Positive Aging, Positive Dying: Intersectional and Daily Communicational Issues surrounding Palliative and End of Life Care Services in Minority Groups

Dedication: to Dipti Shome who made it home late and Allan MCNaught who would like to have made it home!

Carlos Moreno-Leguizamon, PhD, University of Greenwich, London, England
David Smith, PhD, University of Greenwich, London, England
Clarence Spigner, DrPH, University of Washington, Seattle, Washington

Introduction

The journey through life has an end and an ending process: physical death and physical dying. As Kakar (2014) states, objectively speaking, our physical death--when our heart stops working, our kidneys fail, brain dies and we cease breathing -- are actions that should not carry mystery because these are not more than the processes of a body deteriorating and ceasing to exist. However, we humans insist on constructing death and dying as mysteries and, if not, as deniable practices: why? Probably because physical death is the only experience that we do not survive to tell. In the case of dying, societies are increasingly reluctant to reflect seriously about this life event and the social, economic, political and cultural consequences it entails. As some literature already demonstrates, services for the elderly and ageing are a low priority for government agendas, health and medical services (Tinker, 2014 a & b). However, social policy and health care provision for aging populations is being contested from political, economic and social policy angles by the inter-generational equity debate. According to this debate, which focuses mainly on industrialised countries, as elderly groups are growing as a proportion of the population and are more likely to vote than younger voters, they have increasing political power. Similarly it is argued that these elderly populations are in a more advantageous position than their younger cohorts through occupational and final salary pensions that are now largely closed to younger people; higher state pensions (with the triple lock guarantee in the UK) paid for by working age tax payers; rising property prices benefiting older home owners when many youngsters cannot get on the property ladder and, of course, disproportionate use of health services.

Throughout history human societies, cultures and groups, have responded in different, complex, nuanced and imaginative ways to death and, to a lesser extent, to the dying process. From mummifying, cremating and burying the body to planning to send the bodies' ashes into space, humans have always crafted diverse ways to deal with death. However, this is not so true wit regards to the dying process. Historically most people have died at "home" connoting[1] a familiar place and under the care of family, community, friends or, more recently, by health professionals. Gawande (2014) notes that it is only since the mid twentieth century with the rapid progress and consolidation of both "scientific" bio-medicine and the hospital as a site synonymous with cure and the extension of life that the move from dying at home to dying in sites such as the hospital and other institutions has occurred. As a medical doctor, Gawande (2014) states, "the experience of making mortality a medical experience is just decades old. It is young. And the evidence is failing" (p. 9). So is the focus on the physical death a contributing factor in sanitising death and removing it from our daily and familiar landscape -"home"?

Contemporary societies are being challenged to rethink death and dying mainly due to the fact that humans are living longer and, secondly, national populations are becoming increasingly diverse racially, ethnically and religiously at the same time as they are ageing. This means that practices and customs surrounding death and dying are increasingly heterogeneous, posing significant challenges for healthcare providers who deal with death and dying on a daily basis. Thus, keeping in the background this new emerging and controversial global question on how our physical death and dying processes are taking shape, this chapter aims to contribute to the debate over what a "good" or "positive" death and dying process might mean. Specifically in the context of palliative and end of life (EoL) care services in the United Kingdom (UK) and the United States of America (USA) the article seeks to i) discuss what the main themes about death and dying are according to the literature for both minorities and palliative and EoL services and ii) bring to the forefront what intersectional and communicational issues could affect individuals and the respective services they receive at the EoL who, in either society are defined or self-identified as members of ethnic minorities.

---

[1] In anthropological research when it comes to meaning there are two notions: denoting and connoting. The denotation of a word is its explicit definition as listed in a dictionary. Home for example is a place where one lives; a residence. Meanwhile connoting refers to the set of associations that a word usually brings to mind. The connotative meaning of "home" is a place of safety, comfort, and above all a familiar site. It is the connotation of the meaning of home when it comes to service users of palliative and EoL care what this chapter wants to use.

The justification for contrasting the UK and the USA is centred on various reasons but the quintessential one is that the authors annually conduct a seminar series (Dark Empire: Health and Race), with undergraduate students from the universities of Washington (USA) and Greenwich (UK). The main objectives are to invite the students to reflect on healthcare issues such as (i) why the USA has a market-oriented health care system compared to the UK's national health system; (ii) the USA's entire 237 year history (since independence) is of multiculturalism, while the UK's much longer history is roughly only 60 years; (iii) the USA is forty times the size of the UK with 321 million persons compared to just over 64 million in the whole of the UK; and, finally, and a very significant issue in 2015 iv) the UK was ranked number 1 on the Quality of Death Index compared to the USA which ranked number 9 along with Canada (Economist Intelligence Unit, 2010).

The chapter is structured around four components: i) a definition and characterisation of palliative and EoL care services ii) how ethnic minorities are classified in both countries iii) how more culturally sensitive communicational and intersectional approaches could capture the complexities of identity markers in minorities around physical death and the process of dying, and iv) what the literature in both countries, supported by some empirical data from a one year study in the UK[2] illustrate are common themes in both countries for minorities in general and for some country-specific groups.

Palliative and EoL Care Services

Gawande (2014) notes that the medicalisation of physical death is a relatively recent biomedical phenomena taking place mostly in hospitals, nursing homes and care homes. The process of dying has been removed from what most patients denote and connote as "home", and this trend is apparently not satisfying populations particularly the elderly. Why is this the case? Recent historical developments in the management of death and dying in the past 60 years and the definition and characterisation of palliative and EoL care may contain the clues to why this is the case.

