even in-between they have my number and they can ring me, so I suppose it’s, urmm, I don’t know, and they don’t see the doctors that often, unless there’s a real problem we can’t deal with”</p>		7 – p.8
<p>“this post came up, a new post setting up the service basically, then moved over, set up the Upper GI Specialist Nurse, it was just me for a number of years doing this, looking after Pancreatic cancer, Stomach cancer, Soft-tissue cancer and Liver cancer”</p>		8 – p.1
<p>“I’m pretty good, I try to, sort of, compartmentalise things, so if I’ve had something happen in the office, I’ve got this, this is my stress ball [<i>slight laugh</i>]. So, you know, if I’m, but I try to talk myself down if I’m going to a clinic or I’m going to meet a patient, for instance, and one of my common phrases in my head is ‘in the scheme of things’, that’s one they laugh at me now, because in our world in the scheme of things, small things are trivial things because what we are dealing with is life and death, people dying. So, we, sort of, I talk myself down a bit in a, you know, actually that’s really frustrating but I suspect it will sort itself out, I just</p>		8 – p.8

<p>need to let that go now and move onto the next thing, and I'm quite good at doing that"</p> <p>"very often you get people who you might never be able to develop that relationship with and sometimes you've got to accept that you're just not the right person to for them to talk to"</p> <p>"something you don't know much about, urmm, your listening skills go out the window for a start, because you're too busy thinking 'how am I going to do this? I really don't know what to do'"</p> <p>"if there's somebody else in the team that we know is far more skilled then we will always say 'look my skills are limited but I do know somebody who could probably answer all these questions without even thinking about it', and that comes down to confidence"</p> <p>"it's very honest to say 'I really don't know, you're talking about something now that I have no experience of, but I know a person who does', and I think that gives them more confidence in the service, as well, that they're saying 'Ok, well I can ring them and if they don't know, they will be truthful'"</p> <p>[referring to patients] "you just have to follow their lead really and not be afraid to say the words that most people are too scared to discuss, you have to talk about death and funerals and things like that and ask questions and just not be afraid to take that extra step, and I think my previous experience probably helps me with that"</p> <p>[referring to own cancer diagnosis] "I wasn't the least bit surprised really, because something had caused that, it wasn't normal, so, for me for somebody to say 'actually you've got cancer', that wasn't too much of a problem, and then when I had all my planning and I spoke to my consultant, he said 'well, I'm confident that I can cure you', not a problem"</p> <p>[referring to patients] "they're having confidence in you, so, you need to have confidence in yourself"</p> <p>"it's getting information off them so you can give information back, it's getting the facts ... one of the most important things is we haven't got any medical, urmm, any medical details at all, we've only got what the patient is telling us, so we've got to give that, the feedback on what you're having"</p> <p>"I think it changes as you get more experienced probably, I think you did always have some patients that are more difficult to communicate with than others, but as you get more confident, I suppose you get a bit more used to trying to get people to talk and getting more out of them"</p> <p>"I think just learning to be brave enough to ask the questions like 'what's important to you?', that kind of question, and that's quite hard to ask sometimes, but, you know, it's crucial that we do ask that, at appropriate times"</p> <p>"It's really nerve-wracking when you don't know. It's probably just age as well, the older you get, it does get easier, but yeah, it's harder when you're in a new</p>		<p>1 – p.4</p> <p>1 – p.8</p> <p>1 – p.8</p> <p>1 – p.8</p> <p>2 – p.3</p> <p>2 – p.6</p> <p>2 – p.11</p> <p>3 – p.4/5</p> <p>6 – p.3</p> <p>6 – p.3</p> <p>6 – p.4</p>
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<p>situation and you're not quite sure how to say it or is this the right thing to say, what if I upset somebody. There's all those kinds of things that when you've, sort of, done it more often it gets a little bit easier to do"</p> <p>"there's a lot of emotional needs as well that our patients have when they come and see us for the first time and again when they're trying to make decisions as well, when they've got a decision, you know, they need to make decisions, so giving them a lot of information about what happens if I don't go into a trial, what happens if I do"</p> <p>"There's definitely days where you feel less confident, yes. I mean, especially if you have dealt with very tricky patients which on reflection could've gone better or perhaps you didn't make quite the right decision or the best decision for the patient at the time. I think it does knock your confidence a little bit"</p> <p>"So, we tend to build up a relationship, not just with the patient but with their families because they're waiting. With our staging process sometimes it can go on for quite a number of weeks, so families then are very anxious because they're a little bit in limbo and they're not sure what's coming next and so we get a lot of calls from family members, you know, questions really about what's going to happen next, who are they going to see next and when are we going to know about this, and, cos obviously people are trying to plan their lives and things around it. It's not just about the cancer care it's about life, work, holidays that they've booked, family weddings, urmm, all the things that life involves, trying to fit that in to suddenly having this devastating diagnosis and a treatment of, we're talking months and months and months, you know, for some people it's going to be sorted in a week or 2, a lot of them can go on for months, years, you know, and it's really difficult for people to manage. So, they tend to build up that relationship with us and everybody's very different, we'll have people who'll ring us every day, we'll have people who maybe have 1 or 2 contacts and then won't need our contact again, so it's very individual, urmm, as to the sort of access that people need, or the things that people need from us really, but they know we are here if they want us, if they need us"</p> <p>"I think for me when I'm thinking about communicating with patients, and we always prepare very well, whether we're talking to them or over the phone, or when we're going into clinic, it's to make sure we've got all the information upfront before we go into a consultation, which is very important to make sure that we have a clear plan of action of what we're gonna do, sometimes that means not answering all the questions, it just means that actually we've got to this and we've got to do that, but it's being clear about what we're going to do and not have unanswered questions in our head. I think the worst thing, and as I say I've been in nursing for many, many years and I've worked a lot on the wards, and the worst things about going into a consultation, sometimes, was the other members of staff who were giving information who were flicking through books and trying to work out what's going on and I was sort of thinking 'oh, for goodness sake'. We should know all that, we should come across that we know exactly where we</p>		<p>7 – p.3</p> <p>7 – p.5</p> <p>8 – p.2/3</p> <p>8 – p.4</p>
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<p>started, what information we've got and where we're going with it before we go in and speak to people"</p> <p>"It's important that you know what you're going to be talking about when you're there, because I think if you lose somebody's confidence early on, as a clinician you're going to be in trouble really, urmm, so I think it's really about being prepared for the clinic"</p> <p>"If you don't look after yourself then how can you look after other people, you can't function at you're best if you don't look after yourself"</p> <p>"So, it's all about learning about you [<i>emphasis on you</i>] as a person and, you know, being quite self-aware of what you can do and then developing that"</p> <p>"I think I'm pretty much a glass half-full kind of person, urmm, I think that's because, urmm, I was born wonky, it's not stopped me doing the job I wanted to do"</p> <p>"I wanted to work and I wanted to get into it, so, I've always, I've always done things despite what probably was a disability for the whole of my life, so, I've never let, I've always found a way around things, I've never let things stop me, and that's the way I've always been"</p> <p>"I've been through some quite traumatic things in my life but I've always managed to pull myself out of them and always managed to make the best out of the situation and I think that's just me, I always, I'm disabled but I'm not- that doesn't define me"</p> <p>"I think, it's just a lot to do with your attitude as well, it's not panicking, not reacting to them, just, sort of, try and calm things down, be reassuring, and I'd say just put their minds at rest that this is, you know, it's a lot of information giving basically"</p> <p>"I'm pretty good, I try to, sort of, compartmentalise things, so if I've had something happen in the office, I've got this, this is my stress ball [<i>slight laugh</i>]. So, you know, if I'm, but I try to talk myself down if I'm going to a clinic or I'm going to meet a patient, for instance, and one of my common phrases in my head is 'in the scheme of things', that's one they laugh at me now, because in our world in the scheme of things, small things are trivial things because what we are dealing with is life and death, people dying. So, we, sort of, I talk myself down a bit in a, you know, actually that's really frustrating but I suspect it will sort itself out, I just need to let that go now and move onto the next thing, and I'm quite good at doing that"</p> <p>"So, there's lots of little bits and pieces to keep your confidence levels up but without being, tipping over into arrogance, which is different, because if you're arrogant, then you're confident about, but you don't exactly, how can I put this? If you're arrogant about it you're not going to want to learn any more because you then think I can do this"</p> <p>"I think, as I said, I am quite confident, but I try not be arrogant because I don't know it all, and I'm quite happy and secure in myself to be able to say 'I'm not sure, I'll find out for you'"</p>		<p>8 – p.4</p> <p>8 – p.7/8</p> <p>1 – p.9</p> <p>2 – p.7</p> <p>2 – p.7</p> <p>2 – p.7</p> <p>7 – p.3</p> <p>8 – p.8</p> <p>1 – p.9</p> <p>2 – p.10</p>
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<p>“even if you’re not completely confident in it, provided you’re not bullshitting it, providing you’re not arrogant and thinking you know it all, provided you have the ability to say ‘I will go and find out if I don’t know things’”</p>		2 – p.11
	<p><i>Facilitators and Barriers of Perceived Competence and Self-Efficacy</i></p>	
	<p><i>Facilitators</i></p>	
<p>“Everybody has good days and bad days but everyone deserves a minimum amount, a minimum amount of service, so, even if you’re having a stressy day, the person on the end of the phone, or the person that you’re having a face to face with, is dealing with you, they have a right to the minimum goodness of you, and that still needs to be really high. So, it doesn’t matter what shit you’re going through, you have to park that”</p> <p>“everyone has good and bad days so you do know what it’s like, so I think yeah we do support each other quite well, yeah”</p> <p>“some nights you can just be up all night worrying about patients and families”</p> <p>“you definitely don’t feel confident all the time, I think especially when it’s really busy in clinic you can feel really under pressure and you don’t feel as if you’re giving people the time that they need and then that can make you feel stressed and then you’re not as good at communicating”</p> <p>“I’d done about 10 years of ICU and felt that a little bit of that, sort of, burning out, it’s sort of quite intense”</p> <p>“I think it really is important and we haven’t got enough of it, we haven’t got enough support from our employees, certainly here, because I think it’s underestimated the impact of the role and the impact of giving bad news and the impact that has on us, but if you work as a clinical psychiatrist or a clinical psychologist you have your own counselling sessions, I’m sure you’re aware of that. We don’t get anything, we don’t get anything, there’s no structured supervision, if you want it you’ve got to go and find it”</p> <p>“So, we’ve got a really good consultant team and they’re very good for, in fact when I was lacking in nursing support, they were the people I could talk to and run by problems and if there were issues in the working day. So, I think it’s really important to talk to people, I think it’s really important to say how you’re feeling, to be able to say if you’re having a bad day, to be upset if something’s upset you, you know, we spend a lot of time with people and prognosis for our cancer is bad, I’ve had patients die, so, you’ve built a relationship who is ultimately, a few months down the road or who 6 months down the line is going to die. That has an impact so it’s, sort of, dealing with that and knowing how to deal with it and looking after yourself really”</p> <p>“if you don’t look after yourself then how can you look after other people. You can’t function at you’re best if you don’t look after yourself”</p>	<p><i>Importance of Coping</i></p>	<p>2 – p.11</p> <p>6 – p.5</p> <p>6 – p.5</p> <p>6 – p.6</p> <p>7 – p.2</p> <p>8 – p.6</p> <p>8 – p.7</p> <p>8 – p.7/8</p>

<p>So, I think it's about being sensible really and trying to clock off when it's your time to clock off, and again when I was on my own I didn't do that because the workload was so busy I couldn't get out of the door a lot of the time and then you felt like you were letting people down, so you stayed an extra hour or extra 2 hours, and it's very easy then to clock up a working week and I suspect that's very normal in the NHS, to clock up a working week that's, you know, above what you should be doing"</p> <p>"I coped but it was hard going and, urmm, it, some days it would cause me to feel very, at the end of the day, very tired, and not able really to do anything other than work, because by the time I got home from work, there was no energy left for anything else. So, it used to just, it took over my life a bit really, to be honest with you, I mean a job like this will take over your life, there's no getting away from it, but it completely took over my life because there wasn't, there was no energy left really, or very little energy left to give to anything outside work, urmm, and I think when you get to that point you are reaching a bit of a crisis. I don't think anyone should have to work like that, where they've got nothing to give, you know, to their family and relationships and that can start cause a real problem as well. It can lead to burnout, compassion fatigue, all those sorts of things that we hear"</p>		<p>8 – p.8</p> <p>8 – p.9</p>
<p>"I come from a family of singers, urmm, so, I love to sing and I was determined that if I wasn't going to be able to nurse then I was damn well going to sing"</p> <p>"I suppose outside of work, urmm, yeah just exercise is quite good [<i>slight laugh</i>], it kind of gets my head straight and I can just, yeah, just switch off a bit and that does make my head feel better"</p> <p>"We have huge challenges really, because the information that we're giving is difficult information, it's complex information, it's life-changing information, it's distressing information. Urmm, so I think for me when I'm thinking about communicating with patients, and we always prepare very well, whether we're talking to them or over the phone, or when we're going into clinic, it's to make sure we've got all the information upfront before we go into a consultation, which is very important to make sure that we have a clear plan of action of what we're gonna do"</p> <p>"We're very good as team, as I said there's 3 of us in the team now, at looking at self-care and obviously we're MacMillan funded now, so we do a lot of MacMillan courses with them where we go off on these days and it's all about supporting ourselves and looking after ourselves"</p> <p>"Self-care, we go to Tai Chi classes, we do Tai Chi here in the hospital on a Thursday morning before work. Urmm, we're good at, you know, the pace of the work during the day, some days become really mad and hectic, but we're very good at having a cup of tea, taking 5 minutes out, we always have a lunch break. I say always, we don't always quite make it, but most days we have a lunch break, we go and we have lunch with other people, we sit down, we have the opportunity to talk, it's not a very long lunch break but again going</p>	<p><i>Adaptive</i></p>	<p>2 – p.2</p> <p>6 – p.5</p> <p>8 – p.4</p> <p>8 – p.6</p> <p>8 – p.7</p>

without food and drink and all those things, it affects you”		
<p>“a lot of people have asked me ‘well, how do you cope with it?’, and I honestly don’t know [<i>slight laugh</i>]”</p> <p>“We’re quite into self-care and that really, urmm, here. I’m not saying I’m the best at doing it because over the years I have put other people before myself and then the work’s suffered a bit for it”</p>	<i>Maladaptive</i>	<p>1 – p.5</p> <p>8 – p.8</p>
<p>“they find themselves coping mechanisms that suit them, some people still exercise, you know, they use a lot of variety of different – or just rely heavily on family and friends, or some people just become more insular and they find that’s their way of coping with it”</p> <p>“it’s just amazing to see how different as human beings we all are and the way, there isn’t one size that fits all when it comes to what’s right for somebody”</p> <p>“You’ve got to be aware of, you know, different personalities and how they’ll deal with it”</p> <p>“it’s working with what you’ve got to be the best that you can with the style that you use, you know, if you listen, there’s 4 of us on the support-line and we’re all very different in the way we approach things but we all get the job done in a different way. And it’s accepting that you can’t be what you’re not, you know, you can learn – yes, you can learn some skills but you’re still going to use them in a way that’s right for you. You know, some people are very loud when they talk, urmm, I’m much more, I’m much quieter when I speak, urmm, and there’s nothing wrong with either, it’s just whatever suits”</p> <p>“So, it’s all about learning about you [<i>emphasis on you</i>] as a person and, you know, being quite self-aware of what you can do and then developing that”</p>	<i>Individualised</i>	<p>1 – p.2</p> <p>1 – p.2</p> <p>1 – p.2</p> <p>1 – p.9</p> <p>1 – p.9</p>
<p>“having people around you saying ‘oh, you handled that call really well”</p> <p>“we try and do a lot of positive reinforcement with people”</p> <p>“I would always say to my team ‘well that bit wasn’t very good, but actually that bit was really good, so, you know, carry on doing that”</p> <p>“also, when people say little things like ‘I feel a lot better now I’ve spoken to you’, a simple little phrase but it boosts your confidence”</p> <p>“I always try and put things in my happy bank”</p> <p>“nurses are quite bad at recognising when they’ve done something good, I’ve found, as a ward nurse. So, if something nice has happened I acknowledge that thing”</p> <p>“if you do something good, don’t shy away from recognising that and taking that on, because that’s brilliant, because you’re going to have enough crap times where things aren’t going to go right, that you’re going to need all those good times”</p> <p>“they’re the things that will remind you why the job is worth having”</p>	<i>Positive Environment</i>	<p>1 – p.8</p> <p>1 – p.8</p> <p>1 – p.8</p> <p>1 – p.9</p> <p>2 – p.10</p> <p>2 – p.10</p> <p>2 – p.10</p> <p>2 – p.10</p>

