INTRODUCTION

In the UK 0.8 million people aged over 75 were admitted to hospital at some point in the last year of their life (Public Health England 2020). In Europe between 52% (France) and 76% (Austria, Slovenia and Israel) of the population aged 66-80 had at least one hospital admission in the last year of life (Overbeeck et al 2017). In England 81% of people aged 75 years and older had at least one hospital admission in their last year of life who died in 2017 (Public Health England 2020). As the aging population increases the utilisation of health services is predicted to increase among those aged 65-80 (Rechel et al 2009). In England the figure for hospital admissions in the last year of life is dropping, but there were still 227,272 deaths in UK hospitals in 2017 (Public Health England 2019) indicating that palliative and end-of-life care continues to be important in the hospital setting.

Despite this there is an emergent suggestion that in hospitals nurses' end-of-life practice may be challenged by a competing set of demands between treatment and ideas of palliation. The treatment focused nature of the hospital setting may challenge the principles of palliative and end-of-life care. Gott et al. (2012) revealed a perceived lack of responsibility for palliative care, with hospital nurses viewing their core task as treatment and not generalist palliative care. Ambiguity regarding the priority end-of-life care patients receive over curative routines, as well as a lack of understanding of the nature of end-of-life care has also been reported among hospital nurses (Bergenholtz et al. 2016; Gott et al., 2012; Dahlborg-Lyckhage and Lidén, 2010; Willard and Luker, 2006). A UK parliamentary report into hospital end-of-life care identified poor care and poor communication was a recurrent theme of complaints (Parliamentary and Health Services Ombudsman 2015). This implies care of the dying patient in hospitals is challenging. The outcome questions hospital nurses experience of providing end-of-life care and the competing priorities between treatment and palliation/end-of-life care. Consequently, this study aimed to find some clarity by understanding more about hospital nurses experience of providing end-of-life care. The findings of the study contribute to emergent knowledge and future research regarding end-of-life nursing care in the hospital setting. The findings also contribute to the development of hospital nurses' education, policy and practice.

Research question What is the lived experience of hospital nurses providing end-of-life care?

Objectives:

1. To understand hospital nurses' approach towards death

2. To explain how hospital nurses' authentic-self is negotiated when providing end-of-life care

3. To identify how hospital nurses use power and knowledge in end-of-life care situations.

DEFINITIONS

For clarity and consistency in this study the GMC definition for end-of-life and palliative care was used (see fig 1) (GMC 2010).

DEFINITION OF END-OF-LIFE CARE	DEFINITION OF PALLIATIVE CARE
Patients are 'approaching the end-of-life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: **(a)** advanced, progressive, incurable conditions **(b)** general frailty and co-existing conditions that mean they are expected to die within 12 months **(c)** existing conditions if they are at risk of dying from a sudden acute crisis in their condition **(d)** life-threatening acute conditions caused by sudden catastrophic events.	The holistic care of patients with advanced, progressive, incurable illness, focused on the management of a patient's pain and other distressing symptoms and the provision of psychological, social and spiritual support to patients and their family. Palliative care is not dependent on diagnosis or prognosis and can be provided at any stage of a patient's illness, not only in the last few days of life. The objective is to support patients to live as well as possible until they die and to die with dignity.
General Medical Council (2010)	

Figure 1 Definitions

METHODOLOGY AND METHODS

Interpretative phenomenology was used as the methodology to explore the nurses experience. The focus of interpretive phenomenology is on understanding the human experience of the *life-world* and is the method of bringing out and making visible human experiences that are normally hidden (Van Manen 2017; Lopez, Willis, 2004).