---

[2] Smith, D., Moreno-Leguizamon, C., and Grohman, S. (2015) EoL Practices and Palliative Care among Black and Minority Ethnic Groups (BME), The one year feasibility study was supported by Health Education Kent Surrey and Sussex (UK).

Firstly, like any other social movement the consolidation and mainstreaming of palliative care medicine within mainstream biomedicine – a process still very much in progress-- has been the result of creative and innovative health professionals advocating for a change on what, based on anecdotal evidence and individual cases, some saw as failing to maximise quality of life for those near death. In the UK Cicely Saunders was central in developing hospice and palliative care. She, herself an intersectional case – woman, nurse, social worker and medical doctor - collected 1100 individual experiences of patients in the final stages of life between 1960 and 1967. According to Clark (2007):

> "[a] striking feature of her papers was her articulation of the relation between physical and mental suffering, seen in almost dialectical terms, each capable of affecting the other. Her description of this relation reached full expression in her idea of total pain, which was taken to include physical symptoms, mental distress, social problems, and emotional difficulties –captured so comprehensively by the patient who told her: "all of me is wrong" (p.431).

The work of Saunders was significant in advancing the view that death and dying were more than merely biomedical or physical processes. They were also social, emotional, psychological, and cultural processes involving various intersectional identity makers such as gender, ethnicity, class, sexual orientation, disability, age and religion.

Secondly, Saunders' work on the concept of total pain challenged the historical body-mind dichotomy so pervasively used in biomedicine in the last three hundred years in which the physical or material has been prioritised over the mental (Moreno-Leguizamon, 2005, 2012). The failing evidence of medicalising death and dying that Gawande (2014) observes is reflected in Saunders' concepts of total pain and the modern hospice as the site for providing a different type of care. The biomedical emphasis that all physical processes of the body including its death are material processes, has disregarded the complementary role that the mind or the psyche plays and the corresponding influence of this in the behaviour of health services. Even today in palliative inter-disciplinary teams, the professions that are less present are psychology and psychotherapy. Heubber and Sellschopp (2014) observe that in Germany,

"[t]he membership statistics of the German Association for Palliative
Medicine confirm the impression that psychological competences are
still a project in progress: Less than 10 percent of the members are
psychologists or psychotherapists by profession, and the statistics do
not offer any information about the quality of their psychotherapeutic
and phsyco-oncological training" (p. 216).

The fact that the modern hospice is increasingly considered as a friendlier site for death
and dying compared to the hospital or nursing home is in many ways due to the total
pain approach in which the physical, mental and social is taken into account. As
Heubber and Sellschopp (2014) note, Saunders herself stated that the "Hospice is not a
place to go to die, but rather a concept of care based on the promise that when medical
science can no longer add days to life, more life will be added to each day" (p. 215).

Thirdly, although palliative care and EoL care services are offered to all cases in which
patients' diseases are malignant and non-malignant (Keeley & Noble, 2011), the origin of
palliative care is rooted in cancer as the disease and the modern hospice as the site.
Clark (2007) notes that palliative care has contributed to a considerable shift in attitude:
from a "casual" attitude in the 1970's when doctors would send patients to die at home
because they could not offer anything else, to the continuous effort of expanding
palliative care and EoL services globally for malignant and non malignant diseases
today. Clark also mentions that in the USA Elizabeth Kubler Ross' work at the end of the
sixties –another woman and a psychiatrist-- at the Billings Hospital in Chicago initiated a
groundbreaking work on death and dying in that country. However, despite the
pioneering work of these women in the 1970's it was only towards the end of the 1980s
(1987) in the UK and near the end of the first decade of the twenty first century (2008) in
the USA that palliative care became recognised as a specialty of biomedicine.

The first definition of palliative care by the World Health Organisation (WHO) was in
1986 and from then onwards re-definitions have taken place. Accordingly the definition
today states that:

"Palliative care is an approach that improves the quality of life of patients and
their families facing the problems associated with life-threatening illness, through

the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2015).

Additional underpinning characteristics of the WHO's definition of palliative care include those suggested by Saunders and Kubelar Ross such as a more ample conceptualisation of pain, the affirmation of life, a better attempt to integrate body and mind, an ordinary and reflexive acceptance of death as an inevitable process, and care rather than treatment at the moment of dying.

In fact care at the moment of dying or near the moment of dying is what EoL care services comprise as a more focused and specialised activity within palliative care. Incorporating, the philosophy, concept and approach from palliative care, EoL care addresses issues such as i) death with dignity and autonomy, ii) identification of wishes and preferences of the dying individual (part of patient centred care), and decisions on the preferred site of death. On the side of the service providers EoL care services addresses the ethics and responsibility of the multidisciplinary team to provide high quality care that involves, as earlier as possible, a death without too much total pain. In the National Health Service (NHS) in the UK this gets summarised in a compassionate, competent and respectful EoL care service (NHS, 2015). Similarly, after having scrapped the Liverpool Care Pathway in the UK for being perceived as a speedy pathway to get rid of dying people, the NHS is now talking in terms of the EoL care pathway in which six key activities are deemed noteworthy: i) frank an honest discussion as the EoL approaches, ii) assessment and agreement of care planning and its review, iii) coordination among all parties involved, iv) delivery of quality care as per site chosen, iv) specific care for the last days, and v) care after death for the ones in mourning and bereavement (NHS, 2015)