<p>“I would do that in my previous job, you know, ‘we’ve had a really crap day today but everybody’s done really well’, or ‘god that was really good, we’ve worked so well as a team’”</p>		2 – p.10
<p>“when I first started I had a line manager at the time who worked in cancer herself and so that was very supportive to have somebody I could go to but then she moved on and after that I had management support which wasn’t, they weren’t working in cancer care so didn’t really understand the impact on the job and the impact of needing some type of clinical supervision really”</p>		8 – p.6
<p>“It’s having that support system isn’t it? And I think as a team we’ve got that, we work, we spend a lot of time reflecting, analysing, thinking about what we’re doing, and talking it through, but when I worked on my own it was extremely difficult”</p>		8 – p.6
<p>“over the phone, because that’s what we were there to do, we could give as much time as we wanted to each individual, and it really helps, it helps you and it helps them, I hope! [<i>slight laugh</i>]”</p>		1 – p.2
<p>“it’s also having people around you saying ‘oh, you handled that call really well’, and we try and do a lot of, you know, when we’re talking about calls, we try and do a lot of positive reinforcement with people, and if they say it’s rubbish you, you know, I would always say to my team ‘well that bit wasn’t very good, but actually that bit was really good, so, you know, carry on doing that’”</p>		1 – p.8-9
<p>“it’s trying to get some positive reinforcement from them, but also when people say little things like ‘I feel a lot better now I’ve spoken to you’, a simple little phrase but it boosts your confidence, that yeah, I’m doing the right thing”</p>		1 – p.9
<p>“I’ve always worked with giving the, ‘right, let me just give you the benefit of my experience and see if that’s any good for you’, and I’ve always done that, so, I’ve always brought into people”</p>		2 – p.8
<p>“if you can make things a little bit better, and they leave, at the end of the call, they’re happier than when you first spoke to them”</p>		2 – p.8
<p>“Don’t go blowing your own trumpet, but why not go and tell somebody that somebody said thank you to you for everything that you’ve done. Ummm, I, you know, I would do that in my previous job, you know, ‘we’ve had a really crap day today but everybody’s done really well’, or ‘god, that was really good, we’ve worked so well as a team’, because then when the day is bad you can look back those ones and it just helps a bit”</p>		2 – p.10
<p>“I’ve come out of an acute, sort of, crisis led environment, I think that has been invaluable to everything that I’ve done, and I’m a big mouth and I’m not frightened to say things, so, ummm, yeah, I, I’m very rarely lost for words [<i>slight laugh</i>]. And I listen, I’m just very rarely lost for words”</p>		2 – p.10
<p>“I know for a fact that until I went to, ummm, Tenovus, if somebody had asked me to do interviews, or do</p>		3 – p.7

<p>presentations, I would've run a mile. Ummm, but through, perhaps, the confidence, and the knowledge I've gained, urmm, doing this, I would be, I've done quite a few interviews for radio, for TV, I do presentations, or I used to do presentations, on, on Prostate, on male cancers, and, urmm, I've done sort of GP training days where we've talked about, sort of, the man van and what we do, and urmm, give them a bit more awareness of what Prostate Cancer is, you know. So, yes, it has given me confidence in my field of expertise”</p> <p>“we've done quite a few communications courses ... and did a lot communication skills courses within nursing”</p> <p>“Different areas of nursing, one was to do with clinical trials, so it's all about talking to people in different ways”</p> <p>“So, mine has come with, basically, too many years of experience of dealing with people, as I said, in distress. I've not done any communication courses, urmm, I did do a counselling course many, many years ago but I couldn't say 'and how does that make you feel?' with any kind of sincerity because I can see it written on people, I can hear it in their voices, so, I was a bit crap at that, I'll leave that to the counsellors”</p> <p>“it's a learning experience, because, you know, if anybody ever tells you they don't need to learn anything else, they're fooling themselves [<i>slight laugh</i>]”</p> <p>“So, you learn how to, you learn how to sort of gauge the way you talk to people from what you hear, urmm, and you go quietly to start with but then perhaps you, you're sort of a bit more confident in the best way for people. It is very much about adapting things and being able to respond to the person because not everyone can cope with the same amount of information, or the same way of speaking to them”</p> <p>“I think my cancer, having been a patient has helped me greatly and I think every nurse and doctor should be a patient before they become a doctor or a nurse because then they know what it's like, perhaps to be stuck in a bed and have to go to the toilet, you know, and buzz and that type of thing. They've more of an insight, not even empathy, an insight to what the problems are, and, urmm, perhaps how difficult it is to sometimes live with those problems. So, yes, I think it's helped me in my role, not so much in my knowledge of different cancers, because, you know, it's more about the patient experience than anything else”</p> <p>“We're very good as team, as I said there's 3 of us in the team now, at looking at self-care and obviously we're MacMillan funded now, so we do a lot of MacMillan courses with them where we go off on these days and it's all about supporting ourselves and looking after ourselves”</p> <p>“I think as a team we've got that, we work, we spend a lot of time reflecting, analysing, thinking about what we're doing, and talking it through”</p>		<p>1 – p.6</p> <p>1 – p.6</p> <p>2 – p.10</p> <p>1 – p.6</p> <p>2 – p.3</p> <p>3 – p.3</p> <p>8 – p.6</p> <p>8 – p.6</p>
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<p>“the patients, and their families, for somebody going through such terrible times, a lot of them were very inspirational, and Velindre itself, although you think it’s quite a depressing place to work is actually quite an upbeat place to work and I think patients find that when they go there is that as well, they always think it’s going to be all doom and gloom but it’s not”</p> <p>“there is an assumption that everyone who has cancer is going to be depressed all the time, urmm, but you know some of these people are very, very strong, their families are very, very strong, urmm, and they come in with a sense of humour, so there is a lot of laughter in a place where you wouldn’t expect there to be any and I think that’s lovely for other people coming in as well, that, you know, the nurses and the patients have banter with each other and some laughter”</p> <p>“if you’re going to be in a dark place, then you’ve got look at the way some people manage it and try and find the positives in that as well”</p> <p>“black humour, and that’s not because you’re ever being disrespectful, it’s just that it’s a coping mechanism, and that’s just a medical thing all the way through, urmm, because sometimes things are so horrific that the only way that you can get through it is to make a joke of it”</p>		<p>1 – p.2</p> <p>1 – p.2</p> <p>1 – p.2</p> <p>2 – p.9</p>
<p>“knowing what your triggers are as well, I think that’s important for people because we all have different triggers, you know, what winds us up”</p> <p>“sometimes I don’t think you know what they are, but if you can identify them as you come across them you think ‘ok, next time I won’t fall into that trap and I know what my triggers are”</p> <p>“the only time I’ve ever, ever, in 16 years, raised my voice to somebody, and it was commented on that I’d raised my voice, and afterwards I went away and said ‘yeah, he pressed my buttons big time’, but when he called again, I straight away gave the call to somebody else because I knew I couldn’t have a decent conversation with him, without him setting the hairs on the back of my neck up so I just passed him straight onto somebody else, and I thought well that’s a learning curve for me now so if somebody else is similar to them I’ll say ‘oh, I’m probably not the best person to talk to, but my colleague will deal with you”</p> <p>“Admit if you don’t know what they’re talking about, try and reassure them that you will go and find out for them, from a responsible source, urmm, and that, and that that’s the best thing to do. Admitting you don’t know things is not a vulnerability, it’s not a lack, it’s actually a strength to say ‘well, I’m not actually sure but we’ll find out together’, or ‘I know somebody who knows, I’ll go and ask somebody’, and I think that that’s the best way, just be yourself with people, don’t fib”</p> <p>“Just read people, and if it’s going wrong, if it’s going wrong and they’re really are not getting you, that’s fine, that’s also fine, if they don’t like you, that’s fine. You’re not going to be universally liked by everybody, but reassure them that look ‘I’m not sure that I’m the right person to talk to at the moment but I’ll get one of my colleagues and perhaps you’ll be better talking to them, I</p>	<p><i>Learning from Weaknesses</i></p>	<p>1 – p.6</p> <p>1 – p.6/7</p> <p>1 – p.7</p> <p>2 – p.4</p> <p>2 – p.4</p>

<p>think their experience will be better for you', nothing wrong in doing that [<i>slight whisper</i>]"</p> <p>"I'm not too proud to find out and go and read, so, yeah, if I don't know it, I'll tell people I don't know it"</p> <p>"recognising that, and facing it and doing something about it, rather than cowering away in your inadequacies and making an arse of the whole thing"</p> <p>"Ummm, the death and dying stuff is always, I used to find it difficult because of being taught how to deal with those difficult questions as well, it's, I need to ask them, ask difficult questions"</p> <p>"a lot of people are worried about those questions because they think they're going to open a can of worms, which rarely happens, rarely, it's happened twice in my whole career I think where I just couldn't cope, I didn't feel as though I coped with the response as well as I could have"</p> <p>"I'm one of these people who can't leave the building if there's something outstanding, I'm a little bit, I need to make sure I've done everything I can before I leave on a Friday and then when I leave I can, the minute I'm out the door I can shut it down. But if I don't make that phone call or answer that, or don't do that then at the weekend people will be popping into my brain in the middle of the night"</p>		<p>2 – p.10</p> <p>4 – p.8</p> <p>4 – p.12</p> <p>4 – p.12</p> <p>8 – p.8</p>
<p>"if something nice has happened I acknowledge that thing ... because they're the things that will remind you why the job is worth having, and they will help to, being in your happy bank, so, they'll help to deal with all of the shit that happens as well. But if you don't acknowledge them, if you don't take them on board, if you just think that that's the way things are supposed to be, then you've got no armour, you've got nothing to protect you from the bad times"</p> <p>"you never make a decision on your own, you always have somebody above you that always agrees with you"</p> <p>"it's not shameful to check things with other people, that's safety, never be frightened to ask and check, and that, it doesn't matter what environment you're in, that's a safety thing to do, is to check with your colleagues"</p>	<p><i>Protection</i></p>	<p>2 – p.10</p> <p>2 – p.10</p> <p>2 – p.12</p>
<p>"the opportunity came up to do something very, very different which is working on what was then the helpline, ummm, and I thought yeah let's give it a go, it actually fitted in with my work life balance a little bit better"</p> <p>"I've always tried to make sure that my work life balance is good, and I've always tried to make sure that I don't take my work home with me"</p> <p>"I've always been pretty good at leaving things at work because it's always been a feature of my life"</p> <p>"I'm one of these people who can't leave the building if there's something outstanding, I'm a little bit, I need to make sure I've done everything I can before I leave on a Friday and then when I leave I can, the minute I'm out the door I can shut it down. But if I don't make that phone call or answer that, or don't do that then at the weekend people will be popping into my brain in the</p>	<p><i>Work-Life Balance</i></p>	<p>1 – p.2</p> <p>1 – p.5</p> <p>2 – p.8</p> <p>8 – p.8</p>

<p>middle of the night, you know, 'what happened with that?', that does happen. Ummm, again I'm better at that now, in the early years I'd be in on a Saturday morning be ringing people that I hadn't rang on the Friday, but I don't do that anymore because there's more of us. I think the important thing is to try and deal with what you can deal with and not leave anything undone and then you can go home and rest easy because you, there's always going to be something that has to wait 'til the following week, but if you know that that's going to have to wait 'til the following week and you know it's not going to impact on that person immediately or cause them distress, then you can, sort of, go home and shut off from it really. Yeah, I'm pretty good at doing that and if I go on holiday I can have half a day of going about work, you know, if I'm with work colleagues, and then I can just shut it off then"</p> <p>"If you've got a supportive, and I have got a supportive people around me at home, if you haven't got that it can have an effect, it really can, urmm, and again, it's important to talk in work because you cannot take this work home with you, you can't take this home and talk to your family members and relatives and talk to them about it, you can't do that, urmm, you know, nobody wants to be sitting around having dinner hearing about somebody being sick. You shouldn't do it really, although you may tell them little snippets of stuff, you know, there's no confidentiality broken, it's just 'oh, I've had a bad day' or 'I had this situation today', you know, but your family they don't want to hear that. So, you have to find another way of dealing with that and, as I say, reflection and talking and supervision if that's what you need, I think"</p>		<p>8 – p.9</p>
<p>"That's something that you can project. So, even though this job is what I feel I should be doing, as in nursing in general and this I'm very privileged to do, there is a way of doing it, in that nurses are performing a role, it's like any other role, it's an act"</p> <p>"with people who don't have a lot of confidence, provided they're not arrogantly thinking they know everything, you can, I use to have a 'bullshit hat'"</p> <p>"they wear the 'bullshit hat', which means that they are pretending in their own minds that they know exactly what they're doing ... they're doing it with confidence, they're taking on this role of somebody who knows what they're doing, so they're being confident in their actions"</p> <p>"You can become this person, it's all a role, it's all pretend, you put the uniform on, you become somebody different. So, you get that, sort of, confidence by, uniforms really helpful actually, by putting on the uniform you become somebody else, or something else, and that, sort of, that imbues you with a certain amount of confidence within a situation. It's quite funny, they think you know it all, so, let's, let's, as long you don't, like I said, give them a load of rubbish, they think, they're having confidence in you, so, you need to have confidence in yourself, so you need to put on the hat, put the uniform on and go out and play the role"</p> <p>"if you're ever having a very stressy day, but I think, again, you put that uniform on, you take on the role, you put the hat on, you have to do that. Everybody has good</p>	<p><i>'Faux' Confidence</i></p>	<p>2 – p.11</p> <p>2 – p.11</p> <p>2 – p.11</p> <p>2 – p.11</p> <p>2 – p.11</p>