Discussing end-of-life can be an emotive topic. Visual research methods can offer ways of exploring emotions that language-based methods do not achieve, providing opportunities to express the unsayable and record meaning where verbally articulating a response is difficult (Manny, 2016; Kara, 2015; Gauntlett, 2015; Guillemin, 2004). Creative research methods were used but can be inhibitive for adults (Vaart et al 2018; Guillemin and Drew 2010). Consequently creative options were restricted to participants being asked to cut out images from a range of magazines and create a montage of visual metaphors representative of their experiences. Participants at the beginning of the interview were asked to silently reflect on their end-of-life care experiences and to select from the magazine images that represented how they felt when providing end-of-life care. Participants were left alone to freely complete this without the intrusion of the researcher. This was immediately followed by an audio recorded discussion of their images to explore further as an elicitation interview the meaning attributed to the visual metaphors.

The researcher had experience with the topic and environment as a nurse positioning them as a practitioner-researcher with an insider (emic) view of what is being studied, rather than an outsider (etic) position (Holloway, Biley, 2011; Jooton, McGhee & Marland, 2008). The shared vocabulary and understanding demonstrated from by this emic position dispersed any power or authority held and nurtured a relationship with the participants that contributed to an honest disclosure of experiences. The interviews were structured to be free flowing, with participants answering questions, but simultaneously engaging in conversational forms (Holstein, Gubrium, 2011). Wengraf's (2001) model of lightly structured interview preparation, as a set of trigger questions, an interview schedule was used. The average length of each interview, including selecting images, was 120 minutes.

Participants were enlisted following a recruitment campaign in targeted hospitals and post registration University courses. The eligibility criteria for the participants was; registered adult nurses practicing with experience providing end-of-life care in the secondary care setting. Potential participants were excluded if; they were not registered nurses, were not adult nurses or did not have experience of end-of-life care in the secondary care setting.

Ten participants were recruited following a recruitment campaign in three hospital trusts and post registration University courses. All the participants were registered general adult nurses with clinical experiences of providing end-of-life care in the acute hospital setting. Recruitment was slow taking 18 months to achieve a sufficient number. This was directly attributed to the creative aspect of the interview (Vaart et al 2018; Kara 2015). All 10 participants were female with a mean age of 47 years and a mean of 26 years in nursing. All the participants had experience providing end-of-life care in the secondary setting, 6 at the time of recruitment were providing frontline care. Participants had a background in surgical care, rapid response, A&E, critical care, high dependence, coronary care, urgent care and ITU.

DATA ANALYSIS

The elicitation interviews were conducted to obtain details regarding the visual metaphors and the participant intentions to arrive at common concepts integral to the experience. The interview audio was transcribed and data was analysed following Ricoeur's approach to hermeneutics, which is to determine the meaning of the text by interpreting the intention of the author (Ricoeur 2016).

The text was read with an explanatory attitude and then with an interpretive approach (Ricoeur, 1981). The researcher followed Ricoeur's method of structural analysis to achieve this by moving between a series of possible interpretations of the text which are tried against potential explanations and either dismissed, or accepted. Using the participant Mary's Professional Hat metaphor as an example the structural analysis was informed by a triangle of interpretations; the text itself, semantics and a series of interpretants. Different judgements of Mary's explanation and meaning of the image of the hat were explored (*fig 2*). Notes were taken on possible meanings and links to similarities with other areas in the texts to substantiate or dismiss the meaning, facilitating a reasoned interpretation and understanding (Ricoeur, 1981, 1984). Explaining the text was a duel process being both deductive and inductive. The connection with the text and events Mary described about the hat is a deductive process. Making judgements on the latent factors being inductive, giving weight to opposing arguments and defending, evidencing the reasons (Ricoeur, 1984). Following this process, interpretation was supported and mediated by the text, with ideas of interpretation being supported or dismissed (Ricoeur, 1981). Mary's idea of the hat and the meanings attributed were explored in the other 9 participants transcripts. The interpretation of what was meant by Professional hat; an emotional buffer, was informed by this process. The final stage was appropriation which Ricoeur describes as 'to make one's own' the actualisation of meaning, its base firmly set back in the ground of the lived experience (Ricoeur, 1981 p. 147).