Many of the above characteristics of both palliative and EoL care are among the ones that have led to the UK recently being rated as the best place to die among eighty countries according to "Quality of Death: Ranking End-of-Life Care Across the World " report form the (Economist Intelligence Unit 2010). In the same ranking the USA was ranked 9. However, a challenging issue for both palliative and EoL care is the emerging global discussion on the right to die as one of the maximum expressions of autonomy by

patients. So far the global picture in this discussion does not involve many countries as it is still few countries that have approved it. Assisted dying is legal in the Netherlands, Switzerland, Belgium, Luxembourg and Colombia while assisted dying laws exist in California, Washington, Oregon, Vermont and Montana in the USA.

The UK and the USA ethnic classification and a further need for intersectionality

Marking ethnicity or race chiefly among a range of others possible identity markers is one way that societies like the UK and the USA have governmentally decided to classify and count the non-white and white populations. As Moreno-Leguizamon et al., (2015) point out ethnic recognition has not been an acknowledged and given political right in either society but a right that carries a political history of struggle that in the UK was closely related to the struggle for gender equality and in the USA to the civil rights movement. Obviously a common denominator in both struggles have been issues of racism, discrimination and inequalities in social, educational, political, economic life, including health issues as is the case in this chapter with palliative care and EoL. When discussing the literature from both countries, minorities experience inequalities in life and inequalities even when dying. Table 1 below displays the main ethnic categories used in the two countries. In the case of the UK data is drawn from the national Census of 2011 (Office for National Statistics, Census 2011), and in the USA from the 2010 Population Census (Bureau, U. 2015).

Table 1: Ethnic/Race categories in the UK and the USA

UK Ethnic Categories (England and Wales)	Demographics	US Race Categories	Demographics
White	48.2 million (86%)	One race	
White British	45,1 million (80.5%)	White	223,553,265 (72.4)
White Irish	531.1 (0.9%)	Black or African American	38,929,319 (12.6)
Gypsy or Irish Traveller	57.7 (0.1%)	American Indian and Alaska Native	2,932,248 (0.9)
Other White	2,485 (4.4%)	Asian	14,674,252 (4.8)
		Native Hawaiian and Other Pacific Islander	540,013 (0.2)
		Hispanic or Latino Race	47,435,002 (15.4)
Mixed/ Multiple Ethnic Groups			
	426.7 (0.8)	In the US census there are all type	
	341.7. (0.6)	of consideration to combinations of	

White and Black Caribbean	166.0 (0.3)	two and three races among all the	
White and Asian	290.0 (0.5)	above categories either they have	
White and Black African		been specified or not.	
Other Mixed		Since our interest in this chapter is	
		the ethnic categories, we do not	
		list the combinations. For details	
		see the figures for the 2010	
		census	
Asian/Asian British			
Indian	1,413 (2.5)		
Pakistani	1,124 (2.0)		
Bangladeshi	447.2 (0.8)		
Chinese	393.1 (0.7)		
Other Asian	835.7 (1.5)		
Black/ African/ Caribbean /Black British			
African	989.6 (1.8)		
Caribbean	594.8 (1.1)		
Other Black	280.4 (0.5)		
Other ethnic group			
Arab	230.6 (0.4)		
Any other ethnic group	333.1 (0.6)		

As shown in Table 1 the UK and the USA are both different and yet alike in certain respects. At 321 million residents, the USA has more than 5 times the population of the UK at 56,075 million for England and Wales. Racial and ethnic diversity has been integral to the USA population even before it won independence as a colony from the UK more than 240 years ago. The UK has only dealt with large scale multi-racialism since around 1950. The definitions "race" and "ethnicity" can differ across the two nations. "Race" is generally defined as superficial physical characteristics between people or according to biology. "Ethnicity" is defined as people identified by a shared history, nationality, language or religion. In the UK, the Irish have been defined as a group distinct from the English group whereas in the USA, Irish Americans are part of the white population. The UK's white population is 86% (England and Wales) compared to 79.9% of the USA's population. Racial and ethnic distinctions, critical for assessing the epidemiology of the publics' health can however be deceiving. In the UK, the all-encompassing "Asian/Asian Britain" population include South Asians with ancestry in the

Indian sub-continent. Those with origins in the Far East are excluded and are placed under the "Other" category. In the USA however, the Asian designation comprises 4.4% of the population and includes those with ancestry in South Asia, India and the Far East. The USA's Hispanic designation is an ethnic classification, assessed by surname, and includes those who are "white". The USA white population includes therefore approximately 15% Hispanics. However, Hispanics are not singled out in the UK population and would be classified under "white other" with a diverse range of other national and ethnic groups. The all-encompassing "Black" designation in both nations includes people who are descendants black people from the African continent. The UK has a registered 3% Black population and the USA has a 12.8% Black population

Examining the role of ethnicity without acknowledging how ethnic experiences intersect with wider identity markers or categories and other socioeconomic processes would give a very partial view of the dynamics influencing their engagement with palliative and EoL services. Social class status is closely related to race and ethnicity in both the UK and the USA and impacts hugely on life chances and health status. In the UK 40% of ethnic minority households live in low income households, twice the rate of white British households. Significant differences exist between groups with 70% of Bangladeshi and 60% of Pakistani households classified as low income compared to 30% for Indians and Black Caribbeans and 20% for white households (Poverty.org.uk, 2015). In the USA in 2010 whites and Asians have median household incomes that are higher than the median income of all races combined ($54,620 and $64,308 respectively) while Hispanics ($37, 759) and blacks ($32,068) have median incomes significantly lower. Kessler et al., (2005) identified no social class differences in attitudes and beliefs surrounding death and dying in the UK but found that patients from social class V were less likely to die in a hospice.

