

PALLIATIVE MEDICINE AND HOSPICE CARE

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Editorial

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Challenges in Palliative Care Research: Experience from a Randomized Controlled Trial in Refractory Cancer Cachexia

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There is a paucity of research studies in palliative care with less than 1% of clinical trials being relevant to the hospice and palliative care setting.¹ Difficulties in conducting studies with this client group such as recruitment, retention, methodological and ethical issues are well documented within the literature.^{1,2-6} Nonetheless, conducting research with palliative populations is necessary to ensure the development of evidence based policies and services which reflect and respond to the needs of this vulnerable and often underserved population. Previous research has demonstrated that palliative care patients^{7,8} and their families⁹ are willing to be involved in palliative care research and the onus to conduct high quality rigorous research with this client group lies with researchers.¹⁰ It is only through actively engaging in research with the palliative population that we can build an evidence base that will contribute to the development of evidence based policies, protocols and treatments and allow health care professionals to consistently respond to palliative patients and their families in order to maximise their quality of life as they approach the end of their lives.

One of the areas in which this paucity of systematic research has had a detrimental effect on the care of palliative patients is cachexia. The European Palliative Care Research Collaborative's (EPCRC) guidelines¹¹ on cancer cachexia define it as a multi-factorial syndrome characterised "by an ongoing loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support" (p. 8). Refractory cachexia¹¹ refers to the 'stage where reversal of weight loss seems no longer possible' (p. 8) and the majority of patients at this stage will be receiving palliative care. Previous research in this area has demonstrated the holistic impact of the syndrome.¹²⁻¹⁵

Research in palliative care, has been dogged by recruitment problems.¹ Our own research has faced similar problems. In the absence of a recognized treatment solution, an evidence-based psycho-educational health care intervention has been developed for this patient cohort and their family members by a team of researchers and healthcare staff in Northern Ireland. This DVD intervention has been funded by the All Ireland Institute of Hospice and Palliative Care and will be evaluated in a randomized controlled trial with a palliative cancer population who have refractory cachexia.¹⁶ The team's experience thus far highlights the inherent difficulties in conducting research with this client group.

Members of our team have worked closely alongside multidisciplinary clinical colleagues and have engaged in Patient Public Involvement (PPI) from the early stages of the development of the intervention. Their insights were instrumental in: developing the intervention and study information sheets; and ensuring the clinical soundness and practical utility of the psycho-educational intervention. However, our problems with recruitment lie in the fact that

refractory cancer cachexia, while characterized¹⁷ and documented in the EPCRC's guidelines¹¹ is rarely acknowledged or diagnosed due to a lack of clear clinical diagnostic guidelines and local protocols for clinical management. This reluctance to recognise and diagnose cancer cachexia among the myriad of potential co-morbidities found in end-of-life care has hindered identification of potential participants. Indeed previous research has demonstrated the lack of clinical awareness of this syndrome among health care professionals.¹⁸ While the authors have taken the initiative by: conducting educational sessions on refractory cachexia with health care staff at each clinical site; have harnessed clinical support for the study; and have worked at length with both clinical and PPI colleagues, recruitment into this study has been disappointing.

In order to positively influence clinical practice in palliative care, health care professionals need access to 'best available evidence'. As this and as other studies in palliative care demonstrate, acquiring evidence from this client group presents a great challenge. There is a clear need for the urgent development of evidence based guidelines to aid in the education, diagnosis and management of refractory cancer cachexia. Such guidelines will undoubtedly provide the clinical diagnostic criteria necessary to assist healthcare professionals in identifying refractory cachexia and allow them to respond appropriately. This in turn will make it easier to identify and recruit appropriate patients for future studies in palliative care.

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Review

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Clinical Management of Cancer-Related Cachexia: Review of the Literature

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ABSTRACT

Cachexia is among the most debilitating and life-threatening aspects of cancer, especially in the palliative care setting. It represents a metabolic syndrome affecting essential functional circuits involved in the regulation of homeostasis, with symptoms including anorexia, and fat and muscle tissue wasting. Most patients experiencing cachexia do not receive proper management and suffer a profoundly distressing experience, affecting not only the patients, but also the entire family. Thus, oncologists and palliative care clinicians must understand its complex pathophysiology and treatment. This article will review special considerations about the anorexia-cachexia syndrome and which interventions are most effective in relieving this condition.

KEYWORDS: Cachexia; Interleukins; Metabolic syndrome; Hypercatabolic state; Anorexia-cachexia.

INTRODUCTION

Signs and symptoms of cachexia have been reported since the time of Hippocrates. He described it as a syndrome of wasting and progressive inanition among ill or dying patients.¹ The word cachexia is derived from the Greek *kakos* “bad” and *hexis* “condition”. Cachexia represents the clinical consequence of a chronic, systemic inflammatory response, and its manifestations differ considerably from those of starvation.

Cachexia is a multifactorial devastating syndrome, and is essentially irreversible; it affects about 50-80% of cancer patients, usually in advanced stages of the disease.² It results in substantial weight loss, which is, by definition, more than 5% of the usual weight during the prior 6 months.³ It is clinically distinguished by anorexia, emaciation, weakness, and fatigue. It results in damaged immunologic function, tissue consumption, and status performance decline, and cannot be nutritionally reversed.⁴

Cancer-related cachexia involves fat and muscle mass loss, and reflects catabolic metabolism that is induced by an abnormal host response to the tumor. Its clinical implications are profound, and the weight loss is associated with decreased adherence to treatment, prolonged hospital stays, and reduced survival.⁵ Moreover, unintentional severe weight loss jeopardizes the cancer patient's quality of life and sense of dignity.

The preservation of dignity should be a goal in palliative cancer treatment, because its loss is prominently associated with certain types of suffering commonly seen among the terminally ill.⁶

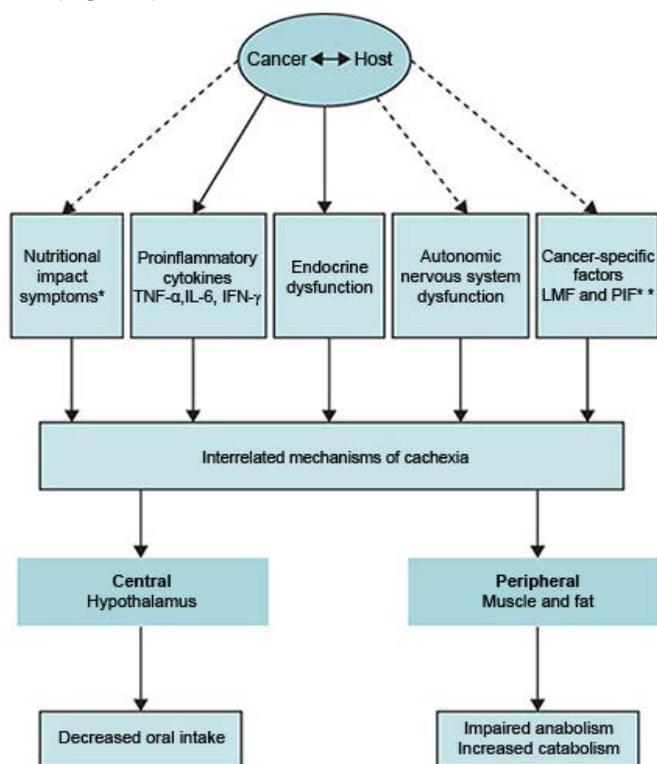
RELEVANT PATHOPHYSIOLOGY

Cancer-related cachexia etiology is not yet fully understood, but is certainly multifac-

torial, with a rather complex pathogenesis. Several cytokines, tumor factors, and hormones have been implicated, particularly Tumor Necrosis Factor- α (TNF- α), Interleukins (IL), proteoglycan, insulin, adrenalin, corticotropin, human growth hormone and insulin-like growth factor.^{7,8} Most studies have detected elevations in peripheral blood mononuclear cell cytokine concentrations, especially TNF- α and IL-6, in weight-losing patients with cancer.⁹