<p>days and bad days but everyone deserves a minimum amount, a minimum amount of service ... they have a right to the minimum goodness of you, and that still needs to be really high”</p> <p>“So, it’s the nurse’s face that comes, so it’s urmm, I mean there’s some days where you’re more tired or whatever and you have a moan, but you have that with your colleagues and as soon as you pick up the phone you’re back to that role, and it is, it is a role, the phone rings and [<i>finger snap</i>] you set”</p> <p>“I think it’s, something that, perhaps, from experience from, urmm, my ward days, because once you walked into a ward you didn’t have time to have, urmm, those, sort of, negative, you know, it was right ok, so, I don’t know how I can do that. I suppose, it’s the same as an actor, it’s like people acting, it just, urmm, it just develops over years, I don’t know, I can’t answer that question. Again, I don’t know [<i>slight laugh</i>]”</p> <p>“You have, to sort of, show that you’re confident and you know what you’re talking about”</p>		<p>3 – p.6</p> <p>3 – p.6</p> <p>7 – p.5</p>
<p>“I think there is an assumption that everyone who has cancer is going to be depressed all the time, urmm, but you know some of these people are very, very strong, their families are very, very strong, urmm, and they come in with a sense of humour, so there is a lot of laughter in a place where you wouldn’t expect there to be any and I think that’s lovely for other people coming in as well, that, you know, the nurses and the patients have banter with each other and some laughter”</p> <p>“Although, we are dealing with something very, very serious, they can still see a funny side of life and, you know, urmm, and just the way, you know, people in really dire circumstances will always find the humour in things”</p> <p>“For nurses, you know, we’ve got really black humour so when somebody else has got that little bit of, that kind of as well, we kind of bounce off each other then a lot but I think that, you know, if you’re going to be in a dark place, then you’ve got to look at the way some people manage it and try and find the positives in that as well”</p> <p>“And the black humour, and that’s not because you’re ever being disrespectful, it’s just that it’s a coping mechanism, and that’s just a medical thing all the way through, urmm, because sometimes things are so horrific that the only way that you can get through it is to make a joke of it”</p> <p>“with people who don’t have a lot of confidence, provided they’re not arrogantly thinking they know everything, you can, I used to have a ‘bullshit hat’”</p> <p>“they wear the ‘bullshit hat’, which means that they are pretending in their own minds that they know exactly what they’re doing ... they’re doing it with confidence, they’re taking on this role of somebody who knows what they’re doing, so they’re being confident in their actions”</p> <p>“So, you can put on your ‘bullshit hat’ and you go out and you be this person, even if you’re not completely confident in it, provided you’re not bullshitting it,</p>	<p><i>Coping Techniques/Strategies</i></p>	<p>1 – p.2</p> <p>1 – p.2</p> <p>1 – p.2</p> <p>2 – p.9</p> <p>2 – p.11</p> <p>2 – p.11</p> <p>2 – p.11</p>

<p>providing you're not arrogant and thinking you know it all, provided you have the ability to say 'I will go and found out if I don't know things', but you can become this person, it's all a role, it's all pretend, you put the uniform on, you become somebody different"</p> <p>"I think every day is different, I think, again, being, urmm, being a nurse you've got to leave any worries or woes that you've had, you leave them at the front door, you just can't, urmm, and you just can't talk to somebody who's had so many problems themselves in a tone that makes them feel worse than they already are, so, basically, when I open that door to work, or close my front door, everything is left behind. So, it's the nurse's face that comes, so it's urmm, I mean there's some days where you're more tired or whatever and you have a moan, but you have that with your colleagues and as soon as you pick up the phone you're back to that role, and it is, it is a role, the phone rings and [<i>finger snap</i>] you set"</p> <p>"it's not very often that things fester, we do have clinical supervision which we can access, but as a team we're also really good, if we've come off the phone and it's been a particularly bad call, then we'll talk about it straight away"</p> <p>"we do instant supervision, if you like, so then you can almost put it to one side because, you know, you've managed to have that conversation with somebody. And because we do work late as well, urmm, as a team, if we have a particularly bad call, say at 7 o'clock at night, urmm, one of us is always open to the other ringing them and saying 'oh you won't believe what's just happened', so instead of that festering 'til the next day, they can talk to somebody, even somebody to bounce off, that understands what you're going through, and I think that's probably one of our biggest assets for how we deal with things that we understand what's going on and we can talk to somebody else about it"</p> <p>"I have had, and I still do have, some supervision where I go and talk to a counsellor"</p> <p>"I've had some supervision, and, yes, that's there but mostly, as with most nurses as you'll you probably find as you go along, urmm, we, we just feedback to each other, and if you're having a crap day somebody else will be there for you and if they're having a crap day, you're there for them and that's always been the way"</p> <p>[referring to suicidal client] "in that case then I phoned a colleague afterwards to discuss it with her to get it, urmm, but that's the only time I'd say that I felt, it was more feeling upset because I had to put the phone down, rather than the call itself because that's the only way I feel I could've handled it, so ... it's like supervision really, like 'what would you have done?', we discussed it and in fact we realised that this caller had called previously in, urmm, in a very similar, not quite as bad situation, and she has called again since, which makes me feel better [<i>slight laugh</i>], but, yeah"</p> <p>"When I first started I had a line manager at the time who worked in cancer herself and so that was very supportive to have somebody I could go to but then she moved on and after that I had management support</p>		<p>3 – p.6</p> <p>1 – p.5</p> <p>1 – p.5/6</p> <p>2 – p.9</p> <p>2 – p.9</p> <p>3 – p.4</p> <p>8 – p.6</p>
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<p>which wasn't, they weren't working in cancer care so didn't really understand the impact on the job and the impact of needing some type of clinical supervision really. So, over time I have had clinical supervision, I went and sought that out myself because at that time I was struggling and needed it. I'd done some work with, we've got a work-based psychology department here who do well-being and 'know your own mind', that sort of thing"</p> <p>[referring to clinical supervision]</p> <p>"I had 6 months and that was really helpful and I wouldn't hesitate to access it again if I needed, urmm, and again I am a great believer in, I think these things that are, sort of, group supervisions, groups where people get together, are necessary for health professionals but again, it's not happening, it's not happening as it should. Ummm, so I think in the future these sorts of things should be compulsory, I'm not saying you have to go every week or every month but every couple of months just to check-in with your peers and just be able to say 'such and such happened to me the other week' or if it's a difficult case, and they might say 'oh, yes I've had that happen or I had similar happen'. Sharing the experiences, because if you don't share the experiences with people how do you learn really"</p> <p>"I think confidence just comes with experience of knowing that you can do it, and your confidence will always get knocked, you know, you will have a call where you think 'yeah, that was rubbish', urmm, but again it goes back to being able to reflect on it and saying 'well, I was rubbish that time but I can be better next time', and just building that confidence back up, and the next time if it does go better that's a confidence boost"</p> <p>"I think every day is different, I think, again, being, urmm, being a nurse you've got to leave any worries or woes that you've had, you leave them at the front door, you just can't, urmm, and you just can't talk to somebody who's had so many problems themselves in a tone that makes them feel worse than they already are, so, basically, when I open that door to work, or close my front door, everything is left behind"</p> <p>"I think it's, something that, perhaps, from experience from, urmm, my ward days, because once you walked into a ward you didn't have time to have, urmm, those, sort of, negative, you know, it was right ok, so, I don't know how I can do that"</p> <p>"really you do just have to sometimes take a deep breath in the clinic and just get on with it because you've still got a huge number of patients to see, yeah, you've just got to get through"</p> <p>"I'm pretty good, I try to, sort of, compartmentalise things, so if I've had something happen in the office, so if I've had something happen in the office, I've got this, this is my stress ball [<i>slight laugh</i>]. So, you know, if I'm, but I try to talk myself down if I'm going to a clinic or I'm going to meet a patient, for instance, and one of my common phrases in my head is 'in the scheme of things', that's one they laugh at me now, because in our world in the scheme of things, small things are trivial</p>		<p>8 – p.7</p> <p>1 – p.8</p> <p>3 – p.6</p> <p>3 – p.7</p> <p>6 – p.6</p> <p>8 – p.8</p>
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<p>things because what we are dealing with is life and death, people dying. So, we, sort of, I talk myself down a bit in a, you know, actually that's really frustrating but I suspect it will sort itself out, I just need to let that go now and move onto the next thing, and I'm quite good at doing that"</p> <p>"I think confidence just comes with experience of knowing that you can do it"</p> <p>"you have to learn that you can't be all things to all people and sometimes you don't know, you don't know the person that's actually on the other end of the phone, you know the persona that they give you on that day but you don't actually know that person. You may think you have an insight into that person and you give yourself in that, always in that same kind of way, but, you know, it's true what they say about any kind of thing, you don't know what goes on behind closed doors, so it could be that that's who they decide to give to you"</p> <p>"one of my common phrases in my head is 'in the scheme of things', that's one they laugh at me now, because in our world in the scheme of things, small things are trivial things because what we are dealing with is life and death, people dying"</p> <p>"as a team we're also really good, if we've come off the phone and it's been a particularly bad call, then we'll talk about it straight away"</p> <p>"I acknowledge to my colleagues when things are horrible"</p> <p>"you share, always share, and that makes it a bit easier then, you can talk them down, because they'll do the same to you, it doesn't matter who you are in the team, someone will talk you down"</p> <p>"it is always about sharing, you don't keep it to yourself because that just goes round and round ... you always let people know how it's been and that, that makes it easier"</p> <p>"you have a moan, but you have that with your colleagues"</p> <p>"I suppose we talk to each other if we've had difficult days because there's only so much your family can understand about what you go through, unless they're working in it as well. So, talking to each other does help, urmm, because everyone has good and bad days so you do know what it's like, so I think yeah we do support each other quite well, yeah"</p> <p>"The outpatient nurses are good, they usually bring us cups of tea and biscuits [<i>laughter</i>], we had a particularly bad clinic on Monday and I asked 'can I have some biscuits please?', so they went to find some. But again, it's just looking out for each other"</p> <p>"we've got a really good peer-group support around us as well so, you know, you can bounce ideas off, or, urmm, if you are dealing with someone who's quite tricky or there's quite a lot of emotional needs or whatever, we've got people we can talk to about what to do and stuff"</p>		<p>1 – p.8</p> <p>2 – p.8</p> <p>8 – p.8</p> <p>1 – p.5</p> <p>2 – p.8</p> <p>2 – p.9</p> <p>3 – p.6</p> <p>3 – p.6</p> <p>6 – p.5</p> <p>6 – p.5</p> <p>7 – p.5</p>
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<p>“It’s having that support system isn’t it? And I think as a team we’ve got that, we work, we spend a lot of time reflecting, analysing, thinking about what we’re doing, and talking it through”</p>		8 – p.6
<p>“If you’ve got a supportive, and I have got a supportive people around me at home, if you haven’t got that it can have an effect, it really can, urmm, and again, it’s important to talk in work because you cannot take this work home with you, you can’t take this home and talk to your family members and relatives and talk to them about it, you can’t do that, urmm, you know, nobody wants to be sitting around having dinner hearing about somebody being sick. You shouldn’t do it really, although you may tell them little snippets of stuff, you know, there’s no confidentiality broken, it’s just ‘oh, I’ve had a bad day’ or ‘I had this situation today’, you know, but your family they don’t want to hear that. So, you have to find another way of dealing with that and, as I say, reflection and talking and supervision if that’s what you need, I think”</p>		8 – p.9
<p>“it’s also having people around you saying ‘oh, you handled that call really well’, and we try and do a lot of, you know, when we’re talking about calls, we try and do a lot of positive reinforcement with people, and if they say it’s rubbish, you know, I would always say to my team ‘well that bit wasn’t very good, but actually that bit was really good, so, you know, carry on doing that’”</p>		1 – p.8/9
<p>“it’s trying to get some positive reinforcement from them, but also when people say little things like ‘I feel a lot better now I’ve spoken to you’, a simple little phrase but it boosts your confidence, that yeah, I’m doing the right thing”</p>		1 – p.9
<p>“Don’t go blowing your own trumpet, but why not go and tell somebody that somebody said thank you to you for everything that you’ve done. Ummm, I, you know, I would do that in my previous job, you know, ‘we’ve had a really crap day today but everybody’s done really well’, or ‘god, that was really good, we’ve worked so well as a team’, because then when the day is bad you can look back on those ones and it just helps a bit”</p>		2 – p.10
<p>“It’s having that support system isn’t it? And I think as a team we’ve got that, we work, we spend a lot of time reflecting, analysing, thinking about what we’re doing, and talking it through”</p>		8 – p.6
<p>“if you get something you don’t know much about, urmm, your listening skills go out the window for a start, because you’re too busy thinking ‘how am I going to do this, I really don’t know what to do’. Ummm, then you’re scrabbling around trying to think of answers but we try and be very honest, urmm, if it’s something we know nothing about, we don’t try and blag because that gets nobody anywhere, and if there’s somebody else in the team that we know is far more skilled then we will always say ‘look my skills are limited but I do know somebody who could probably answer all these questions without even thinking about it’, and that comes down to confidence”</p>		1 – p.8
<p>“if we don’t know anybody who does know, we will go away and look for the information, read up about it ourselves and then get back to them, and that’s how as a</p>		1 – p.8

<p>team, people often say how do you keep yourselves up to date, we probably stay more up to date than a lot of people need to because we constantly get asked about new things”</p> <p>“I went to work with oncology nurses, I did days here and there, I went to spend a day with a consultant in Morrision, who dealt with Prostate Cancer, and that’s where my, sort of, interest in male cancers developed from, so when the job came up working with male cancers I jumped at that chance and got that job as well”</p> <p>“The thing was, there was nothing before, so anything was an improvement, urmm, and as I say I did that for about 9 years, but then I was struggling, really struggling to manage on my own, so put in a bid with MacMillan to get, urmm, well we’ve got another nurse and a support-worker for our support system working around here now, so yeah”</p>		<p>3 – p.2</p> <p>8 – p.1/2</p>
	Barriers	
<p>“I must say the first 6 months I thought I’m not going to be able to do this and although I’d been a nurse for many, many years, talking to people on the phone was quite scary”</p> <p>“I wasn’t 100% confident that I’d be able to do it and hadn’t developed enough communication skills to be able to talk to people competently on the phone”</p> <p>“whilst I didn’t have a lot of experience in that, most of the things like the all of the chemos, apart from my own, I had to learn, or have learned, and I’m learning every day, you know that’s the wonderful thing about having other members of the team, they have massive cancer experience”</p> <p>“Your confidence does sway sometimes as well, especially when you’ve got a new trial, for me anyway, when I’ve got a new trial, urmm, that is probably quite complex and quite complicated and then you see that first patient for the very first time, for, sort of, both of you that’s a new experience because when you’re giving, trying to convey the information about the trial and you have not, you’ve read the protocol but you’ve not read it a million times like with the trials you know very well”</p> <p>“When some patients are very knowledgeable and will ask you questions which perhaps you’re like ‘oh, hang on a minute, I need to actually read through the protocol and find that question out for you’. So, yeah, there’s certainly a lot of times when you’re not as you confident as you would be, certainly with a new trial I wouldn’t be as confident talking about that as with a trial that’s been open for 5 years, that I know on the back of my hand type of thing”</p> <p>“Oncology’s not my area, I’m not an expert in Oncology, I know about it but I’m not an expert in that area, so we would always refer off to someone else, but now we can actually help patients through their Oncology treatment as well”</p> <p>“So, I think my first 6 months on the job was a massive learning curve and all I thought I knew about cancer after 5 years in Velindre was nothing [<i>slight laugh</i>]”</p>	<p><i>Lack of Experience</i></p>	<p>1 – p.6</p> <p>1 – p.6</p> <p>2 – p.2</p> <p>7 – p.5</p> <p>7 – p.5</p> <p>8 – p.2</p> <p>1 – p.6</p>