In both countries ethnic minorities are more likely to live in deprived areas, which impacts on the accessibility and quality of services they receive. In the UK over one in three Bangladeshi and Pakistani households live in a deprived neighbourhood compared to one in five Black, African and Caribbean and one in twelve White British households. In the USA residents of predominately black or Hispanic neighbourhoods have access to roughly half as many social services as those in white neighbourhoods (National Poverty Centre, 2015). When ethnicity intersects with social class and geographical inequalities, Evans et al., (2011) identified an inverse relation between areas of high poverty and

provision of palliative care services with poorer areas being less well provided than more affluent areas. Ethnic minorities therefore face a 'dual disadvantage' being over-represented in areas of deprivation and even within those areas, have lower levels of service use than deprived white British residents. In the USA even after controlling for socioeconomic variables there were differences in the use of palliative care services between whites, blacks and Hispanics (Hanchate et al., 2009). However, in the UK Karim et al., (2000) noted higher referral rates to palliative services in areas with a higher percentage of ethnic minority patients.

Uncritically examining the role of ethnicity without acknowledging how ethnic experiences intersect with other identity and socioeconomic markers (something currently missing in the literature and research in palliative care) therefore, gives a very partial view of the dynamics influencing the engagement of different groups ethnic and otherwise with palliative and EoL services. It is in this specific context that the need for considering an intersectional approach is briefly raised.

As an approach developed by a Black feminist (Crenshaw,1989) to address the limitation of identifying only a singular category (ethnicity or gender) when capturing an act of discrimination or inequality, but not both (gender and ethnicity), this approach brings to the forefront a set of arguments needed to be included in contemporary research and policy in health services. Defined as a promising research paradigm to improve the understanding of and response to diversity in health and illness (Hankivsky & De Leeuw, 2011) intersectionality in broad terms focuses on critically examining the "intersections of life stages with selected identity markers and with axes of power, privilege and oppression" (Hankivsky & De Leeuw 2011, p.6). Further characteristics are a reflection on the dynamic relationship of simultaneity and mutuality of the identity markers or categories rather than their conceptualisation in isolation or as an additive operation. Similarly, as (Hankivsky & De Leeuw, 2011) suggests the approach "provides a way to address the complexity of othering–namely the ways in which difference is produced so as to (re)assert standards of normalcy" (p. 13). Intersectionality also challenges the homogenisation of any group by including differences within differences in specific contexts. Power as another significant element of this approach, is not always an oppressive force but can be a productive one with its corresponding resistances. Finally, the approach considers identity as a necessary element in people's lives.

With the unfolding equality regimes all over the world but particularly in the developed world (for example the UK and the USA) the need for implementing and documenting inclusive research and policy experiences is important. The intersectionality approach aiming at social justice and equality as its goals can help here enormously. Palliative care and EoL services are not the exception from either its research or policy angle. As Krizsan et al., (2012) state, researchers and academics are increasingly noting "that legal frameworks tend to compartmentalize people's experiences into 'prefabricated' legal categories failing to reflect the complexity of social identifications" (p.19). Within intersectionality debates identity rather than a discrete and permanent force is rather seen as a fluid, imagined, constructed and reconstructed element in people's daily life from the self and from relational and structural angles.

Death and Dying Main Concerns for Ethnic Minorities in the UK and the USA as per the Literature

In both the UK and the USA ethnic minority groups access palliative and EoL services less than the majority population. Ethnicity has been recognised as a 'tracer' for measuring the success of palliative services, and it is within this context that healthcare providers have been trying to increase the quality and uptake of such services for minority groups (Calzani et al., 2013). As indicated, some common themes were identified based on a research project in the UK, which explored experiences of and attitudes towards palliative care from the perspective of minority service users and a literature review covering both countries. From the minority perspectives there were differences both between and within groups. However the main overarching concerns were around knowledge of palliative and EoL care services; the levels of trust towards health care professionals and how ethnicity intersects with class, gender, generation and other markers of identity when accessing these services. From the health provider's perspective the themes related to their own understanding of minority's cultural beliefs and practices around death and dying; given this diversity how to communicate effectively and compassionately at what is a traumatic and highly emotional period both for the patient and their family and friends; and policy frameworks that govern service delivery and the way those services are organised and delivered.