Cachexia may be etiologically classified as primary or secondary. Primary cachexia is due to metabolic decompensation caused by the basic illness. Generally, its origin involves an increase in inflammatory activity and insulin resistance, anorexia, hypogonadism, and anemia.¹⁰ Secondary cachexia involves the aggravating factors of primary cachexia, such as poor nutrition (due to a decrease in oral intake or intestinal absorption capacity, or protein loss), muscle mass loss due to other causes (prolonged inactivity, sarcopenia), or hypercatabolic states.¹¹ Cancer-related cachexia often evolves into a negative energy and protein balance, enhanced by a combination of reduced food intake and metabolic changes. Hence, hypermetabolism and reduced energy consumption due to anorexia may constitute a vicious cycle in the development of cachexia.¹²

Understanding the immune response associated with cachexia may improve future pharmacological modification of cytokines. In addition, the multifactorial contributions to the mechanisms of cachexia indicate that a multimodal approach might be necessary to treat cachexia and its associated symptoms (Figure 1).¹³



*Poor appetite nausea, early satiety, and dysgeusia
 **Lipid-mobilizing factor(LBF), Proteolysis-inducing factor(PIC)
 ***Lipid-mobilizing factor(LBF), Proteolysis-inducing factor(PIC)
Figure 1: Cancer related cachexia mechanisms.¹⁴

All palliative care patients should be screened for nutritional status and weight loss. The clinical assessment of patients with anorexia or cachexia includes an accurate history that is focused on nutritional issues, including risk factors that compromise the ability to obtain or take in nutrition, and a physical examination focusing on loss of subcutaneous fat, muscle wasting (temporal region, deltoids, and quadriceps, with loss of bulk and tone assessed by palpation), and edema (sacral or ankle) or ascites.¹⁵ An international consensus recommended five areas to be assessed in cachexia: depletion of stores, muscle mass and strength, anorexia/reduced food intake, catabolic drivers, and functional/psychosocial effects.

A comprehensive assessment for anorexia and cachexia should also take into account other symptoms that may affect appetite and caloric intake. These include symptoms that may be related to the underlying illness, symptoms and syndromes that may contribute to reduced caloric intake, and symptoms that might be the consequence of cachexia. In particular, pain, xerostomia, nausea, constipation, and depression are frequent in patients with chronic illness and may result in decreased caloric intake if not adequately treated.¹⁶

Some other strategies are also being introduced in the evaluation of the patient, such as Bioelectrical Impedance Analysis (BIA)¹⁷ and computed tomography, even when images are acquired during routine care.¹⁸ These strategies can be highly useful in long-term follow-up, when body changes often accelerate and the evaluation becomes more complex.

TREATMENT RECOMMENDATIONS

Cachexia used to be considered an inevitable consequence of cancer progression, without effective therapeutic interventions. Although there have been advances with several clinical essays showing enhanced clinical results, it should be emphasized that there is still no standard treatment for cachexia.¹⁹ Once the syndrome mechanisms are multifactorial, a broad multidisciplinary approach that employs pharmacological and non-pharmacological interventions is the most efficient strategy in order to reverse or stabilize the weight and muscle mass loss.²⁰

Ideally, the treatment should be individualized, taking into consideration the clinical status of the patient, the main mechanisms of weight loss, and a patient’s expectations for treatment. Although many patients and their relatives realize that the lack of appetite is a significant problem, cachexia patients may have different priorities, and their therapeutic options may vary considerably. For most, the maintenance of lean mass and functionality should be important, while others would rather have preservation of appetite in order to enjoy meals with family and friends as the main goal.

It is important to detect and treat the reversible causes, such as dry mouth, stomatitis, severe constipation, pain, and de-

pression, among others. Thus, increasing the nutritional component alone is insufficient.

Pharmacological Interventions

The pharmacological treatment of the anorexia-cachexia syndrome includes the use of orexigenic agents (appetite stimulants), anticatabolic agents (antimetabolic and anticytokine), and anabolic agents (primarily hormonal).^{21,22}

The use of appetite stimulants is supported by solid scientific evidence. The use of progestins (megestrol acetate, starting at 160 mg/day and increasing according to the clinical response up to 480-800 mg/day, or medroxyprogesterone, starting at 1 g/day and increasing up to 5 g/day) is recommended, as they rapidly improve appetite, decrease fatigue, and lead to a general sense of well-being. These benefits were confirmed by systematic analysis²³ and a Cochrane meta-analysis;²⁴ unfortunately, however, the weight gain due to progestational agents seems to be predominantly from fat or fluid, instead of lean body mass. The side effects of progestin use are hypertension, hyperglycemia, water retention, hypogonadism, and thrombosis. These are clinically significant, and must be monitored carefully.

Corticosteroids have long been first-line therapy for appetite stimulation in anorexia-cachexia syndrome, and may still be helpful,²⁵ but positive effects are mainly restricted to a few weeks, due to the risks associated with prolonged use. In spite of this, their use is increasing in cancer patients subsequent to the publication of a phase III clinical trial showing benefit for fatigue relief in this population.²⁶

Dronabinol is a cannabis derivative that stimulates the endocannabinoid system, but despite the expectation that was created with this drug class, its use has not proved effective in cancer patients' appetite improvement.²⁷

The administration of thalidomide in low doses (100 mg/day) significantly improved appetite, nausea, and sense of wellbeing after 10 days of use in advanced cancer patients and cachexia. A retrospective study based on 200 mg/day for six months proved that the drug was tolerated and was effective as a weight and lean mass stabilizer. However, symptomatic improvement was not reproduced.²⁸

Essential amino acid supplementation – particularly Branched-chain amino acids (BCAA) – mitigated cancer anorexia and stimulated protein synthesis, thus maintaining lean muscle mass.²⁹

Eicosapentaenoic acid (EPA, fish oil) showed promising preliminary results, which were not completely confirmed in retrospective studies in advanced cancer patients.³⁰ However,

positive effects on quality of life and appetite were demonstrated in the same patients.

Nutritional Approaches

Intensive and individualized nutritional counseling has proven to be effective for the maintenance of body weight and physical functioning in cancer patients.³¹ In taking a detailed clinical history, nutritional aspects, such as preferences and eating habits, must be taken advantage of. Dietary changes following disease onset should be identified, and, when possible, a daily food log should be kept. The aim of these methods is to stimulate caloric intake and to determine if there is any energy deficit.

Nutritional support is indicated for patients with cachexia caused by obstruction of the digestive tract, or by impediments to eating, such as large head and neck tumors or severe mucositis. The use of enteral or parenteral nutrition in patients with cachexia due to different causes is controversial and generally contraindicated, and is not associated with a meaningful clinical response in cancer and cachexia patients.

Family Support Interventions

It is clear that the multidimensional impact of anorexia-cachexia syndrome spans biopsychosocial domains and affects not only the patients, but also their families and caregivers. Nonetheless, the development and evaluation of psychosocial, educational, and informational interventions for patients with cachexia and their families and caregivers remain in their infancy.³²

Families often rationalize that if food intake is increased, weight will be regained and survival increased; the failure to increase intake is equated with hastening of death. This stems partially from a lack of communication with families about the nature and causes of wasting in cachexia, as atrophy is caused by factors independent of nutritional or calorific intake, and also from the need to take an active role in treatment, with food preparation being highly symbolic of the need to nurture. This often leads to conflict between the patients and their families, as the patients' refusal of food is interpreted as a rejection of care and support, increasing anxieties over food, and ultimately contributing to a decreased quality of life.

It is important to recognize that cachexia is a condition that has profound psychological as well as physiological implications for patients and their families. Better communication from researchers and healthcare professionals with patients and their caregivers is of great importance to not only reduce the burden of disease but also provide better understanding and support during disease progression.

Social Support Interventions

Psychosocial evaluation in cachexia risk is essential. Many family problems usually fully emerge with cachexia, often based on the almost automatic association between the cachectic physical appearance and the proximity of death. Therefore, an in-depth evaluation of the patient’s psychological status, as well as of relatives and caregivers, might be useful in the management of a case.

