

Opinion Piece for Palliative and Respiratory Care Tweet Chat 6th January 2015:8pm

Sarah Russell @learnhospice

sarahjfrussell@yahoo.co.uk**Advance Care Planning Doctoral Research Student.****Do terminology and definitions matter: What do we mean by palliative care?**

So what do we mean by the term 'palliative care'? Palliative care was founded on a holistic philosophy encompassing the physical, psychosocial and spiritual needs of patients with a terminal disease and their families (Saunders 2001). In the examination of the origins of the term and meaning of 'palliative care' the Canadian Physician Balfour Mount is acknowledged as the first to coin the term 'palliative care' in the 1970's after spending time at St Christopher's hospice (London) and identifying that exactly the same approach was not transferable to Canada (Woods 2007, Billings 1998, Hamilton 1995). Arguably developed as part of or even indeed successor to the hospice movement (Woods 2007), palliative care is both a philosophy of care and an organized, highly structured system for delivering care (Cherny 2009). Its fundamental principles and values are concerned with a holistic, multi professional team approach to the patient and family assessment and support. Holistic care is based upon the view that the person is a complex, physical, psychosocial and spiritual entity (Henderson 1960).

Over the last 30 years the term 'palliative care' has undergone a series of transformations in its definitions, tasks and goals and there remains a lack of consensus about its definition (Pastrana et al 2008) as well as its relationship to other overlapping terms such as 'supportive', 'hospice', 'end of life' and 'terminal'. There are multiple terms and definitions in palliative care. Since the 1970's, there has been a struggle for a common language for palliative care hampering the development of international standards and norms (Radburch and Payne 2009), relevant for meaningful clinical or research comparisons (Mid-Western Health Board 2001, Bausewein and Higginson 2012), implementation of research findings into practice (Van Mechelen et al 2013) and for service development (Radburch and Payne 2009), administrative, clinical and research operations (Hui et al 2012). Concerns have been raised about the lack of definitional clarity (Hui et al 2012) and the variable and inconsistent terms (Fallon and Smyth 2008). Differences in terminology appear in texts of law, government bills and expert statements of relevant associations (Nemeth and Rottenhofer 2004), with overlapping terms such as 'supportive, palliative and end of life care' in different medical fields (Pastrana et al 2008). Not all languages have a word for 'palliative care' e.g. there is no direct German translation for 'palliative care' leading to a synonymous term 'Palliativmedizin' with 'palliative care' and concerns of the over medicalisation of palliative care in Germany (Elsley and McIntyre 1996).

Terms are used inconsistently. Hui et al (2012) systematic review identified that the most frequently used terms in palliative care journals were 'end of life' and 'palliative care' (alongside 'terminal care'). In oncology journals 'supportive or best supportive care' was used more often (Hui et al 2012). There were multiple definitions with 16 variations in the definition of 'palliative care' and 13 in 'hospice care' (Hui et al 2012). 'Supportive care' is rarely defined (Hui et al 2012) and there is no consensus definition for 'supportive care' (Hui 2014). The definition of 'hospice care'

varies across countries (Calanzani et al 2013) with its definition reaching less consensus than that of 'palliative care' (Radburch and Payne 2009).

The diversity of the meaning of these terms bewilder patients, family members and health care professionals (Billings 1998). There is confusion about the meaning of palliative care with examples arguing that it is only personal experience of palliative care that generates understanding of it (McIlfatrick et al 2014). A recent survey about the terms 'palliative and end of life care' further reported that *'individuals did not always understand the words being used'* (National Council for Palliative Care and Marie Curie Cancer Care 2014). The findings illustrated the confusion, the impact and the range of understanding and feelings towards the words (National Council for Palliative Care and Marie Curie Cancer Care 2014).

There is another tension. Palliative care is frequently misconstrued as synonymous with end-of-life care (Smith et al 2012), associated with care for dying people (NICE 2004) and projecting a negative image (Miyashita et al 2008). As the divisions between active oncologic and palliative care blur (Rayson and McIntyre 2007), the relationship between curative and palliative care is different across the globe (WPCA 2014) and there is a lack of consensus about the attributes of illness needing palliation (Van Mechelen et al 2013) or when in the disease trajectory (Bruera and Hui 2010). Epstein and Morrison (2012) report the conceptual leap that USA oncologists are having to make to view palliative care as running parallel to oncological life prolonging or curative care programmes as opposed to being an alternative if cure directed care has failed. This leap is reflected in the recent American Society of Clinical Oncology stated vision to incorporate palliative care into concurrent oncological care (Bruera and Hui 2010).

Definitions require further explanation (WPCA 2014) and exploration as to the impact and meaning they hold for individuals, service providers, commissioners and evaluators in terms of care design, delivery, evaluation and experience. However, there is another view. Kathleen Foley in Cherny (2009: 1811) argues that clinicians and researchers need to 'get real' about palliative care. Nathan Cherny, Director of Cancer Pain and Palliative Medicine service in Jerusalem, Israel provides an honest, directive opinion on the challenges of terminology and stigma in palliative care. Cherny (2009) referring to the multiple definitions and terminology and associated stigma that they may have argues that clinicians and researchers should *'get around it', 'live with it' or 'get over it'*. His call to arms is passionate: *'Despite the labels that are adopted, it is incumbent upon all oncologists and cancer clinicians to work toward common goal that all patients will have access to an approach to care that improves the quality of life of patients and their families through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial, and spiritual problems. Call it what you may, this is palliative care and it is a clinical, ethical, and humanistic imperative for all oncologists!'* (Cherny 2009:1811).

Full references on request.