Embracing Multidisciplinary Approach to Palliative Care: The Role of Medical Anthropology in Palliative Care

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Abstract

Medical anthropology is concerned with how different cultures and social groups explain causes of ill health, types of treatment take n and where they turn to when ill. The discipline complements palliative care by aiding care providers to understand human beings in their cultural context. This paper discusses the role of medical anthropology in palliative care and proposes that palliative care capacity building should consider training in related disciplines like medical anthropology. The paper is based on review articles on linking palliative care to medical anthropology field. The review targeted key words: 'palliative care'; 'medical anthropology' and 'life threatening illnesses' for all relevant papers up to July 2014. Palliative care seeks to improve the quality of life of patients and their families facing problems associated with life threatening illnesses, 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). Medical anthropology explains the influence of culture in the health seeking behaviours of people; appreciates medical pluralism, validates peoples' interpretation of health and illness even before biomedical diagnosis is undertaken for palliative care interventions. Medical anthropology provides an important facet to understanding patients, family history, and the journey through health and illness, which is a useful foundation for palliative care provision. Medical Anthropology can be one of the essential complementary disciplines to palliative care.

Keywords: *palliative care, medical anthropology, multidisciplinary approach*

Introduction

Background information

Palliative care and Medical anthropology

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, 2002). Palliative care for children represents a special, closely related field to adult palliative care: It *is the active total care of the child's body, mind and spirit, and also involves giving support to the family. (WHO 1998a)*. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated.

According to Choi (2002) the key goals of palliative care include eexcellent pain and symptom control, psychosocial and spiritual support for the patient and family, informed decision-making, and coordinated services across the continuum of care – communication, information sharing, patient preferences, advanced care planning, bereavement care, ethical principles related to hastening death.

Anthropology has a Greek origin meaning the 'the study of man' looking at man holistically in terms of his origins, development, social and political organization, religions, languages, arts and artifacts. Medical anthropology borrows from cultural, cognitive, philosophical, biological and social anthropology. It is a branch of anthropology that looks at how people in different cultures and social groups explain the causes of ill health, the types of

treatment they take and where they turn to when ill (Helman 1994). Leigh (2013) explains that medical anthropology focuses on how human cultures define and affect medical and health issues.

Problem statement and objective

Who is this patient?

Patients come from a community and ascribe to a culture, which influences their perception on the meaning of their illness and perception of cure. As the patient belongs to a wider system, the patient's condition has implication on those in wider system including the immediate & extended family, friends, community members and systems of worship. Bronislaw Malinowski's paper (1944) proposed that people could not live without culture, which fulfilled the biological needs of humans. In fact it is argued that even in medical pluralism, where the biomedical system and other medical systems exist, people (sometimes even the well-educated) still choose a health system based on their judgement within their cultural context. Some illnesses may be considered normal in one ethnic culture but abnormal in biomedicine, or if abnormal, the mode of treatment is different.

Theories and models of health seeking behaviors place the individual's perception and the prevailing cultural socialization as key aspects. Examples are Mechanic's (1978) general theory of health seeking, Suchman's stages of decision making and the Health Belief Model by Rosentocket.al (1994). Similarly, palliative care is interpreted differently by different cultures with different approaches to health seeking behaviour.

Palliative care as a multidisciplinary approach

As indicated in the APCA Standards (2011), interdisciplinary teamwork is an essential component for comprehensive delivery of palliative care. It involves care providers with different skills working together to provide holistic care to patients and families including children facing illness and bereavement. The needs of individuals receiving palliative care are multifaceted, including physical, emotional, social, spiritual and cultural needs. These needs can effectively be addressed by several people working together as a team collectively concerned about the total wellbeing of the patient and family as indicated in table 1 below

Table 1: Domains for palliative care and issues addressed

Domain	Issues
Physical	Pain, infection, wounds ,cough, cancer, ethical issues i.e. withdrawal of/ giving of treatment, non-resuscitation orders, control of infections
Psychological	Shift in role, self-image and esteem, autonomy, decision making
Social, economic	Family & community perception of illness, influence of culture, money, will making, succession, inheritance, advance directives, getting insurance benefits e.g. NSSF
Spiritual	Why me? What is the meaning of this? Where do I go after death? Is this punishment from the ancestors? Refusal for some intervention i.e. Blood transfusion, body part grafting

In practice however, palliative care training incorporates some aspects of palliative care which is not satisfactory. this is evident when the biomedical approach is still seen as the as the gold standards and peoples culture and background do not always play the critical role it should play, especially in the social, economic and spiritual domains of care.