EVIDENCED	NOT EVIDENCED
Identity Protection Emotional buffer Personal-Distance	Physical hat Avoidance

Figure 3 Unicorn (Mary)

FINDINGS

Analysis of the participants discussion led to the development of several themes that explained hospital nurses' experiences of providing end-of-life care. What follows is a summary of these themes: 1 Hospital nurses' approach to end-of-life care, 2 Hospital nurses' protection of Self, 3 Hospital nurses' use of authority in end-of-life care.

Hospital Nurses' Approach to End-of-Life care

The nurses in this study demonstrated that their individual approach to death was a significant influence on how they provided end-of-life care. This was based on a belief that a good death should be calm and tranquil with the nurses describing the process leading up to the final stages as 'stormy'. After the

trauma the aim of treatment, for most of the nurses in the study end-of-life care was about creating calmness. Louisa explains; "*making your patient comfortable, clean and hair brushed, actually what you are saying is it's calm and look how well looked after dad has been and loved*". This is echoed by other nurses in their descriptions of how they manage the hospital environment for their patients. In particular Virginia describes the peace she tries to create to shield patients from the busy ward.

As well as *calm* the nurses described an approach towards end-of-life care of *human-connection*. This was presented as the person not being alone, being with family as well as knowing the person as an individual. Barbara's exposure to death in A&E led her to believe in the importance of identity, which she describes as "getting alongside the person" by making the effort of getting to know something about them. Her metaphor of a bird represents a patient who she knew was a keen bird watcher, knowing this and taking the time to be interested as he was dying Barbara felt was important in "getting alongside" him and preserving his identity. For Martha the presence of another person is essential, without human connect death becomes a cold forest and the forest needs to be made warm by human presence in end-of-life care.

A third approach towards end-of-life care that was evident from the nurses' experiences was *death-as-process.* Louisa describes "grotty situations", they are physical, "brutal", involving body fluids, end-of-life care can be "a physical thing" and *death-as-process* hides the physical trauma.
This is the 'doing' of care and for several of the nurses this was about the environment. Remarkably Ethel uses the metaphor of a 'shawley blanket' for making the environment homelier. Her encounter with a dying patient who brought her shawley blanket from home, reminded her of this. When she died, the patient's family commented the shawley blanket made a difference; *"bringing home into the place".*

The dominant approach to end-of-life care was calm, but this was not exclusive, with the other approaches being interwoven explaining hospital nurses' end-of-life care is influence by these three concepts that construct the nurses' idea of what end-of-life care should be, leading to their individual ideas of a good death and end-of-life care.

Hospital Nurses' Protection of Authentic-Self in End-Of-Life Care

The nurses' experiences of end-of-life care indicate when engaging in such care they protect their own emotions to enable them to continue to deliver end-of-life care. The hospital nurses in this study described two forms of protecting their authentic-self from the emotions encountered while providing end-of-life care; *professional-identity* and *defence-of-self*. Protection as *Professional-identity* utilised nursing's professional image to distance the nurses' authentic-self from the situation and contain emotions in end-of-life care situations by being a professional nurse and emotionally removed. Mary uses and image of a hat and describes when having her professional hat on she is protected from getting too involved in the patient who is dying. *When I go home to my family, I take my uniform off. (*Mary)

In this example of protection as *professional-identity* Mary describes how she uses her uniform as an emotional buffer, protecting her authentic self. Hilde and Louisa hold similar views, using the role of being a nurse to separate their emotions so they can remain professional, focusing on the patient. Hilde describes this as being in 'nurse mode' but allows herself "a *few moments to just to think 'come on, catch your breath', park any emotion in that corner, and do your stuff and be clinical* (Hilde).

Defence-of-self uses the idea of a shield to defend against the potential emotional trauma in the end-of-life situation by cognitively engaging, presenting themselves as approachable, understanding, whilst being emotionally distant.

