Abstract:

This assignment utilises reflection of the film ‘WIT’ used as an educational resource and clinical placement experience of providing supportive care for patients requiring supportive end-of-life care. Critical analysis is focused on the patient experience, this is linked to the World Health Organisation’s palliative care definition, suggesting care of this type should encompass the full holistic nature of the patient, not just manifest itself in symptom control. This is examined in conjunction with the stages of grief observed in such patients, critically analysing the Kubler-Ross model. The psychological and emotional changes that occur at the end-of-life are also explored in which the importance of therapeutic communication is demonstrated. This is reinforced by the recommendations made by the National Institute for Clinical Excellence guidelines. This assignments then goes onto discuss the ethical principles involved in supportive care and the nurses’ role in supporting the patient and their loved ones during this time. The ethical implications are discussed in relation to the increased autonomy palliative care patients now have. This is due to changes influenced by United Kingdom policy reforms, particularly in promotion of preferred place of death. This is evident from observed reductions in hospital deaths. The ethical principles relating to palliative care are then explored further in relation to the principles of biomedical ethics. In particular, autonomy, and how policy interventions have aided the development of advanced care directives. Finally, a lesson learnt from clinical practice is explored in the form of a critical reflection, highlighting the continued efforts of nursing practitioners to ensure they are culturally competent in their care, achieving individualised care. This is especially important given that palliative care often exacerbates cultural differences.
The Nurses’ role in supporting the dying: a critical reflection of supportive and palliative care in practice.

The World Health Organisation (WHO), (2011) provides a useful basis for defining palliative care; it focuses on care which is centred on improving quality of life and achieving symptom management based on the needs of the individual. Their definition then goes onto raise the importance of the patient-centred approach in which care should address spiritual and psychological needs alongside the physical needs. The importance raised in relation to the patients care from this definition, can be examined through the experiences of patients, with application to the nursing role. This nursing role also extends to having an awareness of the ethical principles which underpin palliative care. United Kingdom (UK) policy has influenced the structure and delivery of palliative care, including nursing, such as the Gold Standards Framework and the national end-of-life care strategy, which have achieved longitudinal changes to the provision of palliative care (Gomes et al, 2011; Mahmood-Yousuf et al, 2008).

The WHO definition demonstrates the importance of the patients’ experience through the provision of holistic care. Addressing the physical, symptom related complications but also any psychological and spiritual complications associated with their palliative prognosis. The importance of care encompassing all these factors is provided by Dickinson et al., (2008)
who reinforces that terminal illness manifests itself not only in physical implications, but socially and psychologically.

Addressing palliative care patients’ physical symptoms is crucial, given that patients rank symptomatic relief as an important aspect of their care (Rocker et al., 2008; Geoghan, 2008; Fleming et al., 2011). These findings are mirrored by a more recent study also identifying how important symptom control is to patients (Robinson et al., 2014). This is also reflected in my own practice, observing that the main bulk of referrals were centred on symptom control. This is supported by Eagle & De Vries (2005) who found that the main reason for admission was the need for symptom control. Symptom control is also explored in the WIT film, especially to the latter stages of the storyline, when analgesia and catheterisation are required for symptomatic relief opposed to acting as a source of curative treatment. This links well to the work of Phillips et al., (2011) raising that there is often a conflict between the transition from curative treatment to palliative symptom control, within acute care settings. As Richards et al., (2013) & Coombs et al., (2012) demonstrate, UK policy has attempted to address this, by promoting a culture that ensures a smooth transition from active treatment to palliative care, regardless of clinical setting. This is reflected in the Department of Health’s (DH) end-of-life care strategy in targeting shortfalls in maintaining such a transition in care (Department of Health, 2008; Gardiner et al., 2013).