Minorities' lack of knowledge and awareness surrounding Palliative and EoL Care services

Lack of knowledge and awareness of available services is an important factor shaping differential access. Palliative services are often unavailable or minimal in under-developed or medium-developed countries compared to in Europe and in English speaking countries meaning immigrants may have had little or no prior exposure to palliative care services and be unaware of available palliative services in their new countries (Koffman, 2014). Likewise focus groups conducted as part of the study conducted by the authors with Gypsies and Travellers and South Asians in the UK (see footnote 1) indicated relatively low levels of knowledge about available services. In the USA Latinos, Chinese and Koreans all demonstrated low familiarity and a lack of knowledge about palliative services but a high level of interest in learning about them (Pan et al., 2015). The issue of knowledge and increased likelihood of accessing services however, varies according to first, second and third generation migrants. Diver, et al., (2003) note that social scientists and health professionals often neglect the process of acculturation and change in the minority individual's orientation to the majority culture. An apparent acculturation factor in the USA was revealed in Park et al.'s (2015) survey of older Floridians comprised of 504 non-Hispanic whites, 360 African Americans, 328 Cuban Americans and 241 non-Cuban Americans willingness to used hospice services. They found a greater willingness among younger non-Hispanics whites and African Americans who had less functional disabilities. Interestingly, among non-Cuban Hispanics they also found English proficiency increased propensity to access hospice care.

Randhawa et al., (2003) observed how communication was a significant problem in the delivery of palliative care to South Asians in the UK. Similarly in the USA, Johnson et al.,'s (2009) survey of 200 community-dwelling people aged 65 years or older (comprised of 95 whites and 105 African Americans) found African Americans reported less exposure to information about hospice that whites. Reynolds et al., (2008), in their study of nursing home residents in the US recommend that in-depth discussions on the values and goals of care can upgrade palliative care and lessen racial disparities in end-of-life care. Cintron and Morrison (2006) recommended educational interventions to improve patient-provider communication regarding pain treatment. In the UK, Jack et al., (2001) recommend a strategy to promote racial and ethnic sensitivities in palliative care

services. However, better promotion of palliative care services is insufficient in encouraging uptake by itself according to Phillips and Taylor (2012). Their study found that an intervention to increase use of palliative care by using translated leaflets made little difference to access rates, as it failed to address why some individuals and groups view palliative care as inappropriate, discussed further below.

Lack of trust due to relational prejudice

A lack of trust between minority groups and providers of health services has been identified as a barrier to access. Focusing on mistrust however, frames the problem as rooted in the attitudes of ethnic minority group members. The historical context of prejudice and discrimination can result in minority mistrust of the medical profession as well as the wider society. Vulnerability or the threat of being subjected to harm due to ethnicity is an issue in both countries which can make palliative care an arduous task (Waisel, 2013). Koffman et al.'s (2009) secondary analysis of qualitative data found vulnerability in health care settings more prominent among black Caribbean patients than white British patients. Such views concerning accessing health care and treatment in health care settings have also been prominent in studies of Gypsies and Travellers in the UK and contribute to their reluctance to use such services as the authors found in their UK study (Parry et al., 2007; Smith and Ruston, 2013). The US, with its longer history of racial dynamics reveal similar concerns of vulnerability especially regarding African Americans who often cited previous racial discrimination and medical mistreatment as influencing their willingness to access health care in the present (Duffy, 2006).

EoL Care Preferences for Minority Groups

As discussed increased referrals, improved information and more accessible palliative care services will not necessarily increase use of those services by minority groups as they fail to address why some groups may reject this form of care. Koffman and Higginson's (2004) survey of 50 first generation black Caribbean and 50 native born white British patients with terminal illnesses found no significant differences in preferred place of death between the two groups. 34% of Caribbean compared to 27% of white patients expressed a preference for place of death. 80% of all patients wished to die at home and of these similar levels of Caribbean patients (53%) and white patients (56%) who wished to die at home did so. Coupland et al.'s (2011) database examination of

over 68,000 patients who died from cancer between 1998 and 2006 in South East England however indicated significant differences in place of death by ethnicity. Pakistani Indian and Bangladeshi patients were significantly less likely to die in a hospice. Black African, Black Caribbean and Chinese patients were more likely to die at home and all groups had a higher likelihood of dying in hospital than white patients. Johnson et al., (2005) found that in the US elderly minorities are more likely to die in inpatient settings than white people while older African Americans were more likely than older whites of dying in an inpatient hospice setting than a nursing home. However these studies were unable to determine the extent to which these patterns indicate the ethnic/cultural preferences of different groups; knowledge of available services or institutional and practice based factors discussed above.

Studies indicate differences in the role of the family in relation to individual decision making at the EoL. Among frail elderly people in the USA, whites were more likely to express their healthcare preferences than Hispanic, Asian and Black patients and were less likely than the other groups to have an alternative decision maker (Hornung et al., 1998). This is consistent with more recent research from the USA which indicates a higher preference for family-centred decision making at the EoL among Asians and Hispanics than among other groups (Kwak and Haley, 2005). A study of elderly South Asians in London highlighted two themes relevant to understanding perceptions of EoL discussions and their role within those discussions. The first was 'avoidance as a cultural norm' – referring to a lack of discussions around death and dying within the family and a reluctance to play a role in decision making. The second was 'avoidance as protection' and referred to beliefs about delegating such decisions to family members (Venkatsalu et al., 2013). Among Korean Americans a lower percentage (73%) reported that they were willing to consider hospice care than white Americans (94%) and African Americans (90%). Younger and more educated Korean Americans; those with more chronic conditions; with health insurance and a higher level of acculturation indicated a greater preference for hospice care (Jang et al., 2010).