For Nancy the metaphor of Baked Alaska describes this shield, the ice-cream is shielded by the soft outside, this way you are protected when a mum dresses an 8 year old who has died in his football kit.

The nurses in this study were all successful in protecting their authentic self to allow them to continue providing care. But this does not mean they were not affected by the care they provided. Hilda describes allowing herself to go to the toilet to release all the emotion because someone has died before she sees the next patient. When describing emotional support Nancy discussed the formal support that was available to the team particularly after a difficult or traumatic death. In contrast Mary reported "*Nobody has ever asked me if I'm all right after a death".*

Hospital Nurses Utilisation of Control and Power in End-Of-Life Situations

The uncertainty of the end-of-life situations also had an impact on how the nurses managed end-of-life care situations. For some of the nurses the achievement of 'calm' for the patient was not easy and related to empowerment. This was clearly expressed by Virginia when she reported "*sometimes you have to fight for your patient".* Virginia also describes the tensions that can occur with near death situations in the acute setting. Virginia discusses 'juggling' and 'appeasing' to achieve her end-of-life care but also having to battle for what she believes is right for her patients. This implies a negotiated form of power. Mary also describes conflicted situations and recalls instances where she has been asked "*How long did I think somebody was going to take to pass away? Because they want the bed?"* Mary reminds them that patients are human beings and it's about the care they need.

Other nurses in the study had more autonomy and were more empowered to achieve the desired *calm*. Ethel and Louisa described the actions they took to transition patients to calm: preparing the environment, focusing on more personable things, using a 'shawley blanket' as a metaphor for the change in

environment when someone is dying. Hilda describes her careful preparation of the death and detailed the planning involved so the family do not have painful memories to recall.

DISCUSSION

The nurses in the hospital setting presented three approaches to end-of-life care. The dominant approach of *calm* was not exclusive, with the other approaches of *Death-as-a-process* and *human connection.* These were interwoven to influence the nurses' idea of what end-of-life care should be, leading to their ideas of a good death and end-of-life care. This contrasts with Costello's (2006) study which found hospital nurses idea of a good death focused on the death event rather than the dying process. The concepts of creating peace and maintaining human presence were similar to other findings (Becker et al. 2016; Hopkinson and Hallett 2002).

The evidence from this study suggests the hospital nurses used two categories of protection of authentic-self; *Professional-identity* and *Defence-of-self*. Both these forms of protection were successfully utilised to enable the nurses to manage their emotions to continue providing end-of-life care. Previous studies have identified that nurses regulate their emotions to protect themselves, with individual nurses choosing how to connect emotionally (Roche-Fahy and Dowling 2009; Hayward and Tuckey 2011; McMillen 2008; Henderson 2001; Froggatt 1998). This study supports this concept but develops understanding further by exploring how nurses in the hospital environment regulate their emotions when providing end-of-life care. As methods of containment of emotions *Professional-identity* and *Defence-of-self* enabled the nurses to continue with end-of-life care while protecting their

authentic-self. Similar to Hayward and Tuckey (2011) study nurses continued to cognitively engage with the patients and their families but contained their emotions, indicating emotional distancing, to enable them to continue providing end-of-life care. As in this study nurses have been shown to use emotional containment to mentally distance themselves from threats encountered in their work (Decker et al 2015; Peters et al. 2013; Hayward and Tuckey 2011; Froggatt 1998). This is described by Hayward and Tuckey (2011) as cognitive engagement with emotional distancing. Although Mary reported "*Nobody has ever asked me if I'm all right after a death"* it should be noted the study was conducted prior to recent emphasis on staff's wellbeing (NHS People Plan 2020). The NHS People Plan (2020) sets out a detailed wellbeing strategy for staff.