Nurses have a unique position, to identify and serve the holistic needs of the patients through the formation of therapeutic relationships (Carmen Portillo & Cowley, 2011). This position, therefore, demonstrates how the nursing role is suited to meeting other dynamics of the patient’s condition, such as their psychological welfare. Nurses are also within a good
professional position to ensure the recommendations, outlined by the end of life care strategy (Department of Health, 2008) are fulfilled. Especially, in relation to respecting and acting on wishes of their end-of-life patients (Wilson et al., 2014). Meeting the psychological needs, Price et al., (2012) reinforces how nursing care is able to explore the patients’ personal perception of their illness, allowing for an individualised approach. This suitability of the nursing role is shown within WIT, as the lead character, has a unique bond with the primary nurse. This relationship does not appear to have developed in the case of the medical team. The knowledge of being terminally ill and receiving palliative care is likely to affect the individual. As Price et al., (2012) demonstrate, the perceptions one holds in relation to their condition are truly individual and different people may cope in entirely different ways. Although, anxiety and depression are considered to be prevalent clinical presentations within the palliative population (Mah et al., 2013; Hallford et al., 2012). Such psychological presentations can be grouped under the heading of existential suffering. This is defined as feelings that one can voice which typically, but not exclusively involve feelings of isolation, fear of death, worrying that they are being a burden and loss of identity (Boston et al., 2011; Morita, 2004). This is featured in the film in that the main character’s intellectual status becomes almost obsolete, resulting in her loss of identity. Existential suffering also fits well into the need for nursing awareness of grief stage theories, of which Kubler-Ross model is one. This model proposes five stages to the grief process, these are: denying grief, anger towards to situation, bargaining, depressive outlook and finally acceptance (Dunne, 2004). This model is met with criticism due to the nominal approach to what is considered very individual and complex (Buglass, 2010). Spiritual care is also another domain, often intertwined with the psychological impact of palliative care. The importance
of nurses being open and responsive to any spiritual needs is demonstrated by Cobb et al., (2012) who state that patients positively reported the benefits of spiritual care.

One of the important implications for nursing practice in relation to the psychological and spiritual care of our patients is communication, used appropriately is our most useful tool. For instance, Goldsmith et al., (2013) highlight the therapeutic qualities of open communication. This is further supported by Kaldijian et al., (2009) who argue, within their literature review, that communication greatly promotes a goal orientated culture. This is aided by communication that is patient centred (Kennett & Payne, 2010; Hack et al., 2005).

The overall importance of addressing psychological and spiritual needs of patients is reflected within the National Institute for Clinical Excellence (NICE) guidelines, which outlines the importance of assessment to ensure that these needs are identified and addressed (Thomas & Richardson, 2004).

Unique challenges are presented to healthcare practitioners in relation to the ethical implications of caring for the palliative care patient. The issue of increasing patient choice is particularly prominent given the UK policy reforms that have promoted choice for palliative patients (Jack et al., 2013). The reform is influenced by policies such as the end-of-life care strategy, particularly in choice towards their preferred place of death (Agelopoulous, 2009). These reforms are reflected in the observed reduction of hospital deaths (Gao et al., 2013). The Dying Matters Campaign from the National Council for Palliative Care (National Council for Palliative Care, 2011), also reflects the policy strive to increase the importance of patient choice (Paul, 2013). In order to apply the ethical implications to palliative patient care an understanding of biomedical ethics is required. These are often collated into 4 main principles, which are, autonomy, non-maleficence, beneficence and justice (Herrisone-
Kelly, 2011). Autonomy is defined as the individuality one can express towards their own life decisions, based on personal morality (Rehbock, 2011). The importance of nurses understanding the role of autonomy is crucial. Given, that respecting patient’s wishes is now an ever increasing prominence (Brassington, 2012). Informed consent is coupled with this reforms and a stumbling block for palliative care services. Especially as ones capacity can deteriorate as a result of chronic terminal illness (Karlawish, 2003). Despite the benefits of such reforms, in providing patients with increased autonomy, it is not without its complications. Wilson et al., (2013) argue that such a right can often be complicated by the patient’s social situation and their vulnerable position. UK Policy initiative has attempted to address the complications of an increased patient autonomy, through the introduction of advanced care planning. This is the documented wishes of a patient, to be acted upon if their capacity is reduced as a result of their condition, such a document is still a form of autonomy for that patient (Waldrop & Mecker, 2012; Stewart et al., 2011). Although the use of the advanced care plans is not without its limitations, for instance Stein & Fineberg, (2013) report that some clinicians feel that their use actually detracts from an individualised approach, formed from current need. Furthermore an advanced care plan does not specifically request a type of treatment to be performed, as this in itself would present ethical issues. For instance, the treatment requested may not be in the best interests of the patient, so would be against the principle of beneficence (Kinlaw, 2005). This is supported by Wheatley & Finlay, (2011) and Gillett, (2003) who state that healthcare professionals are under no pressure to offer a procedure or treatment if it is likely to prove unsuccessful and reduce the patients’ quality of life. Continued critique of advanced care plans surround concerns, cited by clinicians in regards to the litigation risks, by acting contrary to the patient’s wishes outlined in advanced care plans, especially in regards to the ethical
principle of beneficence (Robinson, 2012). The use of advanced care planning, is likely to become a mainstay feature of palliative care, as recommendations for its use are featured in the national end of life care programme, suggesting it should be in place for all adults deemed to have capacity with a terminal condition (MacPherson et al., 2012).