Depressed mood may also lead to decreased oral intake and must be treated with counseling and antidepressants, if indicated. Some psychotropic’s might have an indirect effect on cachexia, both for the treatment of depression that can lead to anorexia, because of a direct orexigenic effect (tricyclic antidepressants), or because of the effect on other symptoms, such as nausea (mirtazapine and olanzapine).³³

Psychotherapeutic Interventions

To eat a meal is a social activity *per se*. Therefore, for patients able to feed themselves, in the event of poor appetite or early satiety, counseling is important to maintain this activity

as long as possible. General measures, such as avoiding odors during food preparation, the use of condiments according to patient preferences, reduction of portion sizes, and having more frequent meals may improve the nutritional component, but do not seem to have an effect on symptoms or survival.³⁴

POTENTIAL FUTURE TREATMENTS

Melatonin is a pleiotropic hormone that may modulate multiple mechanisms promoting cachexia in cancer, including inflammation, autonomic failure, and malabsorption. In cachectic patients with advanced cancer, oral melatonin 20 mg at night did not improve appetite, weight gain, or quality of life compared with the placebo.³⁵ Further research is required to determine whether melatonin has a role in the supportive care of patients earlier in their disease course (Figure 2).

Promising results have been seen with ghrelin, a Growth Hormone (GH) – releasing peptide that induces a positive energy balance both by decreasing fat utilization and by simulating feeding through GH-independent mechanisms, and with anamorelin, which is an oral ghrelin mimetic. Some studies in cachectic patients suggest that repeated intravenous administration of

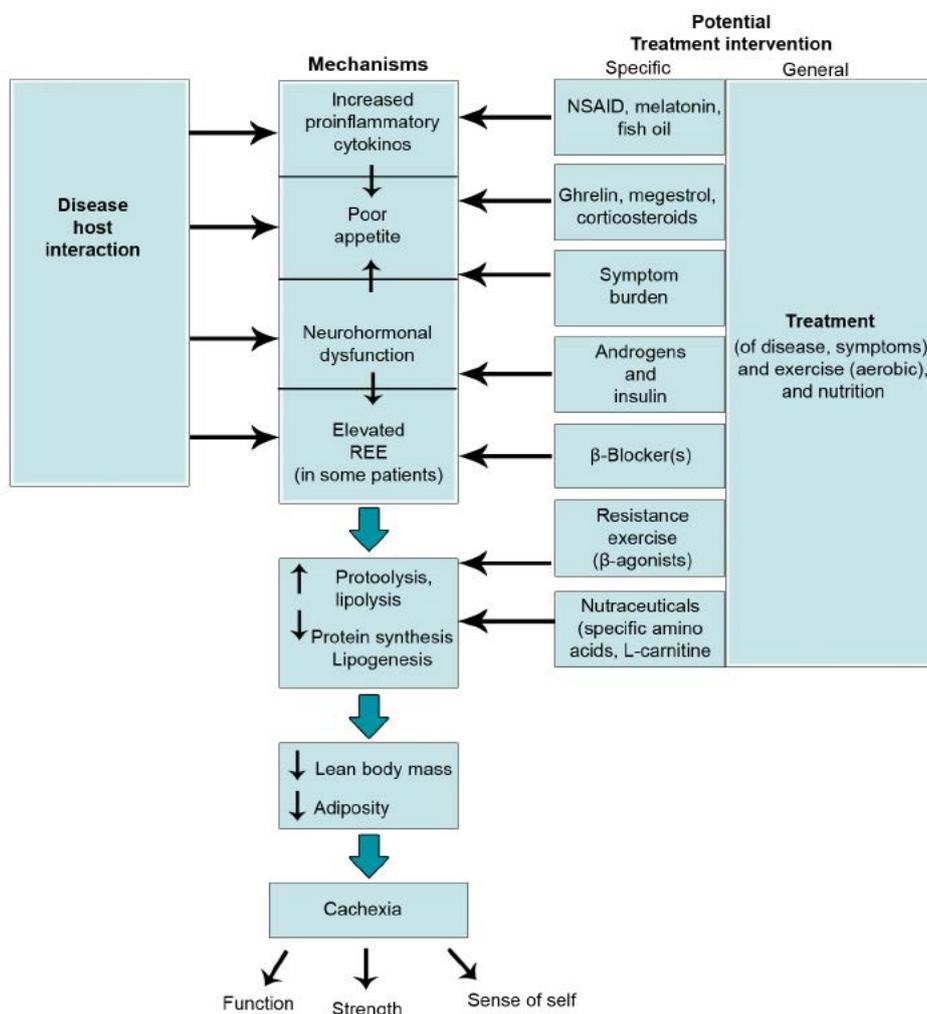


Figure 2: Multimodal treatment.¹⁴

ghrelin lessens muscle wasting and improves body composition, functional capacity, and an increase in satisfaction. However, ghrelin or anamorelin are not commercially available.³⁶

CONCLUSION

Cachexia is a hypercatabolic state defined as accelerated loss of skeletal muscle in the context of a chronic inflammatory response that frequently occurs in the setting of cancer, notably in those patients in palliative care. Early treatment also facilitates the use of oral nutritional supplementation, which is preferable to parenteral nutrition in the majority of cases. Once a patient has severe wasting, it may be neither practical nor ethical to intervene with anything more than supportive care.³⁷

The best therapeutic choice for cachexia is the effective treatment of the underlying disease. Recent progress in the understanding of molecular mechanisms in cachexia may lead to new therapeutic approaches.

CONFLICTS OF INTEREST: None.

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Review

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Hospice and Palliative Care for Older Lesbian, Gay, Bisexual and Transgender Adults: The Effect of History, Discrimination, Health Disparities and Legal Issues on Addressing Service Needs

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ABSTRACT

The acronym LGBT refers to groups of people who are lesbian, gay, bisexual and transgender, groups historically marginalized, mistreated, ignored by society and the health care delivery systems, including hospice and palliative care services. The purpose of this literature review was to explore the characteristics, history, health and health care disparities, social support systems and legal issues of LGBT persons with a particular focus on older adults, end-of-life care, and ways in which hospice and palliative care organizations can better meet their needs. Despite the fact that sound enquiry is needed to improve health-related outcomes, what little research has been done with LGBT adults in general and, specifically, with older LGBT adults, has focused mainly on HIV/AIDS and other sexually transmitted diseases. As a social minority, LGBT persons are more likely to experience economic insecurity, lack health insurance, experience invisibility, and be victimized and mistreated. This is especially true of older LGBT adults who grew up in a less tolerant era when sexual minorities were criminalized and stigmatized as pathological, sinful, and immoral. Their minority status has led to health issues and health care disparities, and requires health professionals to consider systems in a way that redefines family, addresses legal concerns, and responds with options of care unlike those of their heterosexual counterparts. With recent changes in societal attitudes and some progress in addressing legal concerns, hospice and palliative care organizations now have a unique opportunity to lead the health care community by pioneering culturally sensitive and appropriate methods to better serve this population.

KEYWORDS: Lesbian, Gay, Bisexual and Transgender (LGBT); Health disparities; Hospice; Older adults; Palliative care; End-of-life; Cultural sensitivity.

ABBREVIATIONS: LGBT: Lesbian, Gay, Bisexual and Transgender; DHHS: Department of Health and Human Services; ACA: Affordable Care Act; DOMA: Defense of Marriage Act; SAGE: Services and Advocacy for GLBT Elders.