In the study conducted by the authors (see footnote 1) most of the African women interviewed expressed a strong aversion to ending their lives in an institutional setting whether hospital, hospice or nursing home and was based in three factors: first a high proportion had worked in the health and social care sector and their perceptions of low

standards of care towards the elderly and of experiencing racism and discrimination from other staff, making them reluctant to enter such environments themselves when they became old and vulnerable. Secondly was the strongly engrained belief that it is the responsibility of the family and particularly, the (adult) offspring to provide appropriate care. Thirdly was a preference for either returning to their land of birth to die or if this is not possible having their bodies buried 'at home'. The theme of family (primarily female) based care and a desire to die in their home country or be buried there was also prominent in focus groups with South Asian participants particularly among first generation migrants though there was a feeling among the focus group participants (mainly second generation South Asian women) that this preference would decline in subsequent generations supporting the acculturation arguments discussed above.

Health Professionals and use of Palliative and EoL Services

Studies have identified how the practices of health professionals may lead to lower use of Palliative and EoL services among minority groups. The main reasons include a lack of knowledge of different groups customs and practices surrounding the EoL among health professionals and practitioners and an assumption that minority groups prefer family based to 'formal' care. Another factor was language and communication difficulties, which can contribute to a lower level of referrals (Ahmed et al., 2004). Family members may be asked to interpret between the patient and healthcare professionals increasing the risk of misinterpretation and non disclosure (Firth, 2001). Problems may continue after services have been accessed with poor communication between patients and staff a common theme in the literature (Evans et al., 2011). Bereaved Caribbean relatives in the UK were more likely than bereaved white relatives to feel that the deceased relative was not given sufficient choice regarding place of death (Koffman and Higginson, 2004).

The age and gender of the health care professional can also effect what type of care is provided with older male physicians more likely to end life support and life sustaining methods than younger female physicians (Hinkka, 2002). Mebane et al., (1999) found that in the USA the racial and ethnic background of the physician was significant with white American physicians more likely to promote advance directives and to support early discussion of EoL options with their patients than their black counterparts. Moreover a diversity of cultural beliefs and practices surrounding death and dying means

that the potential for conflict when considering EoL care for patients from minority ethnic groups in a western medical system 'dominated by the principles of patient autonomy, beneficence, non-maleficence and avoiding futile care' (Brown, 2014, p.3). Difficulties arise from often implicit values around disclosure, care and responsibility the desire to carry burden collectively; resistance to talking explicitly about death and dying in healthcare settings; preferences over place of death and the use of traditional methods as an element of supportive care (Broom et al., 2013).

Conclusion

The way the physical process of death and dying is handled by most western societies is showing signs of exhaustion due to some basic phenomena this chapter has addressed. First, the biomedicalisation of dying insists on treating, curing and extending life at any cost rather than ensuring a high-quality standard of life during the last days of life. Second, the dying process has been removed from familiar sites ("home") to hospitals and other such sites where many dying people do not want to be in their final days. Third, this perspective persists in emphasising the material side of the dying process at the expense of the integration of psyche/mind and body. Even careful and novel palliative care services do not give the same level of importance to the professionals of the mind when forming interprofessional or interdisciplinary teams. Fourth, the biomedicalisation of death is a phenomenon of the last 60 years, and there is still time to correct the excesses.

The brief history of both palliative and EoL care in as much as a social and a research movement has been linked to two interesting and intersectional cases of women doctors in the UK and the USA. It is due to these two figures that palliative care has been acknowledged as a branch of medicine with the corresponding global adoption by the WHO. With the innovative concept of total pain as something not only physical but also social, emotional, psychological, and cultural, Saunders opened the ground for thinking about the relationship between body and mind, which gave birth to the hospice movement. Historically her work has contributed to the fact that the UK is ranked as the best place to die.

In multicultural societies like the UK and the USA there is a need for government authorities, including health service planners, to be more sensitive culturally. Ethnicity,

gender, age, disability, class and religion among others are categories or identity markers that help to capture when acts of inequality and discrimination occur. One advantage of the intersectional approach is that it helps to capture simultaneously and mutually, when discrimination and inequity take place in more than one category rather than to each one in an isolated and discrete way.   Identity and power as two of the underpinning concepts of the intersectional approach bring innovative light to how health professionals can think of these concepts in their daily interaction with service users. Palliative and EoL care services will benefit from using the intersectional approach. Examining the role of ethnicity without acknowledging how ethnic experiences intersect with wider identity markers or categories and other socioeconomic processes would give a very partial view of the dynamics influencing their engagement with palliative and EoL services.

Research and literature on palliative and EoL services regarding ethnic minorities in the UK and the US demonstrate that these groups access these services less than the majority population. The main overarching concerns found from the perspective of minority service users were around knowledge of palliative and EoL care services; levels of trust towards health care professionals and how ethnicity intersects with class, gender, generation, religion, disability, age, sexual orientation and immigration status when accessing these services. From the health provider's perspective the themes related to their understanding of minority cultural beliefs and practices around death and dying; how to communicate effectively and compassionately with the patient and their family and friends and the organisation and delivery of those services.

Racial/ethnic commonalities about palliative and hospice care cut across social, economic and cultural dimensions in both nations. In the UK and the USA, dying with care must be communicated to patients and caregivers as a medical intervention that is well within the framework of health care. With expressions of pain still falling within frameworks of ethnicity and determining a patient's discomfort risk being an arbitrary and capricious judgement by health providers and relieving patients' pain, mental anguish and physical stress should be conveyed as improving the patients' quality of life as they face the inevitability of death.