All of the above policy initiatives and ethical considerations surrounding have implications for nursing practice in addressing patient and family expectations. Ensuring they are aligned with the palliative care ethos (Sorensen & Iedema, 2011). In relation the autonomy the palliative patient is now equipped with, nurses can address this within everyday practice. For instance, this was experienced within clinical practice, through discussing a patient wishes during assessment on admission, ensuring these were fully integrated into care plans.

One of the situations encountered whilst on clinical placement, relates well to the patients experiences of palliative care, ethical considerations and policy implications. This situation involved a patient of South Asian Origin, whose relative was especially reluctant to allow opiates to be administered, as he believed this would hasten death and consequently would go against his cultural beliefs. This proved a great source of insecurity for both the medical team and nurses as it was very much in contrast to the palliative care ethos they were used to. Clark & Phillips, (2010) present a useful consideration in regards to this conflict between the relative and staff, they suggest, that palliative medicine has its own set of values or views on care. This demonstrated a lack of consensus between the relative and the professionals. On reflection, such an issue is well grounded within UK policy, for instance Evans et al., (2011) highlight the way in which the end-of-life care strategy states the need for culturally appropriate care. This is especially important given that the care of the dying is
one area in which cultural differences or beliefs are likely to be particularly prominent (Krakauer et al., 2002; Bosma et al., 2010). Seymour et al., (2007), however, suggest that policies guiding palliative care may actually be biased to the views of the cultural majority. Examining this scenario, there are a number of ways in which this problem may have been alleviated, for instance, utilising family consultations, to educate on the goals of palliative care and the need for appropriate symptom management may have proved particularly beneficial (Gaudio et al., 2012). Culturally competent care may have been useful here, by appropriately assessing the cultural concerns of the patient and family (Giger et al., 2006; Jovanovic, 2012). This concept is supported by Owens & Randhawa, (2004) who state that the South Asian participants studied reported that individualised approaches to their cultural needs were considered important by this demographic. Culturally sensitive palliative care has been shown to be an important consideration, which can be achieved, through good communication and individualised care. These are clearly qualities already well integrated into palliative care. Demonstrating that applying such qualities is likely to appropriately address similar situations in the future.

In conclusion, Palliative care patients can now expect to receive a fully holistic approach to their care, which encompasses physical, emotional and spiritual care. This is in conjunction with the now increased autonomy provided to such patients, especially around preferred place of death. This is clearly being made available to patients, as a downward trend in hospital deaths can be observed. Given the growth and diversity of palliative care, there are several implications towards the nursing role in response to this. Firstly, the nursing care remit can be clearly attributed to being ideally suited to meeting these holistic needs. Greater pressure is also placed on nurses however, in relation to the ethical and legal
implications that stem from the policies. Particularly that of advanced care directives, given the now increased autonomy of patients in regards to their care. Reflection is also demonstrated as a useful tool to meet the ever changing diversity of this care type. For instance, the importance of cultural competence on behalf of nurses has been demonstrated within this text, highlighting that there is need for nurses to aid the consolidation of what palliative care is set out to achieve for patients. Communication has also been demonstrated as an overriding factor, in the role of the nurse in palliative care. Communication links well with the patient centred approach, allowing the nurse to meet the diverse needs of the patient, but also strive to achieve the policy goals.
References:


Evans, N., Menaca, A. and Andrew, E.V.W. et al. (2011) 'Appraisal of literature reviews on end-of-life care for minority ethnic groups in the UK and a critical comparison with policy recommendations from the UK end-of-life care strategy'. *BMC Health Services Research, 11*: 141.