INTRODUCTION

The acronym LGBT refers to groups of people who are lesbian, gay, bisexual and transgender. Although, the abbreviation suggests a homogeneous group, it includes a wide range of people¹ in part because it combines sexual orientation with gender identity.² Sexual orientation is the “enduring emotional, romantic, sexual or affectional attraction to another person”.³ For

gay men, this attraction is primarily to men, and for lesbians, this attraction is primarily to women. Gender identity is a person's self-perception as a man or woman. Sexual identity, in contrast refers to the cognitive and emotional meaning one attaches to expressions of sexuality in all of its forms, from fantasy to attraction and value judgements to behaviour. Although this means that sexual identity and sexual orientation are inextricably bound together, it would be a mistake to assume that the two are necessarily congruent or, if they are, that they would remain that way over time.³ In other words, there is no reason to assume that sexual orientation, sexual identity, and gender identity are static; as environments change, individuals, too, may change over their life course.³ Thus, each person of the LGBT group is a distinct individual with unique experiences that are shaped by multiple factors such as race/ethnicity, socioeconomic status, geographical location and age, not just sexual orientation.^{4,5}

Sex, gender, gender identity, and sexual orientation are the terms around which we organize our scientific exploration and social thinking. One's sex is seen as either male or female, characterized by the biological evidence of obvious genitalia and chromosome pair. Gender is purely a social construct and denotes a role-based distinction between men and women. From an institutional perspective we assume that being male should synchronize with behaving the way "a man" is expected to behave. Similarly, designated females are expected to act like women. This expectation is so locked into our organizational structures that forms and questionnaires are typically restricted to checking off one of two choices as if a third choice were almost unthinkable. This questionable binary assumption is further confounded by science's inconsistent use of the terms sex and gender, often treating them as interchangeable variables.⁶

Data on the size of the LGBT population are limited. In part, this is due to a socially-constructed ambivalence about formally recognizing this population as a unique group. In the US, institutionalized tracking of this large and diverse population began with the 1990 Census that included a module on same-sex, unmarried partners.⁷ Despite recent modest political gains, such as the legal right to marry in many states, prevailing social attitudes continue to assume sex-gender-sexual identity congruence and favour heterosexual behaviour making accurate census data of lesbian, gay, bisexual and transgendered population difficult to obtain.

Estimates indicate approximately 3.4% of the US population identify as members of LGBT communities.⁸ Approximately 3% of adults self-identify as LGB⁹ persons including about 3 million older adults.¹⁰ An estimated 1.5 to 7 million Baby Boomers, the first generation to be 'out', fall within this category.⁸ In spite of these significant numbers, little research has been done with LGBT adults in general and, specifically, with older LGBT adults.¹¹ The research that has been done has focused mainly on HIV/AIDS and other sexually transmitted diseases.^{11,12}

This makes sexual minorities one of the most understudied and consequently underserved groups in health disparities research.² A history of perceived and endured social stigma attached to being a sexual minority ties into a reluctance of some, particularly older adults, to self-identify as LGBT, resulting in their absence from research and its findings.¹¹ And yet, research suggests that most LGBT adults will provide information on sexual orientation and gender identity if told why the information is needed and if privacy and confidentiality are assured.³ The small size of this population relative to the total population adds to the difficulty and expense of recruiting participants into research studies.⁵ And yet, good, sound research is needed to discover mechanisms to improve health and reduce health disparities and inequalities for sexual minorities.³ The IOM⁵ has stated that data on sexual orientation and gender identity need to be collected regularly within all national studies. In response, several government agencies have, according to a recent Department of Health and Human Services (DHHS)¹³ report, taken steps to identify and correct health-related gaps, including services for LGBT seniors.

The purpose of this literature review is to explore the characteristics, history, health and health care disparities, social support systems and legal issues of LGBT persons with a particular focus on older adults. This review will also explore factors related to end-of-life planning and how hospice and palliative care organizations can meet the needs of this population at the end of life.

METHODS

One of the challenges of this review was the lack of a universally-accepted acronym for those who self-identify as LGBT. Depending on region, agency, or perhaps even whim of the research team, a variety of acronyms have been used: LGB; LGBT; LGBTQ (the Q referring to queer); LGBTQQ (the second Q referring to questioning); LGBTQU (the U referring to undecided); LGBTQI (the I referring to intersexed); and flipping the script, GLBT. In this literature review, the following search terms were used in addition to the acronyms listed: lesbian, gay, homosexual, bisexual, transgendered, sexual orientation, sexual minority, sexual preference, health, health disparities, hospice, palliative care, end-of-life, social support, legal issues, elder, older adult, aging and gerontology.

The next step was to identify target databases broad enough to draw a relatively complete profile of the LGBT population and end-of-life needs; these included EBSCO, PubMed, Medline, PsychInfo, Socindex, Social Science Index, and JSTOR. Inclusion criteria included publications must be scholarly, peer-reviewed journal articles, reports and books, published within the last ten years, which focused on issues directly or indirectly affecting the health of individuals who identify as LGBT persons in the US. This included general characteristics and experiences, health and health care disparities, social sup-

port systems, and legal issues. An exception was made for historical data provided by earlier research. Geographical location was limited to studies done in the US as the ultimate goal was to discover ways to improve hospice and palliative care practices within this country. However, the findings provide understandings for other countries who share parallel issues affecting the health of the LGBT community.

Sixty studies were systematically and comprehensively reviewed to generate a cohesive understanding about the history, health and health care disparities, social support, legal issues, and end-of-life attitudes and beliefs of sexual minorities through analysis of both the knowledge and the context in which it was produced.¹⁴

LITERATURE REVIEW

LGBT persons are part of every community; many live in poverty and, prior to the Affordable Care Act (ACA) of 2010 in the United States, had little or no health insurance, all of which increase the risk for poor health outcomes.⁴ Although it remains unclear what, if any, impact the ACA will have for LGBT elders, the law did incorporate language to allow for more options and benefits for sexual minorities.¹⁵ Nonetheless, a 2013 study found that a third of LGBT persons surveyed were not insured, with about two thirds of them having been uninsured for two or more years.¹⁶

As a group, LGBT persons are more likely to experience economic insecurity, especially if they are rural and female.⁸ A lifetime of discrimination, less likelihood of having employer sponsored pensions and health insurance, not being covered under their partner's plan, having to pay more for health care even with insurance, and denial of most survivor and death benefits, all increase the likelihood of financial and health problems in later life.⁸ Older LGBT persons are twice as likely as heterosexuals to live alone^{17,18} and four times more likely to be childless¹⁸ which impacts their support networks. Policies on aging have long ignored the needs of older LGBT adults and, as a result, older LGBT persons experience institutionalized discrimination *via* unequal access to benefits and services.¹⁷ For example, agencies serving the elderly tend to be less accepting of older LGBT adults than the health care system in general.¹⁹ One of the main obstacles to changing public policy has been heterosexist public opinion.¹⁷ This heterosexist attitude outside the LGBT community is further complicated by an ageist attitude within the LGBT community which tends to value beauty and youthfulness, not age, and is more ageist than society in general.¹⁹

From a social perspective, LGBT persons constitute a minority group. As such, they are not recognized as being legitimate and equal; they are marginalized, discriminated against, and may experience violence or invisibility.²⁰ Discrimination against LGBT persons is lifelong and permeates all aspects of life.²¹ Victimization of LGBT people may occur at multiple levels beyond

sexual orientation, including cultural differences, the impact of living within a heterosexist culture, and indirect discrimination suffered by friends, family members and loved ones.²²

The literature explains issues of minority stress of the LGBT population. Living within the societal prejudice of a heterosexist society is associated with negative mental and physical health outcomes.²³ A unique aspect of minority stress for LGBT persons is that sexual orientation is usually invisible; this leads to lack of sensitivity and inadvertent insensitivity from people unaware of a person's sexual orientation as well as overt discrimination.^{19,23} LGBT people may be subject to ridicule, become targets for demeaning and derogatory slang and insensitive jokes, and have their personal morality and value as human beings questioned.²³ Prejudice may be internalized due to living within a culture in which a group is devalued; this may lead to an internal struggle to balance the need for equality with the need for peace and escape from public scrutiny and discrimination.²³ Striving for peace and escape may involve the practice of covering, "toning down a disfavored identity in order to fit into mainstream".²⁴ Some research considers homosexuality a master status, a status that overshadows all other statuses and defines who a person is.^{19,20} Intersectionality theorists refute this and suggest that people, including those who self-identity as LGBT persons, have multiple intersecting marginalized statuses that are equally important.⁵