<p>“if you get something you don’t know much about, urmm, your listening skills go out the window for a start, because you’re too busy thinking ‘how am I going to do this, I really don’t know what to do’”</p>		1 – p.8
<p>“Probably when I was first qualified, I would’ve tried to blag it because you just assume then that you need to know everything, but I think as you get more experienced, and as time goes by, you realise you can’t be all things to all people and you’re doing them a disservice by not giving them the information that they need or maybe even giving them misinformation”</p>		1 – p.8
<p>“whilst I didn’t have a lot of experience in that, most of the things like all of the chemos, apart from my own, I had to learn, or have learned, and I’m learning every day”</p>		2 – p.2
<p>““I think the most, the most challenging thing is trying to keep updated with all the technology and new information, the new treatments, we have such a variety of cancer, urmm, and trying to keep up with that knowledge and training, especially when there’s no training fund available, so, urmm, either you have to self-fund your training or get a lot of, urmm, of the knowledge google or, you know, research papers, but which again is time consuming, which, urmm, again, takes up a time factor as well”</p>		3 – p.4
<p>“It’s really nerve-wracking when you don’t know. It’s probably just age as well, the older you get, it does get easier, but yeah, it’s harder when you’re in a new situation and you’re not quite sure how to say it or is this the right thing to say, what if I upset somebody”</p>		6 – p.4
<p>“If I went back to the wards to work, because currently I’m working in trials, you know, I work in the outpatients, I see patients in the outpatient clinic, but I don’t give them treatments anymore or treat patients, so, urmm, I probably think that if I went back to those places I’d need an awful lot of re-learning shall we say. Urmm, so in some respects I’ve lost a lot of your clinical skills by doing, urmm, trials, at least I’m still up to date and aware of the new treatments and the process of what happens on the ward, what happens to the patients when they actually go through the ward, and I think that experience of working everywhere in the hospital has actually given me the experience of, or a good knowledge of what the patient experiences throughout their whole journey, through the hospital, through their diagnosis, through their treatments, because I know about the treatments they’re having and what experiences they have when they’re actually sat in the treatment unit and that type of thing”</p>		7 – p.2
<p>“I think the worst thing, and as I say I’ve been in nursing for many, many years and I’ve worked a lot on the wards, and the worst things about going into a consultation, sometimes, was the other members of staff who were giving information who were flicking through books and trying to work out what’s going on and I was sort of thinking ‘oh, for goodness sake’. We should know all that, we should come across that we know exactly where we started, what information we’ve got and where we’re going with it before we go in and speak to people”</p>		8 – p.4

<p>“when somebody comes at you like that, immediately your hackles go up, it’s like butting heads then isn’t it, but on the phone you can’t do that, so you learn how to bring them down to a decent level so you can, hopefully, have a valid conversation”</p>	<p><i>Challenging Conversations</i></p>	<p>1 – p.8</p>
<p>“being available for anybody that phones up to ask any kinds of question”</p>		<p>2 – p.3</p>
<p>“So, we get really random calls, so you’re very much thinking on your feet, but obviously the other thing you can do is just pick up the phone and just have somebody crying down the phone to you”</p>		<p>2 – p.3</p>
<p>“Unfortunately, some of my clients at the moment, they’re, I’m now talking to their widows and widowers, because the clients themselves have passed away but the widow or widower really would like to talk to somebody that they don’t have to tell people they’re just ok with. They can carry on and talk about the person that’s died, and we can cry and have a laugh and do both of those things, but they feel they can then speak openly then about the person they’ve lost, and perhaps how hideous that was, or how good that was, or, you know, you just have to follow their lead really and not be afraid to say the words that most people are too scared to discuss, you have to talk about death and funerals and things like that and ask questions and just not be afraid to take that extra step”</p>		<p>2 – p.3</p>
<p>“Ummm, just had a lady cry on the phone to me know, one of my regular, sort of, regular patients, who’s really, really depressed, and the instant she answered the phone, I could tell, I could hear it in her voice, ummm, and that does hurt”</p>		<p>2 – p.8</p>
<p>“I’ve had one episode where somebody I was speaking to for a very long period of time, who also had quite profound mental health issues, who then decided to misconstrue something I said to her one day and never wanted to speak to me again, and I found that extremely difficult because I’d been supporting her virtually weekly for months”</p>		<p>2 – p.8</p>
<p>“Angry, angry people, and hurt people, they’ll shout and scream at you because really they want to be shouting and screaming at somebody else, so, you know, you have to learn to manage those situations, and even that, that people who have threatened suicide, you have to manage extremes of behaviour as well, because we’re a 24 hour help-line, so you don’t know who’s going to be on the end of the phone”</p>		<p>2 – p.9</p>
<p>“we’ve had regular callers who literally phone us every 3 days, the same thing again and again and again and again [<i>clicking</i>], and that can be really difficult because you start off trying to help them, all bright and sparkly, and by the 50th time you’ve spoken to them and said all the same things to them, it can be really, really, difficult to have that same kind of interaction with them”</p>		<p>2 – p.9</p>
<p>“the other challenging thing is, perhaps when you’ve got a very anxious patient, or, ummm, suicidal patient, ummm, I think that can be quite a challenge, but sort of, the inappropriate callers you can put the phone down on them, that’s not an issue at all, but the ones that are in a</p>		<p>3 – p.4</p>

<p>very bad state, that is something that, urmm, can be quite difficult”</p> <p>“it can affect me, I can just remember one caller, more than anything that was threatening to commit suicide at half past 7, no, half past 8 on a Friday evening, it was caller withheld so she wouldn’t give me any information, and that was a really difficult situation to the point where I had to take control and end the conversation, urmm, because I probably would’ve been on the phone Monday morning trying to, so, I probably, I don’t know if I did it right or not but I gave her back control, you know, I said ‘you either give me your name, to get someone out to you, or, urmm, or you contact somebody yourself’, and that’s what I did, and in that case then I phoned a colleague afterwards to discuss it with her to get it, urmm, but that’s the only time I’d say that I felt, it was more feeling upset because I had to put the phone down, rather than the call itself because that’s the only way I feel I could’ve handled it”</p> <p>“I may have the same story a dozen times that day, kind of thing, and I’m trying not to glaze over but I’ve learned when to say the ‘mmm’s’, so, they still believe I’m interested, and I am up to a point, but sometimes I think ‘well, what’s for my tea tonight?’, and that’s what gives you tools to be able to separate yourself away a wee bit from it, you know”</p> <p>“challenging when you get someone who it’s like drawing teeth sometimes and you don’t have that non-verbal stuff to go off either, so you’re doubly hard to try and get the minimal information as well, which is challenging in a good way, I think, as well, you all need a bit of challenge in your job, we all need a bit of stress, there’s good stress and there’s bad stress, I think being able to handle that and, sort of, you know, if you’ve got a difficult call, as I said, we’re lucky, we’ve got someone we can talk to straight away”</p> <p>“So, those calls are usually much more, I suppose maybe shorter because your time’s going to be, you know you’re going to get annoyed with this call, but your communication skills come into that as well, and you’re taught in the communication skills courses, you know, how to, because people can ramble on for ages and say nothing”</p> <p>“I think you did always have some patients that are more difficult to communicate with than others, but as you get more confident, I suppose you get a bit more used to trying to get people to talk and getting more out of them”</p> <p>“I think just learning to be brave enough to ask the questions like ‘what’s important to you?’, that kind of question, and that’s quite hard to ask sometimes, but, you know, it’s crucial that we do ask that, at appropriate times”</p> <p>“I see a lot of my patients when they’re first diagnosed so they’re highly anxious and, urmm, and sometimes very upset and still, sort of, getting their way, feeling their way around what is happening to them, without, you know, me bombarding them with treatment options, and then we throw a trial in to the mix as well”</p>		<p>3 – p.4</p> <p>4 – p.6</p> <p>4 – p.16</p> <p>4 – p.16</p> <p>6 – p.3</p> <p>6 – p.3</p> <p>7 – p.3</p> <p>7 – p.3</p>
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<p>“So, you know, when they come to clinic, some people are very laid back and quite, sort of, with it and have looked up the trial previously, you know, quite in control, other patients are really, urmm, they can be, not aggressive I wouldn’t say, they can be quite angry and, you know, sort of confrontational and have a lot of questions. Urmm, so, yeah, there’s a lot of emotional needs as well that our patients have when they come and see us for the first time and again when they’re trying to make decisions as well, when they’ve got a decision, you know, they need to make decisions, so giving them a lot of information about what happens if I don’t go into a trial, what happens if I do”</p>		7 – p.5
<p>“There’s definitely days where you feel less confident, yes, I mean, especially if you have dealt with very tricky patients which on reflection could’ve gone better or perhaps you didn’t make quite the right decision or the best decision for the patient at the time. I think it does knock your confidence a little bit”</p>		7 – p.7
<p>“it can be and it might be that that particular patient might need to come off the trial because they’re unwilling, it’s a safety thing, and again this doesn’t happen very often, but I can think of two incidences where it’s happened where the patient has refused, or not refused, but doesn’t want to come into hospital, or won’t come into the hospital to be assessed and they’re on a particular drug that can be quite toxic and we have to keep an eye them quite closely, and we’ve had to say them ‘well, if you don’t come and see us then we’re going to have to take you off the drug because we don’t want you out there getting sick, and you’re on a trial’, you know, it’s hard. And that is a tricky conversation to have with some patients so that can be quite challenging”</p>		8 – p.3
<p>“families then are very anxious because they’re a little bit in limbo and they’re not sure what’s coming next and so we get a lot of calls from family members, you know, questions really about what’s going to happen next, who are they going to see next and when are we going to know about this, and, cos obviously people are trying to plan their lives and things around it, it’s not just about the cancer care it’s about life, work, holidays that they’ve booked, family weddings, urmm, all the things that life involves, trying to fit that in to suddenly having this devastating diagnosis and a treatment of, we’re talking months and months and months, you know, for some people it’s going to be sorted in a week or 2, a lot of them can go on for months, years, you know, and it’s really difficult for people to manage”</p>		8 – p.4
<p>“we have huge challenges really, because the information that we’re giving is difficult information, it’s complex information, it’s life-changing information, it’s distressing information”</p>		8 – p.4
<p>“On the phone sometimes it’s a little bit more difficult because we get calls come out the blue ... we do get a lot of distressed calls, urmm, and that’s just really being, listening, we do a lot of listening, and then just identifying what’s the most important thing for that person at that time and then just trying to support them with that need”</p>		8 – p.8/9

<p>“clinics can be challenging, because if you’ve got 7 patients to see in the morning and some of them have got bad news or they’re not well or there’s something traumatic going on, that can be quite difficult sometimes going through because you’ve got your 20 minute slot, so going from 1 consultation straight into the next one, and the next one, and the next one, and the next one, without feeling some days a little bit overwhelmed”</p>		
<p>“I think there is an assumption that everyone who has cancer is going to be depressed all the time”</p> <p>“When I go anywhere, I avoid telling people what I do because they’ll be like ‘oh! That must be such a tough job’, but I say I love what I do, they say ‘how can you possibly love that? It must be so miserable”</p> <p>“male nurses were seen as the big jailer in psychiatry or the screaming queen, you know, so, in general nursing as the guys you were seen as gay, nothing wrong with that, it’s fine, you know, but that was always the perception and that outside perception is, sort of, coming into nursing as well”</p>	<p><i>Stigma</i></p>	<p>1 – p.2</p> <p>1 – p.5</p> <p>4 – p.4</p>
<p>“You’ve got to be aware of, you know, different personalities and how they’ll deal with it”</p> <p>“I think you start off quite tentatively, urmm, and test the waters, and see what you get a response to”</p> <p>“from their point of view it’s being able to fulfil their needs, urmm, the difficulty you get when you talk to one person is that you don’t get a rounded view ... that’s only that person’s opinion so you’ve got to be mindful of that”</p> <p>“accepting that some people are always going to be better at things than you, but not necessarily better, we all have different styles, and it’s no good saying ‘I want to be like Angela’ because if your personality is very different, you’re never going to achieve that, so, it’s working with what you’ve got to be the best that you can with the style that you use, you know. If you listen, there’s 4 of us on the support-line and we’re all very different in the way we approach things but all get the job done in a different way. And it’s accepting that you can’t be what you’re not, you know, you can learn – yes, you can learn some skills but you’re still going to use them in a way that’s right for you”</p> <p>“it is very much about adapting things and being able to respond to the person because not everyone can cope with the same amount of information, or the same way of speaking to them”</p> <p>“Unfortunately, we deal with everybody in this service, so we may deal with somebody who’s not the brightest bear in the forest to somebody that’s really, really intelligent, and you have to be able to make the information available for all”</p> <p>“you don’t know what goes on behind closed doors, so it could be that that’s who they decide to give to you”</p> <p>“you can get people with all kinds of personality and mental health issues ringing you, so it can be difficult”</p>	<p><i>Individual Differences/Needs</i></p>	<p>1 – p.2</p> <p>1 – p.3</p> <p>1 – p.5</p> <p>1 – p.9</p> <p>2 – p.3</p> <p>2 – p.3/4</p> <p>2 – p.8</p> <p>2 – p.9</p>

<p>“it’s very individual, urmm, as to the sort of access that people need, or the things that people need from us really, but they know where we are if they want us, if they need us”</p>		8 – p.3
<p>“Angry, angry people, and hurt people, they’ll shout and scream at you because really they want to be shouting and screaming at somebody else, so, you know, you have to learn to manage those situations, and even that, that people who have threatened suicide, you have to manage extremes of behaviour as well”</p> <p>“you start talking and, urmm, you can, I suppose, squeeze things out of people, because they don’t want to waste your time, ‘oh, I didn’t want to phone you over the weekend because...’, ‘well, why? I’m here anyway, I’m working’, you know, and it’s the same if they’re not very well in the middle of night, they’re very reluctant to contact the pager, the chemotherapy pager, or somewhere and I tell them ‘there’s nobody in bed during the night, these are nurses that are working nights on the ward, that are carrying a pager that will answer your call, so, they’re not sleeping, they are working, probably waiting for your call anyway’, so, you know, that type of thing”</p> <p>“there’s so much misinformation, so, it just, it creates anxiety, it creates uncertainty, and all sorts of stuff like that”</p> <p>“it is a learning process and you will get on better with some people than others, urmm, but it’s more in the boundaries and realising your own boundaries, and what the patient’s boundaries are, and managing their expectations”</p> <p>“So, we can make the time, or if you don’t have the time to give to patients, because sometimes you can spend 10 minutes with them, if you sit down and go ‘ok, let’s focus on what we need to talk about today, if we focus on this for the next 10 minutes and you tell me what you’ve got to tell me, or we’ll have to finish it half way through something’, you know, you give them boundaries, which is a good thing to do as well, because if you have somebody with you for an hour, it’s managing their expectations, so that’s really important”</p> <p>“it can be hard because you’ve got a limited amount of time in a clinic and, urmm, we have got quite a reputation in all our clinics that there’s often a bit of a waiting time, but generally speaking most patients understand, because some visits they will need more time than others and it’s not until that visit that you know that that’s going to happen. So, generally people are understanding, so, sometimes it does mean that you have to run over your time and you give them more time there and then, urmm, but then usually you can follow it up with a call afterwards as well, just to make sure that they haven’t got any ongoing questions or things they want to say that they’ve forgotten about when they were there”</p> <p>“I suppose it starts when you start to see a patient, straight away you just introduce yourself, make sure they know who you are, make sure they know how the clinic is run, because we run our clinics quite differently as we’re a nurse-led clinic. Sometimes they’re expecting to see a doctor so you explain how the clinic works, urmm,</p>	<p><i>Managing Expectations and Boundaries</i></p>	<p>2 – p.9</p> <p>3 – p.4/5</p> <p>4 – p.4</p> <p>4 – p.5</p> <p>4 – p.17</p> <p>6 – p.4</p> <p>7 – p.4</p>