This paper discusses the role of medical anthropology in palliative care and proposes that palliative care capacity building should consider training in related disciplines like medical anthropology.

Literature review

Theoretical approaches in medical anthropology and relation to palliative care

Theoretical approaches applied by medical anthropology apply to palliative care and can address all the dimensions (physical, psychological, socio-economic and spiritual). Patients with palliative care need experience multifaceted suffering, and medical anthropology agrees with Kleinman et al. (1997) on

the social suffering approach which label suffering as a social experience. Suffering is seen as a cultural experience ascribing to models of suffering in place in that particular culture, authorised by the community. This suffering goes beyond the illness itself and incorporates the social, political and economic influence of human suffering, thus its remedy should encompass cultural, social interventions influenced by the political and professional systems in place to respond to the suffering.

The ethno-medical approach stress the importance of health professionals discussing the patients' beliefs on causes of their illness and options for cure considered effective and acceptable and agreeing on the most effective remedy. Examples of successful contribution to health through the ethno-medical approach include the discovery of the cause of *Kuru* (Lindenbaum, 2008) *[Kuru is defined by Wikipedia as a disease of the nervous system*], which caused death of many people in Papua New Guinea. Other culture-specific disorders include Windigo Psychosis in the Northern

Algonkian Indians and *Koro* in China (Chowdhury, 1996) [*Koro is defined by Wikipedia as a culture-specific syndrome in which an individual has an overpowering belief that his or her genitals (e.g., penis or female nipples) are retracting and will disappear, despite the lack of any true longstanding changes to the genitals].* Currently, alternative medicine has also emerged with more people reverting to 'herbal' remedies compared to classic biomedical medicines. The use of herbal concoctions and other natural therapies are being taken up by many people with the argument that they are natural, and thus 'safe'. Examples include the use of complementary therapies like acupuncture and reflexology, and herbal products from the Golden Neo-Life Diamite International *(GNLD)*, *Forever Living* products and other groups that offer substances that promote health rather than cure diseases and illnesses, through providing body cleansing and revitalising agents, nutritional supplements and other alternative natural therapies. There has been a lot of popularity on the usefulness of Aloe Vera and charcoal for health. To date, you can obtain almost any product in herbal form, from toothpaste to herbal condoms. Alternative therapies have been known to work and are less harsh than classic medicines that go into the body system. It is a common scene to find the *Maasai* in the streets with small containers and folding of herbal concoctions that literally 'cure' all illnesses. These examples explain the importance of ethno-medicine, which also applies to palliative care.

The critical approach to medical anthropology provides linkages between the individual interpretation of disease and illness and upholds the role of personality, situation and culture in influencing issues of power, control, resistance surrounding health, sickness and healing (Morsy, 1990). In Kenya, forinstance, the HIV/AIDS fight would have not been successful if interventions excluded considerations to the cultural explanation of the syndrome. Among the Luo, AIDS was first explained as a result of '*Chira'* [which was a Luo term for a wasting disease attributed to a breach of taboos], which came because of not adhering to the set society norms and traditions (Owino, 1998). This personalistic view was a barrier to HIV prevention as other practices like wife inheritance and polygamy persisted. HIV prevention programs had to demystify this view that AIDS was real and not a '*Chira',* which helped clarify the cause of HIV and subsequently its prevention and management. Despite sensitisation on HIV for over two decades and glaring lessons on the scourge; in 2012 UN implied that Uganda, is losing the battle for HIV, as there is evidence of increasing prevalence of 7.3% in 2011 up from 6.4% in 2004. An example of rationalised explanation for this is that "it is better to die in the next ten years from 'Typhoid of HIV' than to die tomorrow in misery and poverty" a reason that may be regarded as 'ridiculous' by the health practitioner.. In Uganda, a study of the aetiology of low back pain in Mulago Hospital showed that 67% of incidences had unknown causes and were higher in women than Men at the ratio of 2:1. (Africa Health, 2005*) I*n the Luo community and many other communities, low back pain in women is associated with age and taken as normal. Thus, the low back pain could be exacerbated through the productive roles when the women undertake tasks that require bending soon after childbirth, contributing to early development of back pain. Medical anthropology could elicit this knowledge and help address the unknown causes of low back pain.