Today's older LGBT adults are unique because they grew up in a significantly less tolerant era.¹ It was common for older LGBT people to conceal their sexual identity and/or orientation and, thus, many experienced invisibility²⁵ or denied their nature and conformed for the sake of public acceptance. Their early socialization took place at a time when LGBT status was considered pathological, sinful, and immoral.²⁰ It was criminalized, stigmatized, and classified as a mental illness.^{20,26} Many of today's older adults came of age before the gay rights movement, initiated by the June, 1969, Stonewall Rebellion²⁷ in which gay male and transgender patrons of the Stonewall Inn in Greenwich Village, New York City, took a stand against police harassment and refused to hide their sexual orientation.^{19,20} Many older LGBT persons have experienced adverse psychosocial repercussions from the movement²¹ that are different from their younger counterparts;¹⁹ while the latter gained a public political identity, older adults now had to find ways to reconcile a new reality with years of enduring stigma and self-imposed isolation.²⁷ Therefore, it is important to keep the social context of discrimination and victimization experienced in early and later years in mind as possible links to mental health and disability problems in later life.^{20,26}

Studies also show that older LGBT people are at an increased risk over the life course for interpersonal violence in intimate relationships, violence perpetrated by other LGBT people, and hate crimes.²² Rates of victimization may be higher among those who are open about their sexual orientation.²² Compound-

ing this vulnerability is the stress related to their social status as a minority group. Minority stress results from the incongruity between personal needs and experiences and the structure and morality of the dominant society or culture.²⁰ Lack of rights and marginalization within a society increases stress which can, in turn, add to physical and mental health problems.²⁴

HEALTH AND HEALTH CARE DISPARITIES

The United States is an aging society. As people live longer, they are more likely to experience chronic co-morbidities; the LGBT community has the added burden of poor health outcomes related to health disparities. The LGBT population has encountered, and continues to experience, disparities in health and health care. Healthy People 2020 defines health disparities as “differences in health outcomes for communities that have encountered systematic obstacles to health as a result of social, economic, and environmental disadvantage”.²⁶ For LGBT elders, economic problems and marginalization have both caused and resulted in health disparities.⁸ For example, LGB and transgender persons are less likely than their heterosexual counterparts to have employer-based health insurance (77% and 51% vs 82%)⁸ and far less likely to be covered under their partner’s health insurance.²¹ This can lead to unmet health needs during the working years and earlier onset of chronic conditions. Lack of health insurance is mainly due to discriminatory employer practices and the absence of federal laws that prohibit discrimination based on sexual orientation.^{21,28} Studies comparing the health status and prevalence of health conditions of heterosexual and LGBT adults have been inconclusive; some show more health problems among LGBT people such as diabetes, hypertension, disability, and mental health problems,⁸ while others have found no differences in physical health but higher levels of disability and poor mental health.²⁶

An additional barrier to accessing quality health care is lack of provider knowledge about LGBT populations.⁵ Many LGBT people avoid the health care system due to fears of discrimination and poor treatment within the system.¹ Studies have revealed that six percent of physicians are uncomfortable caring for LGBT patients¹ and that a small but important minority of medical students, especially male students under the age of 25, held a narrow view of male identity and were uncomfortable with gay male behaviour.²⁹

A 2009 national study by Lambda Legal³⁰ found that discrimination and barriers to care prevalent among LGBT populations included: refusal of care due to sexual orientation, gender identity, or HIV status; care delivered without touching the patient or with the use of excessive precautions; harsh or abusive language; blame for health status; and physical roughness or abuse. The findings of this study probably underestimate the problems because LGBT study participants had health insurance and relatively high socioeconomic status.

Some argue that health risks are not caused by being an LGBT person, but by “living as an LGBT person in a homophobic society”.²⁵ LGBT populations are at a higher risk of disability, poor mental health, smoking, and excessive drinking,²⁶ experience higher rates of HIV infection, suicide attempts, violence and homelessness, and have less access to preventive health care.¹⁶ The stress of living within a heterocentrist, homophobic society, leading marginalized lives, enduring the stress of hiding one’s sexual orientation, facing verbal, emotional or physical abuse from both family members and the larger society, may lead to engagement in risky behaviours and a wide range of mental health problems.^{11,22,25} The risk of depression, generalized anxiety disorder, panic attacks, and the possibility of social isolation is higher within this population.²⁵

Studies have shown that better health has been linked to living with a partner, having a higher income and less lifetime victimization, having good physical and mental functioning, higher self-esteem, being a parent, and having a favourable attitude towards one’s own sexuality.²⁰ However, there is also evidence that older same-sex couples do not gain the same health benefits as heterosexual couples and are at a significantly greater risk for needing some type of long-term care assistance than their heterosexual counterparts.³¹ This difference may be due in part to public policies that discriminate against same-sex couples reinforcing the interwoven nature of policy, practice, and health outcomes.

SOCIAL SUPPORT

Although minority status and stress are often linked to poor health outcomes, this stress is typically mitigated by social support, personality, and personal characteristics like self-esteem and hardiness.²⁰ For example, older LGBT adults are often supported by their families-of-choice and are no more likely to be depressed than their heterosexual counterparts.²⁷ Many LGBT persons who deal with stigmatization and victimization on a daily basis develop competence, resilience, strength and coping skills that protect them against poor health outcomes and may even help prepare them for old age.^{1,22,32} The coming-out process involves personal growth and self-awareness which may, in turn, increase coping resources.²²

Support networks are an important source of assistance for people who need help. LGBT persons may have smaller, thinner support networks for a variety of reasons including less likelihood of being partnered and increased probability of living alone and being childless.¹⁷ Fewer family support options and a more precarious economic situation may make formalized, paid care less of an option.¹ Families of choice or chosen support systems may be used more frequently than biological families by older LGBT persons.^{5,22,27} However, inherent challenges to support and caregiving by friends must not be overlooked; caregiving friends lack legal power and authority to make medical or end-of-life decisions and may be unable to perform sustained

caregiving tasks over a long period of time.³³

LEGAL ISSUES AND END-OF-LIFE PLANNING

Although legal treatment for lesbian and gay persons is improving, LGBT groups continue to experience legal issues and challenges not faced by heterosexuals.³⁴ Basic family rights and protections are still denied to most LGBT people. As older non-heterosexual adults, they have a long history of being ineligible for most protections provided by the federal elder safety net, although this is changing.³⁴ Most policies, protections and assistance programs are geared toward heterosexuals.³⁴ There is a wide discrepancy in local, state, and federal laws.³⁴ For example, in the United States, Section 3 of the Defense of Marriage Act (DOMA) was struck down by the Supreme Court on June 26, 2013, allowing Social Security benefits to be extended to include partners in legalized unions.^{8,35}

Legal uncertainties and lack of recognition of same-sex couples and families of choice increase the need for end-of-life planning to ensure that a person's wishes are honoured and executed and, specifically, to limit the legal power of their families of origin if so desired.^{11,19} End-of-life planning documents include advance directives such as living wills and health care powers of attorney; these documents are particularly important for older LGBT adults "because they are the only legal means of safeguarding the authority of a significant other in situations of medical decision making".¹¹ However, there is no guarantee that these documents will work, and that families of origin will respect same-sex relationships; good communication among affected parties is essential.¹¹

MEETING THE NEEDS OF LGBT PERSONS IN HOSPICE AND PALLIATIVE CARE SETTINGS

Older LGBT adults have identified seven areas of concern including medical/health care, legal, institutional/housing, spiritual, family, mental health, and social issues.³⁶ Of these, medical/health care, including failing health, financial concerns and rising health care costs, was the primary concern. Spirituality and connection to organized religion is an important aspect of life for many LGBT people, particularly LGBT people of color.²⁴ Although some religious groups condemn homosexuality³⁷ which may add stress to a person's life, much depends on how religious doctrines are interpreted and internalized.¹¹

With all of the challenges facing the LGBT population, how can hospice and palliative care organizations and services adapt to meet their needs? A welcoming, inclusive, culturally sensitive environment is essential; this would include LGBT friendly forms that acknowledge multiple family types and relationships and appropriate questions about sexual orientation and gender identity, development and display of non-discriminatory policies, brochures and art work that is inclusive, a diverse staff including a designated LGBT liaison, staff training on sensitiv-

ity to LGBT culture, issues and concerns, educational materials on topics pertinent to this population, and LGBT persons' rights to decide who may visit them in accordance with 2011 Medicare and Medicaid policies.^{1,4,19,30,38} Ideally, service providers such as hospice and palliative care would be welcoming to all persons and not wait until someone openly identifies as LGBT to activate appropriate services.³⁸