<p>obviously we talk a lot about the trial, say that the, you know, we do give them our contact details for reassurance that they've actually got somebody that they can phone and they've got a number to take away with them"</p>		
<p>[referring to drug trial patients] "we just have to explain that it is really important that they come and see us ... you just try to be as encouraging as you can really"</p>		7 – p.7
<p>"We have patients from all over the place ... travelling nearly 100 miles to see me, just for me to say 'everything's fine, off you go', sometimes it can feel from a patient's point of view as if that's a waste of time, well, it's not a waste of their time, it really is important. And once they know that, they're generally ok"</p>		7 – p.7
<p>"when I first started I had a line manager at the time who worked in cancer herself and so that was very supportive to have somebody I could go to but then she moved on and after that I had management support which wasn't. They weren't working in cancer care so didn't really understand the impact on the job and the impact of needing some type of clinical supervision really"</p>		8 – p.6
<p>"we haven't got enough support from our employers, certainly here, because I think it's underestimated the impact of the role and the impact of giving bad news and the impact that has on us, but if you work as a clinical psychiatrist or a clinical psychologist you have your own counselling sessions ... we don't get anything, there's no structured supervision, if you want it you've got to go and find it"</p>		8 – p.6
<p>"you're basically expected to just get on with it ... for me because my line managers don't work in the same field, don't understand, I don't feel like if I'm having a bad day I can just knock on their door"</p>		8 – p.6
<p>"Some days it would cause me to feel very, at the end of the day, very tired, and not able really to do anything other than work, because by the time I got home from work, there was no energy left for anything else. So, it used to just, it took over my life a bit really, to be honest with you, I mean a job like this will take over your life, there's no getting away from it, but it completely took over my life because there wasn't, there was no energy left really, or very little energy left to give to anything outside work, urmm, and I think when you get to that point you are reaching a bit of a crisis. I don't think anyone should have to work like that, where they've got nothing to give, you know, to their family and relationships and that can start cause a real problem as well. It can lead to burnout, compassion fatigue, all those sorts of things that we hear"</p>		8 – p.9
<p>"the biggest thing is probably communication, I suppose, urmm, and knowing how to get a history from the patient and then how to manage what they're telling you, yeah"</p>		6 – p.5
<p>"you definitely don't feel confident all the time, I think especially when it's really busy in clinic you can feel really under pressure and you don't feel as if you're giving people the time that they need and then that can</p>		6 – p.6

<p>make you feel stressed and then you're not as good at communicating"</p>		
<p>"I think that, you know, a lot of the time they spend, especially with their families, putting the brave face on it, if they're feeling pretty lousy, whereas, a disembodied voice on the phone, often they feel like can just say what they want"</p>	<p><i>Phone Conversations</i></p>	<p>1 – p.3</p>
<p>"They're never going to meet us, we're not emotionally invested in them, you know, we have no connection with them, so, if they're having problems talking to their families, or something, because they don't want to burden them, then they often say 'well, it is good to unload because I didn't want to burden my family with</p>		<p>1 – p.3</p>
<p>"they will arrange for us to call when they're on their own so they can be extremely honest about how they're feeling"</p>		<p>1 – p.3</p>
<p>"are you telling me everything and we can work with this, but because it's over the phone, again, you know, you can't just sit and go and put hand on their knee but you kind of allow them to have space to take time"</p>		<p>1 – p.4</p>
<p>"I think you learn a lot more, I don't know if it's patience, but you ask a lot more questions because you need to"</p>		<p>1 – p.7</p>
<p>"never assume, always investigate"</p>		<p>1 – p.7</p>
<p>"I know a lot nurses do telephone call-backs, especially the specialist nurses, but even for those that don't, it would be nice almost to have this sort of thing included as part of training"</p>		<p>1 – p.7</p>
<p>"I think my main skills are communication skills, listening, listening to, urmm, what the patient is trying to tell you in not so many words, the undertones, urmm, you get, you get knowledge just by the tone of voice, the loudness of the voice, you learn so much when they first open "hello, who's there?", you know straight away if they're not well, you can see by the tone, the, sort of, demeanour of the voice, so that's, sort of, a good start and then you start talking and, urmm, you can, I suppose, squeeze things out of people"</p>		<p>3 – p.4/5</p>
<p>"Face-to-face is, urmm, more, probably, intense because if they've come and they're in total shock or they're in the crying mode and not absorbing all the information, urmm, where on the phone you can't see that, you can hear it in their voice perhaps, but, and they've got to concentrate more on you on the phone, urmm, yeah, it's totally different, but just as intense, in a different way"</p>		<p>3 – p.5</p>
<p>"I have found in my role with the support-line, urmm, the medical part of it is dealt in the hospital, so, you know, I can give a little advice on the side-effects and I can give advice on what I'm confident on giving advice which is general side-effects of chemotherapy or all of that knowledge that I've got, but I wouldn't dream of giving them medical advice, I would automatically push them back to the team in the hospital. So, that takes away some of the worry, so, that gives you the confidence - well you're not going to deal with that anyway, you know, if somebody says 'well, hang on,</p>		<p>3 – p.6</p>

<p>you need to call the unit now' or "You need to go to A&E now", so that medical side of it"</p> <p>"Listening skills, urmm, and, listening skills more for the support-line because I don't physically see them, but I do visual communication, you know, the way they move, the way the turn. So, you know, you're listening skills are heightened because you haven't got those visual skills to depend on, so then you've got to – I suppose it's like being blind and you're, you know, you're hearing becomes more sensitive or something. But yeah, I think that is the key"</p> <p>"how do you respond when you've got one part of the verbal stuff taken away from you, you pick up on other bits, you do, you end up tuning in on various bits that you, and it comes naturally, I think, as well, because, again, you're still trying to give the best service that you can, despite being limited"</p> <p>"for some people having a stranger is really, really useful as well, somebody you're never going to have to speak to again, or, urmm, or never have to look at, so sometimes talking on the phone is much, much easier, for some people it's much, much more difficult, you know, so, it's advantages and disadvantages, so, it's accepting those as well"</p> <p>"I'd much rather see somebody to talk to them, it's a lot easier ... you can read people's body language, you can provide reassurance a lot more easily, because you can see expression changes, whereas you can't see that over the phone. Urmm, so, yeah, in the clinic they might have someone with them and that's quite nice, but over the phone you don't necessarily know whose around. So, yeah, it's better if you can do it face-to-face"</p> <p>[referring to drug trial patients] "we've had to say to them 'well, if you don't come and see us then we're going to have to take you off the drug because we don't want you out there getting sick, and you're on a trial', you know, it's hard. And that is a tricky conversation to have with some patients so that can be quite challenging ... generally those conversations happen over the phone, which is not great for communicating because, you know, they need, sometimes they don't want to come in to hospital to see us, so we just have to explain that it is really important that they come and see us, urmm, you know, we can't force them, and if they don't want to come they won't come but, you know, you just try to be as encouraging as you can really"</p> <p>"Interestingly I've had a lot more telephone conversations of recent, that's becoming more common, urmm, also, as well, with the logistics of where we are, because we are quite a rural health board, so a lot of our patients are a long way from us, they aren't like 5 minutes away, a lot of them are coming quite distances to come up to the clinic to see us, so phone conversations are actually really good, and of course, the important thing with phone conversations is that we have met the person first, we've had the permission from them to talk to them or to talk to their family members"</p> <p>"consent from the patient first but then working with whatever, urmm, suits the patient and at the moment it's</p>		<p>3 – p.8</p> <p>4 – p.15</p> <p>4 – p.15</p> <p>6 – p.4</p> <p>7 – p.7</p> <p>8 – p.3</p> <p>8 – p.3</p>
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<p>phone but I suspect in the future it will be other forms of WhatsApp and Skype and whatever and, you know, they've been doing tele-linking or something, tele-health aren't they?"</p>		
<p>"one of the main difficulties is these people might ring and some of them can ring for quite a long time, you know, some of our callers rang for years but then they just never ring again, and we don't know what's happened to them"</p> <p>"So, sometimes we don't get closure"</p> <p>"We don't get that closure, and sometimes when you've built up quite a relationship with somebody that's a difficult thing"</p> <p>"oh, I wonder what happened to them?"</p> <p>"obviously if you've been supporting somebody for quite a long time, and then the phone just rings, because that's all we can do, we just ring that number, and if that number just rings and rings every time you call and there's nobody on the end of the phone and then one day you just get beep [<i>dead dial tone</i>], that person's probably passed away, and that can be quite difficult because you don't get that, sort of, closure with them, they're just suddenly, the interaction just suddenly stops, so that can be quite difficult"</p> <p>"There's always those conversations when you get to a time when people aren't responding to their treatment anymore, it's just always horrible isn't it, it always will be, especially as some people you get to know very well. That's hard because then you have to let people go, you know, they're just seen by the supportive palliative care teams, and that's hard for you, it's hard for me and I'm just the nurse, but it's worse for them. But you do, you want to carry on but you know you can't carry on because you know you've got to keep that, you know, you're the hospital and they need the palliative care team now. So, you always keep an open door, if you want to come back that's ok but it always feels a little bit like you're letting people down"</p> <p>"Because you're never sure how quickly people will go downhill once they stop responding and you keep in touch a little bit but you're not really offering much, the other team takes over and that's good because the palliative care team are very good and very expert in what they do. But like you say, closure you don't get, yeah"</p> <p>"you definitely don't feel confident all the time, I think especially when it's really busy in clinic you can feel really under pressure and you don't feel as if you're giving people the time that they need and then that can make you feel stressed and then you're not as good at communicating. So, yeah, yeah, I suppose that's difficult sometimes"</p> <p>"we spend a lot of time with people and prognosis for our cancer is bad, I've had patients die, so, you've built a relationship with someone who is ultimately, a few months down the road or who 6 months down the line is going to die, that has an impact so it's, sort of, dealing with that and knowing how to deal with it and looking after yourself really"</p>	<p><i>Lack of Closure</i></p>	<p>1 – p.5</p> <p>1 – p.5</p> <p>1 – p.5</p> <p>1 – p.5</p> <p>2 – p.8/9</p> <p>6 – p.5</p> <p>6 – p.5</p> <p>6 – p.6</p> <p>8 – p.7</p>

Appendix Eleven: QOL Measures Coding Table

Quote	Theme	Participant/Page No.		
<p>“it’s something that needs to be further explored, but as a stand-alone question, I don’t think it really covers ... it gives them a basis for taking things further”</p> <p>“it brings the conversation then into asking them questions and somebody answering questions, it’s not to, it doesn’t do the, the holistic, they’re on about the holistic approach, this isn’t how, it might be at the end of the structure but how you get to that, you’ve got to think about the holistic”</p> <p>“it’s brilliant that people come up with these ideas to evaluate and to think of a holistic approach, and I know holistic care and, urmm, patient’s individual rights and doing what’s best for the patient has been sort of the crux of nursing in all time but on a hospital ward, urmm, you’ve got to have structure and they can clash”</p> <p>“it’s being able to give some practical stuff as well, and not “oh, that’s a terrible thing that you’re feeling like that” and then move on to something else”</p> <p>“it might be seen as a really positive tool, you know, as long as then you don’t think ticking a box isn’t the end of what you do with quality-of-life information and I think there’s an inherent risk in that”</p> <p>“I don’t think that there’s a problem per-say in any of these questions, or, you know, if you want to rate them or get a score, it’s just that what do you put that score against, what does it mean for you as a practitioner, do you only look at the score at the end of it?”</p> <p>“Generally, we use them because we’re told to use them as part of the study, the study want them, and generally we, I don’t normally look at them, so when I looked through them before the interview I was like “oh, well perhaps I should look through them a bit more often””</p> <p>“I think because they’re just sent away, because we get the patient to fill them in and then they’re just sent straight to the trial company, we don’t look at them, so we don’t actually use them as such, we’re not the ones using them, the trial needs them for their data, so, we get the patient to fill them in and then they’re just sent away, urmm, but on reflection perhaps we should be looking at them a little bit more while they’re in clinic with us”</p> <p>“I think we sometimes think “oh, yeah I know what’s wrong”, but actually it’s not just about us, it’s about what they think, what they feel, urmm, so I think listening, again, listening to what they’re saying, so I think that’s where it has had an impact”</p>	<p>Considerations</p> <p><i>Need for Further Exploration</i></p>	<p>1 – p.10</p> <p>3 – p.9</p> <p>3 – p.11</p> <p>4 – p.14</p> <p>5 – p.7</p> <p>5 – p.9</p> <p>7 – p.9</p> <p>7 – p.9</p> <p>8 – p.13</p>		
		<p>“what we avoid is using them as a question and answer type thing, so, we tend to build them into the</p>	<p><i>Conversational Prompt</i></p>	<p>1 – p.10</p>

<p>conversation ... and you kind of bring it into a conversation rather than a question, because if it's a question and answer it becomes more static, and you don't get people to open up so much"</p>		
<p>"if you're using this then to guide people towards the questions that they should be asking, I think they're an excellent memory jogger"</p>		2 – p.12
<p>"they're an ideal prompt if they're used it as that, urmm, towards people that have not got the experience, so it's not just, you don't forget the important things that you need to ask"</p>		2 – p.12
<p>"because then everybody finds their own flow, and obviously you're talking to somebody you have no idea what they're going to say to you, so they may stick something in half way through the conversation that is not in the order, for that"</p>		2 – p.12
<p>"if there were people, urmm, if there were people that were new to Lung Cancer, as well, it could be a really, good, you know, it could be a good prompt"</p>		2 – p.13
<p>"it's a useful tool, but it shouldn't be the be all and end all, but it's something you can work with the patient with, and not instead of conversation"</p>		2 – p.14
<p>"I think they're fantastic as a guideline"</p>		3 – p.8
<p>"you can learn so much from a general conversation with a person that you can answer most of these questions [<i>referring to QOL measures</i>], urmm, and that's what we used to do, we would use these as a guideline and, urmm, and not ask the specific questions, because it felt so cold and just not right somehow, just to ask a list of questions"</p>		3 – p.9
<p>"I find them useful as a guideline but only as a guideline"</p>		3 – p.10
<p>"I think they've got their place as a tool but you shouldn't be what you work from altogether"</p>		4 – p.13
<p>"it standardises responses and things, so you'd get less experienced people being able to respond to that"</p>		4 – p.13
<p>"So, especially for inexperienced nurses this is a great way to help get them focused on perhaps important things"</p>		5 – p.6
<p>"as a tool for somebody new, maybe it would act as a guide and perhaps stop people then saying "well, nobody asked about my financial situation""</p>		5 – p.6
<p>"I certainly wouldn't use the ones you sent, EORTC ones, for a consultation, I would just use the Needs Assessment questions, which are kind of in your head anyway, cos like I said they're more general and urmm, yes, less daunting for the patient"</p>		6 – p.9
<p>"I have actually noticed that sometimes a patient will actually tell me that they're fine and that they don't have a problem and then when you do actually look at their Quality of Life form that they filled in for you "well, ok, you didn't tell me you felt tired and you didn't tell me you felt a bit depressed", and those are</p>		7 – p.9