To enable an environment of calm in the hospital setting the nurses in this study described a collaborative use of power. Not all the nurses shared the same level of control and empowerment with end-of-life care, with the environment being the main factor in this study. This supports Rao's (2012) view that it is the *individual* nurse that is empowerment to assume control over their practice. A negotiated approach between the nurse and the team to achieve the goal of calm was evident and is indicative of collaborative action and a *power-to,* or *authority-in-fact,* approach (Florckak 2012; Hawks 1991; Tillich 1954). A *power-to* approach involves cooperation, trust and shared leadership and differs to a *power-over* which involves dominance and force (Hawks 1991). *Power-to* is similar to an *authority-in-fact* (Tillich 1954) which is a mutual authority, recognising the authority we all hold and the mutual dependence we have on each other. As with *power-to* it is a collaborative authority that embraces the mutual dependence of those involved in end-of-life care. By using such approaches, the nurses were not utilising their power as a desire for themselves, or a 'nurse knows best' authority, but collaboratively in the in the interest of those in their care

Strengths and Limitations

By using such visual research methods authentic feeling of the nurses' experiences were uncovered which a language only approach may not have exposed. As a phenomenological study the findings cannot be generalised to the population of all hospital nurses. The outcomes are presented as 'meaningful insights'; inceptual meanings of the phenomenon which reveal the primal meaning and significance of a lived experience (Van Manen 2017).

All the participants were female and therefore any gender variations of the experience of the phenomena cannot be accounted for. In particular, emotions and protection of authentic-self among male nurses may be different with a suggestion that male nurses feel uncomfortable with emotional contact (Grey 2010). Male nurses experience of authority in end-of-life is also not addressed in this study. Although male nurses are perceived to hold more power to decision making, they can also be an oppressed group (Brown 2009).

CONCLUSION

The findings of this study suggest the hospital nurses effectively manage the tensions between treatment and palliation. This is achieved by approaches towards end-of-life care that incorporate calm suggesting hospital nurses end-of-life clinical practice may focus of transitioning from the storm of treatment to the calm of dying, as well as the practicalities of end-of-life care and human connection. Further research to include less experienced nurses and nurses that may avoid end-of-life care would contribute further to the understanding presented by this study.

To enable this care the nurses used *professional-identity* and *defence-of-self* to successfully protect their authentic self and continue providing end-of-life care. These protective actions should be recognised in the clinical setting and appropriate measures taken to help hospital nurses mitigate against the effects of providing end-of-life care. This should be recognised in the education setting and effective emotional defence mechanisms evaluated and integrated into education curriculum.

The nurses used a negotiated power, or *power-to* approach, to transition the patient from the storm of treatment to *calm*. Hospital do not use an authoritative 'nurse knows best' approach. This approach to end-of-life care should be recognised so that the potential skills nurses need for managing and leading end-of-life care in the hospital can be realised and developed. Further research developing the understanding of nurses use of negotiated power in end-of-life care found in this study is needed.

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KEY POINT

- Hospital nurses end-of-life clinical practice may focus on transitioning from the storm of treatment to the calm of dying, as well as the practicalities of end-of-life care and human connection.

KEY POINTS

- Hospital nurses protect their authentic-self to be able to continue caring but may be denied the opportunity to express their emotions in the clinical setting. Clinical areas need to take appropriate measures to help hospital nurses to mitigate against the effects of providing end-of-life care.

KEY POINT

- Hospital nurses use a collaborative and negotiated form of authority in end-of-life care. They do not use an authoritative 'nurse knows best' approach. This should be recognised so that the potential skills nurses need to lead and manage end-of-life care in hospitals can be realised and developed.

REFLECTIVE QUESTIONS

1. The experiences of the nurses presented suggests end-of-life care in the hospital setting is about transitioning from the storm of treatment to one of calm. How does this equate to your own experience?

3. The hospital nurses in the study protect their authentic-self to be able to continue providing end-of-life care. Is this part of practice you recognise yourself or others doing?

4. The nurses in this study use a negotiated authority in end-of-life care. Reflect on your own experience of how you use authority in end-of-life practice.