Health care providers must understand the cultural context of patients' lives, take detailed, non-judgmental patient histories, and be self-reflective about their own attitudes.¹ Services must avoid heterosexist or homophobic elements²² and accept gender assignments preferred by transgendered persons.³⁸ Service providers should be sensitive to stigmatization and its history and be knowledgeable about barriers to care that continue to exist.³⁹ Lack of knowledge of LGBT populations by service providers should be addressed and rectified; this knowledge should include understanding similarities and differences among LGBT patients, using a life span approach, the role and importance of self-defined family, legal issues, advance directives, employee benefits, and long term care concerns.²⁵

Health care can be improved by requiring specific cultural competency training for the treatment of LGBT patients provided by members of the LGBT community; most existing competency training focuses on racial/ethnic minorities²¹ without taking into consideration that not all racial/ethnic minority patients will be heterosexual. Since medical personnel receive little to no training regarding LGBT health and cultural competency skills, this deficiency should be addressed.⁴ Competency based education should be embedded into the curriculum throughout medical school, not just as an isolated unit.²⁹ Ongoing competency training for staff is essential.⁴⁰ One study found that providing LGBT aging sensitivity training to service providers resulted in positive change at least in the short term.⁴¹ A first step in developing sensitivity and understanding is exploring one's own homophobic or heterosexist biases.^{19,25} Hospice and palliative care organizations can learn from the policies and practices of LGBT organizations such as Services and Advocacy for GLBT Elders (SAGE).⁴²

The Fenway Institute¹⁶ has suggested some strategies to increase the number of LGBT clients served and the quality of that service. These strategies include the provision of free and low-cost services that meet the needs of LGBT clients, creation of welcoming environments, training for front desk and program staff, provision of appropriate staff training on health insurance issues, and using patient surveys and evaluation forms to elicit feedback. Techniques for creating a welcoming environment include unisex bathrooms, posting 'safe space' or rainbow stickers, and having LGBT magazines or newspapers in waiting areas.¹⁶ To increase enrolment of LGBT patients, recruitment efforts should include going where LGBT people congregate for social support, goods and services, using mobile technology and on-site enrolment techniques, and appropriate advertising.¹⁶ In

addition, these enrolment and recruitment efforts must purposefully and mindfully go beyond solely majority white LGBT people.

CONCLUSIONS

Lesbian, Gay, Bisexual and Transgender (LGBT) persons constitute a diverse group with a long and varied history. Intersectionality argues that sexual orientation is a single aspect of our complex social identities. LGBT persons represent a minority group struggling to gain political and social acceptance in a heterosexist world in which they encounter marginalization, discrimination and sometimes violence. The chronic stress of heterosexism threatens quality of life and increases the risk of poor health outcomes. LGBT elders who grew up when sexual minorities were stigmatized as pathological, sinful, and immoral may conceal their LGBT identity. Fear of discrimination leads many to avoid seeking care due to concerns about reported rejection. For people needing end-of-life care, stress may be mitigated by social support and resilience. However, LGBT families face unique challenges apart from coping with terminal illness; these include possible prior rejection from family of origin and ambiguous legal relationship-status in many states that jeopardizes basic family rights and protections. The needs of LGBT persons at the end of life may be addressed through a welcoming, inclusive, culturally-sensitive environment, non-discriminatory policies, diverse staff, sensitivity training, pertinent educational materials, and visitation rights in accordance with the 2011 Medicare and Medicaid policies. Sound research is needed to shape changes in policy and training, especially regarding end-of-life issues.

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CONFLICTS OF INTEREST

We pledge that there is no known conflict of interest in the preparation and publication of this manuscript.

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Research

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Initial Impressions and Review of Literature Concerning Factors Affecting the Use of Palliative Care Assessment Tools in an African Setting

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ABSTRACT

Introduction: Quality palliative care encompasses early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.¹ Despite the importance of symptom assessment in palliative care, use of assessment tools in practice is limited.² The aim of this study was to assess factors that influence use of symptom assessment tools.

Methodology: 1:1 interviews were conducted using a guideline developed by the researcher. Ten participants who met the inclusion criteria were interviewed. The data was recorded and then transcribed with topics and issues being isolated and grouped together into themes.

Findings: The themes were perception of palliative care, communication, practical concerns and emotions associated with use of assessment tools, spirituality and cultural compatibility with assessment tools, resources, policies and training.

Conclusion: Lack of quality education in palliative care coupled with incompatibility of current tools with cultural and religious practices is a major hindrance to use of assessment tools. Poor communication among clinicians negatively affects use of assessment tools.

KEYWORDS: Palliative care; Measures; Assessment tools; Palliative care practice.

ABBREVIATIONS: WHO: World Health Organisation.

INTRODUCTION

The philosophy of “whole person care” coupled with assessment of patients’ symptoms is the mainstay of modern palliative care.³ Uses of assessment tools increase the likelihood of meeting patients’ goals as well as improving symptom control.⁴

Studies on development and utilization of assessment tools in palliative care have been carried out but none have been carried out on the factors affecting their use in the African setting.^{5,6} Lack of standardization in assessment of symptoms in palliative care pose a challenge for care providers in determining appropriate treatment.⁷

There is often conflict between nurses and physicians regarding communicating patients’ health status and symptom management. Use of assessment tools identified by a palliative care team would minimize this conflict.⁸

Cultural beliefs and parameters guide relationships and communication between health care workers, patients, families and the society in general. Kagawa-Singer, et al.⁹ found out that culture influences patients’ and community’s perception and satisfaction with symptoms control and quality of care being provided.

METHODOLOGY

In this qualitative study, palliative care practitioners included doctors, clinical officers who are physicians’ assistants, social workers and nurses. The participants have experience of working in palliative care settings for at least 3 months since this is adequate working duration to have used or discussed use of an assessment tool. They have also attained a diploma in palliative care at least 3 months before the study commencement date. The participants are registered with their respective professional bodies.

The study participants who comprised 2 males and 8 females were aged between 33 and 53 years (mean=47 years). They included two (2) doctors, five (5) nurses, two (2) clinical officers) and one (1) social worker who have practiced health care between 3 to 16 years (mean=7 years). Their initial qualifications were certificate in nursing (n=3), diplomas in nursing (n=2), diplomas in clinical medicine (n=2), degrees in medicine and Surgery (n=2) and diploma in social work (n=1). There were 3 participants from 2 palliative care settings each and 4 from the third setting.

Individual semi structured interviews were conducted using a guide designed by the researcher. The interviews were in English and took place at the participants’ places of work i.e 2 hospices and 1 palliative care unit located in various geographical sites in Kenya. Some of the interview questions were:

- 7)a) Can you tell me about any assessment tools you use in your practice?
- b) Discuss which tools you use, how often and why you use them?
- c) Can you talk about why you do not use assessment tools in your practice?

- 8) Do you think assessment tools are useful in your practice setting? Discuss.....

- 9) a) Is there any time you have felt that use of assessment tool(s) would have eased the acquisition of information from a patient?
- a) Yes () No ()
- b) Why do you feel so? Expand on this
- c) Why were assessment tools not used ?.....

- 10) a) Who are some of the members of your palliative care team?

 - Nurse
 - Doctor
 - Social worker
 - Clinical officer
 - Others, please name.....

Responses to the interviews were recorded and then transcribed. The responses were thoroughly examined, connections between several messages from all the interviews identified and then clustered together into themes. The predominant themes formed the basis of the data.

DATA ANALYSIS

The following themes were identified:

1. Perception of palliative care practitioners about assessment tools
2. Communication
3. Spirituality and cultural compatibility with assessment tools
4. Practical concerns and emotions associated with use of assessment tools
5. Resources, policies and training

In most tools, symptoms are numbered 0-10 with 0 being no symptom/ distress and 10 being the most severe. The patients and /or families are supposed to mark the number that best expresses the level of the patient’s distress. However, most tools do not give guidance on the intervention to be undertaken.