<p>the sorts of things that if you do actually look at them, that could prompt you to look a bit further then, you know, these can prompt you to actually talk and ask the patient “well, hang on a minute, are you feeling tired? Because you didn’t tell me””</p> <p>“I think when you do look through them and what they’re asking, there are certainly a lot of things that could prompt you, urmm, especially if they’re having treatment, like the nausea and the lack of appetite, those are the sort of things you can address, because that’s a side-effect you can do something about it, so they’re good prompts for you to start conversation with a patient”</p> <p>“for me personally I find the best way is to use them alongside the consultation”</p> <p>“it might flag up something that I didn’t necessarily think was going to be the priority and then actually you think “oh, ok, actually I hadn’t thought about that””</p> <p>“when I first started, I actually made my own little forms like that to remind myself about nausea and to ask about this and to ask about that, to prompt myself”</p>		<p>7 – p.10</p> <p>8 – p.11</p> <p>8 – p.13</p> <p>8 – p.12</p>
<p>it may be something that you could introduce after you’d built a little bit of a relationship with them, urmm, because if you are going to be asking them about whether they worry about dying, that’s a hell of a whack, you have to have a whole phone call on that, that’s, that’s not, that’s not answer that and we’ll move onto this one. So, it’s just, yeah, these could be something that over a series of calls you could work through as well, perhaps, you know, deal with the things that are more immediate”</p> <p>“once you get that rapport with a patient, and that trust built up, you can ask them, “listen, you know, would you mind filling in, have a look and see if you’re happy to do it and would you then fill it in?””</p>	<p><i>Need for Rapport</i></p>	<p>2 – p.13</p> <p>3 – p.9</p>
<p>“you might not even get them to fill that one in, or some of the really hairy ones, because they won’t want to go there, they’ve got enough on their plate, they’re not going to deal with that”</p> <p>“it is about responding to the things at the time that they give you, and also but yeah, I think that’s, they would be ideal prompts, but if you don’t feel that the social side and the well-being side is appropriate to talk about, you leave that for the, perhaps that’s a 2nd or 3rd conversation but not straight away”</p> <p>“I think with the HNAs for us, it was finding the right time to do them, because if you’re giving someone their diagnosis or what treatment they’re having, sometimes it’s not always the main focus of what people want to do, sometimes they want to talk about one thing and until you fix that one issue for them, they can’t possibly think about form filling or, urmm, assessments or things like that because that one particular thing, whatever it may be, is just taking up all of their energy and their thoughts”</p> <p>“So, it’s that, sort of, trying to help them get a plan of action that fits around the wedding, or what we can do about the elderly relative or partner that’s, we’ve had a</p>	<p><i>Timing</i></p>	<p>2 – p.13</p> <p>2 – p.13/14</p> <p>8 – p.11</p> <p>8 – p.12/13</p>

<p>lot of patients recently who've got partners with dementia and, you know, they're carers so they focus then, a big focus is on organising support for the partner and they can't think about their own treatment, their own journey and their own situation, because of all they're worried about at that point in time, trying to a Holistic Needs Assessment with them would be futile, after you've sorted the partner out or made the arrangements for the main focus of their concerns, so which is, again, why I think it is very individual"</p> <p>"making sure people are aware that that supports there when they need it and empowering them to access it as and when they need it, because we can't force it on people really, it's got to be the right time for them"</p> <p>"I think the slight pressure we feel to use them for everybody is a slight negative, because I think we're doing it anyway but recording it we're not so good at, so the fact now that we have to make sure we do one on everybody and we record, and again, it's this when do we do it? How often do we do it? It's not clear cut, so I do think that does impact on us"</p> <p>"When do you use them? Because things are going to change weekly"</p>		<p>8 – p.13</p> <p>8 – p.13/14</p> <p>8 – p.11</p>
<p>"it's about getting that as part of the general reporting of how the patient is, part of the, part of the note-taking rather than having to fill this in [<i>referring to QOL measures</i>] and then write more notes ... making it user friendly in a way that it's something they find easy to incorporate into the note-taking, into the recording that they already do"</p> <p>"it's a time factor again, and communication skills, and not only verbal communication skills and listening but writing skills, writing the notes, you know, if I've got a patient and I'm phoning this week on a primary call-back, because again we, different nurses call this patient, and, urmm, I don't know, his doctor's moving to Australia in a months time and he's a bit upset and whatever, I'm going to write that in the notes. So, that way the next person, and hopefully the next person that will contact him or speak to him will have quickly read the notes, so that they're aware of what's going on in their life, and it might not be medical at all, but that lifestyle or whatever's going on in their life is affecting their medical, and, so, that is something, but have they got the time to look at those notes"</p> <p>"So, a lot of this would come up in general conversation and then key things I would obviously annotate in my medical notes, so I would have that ongoing sort of reference point, a bit like we do here"</p> <p>"without this tool I would naturally have written that down in my notes, read my notes to be able to go back before I see the patient to ask what we'd already talked about in the previous, urmm, you know, consultation, it's important that people need to use their notes"</p> <p>"I think you've got to, maybe there needs to be an area with this where you actually write some of your own notes, I mean nurses keep notes anyway so, perhaps it's important to say this compliments your notes, it</p>	<p><i>Emphasis on Note-Taking</i></p>	<p>2 – p.14</p> <p>3 – p.10/11</p> <p>5 – p.6</p> <p>5 – p.8</p> <p>5 – p.9</p>

<p>doesn't replace your notes and your impression of your patient"</p> <p>"It's not something that's just in isolation and that's, I guess, why annotating after you've done these is important in terms of how they perceive what they've been told, urmm, or what they've observed, what they've advised as a result and importantly what they plan for the next contact with that patient"</p> <p>"we use electronic notes here anyway, so I really don't want to start generating paper again"</p>		<p>5 – p.9</p> <p>6 – p.13</p>
<p>"if that's incorporated as part of their, their natural reporting for the patients"</p> <p>"it's about getting that as part of the general reporting of how the patient is, part of the, part of the note-taking rather than having fill this in [<i>referring to QOL measures</i>] and then write more notes ... making it user friendly in a way that it's something they find easy to incorporate into the note-taking, into the recording that they already do"</p> <p>"it would be easier on our support-line, it's a small number of nurses led by someone who will either think "yeah, this is a really good idea" or "no, we're not doing it""</p> <p>"basically, I feel like we should change our model of consultation rather than just adding another something on to it all the time and it would be helpful if patients were able to flag up problems before they came to see us"</p> <p>"over the years, with information giving, I've tried all sorts of things, I've tried all sorts of efforts, from putting lots of leaflets in pamphlets and I've had a lot of people come up to me and say "oh, that was great, lots of information", or "too much information at once" [<i>slight laugh</i>], so again, no you can't. So, I think now we take the approach of it is there if you want, cos I think it is a lot out there now"</p>	<p><i>Implementation Strategies</i></p>	<p>2 – p.14</p> <p>2 – p.14</p> <p>5 – p.7</p> <p>6 – p.8</p> <p>8 – p.13</p>
<p>"If they could do it online or something, something that flags the areas, in some kind of way, that, you know, might be of concern, so they can concentrate on those but being aware of the others as well. Ummm, I think the less the nurses have to do any paperwork and the more intuitive a system could be to say they talked about staying in bed all day, as a red flag"</p> <p>"majority of people that have cancer are over 60, urmm, so, although, I do have to say, my mother is 81 and extremely good on the computer ... so, that's one restriction, although, that's going to change, in your lifetime, that will change, because people will be more technically aware"</p> <p>"stick it online and mean that they can click it and it's not another piece of paper, while it's a piece of paper, it's something to lose, something to mislay, something to forget to fill in, but if it's something that's part of the, if it's part of something they always do, within their existing checks, it will be easier"</p> <p>"Would they do them online? A lot of our patients are elderly patients, urmm, and getting onto a website and trying to fill in a form – some might, some are brilliant"</p>	<p><i>Online Versions</i></p>	<p>1 – p.12</p> <p>2 – p.13</p> <p>2 – p.15</p> <p>3 – p.9</p>

<p>at it, urmm, but I don't think it's something that would happen very often"</p> <p>"I think they could help with follow-up care"</p> <p>"Some people question how people would cope with the technology but I think they underestimate how many patients do - even the older patients - do have phones or computers that would be able to do that. I know they've used IT buddies to try and link up with the ones that found it more difficult as well, so there's ways around it and I think there is scope for it to work because, like I said, these patients live for a long time, we need to continue monitoring them and treating them and this is a way of doing that and then feeling that they've got a bit of control there, there's a little bit of self-management there, urmm, but then they can get in touch with us as well, so I think there's definite scope for them"</p> <p>"Even if the patients couldn't do it at home, they could do it in the waiting room, they could do it on a tablet that they did, if they did discreetly by themselves, rather than someone talking to them about it. And you know, if everyone was doing it when they walked in that would be routine then wouldn't it? Nobody would be thinking twice about what they were doing, you'd come in, you'd book in, do your little thing and then it would come up on my screen before I go in to see them, it would be great"</p> <p>"we use electronic notes here anyway, so I really don't want to start generating paper again but also it means that data capture is a lot easier so you can actually see where the gaps are and that's the whole idea isn't it, if you can, if we can see where there are gaps and we can see that there's a pattern to the need that's required then we can step in earlier and prevent that need occurring, potentially. You know, so you can amend your service then can't you? You can only do that if you've got electronically"</p> <p>"We have got versions of these Quality of Life's on tablets, the sponsors, they provide the tablets and then we give the tablet to the patient for them to fill it in"</p> <p>"Yeah, and I think most of the patients I think are fine with the electronic tablets that we give them, but they are very few and far between, it is generally if we do use the Quality of Life's in clinic it is paper copies, urmm, yeah. But, yeah, I am absolutely fine with the tablets, I've got no problem at all"</p> <p>"I think I've got one where they fill it in on an app, I think. I think somewhere, I think so. People like their smartphones don't they, they'll happily get their, open an app and do it"</p> <p>"for us doing them, clinicians, it takes longer, which is why it's easier for it to be done on an electronic and sent into us, so we can have open discussions"</p> <p>"But then if you do it on an electronic, and a problem I had recently, two patients who sent it in and I think they had problems with children and, urmm, the meaning of life, so then opening that conversation can be quite difficult, it's like ok, where do I go with this?"</p>		<p>6 – p.11</p> <p>6 – p.12</p> <p>6 – p.12</p> <p>6 – p.13</p> <p>7 – p.10</p> <p>7 – p.10</p> <p>7 – p.10</p> <p>8 – p.12</p> <p>8 – p.12</p>
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<p>How do I open this conversation? How do I signpost them to services that are going to help?</p>		
<p>“I think you’ve got to, maybe there needs to be an area with this where you actually write some of your own notes, I mean nurses keep notes anyway so, perhaps it’s important to say this compliments your notes, it doesn’t replace your notes and your impression of your patient”</p> <p>“in a multidisciplinary team, for me as a breast care nurse, worked because I fed into the surgeons impression and all the radiologists, and they fed into mine which I took forward into a clinic setting to the point where”</p> <p>“I fed my learning and perceptions into a multidisciplinary team role”</p>	<p><i>Multidisciplinary Involvement</i></p>	<p>5 – p.9</p> <p>5 – p.9</p> <p>5 – p.9</p>
	<p>Facilitators</p>	
<p>“from a patient’s point of view, I think that your life-style things, you’re showing that you acknowledge that it’s not just about what chemo they’re having, it’s not, you’re talking about every kind of thing around this”</p> <p>“I suppose we always assume that everybody’s got somebody at home looking after them, but a lot people don’t, so, that would be useful in, “do you live on your own? Is there somebody who is able to take care of you?”, they’re quite important question”</p> <p>“as a tool for somebody new, maybe it would act as a guide and perhaps stop people then saying “well, nobody asked about my financial situation””</p>	<p><i>Covers Range of Topics/Issues</i></p>	<p>2 – p.12</p> <p>2 – p.12</p> <p>5 – p.6</p>
<p>“I think it does gives you a sense of, reminding you, and I think especially for maybe less experienced nurses, who are not used to doing that kind of thing, it gives them a structure for what they need to do”</p> <p>“if there were people that were new to Lung Cancer, as well, it could be a really, good, you know, it could be a good prompt”</p> <p>“People who didn’t have all that experience wouldn’t have done that, so having that questionnaire sometimes can be very, very useful for your more inexperienced people. But you’ve got to start thinking for yourself as well, that’s the dangerous thing, the professionals’, they’re working to a script, rather than working to the person”</p> <p>“something like that would be helpful that then raised red flags or had self-management, because a lot of things that we try to do, it’s not causing increased reliance on health services but to aid self-management is really important”</p> <p>“I have actually noticed that sometimes a patient will actually tell me that they’re fine and that they don’t have a problem and then when you do actually look at their Quality of Life form that they filled in for you “well, ok, you didn’t tell me you felt tired and you didn’t tell me you felt a bit depressed”, and those are the sorts of things that if you do actually look at them, that could prompt you to look a bit further then, you know, these can prompt you to actually talk and ask</p>	<p><i>Identification of Cues/Issues</i></p>	<p>1 – p.10</p> <p>2 – p.13</p> <p>4 – p.15</p> <p>6 – p.8</p> <p>7 – p.9</p>

<p>the patient “well, hang on a minute, are you feeling tired? Because you didn’t tell me””</p> <p>“I think when you do look through them and what they’re asking, there are certainly a lot of things that could prompt you, urmm, especially if they’re having treatment, like the nausea and the lack of appetite, those are the sort of things you can address, because that’s a side-effect you can do something about it, so they’re good prompts for you to start conversation with a patient”</p> <p>“I think they’re brilliant for that, maybe just to prompt people if they are having problems with that difficult thing, especially, not so much in Upper GI, more so in Colorectal, the sexual function is often an issue, so that’s a problem that people find very difficult to talk about and it can help, you know”</p> <p>“I do find it opens up a lot of things”</p> <p>“I think we sometimes think “oh, yeah I know what’s wrong”, but actually it’s not just about us, it’s about what they think, what they feel, urmm, so I think listening, again, listening to what they’re saying, so I think that’s where it has had an impact”</p>		<p>7 – p.9</p> <p>8 – p.11</p> <p>8 – p.12</p> <p>8 – p.13</p>
<p>“because they’re standardised there will be questions that sometimes you may not ask, but if you knew you had to cover those questions, I think you’d get a more standardised approach to be able to measure what was going on”</p> <p>“if you’re looking ongoing and somebody says, “well how do you prove the benefit of what you do?”, having something like this that you could say ”well, when people first started calling they scored all 4s, and the last call they scored all 2s”, then we can say “that’s a measure of our successes” in a way, or how our supporters assisted those people. Ummm, from our point of view, again, you could say “well, we know this works because, you know, the way we’re approaching it is the right approach”, and if it’s not working then we can say “well, what do we need to do different”, so as a team it could help us to develop, maybe, the way we approach different things, even if it’s just specifically lung cancer patients, whose outcomes might not be that good”</p> <p>“What I can tell you, my experience with chemotherapy, I went on a trial, and I think it was every 3 months or something, they sent me a booklet of about 30, to do with the trial, and all of these were on it [<i>referring to QOL questions</i>], and I filled it in. I can’t remember if it was done every 3 monthly or if it was done 6 monthly, or even every monthly I couldn’t tell you, but I had a booklet in an envelope, I filled it out on my own time at home because it was explained to me, a trial nurse spent an hour with me, explaining all of these things, and this is where, perhaps urmm, I’ve got that privilege on the support-line where I can give them that time, whereas the nurses on the unit haven’t got that time. So, that was, you know, and I could fill it in truthfully there, urmm, on the trial, so that is, perhaps, something you could look into”</p> <p>“it was part of a trial and you were filling that in even if you didn’t feel like it because it would benefit</p>	<p><i>Measurable</i></p>	<p>1 – p.11</p> <p>1 – p.11</p> <p>3 – p.10</p> <p>3 – p.10</p>