The political approach to medical anthropology looks at the impact of government policies on all aspect of life, including influence of health; it is helpful in macro planning for improvement of health in regions. In fact, patients with cancer, compared to patients with HIV, are most likely to suffer and die quickly from the disease since their medicines are not in the essential medicines list and most often very expensive. The Kenya Hospices and Palliative Care association (KEHPCA) has supported advocacy strategies to include palliative care in the national cancer strategic plan, which hopefully will support the inclusion of cancer medicines in the essential list or as public health medicines. To date, the acceptance of oral morphine as a gold standard for pain relief of palliative care patients has improved the lives of many patients with palliative care needs.

Methodology

The paper is based on review articles linking palliative care to medical anthropology field. The review was undertaken through Google scholar for key words 'palliative care'; 'medical anthropology'; 'life limiting' and 'life threatening illnesses' for all papers up to July 2014. The review results showed both articles in peer reviewed journals as well as blogs, websites, online books and articles having at least any of the keywords. These resulting items were then reviewed and selected based on relevancy to the topic. All articles cited in this paper are referenced.

Results/Discussion

Palliative care and the interdisciplinary team

As palliative care is holistic, covering all the domains, not one discipline can address adequately all these domains in the patient and family. In addition, the role of a member of the team may shift/change/ become more prominent/ reduce across the domains with the disease progress. Thus, in order to provide effective palliative care, care providers must understand such systems for each patient and their role.

Through ethnography, medical anthropology provides knowledge on the communities' perception of the illnesses, thus aids in developing community friendly messages for early identification and prevention of life threatening conditions.

Medical anthropology thus complements palliative care through supporting early identification, impeccable assessment appreciating medical pluralism, providing information on meaning attached to the illness thus aiding care providers to understand and appreciate human beings in their cultural context; and provide better care.

Early identification: Diagnosis mostly happens at hospital level. From the perspective of medical anthropology and in practice, diagnosis begins long before hospital/clinical encounter, at home. Many patients make their diagnosis and mostly going to specialist to confirm. Thus, early identification needs awareness and mobilization at community level

Impeccable assessment: Medical anthropology helps in understanding the communities' perspective and aetiologies of common labels of syndromes and diseases. For instance some people attribute 'Limonia' [read: pneumonia] to cold or Malaria to when one is rained on. It is important to understand what these terminologies and labels mean to patients. Knowledge on the health seeking behaviour of a person and community provides an idea of how long it takes before the person sees a doctor, and is very key in palliative care and explains late presentations. The role of traditional healers cannot be underestimated. Turin (2010) cited main factors that affected utilisation of health care services in Kenya as including cultural and social influences.

Ethno medicine: Palliative care benefitted from complementary therapy and herbal medicine that has proven to work i.e. use of Frangipani sap used to relieve neuropathic pain in Uganda (Merriman&Harding, 2010). Furthermore the country has an organised association for traditional healers led by a once medically trained dentist and is fully operational. The traditional healers have a university in a forest and provide training in identifying different herbs for remedies, and treating opportunistic infections. Unlike Uganda that has embraced and is working with these traditional healers, who even have an organisation (PCAU,2014) , most of the countries view ethno medical practice as a barrier rather than complementary to biomedical practice due to challenges of patients taking or mixing traditional medicine with modern

therapy. The countries could however refer to findings from medical anthropology to achieve equilibrium.

Finally, it is well known that politics and economy affect health outcomes: In Kenya the price of one litre of milk is more than a litre of petrol. How does the poor man with HIV and AIDS sustain adequate nutrition in such an economy?

Recomendation

Medical anthropology provides an important facet to understanding patients' and family history and journey through health and illness, which is a useful foundation for impeccable palliative care provision. It explains the influence of culture in the health seeking behaviours of people, appreciates medical pluralism thus validates peoples' interpretation of health and illness even before biomedical diagnosis is undertaken for palliative care interventions. This includes providing information on lay definition, interpretation of the illness in the particular community and expected interventions.

Palliative care stakeholders could therefore consider training in medical anthropology as well as refer to various information including ethnographic findings, effect of socio-cultural factors on illness.

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