Dying occurs at home more frequently in the US, Canada and Britain though in the USA, some research found that racial/ethnic minorities would rather die in a hospital than at home. In the UK the need for high-quality palliative and EoL services for minorities is because the majority of deaths still occur in hospitals. The UK, compared to the USA, ranks better in the provision of palliative care. However, inadequate care can be compounded by feelings of vulnerability that many minorities in both nations might experience due to being defined (and treated) as racial/ethnic minorities. Communication does not necessarily mean speaking the same language but the ability to convey compassionate care in a diverse population. Identities are not static and permanent forces but are fluid, imagined, constructed and reconstructed forces and it is to these identities that health services in palliative and EoL care need to respond ethically in a daily basis.

REFERENCES

Ahmed, N. et al., (2004) 'Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals', *Palliative Medicine,* Vol. 18, No. 6, p. 525.

Bureau, U. (2015). *Population*. [online] Census.gov. Available at: http://www.census.gov/topics/population.html [Accessed 23 Dec. 2015].

Broom, A, at al. (2013) 'Negotiating palliative care in the context of culturally and linguistically diverse patients', *Internal Medicine Journal,* 43, pp. 1043-1046.

Brown, E. A. (2014) 'Ethnic and Cultural Challenges at the End-of-Life: Setting the Scene', *Journal of Renal Care,* 40 (Suppl.1), pp. 2-5.

Calanzani, N. et al., (2013) *Palliative and EoL Care for Black And Minority Ethnic groups in the UK,* Public Health England.

Cintron A, Morrison R.S. (2006) Pain and ethnicity in the USA: A systematic review. J Palliat Med 9(6): 1454-73.

Clark, D. (2007) From margins to centre: a review of the history of palliative care in cancer. *The Lancet Oncology*, 8(5), pp.430-438.

Coupland, Victoria H ; Madden, Peter ; Jack, Ruth H ; Møller, Henrik ; Davies, Elizabeth A (2011) Does place of death from cancer vary between ethnic groups in South East England? *Palliative medicine*, Vol.25(4), pp.314-22.

Crenshaw, K. (1989) Demarginalizing the intersection of race and sex: a black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum,* 1989, 139-167.

Diver, F. Molassiotis, A. and Les Weeks, L. (2003) 'The palliative care needs of ethnic minority patients attending a day-care centre: a qualitative study', *International Journal of Palliative Nursing,* Vol. 9, No. 9, pp. 389-396.

Duffy, S., Jackson, F., Schim, S., Ronis, D. and Fowler, K. (2006). Racial/Ethnic Preferences, Sex Preferences, and Perceived Discrimination Related to End-of-Life Care. *Journal of the American Geriatrics Society*, 54(1), pp.150-157.

Economist Intelligence Unit. The Economist, (2010) Quality of Death: Ranking end-of-life care across the world.

Evans N, Menaca A, Andrew EV, Koffman J, Harding J, Higginson IJ, Pool R, Gysels M. (2011) Systematic review of the primary research on minority ethnic groups and end-of-life care from the United Kingdom *Journal of Pain Symptom Management*, 43(2), pp. 261-86.

Firth, S. (2001) *Wider Horizons: Care of the Dying in a Multicultural Society,* NCHSPC

Hanchate, A. et al.,. (2009) 'Racial and ethnic differences in end-of-life costs: Why do minorities cost more than Whites?' *Archives of Internal Medicine,* Vol. 169, No. 5, pp. 493-501.

Gawande, A. (2014). *Being mortal*. New York, N. Y.: Picador.

Hankivsky, O. and De Leeuw, S. (2011). *Health inequities in Canada*. Vancouver: UBC Press.

Heubber, S. and Sellschopp, (2014). Adding Life to the Dying:Palliative Care and Psycho-oncology In: S. Kakar, ed., *Death and Dying*, 1st ed. Penguin India.

Hinkka, H. et al.,. (2002) 'Factors affecting physicians' decisions to forgo life-sustaining treatments in terminal care', *Journal of Medical Ethics,* Vol. 28, No. 2, pp. 109-114.

Hornung C.A Eleazer G.P, Strothers H.S, Wieland GD, Eng C, McCann R, Sapir M. (1998) Ethnicity and decision-makers in a group of frail older people *Journal of the American Geriatric Society*.46(3), pp. 280-6.

Jack CM, Penny L, Nazar W. (2001). Effective palliative care for minority ethnic groups: the role of a liaison worker, *International Journal of Palliative Nursing* 7(8), pp. 375-80.

Johnson, Kimberly S. ; Kuchibhatala, Maragatha ; Sloane, Richard J. ; Tanis, David ; Galanos, Anthony N. ; Tulsky, James A. (2005) 'Ethnic Differences in the Place of Death of Elderly Hospice Enrollees' *Journal of the American Geriatrics Society*, Vol.53(12), pp.2209-2215

Johnson K. S, Kuchibhatla M, Tulsky JA. (2009). Racial differences in self-reported exposure to information about hospice care, Journal of Palliative Medicine 12(10), pp. 921-7.

Kakar, S. (2014). *Death and dying*. Penguin Books, India.

Karim, K., Bailey, M., and Tunna, K. (2000) 'Nonwhite ethnicity and the provision of specialist palliative care services: Factors affecting doctors' referral patterns', *Palliative Medicine,* Vol. 14, No. 6, pp. 471-478

Keeley, P. and Noble, S. (2011). Palliative care: introduction. *Medicine*, 39(11), p.635.