<p>others behind you. So, there was reason behind it, where, perhaps, if I read this list now to my patient, “well, why do you want to know all these things then?””</p> <p>“it standardises responses and things, so you’d get less experienced people being able to respond to that”</p> <p>“I suppose in terms of being able to sort of recall that you’ve touched base on these kind of things, if that’s the way you want to use this tool, urmm, you would have some record of that and you could reference back”</p>		<p>4 – p.13</p> <p>5 – p.6</p>
<p>“So, it had its uses, so, you got the patient to prioritise”</p> <p>“especially for inexperienced nurses this is a great way to help get them focused on perhaps important things but also there’s a little bit of me that’s saying if you chose to go into this then you should have something set that these things are important anyway”</p> <p>“sometimes it’s not always the main focus of what people want to do, sometimes they want to talk about one thing and until you fix that one issue for them, they can’t possibly think about form filling or, urmm, assessments or things like that because that one particular thing, whatever it may be, is just taking up all of their energy and their thoughts”</p> <p>“For me sometimes, what it does do, it flags up, it might flag up something that I didn’t necessarily think was going to be the priority and then actually you think “oh, ok, actually I hadn’t thought about that””</p>	<p><i>Encourages Prioritisation</i></p>	<p>4 – p.13</p> <p>5 – p.6</p> <p>8 – p.11</p> <p>8 – p.13</p>
<p>“it standardises responses and things, so you’d get less experienced people being able to respond to that”</p> <p>“it gives you a tool then to ask, that’s a difficult question to ask”</p> <p>“So, I think something like this has added value in feeding into that [<i>multidisciplinary team</i>], and if it makes nurses more confident to do that, that’s a great tool isn’t it? So, you know, it would have a role there as well, but you know, they need to use it with some judgement as well”</p>	<p><i>Increased Self-Efficacy</i></p>	<p>4 – p.13</p> <p>4 – p.14</p> <p>5 – p.9</p>
<p>“It gives you a good basis for what exactly people are dealing with, as long as they answer them realistically, and I think that’s the problem, a lot of people, like for instance this question “a long walk”, what does that mean to somebody, for somebody who’s never done any exercise, a long walk might be to the end of the street, but for somebody who walks 3 miles a day, a long walk might be 10 miles”</p> <p>“So, it’s qualifying, really, the questions, isn’t it? Urmm, and sometimes it’s quite subjective”</p> <p>“everybody is different, you have no idea when you speak to that person on the phone, what side-effects they’re going to get, they could get all or none, and there’s no knowing where they are on that, so, that’s a real difficult thing sometimes”</p>	<p>Barriers</p> <p><i>Subjectivity</i></p>	<p>1 – p.10</p> <p>1 – p.10</p> <p>2 – p.15</p>

<p>“the other thing about the things about being short of breath, hang on, right so, “during the last week were you short of breath when you walked?”, were you short of breath before? ... Are you more short of breath?... but if you don’t know how short of breath they were at the start you’ve got no baseline ... You need a baseline”</p> <p>“people will interpret that slightly differently from, like if you’ve got a newly qualified nurse, they’re going interpret it totally different from me who’s got 30 years experience, you know, they’ll say “oh, you said about that wee bit there”, and a lot of things they’ll say is questions about sexuality or stuff like that and, urmm, and maybe if they leave a bit blank, I’ll say “oh, you left that bit blank, nothing happening there?”, but they’ll just ignore it”</p> <p>“There you go, and looking at that final score, urmm, but I think it still comes back to the skills of the individual nurse in interpreting what these all mean”</p> <p>I think a human being is more than just a number at the end of it, does that make sense? It’s about intuition, and it’s about that if you’d seen a patient, body language is really important, on the support-line, I suppose, it would give you a quick, sort of, picture of the patient”</p> <p>“I don’t think that there’s a problem per-say in any of these questions, or, you know, if you want to rate them or get a score, it’s just that what do you put that score against, what does it mean for you as a practitioner, do you only look at the score at the end of it?”</p> <p>“generally I don’t help them fill it in because it is very subjective, cos I have a lot of people asking me “well, what’s a long walk?” and I say “well, that is subjective for you, what is a long walk for you?”, so that’s how I would actually get them to fill it in, because, you know, a long walk for me might be a very short walk to somebody who walk the Brecon Beacons miles every day”</p> <p>“it is very subjective, so that’s what I tell patients when they’re filling them in, “it is very subjective but it is about you, what you think”, and I also do tell them not to take too much time thinking over the questions, to actually answer what they think instinctively, and I think you probably get, I think if you spend too much time thinking about the answers, you get do muddled I think, so I do tell them not to spend a huge amount of time trying to fill it and to try and do it instinctively”</p>		<p>2 – p.15</p> <p>4 – p.14</p> <p>5 – p.8</p> <p>5 – p.8</p> <p>5 – p.9</p> <p>7 – p.11</p> <p>7 – p.11</p>
<p>“For some people, it depends how they feel when they fill it out. If they’re having a good day, sometimes their answers are better than they actually are, if they’re having a bad day then sometimes they’re worse than things actually are”</p> <p>“I think sometimes with the emotional side of stuff it depends how you’re feeling on the day, like today I’m having a good day, you know, and I’m quite happy and upbeat, tomorrow I might be feeling like shit, so, so you get totally different answers, you know”</p>	<p><i>Emotional Change</i></p>	<p>1 – p.10</p> <p>4 – p.14</p>

<p>“It’s going to change, it’s a dynamic thing because client’s will change their focus of what’s important as they do that journey through what’s going on with them in terms of treatment and in terms of, you know, their mental health because that’s going to change as well”</p> <p>“When do you use them? Because if things are going to change weekly, probably; and again for some people, interestingly enough, I’ve given them to some people and I’ve asked them all “identify your 3 main?” but then they tick everything [<i>referring to HNAs</i>], you know; and I’ve had some people who, when I’ve tried to do the assessment afterwards and say “oh, look there’s a problem with this”, and they say “oh, well not really, anymore but I had to put something down””</p> <p>“patient’s problems change from week to week and it doesn’t matter how many times we feel like we’ve addressed everything, we haven’t, or it feels like no matter how many times we ask cos people will only tell you what they want you to know at that point in time and 3 weeks later they’ll be like “well, nobody asked me about such and such””</p>		<p>5 – p.7</p> <p>8 – p.11</p> <p>8 – p.12</p>
<p>“What I can tell you, my experience with chemotherapy, I went on a trial, and I think it was every 3 months or something, they sent me a booklet of about 30, to do with the trial, and all of these were on it [<i>referring to QOL questions</i>], and I filled it in. I can’t remember if it was done every 3 monthly or if it was done 6 monthly, or even every monthly I couldn’t tell you, but I had a booklet in an envelope, I filled it out on my own time at home because it was explained to me, a trial nurse spent an hour with me, explaining all of these things, and this is where, perhaps urmm, I’ve got that privilege on the support-line where I can give them that time, whereas the nurses on the unit haven’t got that time. So, that was, you know, and I could fill it in truthfully there, urmm, on the trial, so that is, perhaps, something you could look into”</p> <p>“it was part of a trial and you were filling that in even if you didn’t feel like it because it would benefit others behind you. So, there was reason behind it, where, perhaps, if I read this list now to my patient, “well, why do you want to know all these things then?””</p> <p>“a bit too personal in some, some areas, so “well, what are you going to do with this information then? Is it going to help me?”, urmm, and perhaps, not necessarily because next time you might see a different nurse and she’s not going to have time to look at this or she’s going to ask you the same questions again, so what’s the point? “What do I get out of this? Because it takes me a lot of effort to answer these questions””</p> <p>“There you go, and looking at that final score, urmm, but I think it still comes back to the skills of the individual nurse in interpreting what these all mean”</p> <p>“New junior nurses ... they need to have the tools to translate what these questions mean and what they’re action then is going to be in what those results are”</p>	<p><i>Lack of Clarity on Purpose</i></p>	<p>3 – p.10</p> <p>3 – p.10</p> <p>3 – p.10</p> <p>5 – p.8</p> <p>5 – p.9</p>

<p>“it is very generic so we’re looking at trying to get more prostate specific questions for that group, otherwise it’s just a tick-box exercise”</p> <p>“you’re just doing it because you’ve been told to do it, and then the people who’ve told you to do it don’t even know why they’ve been told to do it, when you actually look at where it’s come from, there’s not much there [<i>slight laugh</i>]”</p> <p>“Generally, we use them because we’re told to use them as part of the study, the study want them, and generally we, I don’t normally look at them, so when I looked through them before the interview I was like “oh, well perhaps I should look through them a bit more often” ... maybe there’s some advice you give them or some sort of intervention that can help with that”</p> <p>“When do we do it? How often do we do it? It’s not clear cut, so I do think that does impact on us”</p>		<p>6 – p.8</p> <p>6 – p.8</p> <p>7 – p.9</p> <p>8 – p.14</p>
<p>“I’ve looked at them, and again, on the man van we had, urmm, the, I think it’s the EORTC-15 or something, regarding the Prostate Cancer, and I looked at them and I, urmm, these you can, ok, they’re not too bad, but when you’re talking about people’s religion, people’s beliefs, people’s spirituality, and people’s sexuality I don’t think you can ask a question and tick an answer, so what we tended to go towards was, well, some of these, “are you short of breath when you walk?”, well, I can tell if they’re short of breath by the way they are actually speaking, and if not I’m saying, well you know, “have you been for a walk today?” or “how was your mobility? How are coping doing the housework?”, and that is something that you have in a conversation, and you can learn so much from a general conversation with a person that you can answer most of these questions [<i>referring to QOL measures</i>]”</p> <p>“the impersonality of it ... perhaps the patient is unwell, you don’t know, urmm, the patient’s understanding, urmm, could they, a lot of patients forget their glasses at home, so can’t fill in forms, urmm, “you can read it to me if you want and I’ll tell you the answer”, that is something that’s often used, especially with older generations, and again, chemotherapy can cause lack of concentration, so giving them a form they couldn’t concentrate on it”</p> <p>“Even the ones that are disease-specific, they do come up with things that that patient isn’t experiencing and then they go “oh, should I be having that? Should I be feeling like that?”, no, it’s ok [<i>laughter</i>]. So, sometimes those, kind of, QOL things aren’t great”</p> <p>“I think the only, sort of, practical issues really, are that we use one, there is one questionnaire that says “where is your pain?”, well, if they haven’t got any pain then they can’t answer that”</p>	<p><i>Inappropriate Method</i></p>	<p>3 – p.8/9</p> <p>3 – p.9</p> <p>6 – p.9</p> <p>7 – p.11</p>
<p>“I think the problem would be, for me, that if it would be used in the wrong way, that when you’re ringing somebody then, it’s just a survey, urmm, and that takes away from developing of any sort of relationship”</p>	<p><i>Structure</i></p>	<p>1 – p.11</p>

<p>“if you focus too much on just answering the questions, there might be things that you miss because, you’re like “I know I need to fit all these bits in” but then they’re telling you something maybe about a family member that doesn’t come into this, that’s having a major impact on them, urmm, but you’re too concentrated on what you need to complete”</p> <p>“The only problems with forms that have numbers on, is that you go from 1 to 10, and a) you might have already got the answer to number 7 when you asked about number 1, as you’ve found out today, urmm and it’s keeping track of what you’re doing, so they’re an ideal prompt if they’re used it as that, urmm, towards people that have not got the experience, so it’s not just, you don’t forget the important things that you need to ask, but because then everybody finds their own flow, and obviously you’re talking to somebody you have no idea what they’re going to say to you, so they may stick something in half way through the conversation that is not in the order, for that”</p> <p>“you’re constrained by numbers”</p> <p>“it may be something that you could introduce after you’d built a little bit of a relationship with them, urmm, because if you are going to be asking them about whether they worry about dying, that’s a hell of whack, you have to have a whole phone call on that, that’s, that’s not, that’s not answer that and we’ll move onto this one”</p> <p>“we would use these as a guideline and, urmm, and not ask the specific questions, because it felt so cold and just not right somehow, just to ask a list of questions”</p> <p>“when you’re asking somebody who’s got cancer those sort of spiritual questions, it’s quite hard but if you, if it comes out in the conversation you’re having anyway it flows, and in fact you get more information. It’s a natural flow, yeah”</p> <p>“it’s being able to give some practical stuff as well, and not “oh, that’s a terrible thing that you’re feeling like that” and then move on to something else”</p> <p>“People who didn’t have all that experience wouldn’t have done that, so having that questionnaire sometimes can be very, very useful for your more inexperienced people. But you’ve got to start thinking for yourself as well, that’s the dangerous thing, the professionals’, they’re working to a script, rather than working to the person ... they work from a script, they don’t deviate from the script”</p> <p>“to go through a questionnaire in a very formal way could be very off putting when you’re face-to-face with people”</p> <p>“if I’m communicating with somebody I don’t want to be, sort of, doing this as well [<i>miming looking up and down from a piece of paper</i>], I find it breaks my flow”</p>		<p>1 – p.11</p> <p>2 – p.12</p> <p>2 – p.13</p> <p>2 – p.13</p> <p>3 – p.9</p> <p>3 – p.9</p> <p>4 – p.14</p> <p>4 – p.15</p> <p>5 – p.6</p> <p>8 – p.12</p>
<p>“I suppose, if you’re looking ongoing and somebody says, “well how do you prove the benefit of what you</p>	<p><i>Organisational Issues/Concerns</i></p>	<p>1 – p.11</p>

<p>do?”, having something like this that you could say “well, when people first started calling they scored all 4s, and the last call they scored all 2s”, then we can say “that’s a measure of our successes” in a way, or how our supporters assisted those people”</p> <p>“Nurses in a unit have so limited time to sit down with people, that they might just hand them it, very often, and it’s a tick box exercise then, they know it needs to be done so they just fill it, to do it. So, it then becomes a waste of time and eventually fades into the background instead of being used as a tool to develop themselves and to help them develop services that the patients might need. I don’t think, it’s not done maliciously, it’s just literally another piece of paperwork and, you know, the NHS is drowning in paperwork, bless them. So, it just, it’s something that’s put to one side probably, it’s a “oh, that’s something else I need to do later”, and then just gets forgotten”</p> <p>“Time... time, another bit of paper ... it’s time, it’s time, it’s always time, time and people, I’m afraid”</p> <p>“nurses feel, especially in a chemo unit or something like that, they haven’t got the time to sit down with the patient and discuss, the only time they have is when they’re giving the chemotherapy and that is usually, that time is taken up with “how have you been during your last cycle?”, or explaining what the chemotherapy is about and what to expect”</p> <p>“it’s a time factor again, and communication skills, and not only verbal communication skills and listening but writing skills, writing the notes, you know, if I’ve got a patient and I’m phoning this week on a primary call-back, because again we, different nurses call this patient”</p> <p>“I know holistic care and, urmm, patient’s individual rights and doing what’s best for the patient has been sort of the crux of nursing in all time but on a hospital ward, urmm, you’ve got to have structure and they can clash ... so, it’s finding the, I don’t know, the, sort of, middle ground really”</p> <p>“it was the Distress Thermometer, so you get a quick glance from that, then you, well, I had 10 patients, the clinic went from 9 til 1 o’clock, and this took half an hour to do, so, you know, so we tried to do it, we tried other ways like giving the patient the questionnaire before, then we’d have this list of stuff that was bothering them, you could only tackle 1 or 2 in the time that you had with them”</p> <p>“I suppose it’s about do they know about them, you know, in the middle of all this busy life they’ve got, urmm, do nurses know about them, has the management embraced them as something that they’d like nurses to incorporate into their practice, because they might be seen as something going on there, that a nurse would like to use it but the management doesn’t, you know, because things should come together”</p> <p>“I would’ve thought straight away people would put their hands up in horror and say “another piece of</p>		<p>1 – p.11</p> <p>2 – p.14</p> <p>3 – p.9</p> <p>3 – p.10</p> <p>3 – p.11</p> <p>4 – p.13</p> <p>5 – p.7</p> <p>5 – p.8</p>
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<p>paper” because, you know, they really have got a lot of paperwork to complete”</p> <p>“we’ve been told that these are what we should be doing, but when we look at the evidence, there isn’t a huge amount of evidence that there are actual health economics behind it which is important because it does take quite a lot of time to do it formally if you do the way that this one is”</p> <p>“intuitively it seems like a good idea, but it has got to work and to provide benefit for the patient and not just open up a load of things that then you can’t sort out”</p> <p>“I think the problem is, as we’ve taken on more roles, like prescribing, probably our consultation models have become a bit more medical. Although, I like to think I can include in there the whole person and not just about their prostate, but you’ve got your limitations in there as well, and if you can get everyone thinking like that, the Doctors as well [<i>slight laugh</i>], that would be, you probably wouldn’t need any of this [<i>slight laugh</i>], urmm, but it is, sometimes it just feels like a process, that’s when I feel miserable really, it feels like you’re not doing your best to them”</p> <p>“Our MacMillan colleagues are now telling us it takes about 6 minutes to a Holistic Needs Assessment, it might take them 6, it will take me about 40, because once patients tell me there’s a problem I can’t just say, it’s different if they do and they’re ticking boxes and you then explore it. So, for us doing them, clinicians, it takes longer, which is why it’s easier for it to be done on an electronic and sent into us”</p> <p>“I think the slight pressure we feel to use them for everybody is a slight negative, because I think we’re doing it anyway but recording it we’re not so good at, so the fact now that we have to make sure we do one on everybody and we record, and again, it’s this when do we do it? How often do we do it? It’s not clear cut, so I do think that does impact on us”</p> <p>“If they were easy and straight forward and they worked you’d think they’d probably be there by now but they’re not. Which tells me something, it tells me they’re not easy to do, personally I think they should be done by non-clinical people because, as I say, MacMillan are saying in they can do them in 6 minutes, well if you have somebody sit down and do that in 6 minutes and they refer it on to clinician, or it’s done in the GPs surgery with somebody, I think that’s where we’re heading, because the minute you sit down with the clinician and do it, you’ve got to address, you feel the need to address every problem that’s there at that point in time”</p>		<p>6 – p.8</p> <p>6 – p.8</p> <p>6 – p.9</p> <p>8 – p.12</p> <p>8 – p.13/14</p> <p>8 – p.14</p>
<p>“as individual nurses we probably have a sense of it just from the conversations we’ve had”</p> <p>“you can learn so much from a general conversation with a person that you can answer most of these questions [<i>referring to QOL measures</i>], urmm, and that’s what we used to do, we would use these as a guideline and, urmm, and not ask the specific questions, because it felt so cold and just not right somehow, just to ask a list of questions”</p>	<p><i>Experience Negates use of Tool</i></p>	<p>3 – p.11</p> <p>3 – p.9</p>