The symptoms are already indicated and numbered... After you assess, it is a dead end... no guidelines on the way forward, how to treat. Participant V.

Doctor-nurse conflict was singled out as a big impediment towards the goal of assessment of patients.

I no longer use assessment tools... When I called the doctor with my findings, he repeated the whole process, I felt very embarrassed and today I leave assessment for the doctor. Participant D.

Collusion between doctors and families not to inform patients their diagnosis and prognosis is a common occurrence in this setting as well as avoiding the use of assessment tools with an aim of not passing information to the patients.

In this case, the son was very angry with us... We had broken an agreement he had with their doctor. Participant M.

The lack of adaptability of the assessment tools indifferent cultural settings is cited as a leading cause of inconsistency in their use.

Some are the age of my father, how can I talk to them about sex with their wives, who are my mother’s age? Participant X.

They are pastoralists and they keep on moving from one area to another... They don’t have much time to answer questions. Participant N.

The assessment tools do not address the most pressing

needs of patients.

They request money for food, school, transport and other home necessities... This is what distresses them most ... The assessment tools do not factor in this. Participants Z.

The assessment tools use language that is not compatible with local terms and expressions.

The tools are difficult to understand... Depression, anxiety, how do you translate these words into a local language? Participant S.

The limited number of palliative care practitioners in relation to the large number of patients and families that require the service is a critical factor in the use of assessment tools.

Being the only nurse trained in palliative care in the hospice... I know I can use these tools but there are very many patients to be seen and I feel pressured for time, I ask about their recurrent symptom and make reference to the clinical notes. Participant V.

Unavailability of medical necessities was regarded as detrimental to the overall quality of care and full patient assessment.

I could see the patient was in pain, the way he walked, we did not have drugs in our store... I did not ask about her pain. Participant S.

Palliative care is not integrated in the mainstream health care training and also the palliative care training being offered currently at the diploma level is not adequate for practical use of assessment tools.

Palliative care module is not part of the training offered in our training. Participant X.

DISCUSSION

Perception of Palliative Care Practitioners about Assessment Tools

The low utilization of assessment tools is attributable to the many challenges facing this field in Africa that ranges from understaffing, lack of knowledge and skills and financial constraints. Greenhalgha, et al.¹⁰ noted that inadequate utilization of assessment tools is a significant challenge in palliative care. In addition, the current training in palliative care is not comprehensive and there are cultural and spiritual challenges meaning that holistic assessment of patients is a daunting task for practitioners. Due to the late referral to palliative care, assessment is usually carried out at the end of life stage and in an incomplete manner.

Communication

There is poor, untimely, insensitive communication with patients and families regarding symptoms and effects of different treatment modalities. Studies by Gunten and Weissman¹¹ found out that untimely, incomplete and insensitive communication with the patient from the time a diagnosis is made is a major cause of failure to utilize assessment tools globally.

It is a big challenge for doctors when there is a shift from cure to palliation which limits their communication skills at end of life since their training is not focused on this state of affairs. This in turn leads to a failure of utilization of assessment measures.¹²

Poor doctor-nurse relationship is a significant factor in medical practice. Nurses choose consciously or otherwise to preserve and protect physicians "superior" status by always deferring to them and undertaking their instructions without even critiquing the same, Gamondi, et al.¹³

Furthermore, collusion occurs between doctors and families preventing practitioners from using assessment tools as by so doing they might raise issues that were not meant to be discussed with patients. Palliative care practitioners therefore find it difficult to use assessment tools in such scenarios as the patients do not have adequate information about their illnesses and as such will not give proper feedbacks, Dunne¹⁴ and Hudson, et al.¹⁵

Discussing prognosis is a complex communication question that hinders use of assessment tools in end of life care. Because prognosis is a major topic in assessment tools used at end of life, practitioners avoid utilizing assessment measures as a way of keeping off this sensitive topic, Orioles, et al.¹⁶ and Manalo.¹⁷

Spirituality and Cultural Compatibility with Assessment Tools

When use of assessment tools conflict with cultural practices, beliefs and norms of the society, the health care workers withdraw and do not pursue issues further. This is because culture is regarded to be supreme and hence resulting to a missed opportunity to assess the patients. For example discussion around death is regarded a taboo due to the fact that death transition is culturally considered an unwelcome occurrence.¹⁷

It is inappropriate to discuss sexuality with elderly patients as culture demands that this can only happen among peers. Tools which assess this parameter are therefore not used in palliative care settings locally. Orioles, et al.¹⁶ found out that clinicians are unwilling to discuss and assess sexuality as this is thought to be a less important aspect for the patient and also as a result of cultural barriers.

It emerged that spirituality is an important way of life in this society where it is seen to be the same as religion. Being this important to the ways of life of this society, assessment of spirituality should therefore be part and parcel of quality assessment. However, spiritual consideration is a major factor missing in common assessment scales and this contributes to failure to utilize assessment tools. Hardings, et al.² and Kagawa-Singer, et al.⁹ made similar findings.

Practical Concerns and Emotions Associated with Use of Assessment Tools

Time used to complete the assessment tools is considered by practitioners as being too much and takes time away from patients. Time is usually limited due to increased workload, few practitioners and the fact that family members who bring in the patient need to go back to work and continue with their income generating activities.

The multiplicity of symptoms reported by patients is a significant turn off to practitioners when they consider use of assessment tools as this is thought to be a huge load. Rhondali, et al.¹⁷ and WHO¹ made similar observations.

Resources, Policies and Training

Poverty, lack of basic resources and the strained nature of the health care system significantly impede use of assessment tools by palliative care practitioners. Evidently, these factors combined are a big source of distress and burnout to those in palliative care practice and are reported as significant hindrances to the use of assessment tools.¹⁸

Education, skills and knowledge on palliative care practice is not broadly available to health care professionals hence leaving big gaps in the availability and accessibility of this crucial service and failure to assess patients. Similar findings are reported by Jazieh⁷ and Weissman and Meier.¹⁹

This study found out that lack of nationally agreed and recognized conglomerate of assessment tools is a big impediment to their utilization or usefulness as different settings use different approaches and tools thus sharing of data and analysis of the same is not nationally feasible. Richardson, et al.²⁰ and Durand, et al.²¹ made similar findings.

CONCLUSIONS

Despite the impressive growth and progress made in palliative care, Marete²² and Weru,²³ widespread adoption of measurement tools is not common in palliative care settings as highlighted in this study.

Lack of training and education in palliative care for

health care and non-health care professionals coupled with lack of practical placements compounds the poor use of assessment measures. It is noted that current tools do not take into consideration the culture, norms, religious beliefs and traditional practices of the society. Further, the language used in the tool is not translatable and understandable to all those concerned and thus it is not easy to interpret the findings.

Poor communication between patients/ families and clinicians coupled with collusion between patients and doctors has also been reported as a strong determinant of the use of assessment scales. Nurse-Doctor Conflict is reported as a big impediment in the provision of quality care and utilization of assessment tools. Palliative care being multidisciplinary will require nurses and doctors to work collaboratively and the way they relate and communicate with each other need to be improved.

A major concern is the practical applications of tools; the questions in the scales, how to record and document the findings, time factors in filling out the tools and the actual benefit the tools offer to the quality of patient care. Poverty and the overall cost of acquisition and application of assessment measures hinder their use. The general lack of basic medical necessities such as drugs and dressing materials limits assessment activities in palliative care.

RECOMMENDATIONS

There is a need for better scientific evidence of palliative care assessment tools clinical utility in this setting as the current available assessment tools do not appear to be applicable, in their current state, in this setting as evidenced by this study. A thorough review of nursing, medical and palliative care curricula should be undertaken to ensure the content of these modules provide adequate, relevant and appropriate information and subsequently equip clinicians to effectively assess patients who need palliative care.

Tools need to be translated into a language that is easily understandable by clinicians, patients, families and other stakeholders. It is also recommended that nationally acceptable standards and guidelines for assessment measure and unified approach to patient needs assessment are developed.