Kessler D, Peters T.J, Lee L, Parr S. (2005) Social class and access to specialist palliative care services, *Palliative Medicine,* 19 (2), pp. 105-110.

Koffman, J. and Higginson, IJ. (2004) 'Dying to be home? Preferred locations of death of first generation black Caribbean and native-born white patients in the United Kingdom', *Journal of Palliative Medicine*, 7, pp. 628-636.

Koffman, J. (2014) 'Servicing Multi-Cultural Needs at the EoL', *Journal of Renal Care,* 40 (Suppl.1), pp. 6-15.

Krizsan, A., Skjeie, H. and Squires, J. (2012). *Institutionalizing Intersectionality*. Palgrave Macmillan.

Kwak J and Haley WE. (2005) Current research findings on end-of-life decision making among racially or ethnically diverse groups *Gerontologist*, 45(5), pp. 634-41.

Mebane, E. W. et al., (1999) 'The influence of physicians' race, age and gender on physician attitudes towards advance care directives and preferences for end-of-life decision making', *Journal of the American Geriatrics Society,* Vol. 47, No. 5, pp. 579-591.

Moreno-Leguizamon, C. J. (2005) Dichotomies in Western Biomedicine and Ayurveda, Health-Illness and Body-Mind, *Economic and Political Weekly*, Vol. XL, No 30, July 2005, India.

Moreno-Leguizamon, C. J. (2012) *Ayurveda, Biomedicine, and Indigenous Medicine: Three Medical Discourses, One Critical Discourse Analysis (CDA)*. Lambert Academic Publishing, Germany. ISBN 978-3-659-22912-1.

Moreno-Leguizamon, C. J., Tovar-Restrepo, M., Irazábal, C. and Locke, C. (2015). Learning alliance methodology: Contributions and challenges for multicultural planning in health service provision: A case study in Kent, UK. *Planning Theory & Practice*, Volume 16, Issue 1, 2015(Issue 1, 2015), pp.79-96.

National Health Service (NHS).UK, (2015). *End of life care - NHS Choices*. [online] Available at: http://www.nhs.uk/planners/end-of-life-care/Pages/End-of-life-care.aspx [Accessed 23 Dec. 2015].

National Poverty Centre (2015). *National Poverty Center | University of Michigan*. [online] Available at: http://www.npc.umich.edu/ [Accessed 23 Dec. 2015].

Office for National Statistics, ONS.gov.uk, (2015). *2011 Census - ONS*. [online] Availableat:http://www.ons.gov.uk/ons/guidemethod/census/2011/index.html?utm_source=twitterfeed&utm_medium=twitter [Accessed 23 Dec. 2015].

Pan, C. X. et al.,. (2015) 'Just Ask: Hospice Familiarity in Asian and Hispanic Adults', *Journal of Pain and Symptom Management,* Vol. 49, No. 5, pp. 928-933.

Parry, G., Van Cleemput, P., Peters, J., Walters, S., Thomas, K. and Cooper, C. (2007). Health status of Gypsies and Travellers in England. *Journal of Epidemiology & Community Health*, 61(3), pp.198-204.

Park, N., Jang, Y., Ko, J. and Chiriboga, D. (2015). Factors Affecting Willingness to Use Hospice in Racially/Ethnically Diverse Older Men and Women. *American Journal of Hospice and Palliative Medicine*.

Phillips, L. and Taylor, V. (2012) 'Addressing the palliative care needs of minority groups', *Primary Health Care,* Vol. 22, No. 1, pp. 26-30

Poverty.org.uk, (2015). *Poverty indicators - The Poverty Site*. [online] Available at: http://www.poverty.org.uk/ [Accessed 23 Dec. 2015].

Randhawa G, Owens A, Fitches R, and Khan Z. (2003) The role of communication In developing culturally competent palliative care services In the UK: a Luton case study. *International Journal of Palliative Nursing* 9, PP. 24-31.

Reynolds KS, Hanson LC, Henderson M, Steinhauser KE. (2008). End-of-life care in nursing home settings: do race or age matter? *Palliative Support Care* 6(1), pp. 21-27.

Smith, D. and Ruston, A.M. (2013) 'If you feel that nobody wants you you'll withdraw into your own' Gypsy/Travellers, networks and health care utilisation' *Sociology of Health and Illness*, Vol. 35, Issue 8, pp. 1196-1210.

Tinker, A. (2014a) Review of Transforming Your Care and Older People. Committee for Health, Social Services and Public Safety. Northern Ireland Assembly.

Tinker, A. (2014b) *Older People in Modern Society 4th edition,* London: Routledge.

Venkatasalu, M.R ; Arthur, Antony ; Seymour, Jane (2013) Talking about end-of-life care: the perspectives of older South Asians living in East London *Journal of Research in Nursing,* Vol.18(5), pp.394-406 .

Waisel DB. (2013). Vulnerable populations in health care. Curr Opin Anaesthesiol 26(2): 186-92.

World Health Organisation (WHO) (2015) 'WHO definition of palliative care' http://www.who.int/cancer/palliative/definition/en/. [Accessed 23 Dec. 2015].

Jang, Y., Chiriboga, D., Allen, J., Kwak, J. and Haley, W. (2010). Willingness of Older Korean-American Adults to Use Hospice. *Journal of the American Geriatrics Society*, 58(2), pp.352-356.