<p>“I would know the questionnaire off by heart, I know what I need to ask, I have my agenda at that clinical appointment, and I know what I need to ask”</p>		4 – p.13
<p>“when I worked in the man-van ... we never used the questionnaire, it was there, we’d fill them out after the patient went, we filled it in, so we did all those questions, you know it was, it was part of our practice, because we were experienced enough to know what needed to be asked and stuff like that and what to pick up on, what to, urmm, talk about another time, which bit was more important at that time”</p>		4 – p.15
<p>[referring to conversation had with client] “all this stuff came out, you know, and then he asked for money and she didn’t have any money to give him, so he stopped her seeing her granddaughters, you know and that was just from asking that question gave me all that information, and it’s having those skills and the confidence to really deal with those”</p>		4 – p.15
<p>“I would say that if you do the job for long for enough this forms part of a general conversation you’d have with someone, you know”</p>		5 – p.6
<p>“I would say that if you’re talking to a client that’s been in work, and they’re chatting to you about their treatment that you would ask those questions about work and about function, how they’re feeling psychologically, because if they say they’re feeling a bit low or I can see here it says “unable to enjoy life” or something like that, that would be something that you would explore without perhaps asking that direct question ... you would explore that because it’s going to be different for every patient or client”</p>		5 – p.6
<p>“I’d hope that a more experienced nurse would not need this, that it would come up in general conversation”</p>		5 – p.6/7
<p>“I’m not good at bits of paper but I am quite good at doing it without the bits of paper, if you know what I mean”</p>		8 – p.11

Appendix Twelve: Nurse Experience Theme Description Table

Theme/Sub-Theme	Definition/Description
Nurse Self-Efficacy	Nurse's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives and their nursing practice in particular (Bandura, 1994)
<i>Importance</i>	The significance of having belief in one's self and ability to succeed in their nursing role
<i>Mastery Experience</i>	Based on individual experiences of the nurse that raise efficacy expectations through the repeated perceptions of success (Bandura, 1994)
<i>Vicarious Experience</i>	Efficacy information gained from observing another individual, e.g. another nurse or a doctor, completing a task (Bandura, 1994)
<i>Persuasion</i>	When significant others, with credibility, prestige and expertise, employ techniques that influence the nurse's behaviour (Bandura, 1994)
<i>Nurse Experience/Continuous Learning</i>	Continually developing and improving one's nursing knowledge or skills to perform effectively and adapt to changes, acquired by a period of practical nursing experience
<i>Strong Nurse Identity</i>	Strong sense of their qualities, beliefs, values and personality that contribute to or characterise the participant's nursing identity
<i>Reflection</i>	The process of making sense of events, situations and actions that occur in the workplace (Oelofsen, 2012)
Quality of Communication, Self-Efficacy and Perceived Competence	
<i>Communication Skills</i>	Ability to convey and share information effectively and efficiently
<i>Counselling</i>	Necessary behaviours for giving advice to, assisting and guiding patients/clients
<i>Listening</i>	Nurses' ability to pay attention to and effectively interpret what is being said
<i>Cue Identification</i>	Prompts and informative behaviours that are conveyed from the patient/client, either verbally or non-verbally
<i>Probing</i>	Close inquiry and deeper exploration of certain aspects of the patient's/client's situation
<i>Adaptability</i>	Adjusting to new or changing events and issues to provide the most appropriate support
<i>Efficiency</i>	Achieving maximum productivity with minimum wasted effort when communicating, whilst being well-organised and competent
<i>Challenge-Approach Mindset</i>	Viewing stressful or competitive situations as opportunities to increase one's own set of nursing resources
<i>Building Rapport</i>	Developing mutual trust, friendship and affinity with a patient/client and the ability to identify and initiate working relationships, maintaining them in a way that is mutually beneficial to both parties
<i>Authenticity</i>	Nurses avoid deceiving the patient/client by being sincere and genuine in nature
<i>Self-Determination Theory (SDT)</i>	Theory that suggests people are motivated to grow and change by innate basic psychological needs: relatedness; autonomy; and competence (Ryan and Deci, 2000)
<i>Competence</i>	The need to gain mastery of their nursing tasks whilst also learning new skills, capable of achieving one's goals by successfully navigating their nursing environment (White, 1959)

<i>Autonomy</i>	The need for control over one's own life and the decisions one makes (Deci and Ryan, 1985)
<i>Relatedness</i>	Want or need to interact, be connected to and experience caring for others (Ryan, 1995)
Needs Satisfaction	Fulfillment of the basic psychological needs through their nursing behaviours (Deci and Vansteekiste, 2004)
<i>Increased Confidence through Experience</i>	Increased belief in one's ability to be successful in the various aspects of their nursing role through their nursing experiences
Facilitators and Barriers to Perceived Competence and Self-Efficacy	
<i>Facilitators</i>	Factors that promote or benefit the nurse's perceived competence and/or self-efficacy
<i>Importance of Coping</i>	The need or significance for coping mechanisms
<i>Adaptive</i>	Effective coping strategies that generally reduce stress
<i>Maladaptive</i>	Ineffective coping strategies that may increase stress
<i>Individualised</i>	Differences between individuals
<i>Positive Environment</i>	Settings and situations that make nurses feel valued and worthwhile
<i>Learning from Weaknesses</i>	Identifying areas of reduced experience, skill or knowledge and developing and improving these
<i>Protection</i>	The use of coping mechanisms to shield and conserve the nurse's mental health
<i>Work-Life Balance</i>	Level of prioritisation between personal and professional activities in the nurse's life
<i>'Faux' Confidence</i>	Projections of confidence that mask the nurse's insecurities and instil confidence in those receiving their care
<i>Coping Resources</i>	Efforts in thought and action to manage specific demands, responsibilities, problems, or difficulties in a calm or adequate manner (Lazarus, 1993)
<i>Barriers</i>	Experiences/events that create mental or physical effort and obstruct or impede the nurse's perceived competence and/or self-efficacy
<i>Lack of Experience</i>	Lack of practical nursing experience that impedes the development of knowledge and skills
<i>Challenging Conversations</i>	Conversations that are repetitive, spontaneous or that provide more challenges to overcome, whether tangibly, mentally or emotionally
<i>Need for Wider Knowledge</i>	Dealing with and needing knowledge about a large range of cancers and patient needs
<i>Stigma</i>	Perceived negative attitudes towards nursing
<i>Individual Differences/Needs</i>	Differences in the personalities, issues and needs of the patients/clients
<i>Managing Expectations</i>	Ensuring that all involved have a clear understanding of what to expect and when to expect it (Wick, 2013)
<i>Phone Conversations</i>	Nurse-patient communication and relationships that are initiated and developed over the phone, with no physical contact
<i>Lack of Closure</i>	Ambiguity and uncertainty around the fate or outcome of patients/clients

Appendix Thirteen: QOL Measures Theme Description Table

Theme/Sub-Theme	Description/Definition
Facilitators	Factors of QOL assessment measures that benefit the nurse or user
<i>Covers Range of Topics/Issues</i>	Large array of QOL-related areas that get covered using these measures
<i>Identification of Cues/Issues</i>	Recognises signals or areas for concern that had previously been overlooked
<i>Measurable</i>	Quantifies the QOL issues that patients/clients suffer from
<i>Encourages Prioritisation</i>	Identifies the most pertinent issues for both the nurse and the recipient
<i>Increased Self-Efficacy</i>	Improves nurses' belief that they can identify and effectively communicate about QOL-related issues
Barriers	Factors of QOL assessment measures that create challenges or obstacles to their use
<i>Subjectivity</i>	Responses can be influenced by individual feelings, opinions or biases and can therefore not be disseminated in the same way
<i>Emotional Change</i>	Feelings and emotions change and vary over time, so responses to certain questions may also change and vary
<i>Lack of Clarity on Purpose</i>	Unclear reasons and motivation for the use of these QOL assessment measures
<i>Inappropriate Method</i>	Not considered a suitable tool for QOL assessment
<i>Structure</i>	The structured nature of QOL assessment measures can be barrier to conversational flow
<i>Organisational Concerns/Issues</i>	Organisational level factors that limit the use or purpose of these QOL assessment measures
<i>Experience Negates use of Tool</i>	Knowledge and skills acquired through practical experience equips nurses sufficiently to deal with QOL issues
Considerations	Factors that require thought and deliberation when using QOL assessment measures
<i>Need for Further Exploration</i>	QOL assessment measure answers need thorough examinations and investigations to gain full understanding of issue
<i>Conversational Prompt/Guide</i>	Assisting the content of and direction of the nurse-patient discussions
<i>Need for Rapport</i>	Importance of a good, harmonious relationship between nurse and patient/client
<i>Timing</i>	Judgement over when to deliver/use the QOL assessment measures
<i>Emphasis on Note-Taking</i>	Still a need for patient information to be recorded and reflected upon
<i>Implementation Strategies</i>	Application and execution of specific action plans for delivering QOL assessment measures
<i>Online Versions</i>	QOL assessment measures being available online
<i>Multidisciplinary Involvement</i>	Involving members from the different healthcare disciplines who are part of the patient's/client's care

Appendix Fourteen: Modified Version of Drauker, Martsof, and Poole's (2009) Distress Protocol for Research on Sensitive Topics

Distress

- A participant indicated they are experiencing a high level of stress or emotional distress
- OR
- They exhibit behaviours suggestive that the discussion/interview is too stressful such as uncontrolled crying, shaking, etc.

Stage 1 Response

- Stop the discussion/interview
- One of the researchers will offer immediate support
- Assess mental status
- Tell me what thoughts you are having?
- Tell me what you are feeling right now?
- Do you feel you are able to go on about your day?
- Do you feel safe?

Review

- If participant feels able to carry on; resume discussion/interview
- If participant is unable to carry on; go to stage 2

Stage 2 Response

- Remove participant from discussion and accompany to quiet area
- OR
- Discontinue interview
- OR
- Encourage the participant to contact their GP or mental health provider
- OR
- Offer, with participant consent, for a member of the research team to do so

Follow Up

- Follow participant up with courtesy call (if participant consents)

OR

- Encourage the participant to call if he/she experiences increased distress in the hours/days following the discussion/interview

Pre-Data Collection

- The researcher should consider the potential physical and psychological impact on the researcher of the participants' description of life experiences
- The researcher should consider how many interviews could be undertaken in a week
- The researcher should be aware of the potential for emotional exhaustion

Appendix Fifteen: Reflexivity Statement

Personal

I am originally from a Sport and Exercise Science background and whilst conducting the present study I have been simultaneously doing a Sport Psychology MSc. The current study my first proper research study, meaning I have had a lot to learn throughout the process. This also meant that I came into this research project with limited scientific knowledge of oncology and the role of the nurses within it. However, I feel that I bring an interesting perspective from the field of sport psychology. In some respects, this lack of relevant experience has been a challenge and has likely led to certain areas of oncology nursing, self-efficacy and communication being overlooked. Despite this, it provides a fresh perspective in this discipline, offering analyses that may not always be considered.

Prior to this project, I have had personal experience of family and friends having suffered from cancer, including during the research. This gave me a better appreciation for the work that oncology nurses do, but also brought my own emotions to the surface. On one hand this was often a significant distraction and challenge I had to overcome, but on the other hand it provided me the motivation to complete the project.

Due to my experiences with oncology nurses (through interactions during the study and through my own personal encounters) being generally positive, this perhaps predisposed both me and the study to be less conscious of potential negative experiences and implications from poor nursing. Although this is arguably covered through the literature review, it was perhaps not a big enough consideration throughout the analysis and write-up stages of the study.

Another important factor that I overlooked is that I was a male researcher in a female dominated environment. This prevented me from gaining a full appreciation and understanding of the female nurses' role and perspective and the gender differences that occur in this environment.

Theory, Ontology and Method

Interpretative Phenomenological Analysis (IPA) was originally considered for the assessment of nurse and patient perspectives on a specific phenomenon, applied with a phenomenological ontology. However, issues with ethics curtailed this study. Therefore, further research was required, and this identified the importance for nurses of communication and self-efficacy and the role of self-efficacy within communication. This meant that the original phenomenological ontology remained as the study was still focused on human perspectives of experience. However, as there was now no specific phenomenon to assess, the IPA approach became redundant. The lead to the use of Thematic Analysis (TA) instead.

The lack of a formal structure for conducting a TA was daunting at first but ultimately allowed for more freedom when analysing the transcripts and the associated data extracts. Of course, this created a greater level of subjectivity within the analysis so constant reminders of the Braun and Clarke's TA guide and referral back to the research questions, to ensure the application of relevant theories, was crucial. Despite a theoretical/deductive approach being the desired method of analysis for this study, an initial inductive analysis was used to provide me with a broader starting point and helped to ensure that the more obscure data extracts were not missed. As this was my first time using TA, it allowed me to build into it and work out my preferred style of TA.

The interviews that were conducted started very well, as the nurses were engaging, easy to talk to and willing to offer as much information as possible. This gave me a good level of confidence for conducting the rest of the interviews. However, after a few interviews, I spoke to a nurse who was less forthcoming, and I felt that I had to work a lot harder during this interview. For me, this showed the importance of being patient during the interview but also the need to establish a better rapport with the participant prior to the interview and to be able to probe more extensively during it.