It would be worthwhile to start documenting assessment findings bit by bit to full completion with multiple visits. This way, time will be saved and the end result will be high quality information. To be able to do this, patients should be referred for palliative care early.²⁴

At the same time, assessment needs to be carried out at the key moments of a patient's illness trajectory which are diagnosis, commencement and completion of treatment, time

of recurrence, time incurability is identified, when death is imminent.²⁵

Report of symptoms need to be via digital media and face-to-face communication. The increased use of electronic media for exchange of information means there is need of development and use of electronic assessment tools and decision-making systems in palliative care. Mobile telephony has tremendously grown and can be used for assessment purposes. For this to work best, the guidelines thus developed will need to be widely disseminated and implemented.²⁰

The author recommends that professionals are trained together on the aspects of communicating with each other and how well to avoid conflicts. Conflicts can be avoided through regular nursing/ medical meetings, regular nurses and physician's surveys for feedback on communication challenges, team building meetings where there will be increased nurses-physicians' interaction. There should be standardized protocols for nurses to communicate with physicians about patients and at the same time institutions need to have laid down procedures of resolving conflicts and punishing those who are culpable.²⁶

The researcher would also recommend a collaborative study between different service providers from different countries in Africa so as to assess the issues affecting use of palliative care assessment tools in practice.

LIMITATION OF THE STUDY

One of the limitation of this study is that few people, ten participants, were studied hence making it difficult to generalize the findings.

It is more difficult to determine the validity and reliability of data realized using qualitative research methodologies as supported by Payne²⁷ and Morse.²⁸

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Opinion

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The Role of Dose-Dense Neo Adjuvant Triple H Therapy, Hugs, Humor and Humility: Palliative Medicine, Oncology, and the Human Spirit – A Clinician's Journey

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The road to becoming a medical oncologist is a unique lattice of spiritual academic stamina. The roots of my academic and spiritual journey began well into my childhood when I was raised in a kind, warm, and genuine family. My mother and father, both immigrants who came from Israel with hardly a formal education or command of the English language came to the United States to provide a greater life for the next generation. As a child, when neither my siblings nor I could no longer receive academic help from our parents after the fourth grade, sometimes I would see other children in my class getting help from parents who were doctors, lawyers, engineers, and university professors. Despite this, however, what helped motivate my success more than anything was the loving reassurance from my parents.

MEDICAL BEGINNINGS

Originally, I started my academic career wishing to be an Academic Immunologist. During my undergraduate studies, I was given the unique opportunity to work with focused and well published investigators who fostered a genuine intellectual curiosity who wished to serve as mentors and role models. The hallways were decorated with abstracts, long elaborate gene sequences, and with pictures of western blots of gel electrophoresis slabs partially run stained with ethidium bromide. What appeared evident to me at the time was that a bridge must exist between the cluttered brilliance of the laboratory bench and that of the bedside of a fellow human being in need of answers.

During my residency in Internal Medicine, I began to notice patterns in the physiology of patients who were admitted to the ICU. A case clearly stood out of a woman with triple negative breast cancer who failed her second cycle of adriamycin/cyclophosphamide who ultimately went into respiratory failure under mechanical ventilation, and was getting to the point of requiring a tracheostomy. Well-meaning family members brought her a plethora of photographs of her 2 grandchildren, yet none of the photographs were in her field of view. In a flash of inspiration, I recall taking the photos out of the frames and taping them directly above the patient. The following week, in clinic, to my shock and astonishment, the patient appeared gleefully reading a magazine in the waiting room with her 2 young grandchildren. Immediately the woman came up to me, shed a single tear, said "Thank you Dr. For reminding me how important my love of my grand children was. It saved my life".

One cannot imagine the emotional, existential, and spiritual depth of taking a fellow human being from the abyss of uncertainty to one of self realization and fulfilment.

PALLIATIVE MEDICINE FELLOWSHIP

At the conclusion of my residency my program director and I had a long discussion about my next career step. Too many choices had to be made in such a short period of time. I felt that I was not quite ready to begin my journey to become an oncologist as I felt an unexplained component missing that was too difficult to truly articulate. My translational curiosity was as strong as my search for the humanity of medicine. My program director made a bold and unexpected suggestion that I seek out a Palliative Medicine fellowship affiliated with a major NCI designated cancer center.

Instantly my life was transformed in a manner I never imagined possible. It was during my palliative medicine fellowship that I realized how little physicians truly knew in cancer pain management. From titrating PCA pumps, opioid drug conversions, knowing when it was appropriate to initiate neuro modulating agents, or when to initiate goals of care discussions, all have added depth and meaning required to treat our most difficult oncology patients became evident to me.

From the eyes of a palliative medicine subspecialist it amazed me to see how many patients on chemotherapy such as bortezomib had peripheral neuropathy, how many patients on irinotecan weren't warned about the diarrhea, and how so many on FOLFOX never were educated about cold sensitivity or crippling mucositis. I have also encountered community resistance to utilizing methadone to treat complicated neuropathic pain, due to its continued social stigmas and necessity for monitoring QT intervals. However, methadone is a powerful NMDA receptor antagonist, attenuates the development of morphine tolerance, and has some activity as a serotonin and norepinephrine reuptake inhibitor. Words such as Relistor, oral cryotherapy, or pallifermin began to be common daily vocabulary.

PALLIATIVE MEDICINE AND THE DEATH OF A PARENT

My father was a vibrant energetic man with a heart of gold. The son of holocaust survivors, his demeanor and attitude towards life was one of kindness and empathy. At the same time there was a strong generational stoic exterior. During my palliative fellowship my father had a cardiac event, an NSTEMI and had been given a drug eluting stent, and placed on dual anti platelet therapy. At the time I implored for my father to remain on the strict course of aspirin and plavix, only to find his compliance far less than optimal. I have vivid memories of lecturing my father near the point of verbal confrontation. As I was preparing to complete my Palliative Medicine fellowship I had received a disturbing call that my father was in the hospital after driving to his photography club meeting. Upon calling back the hospital operator I was directed to the ER and was referred to the attending physician. A short moment later he would mutter those few words that would shake me to my very core, "I'm sorry Dr. Feinsilber, but your father died."

Nothing can quite articulate the cruel irony I had felt at the time nearing the completion of my training, dealing constantly with end of life issues and the complexity of family grief, when in an instant I became the very person I was training to advocate for. It was a great and unanticipated existential challenge. The untimely passing of my father only strengthened my resolve to enhance greater advocacy among Drs. On behalf of their patients.

TRANSLATIONAL PHASE

With the difficulty in losing a parent early in life and greater understanding of clinical medicine I developed a fiery passion for patient advocacy at both the clinical and basic science levels. My intellectual curiosity began to blossom and as such I sought more mentorship and guidance. I was honored and fortunate enough to cross paths with a highly respected medical oncologist drug developer and translational researcher. From an existential, spiritual, and intellectual level I felt prepared to finally make that leap. I recall spending countless hours for nearly an entire year working in the lab and befriending the laboratory staff in what was the most unique symbiotic relationship one could imagine. I was an active attending physician with a busy clinical schedule during the day while working with laboratory technicians, research scientists, and post-doctoral fellows in the afternoon and nights attempting to get experiments to work. This was done while sharing clinical and human interest stories during the process. I recall asking the post-doctoral fellow running a western blot, "Would you ever imagine wanting to see a patient with stage 4 pancreatic adenocarcinoma with biliary obstruction going to hospice? I have a patient like that now I would love to sign you up as an observer to see this." The answer was always a nervous and hesitant yes. By the end of the year, I was able to successfully present data at the gastrointestinal symposium of the American Society for Clinical Oncology (ASCO) that dealt with the concept of synergism with statins and chemosensitization to nab-paclitaxel.

ONCOLOGY FELLOWSHIP AND INTEGRATION OF PALLIATIVE MEDICINE CORE PRINCIPLES

One could not believe the sheer feeling of euphoria and accomplishment knowing that I had obtained a fellowship position in Medical Oncology. My father up to the day of his passing knew this is what I had wished to dedicate my life to, and only now had the emotional composition to truly appreciate what it was I needed to do. My experiences in Medical Oncology as a trainee showed to me how critical it was to educate faculty and other colleagues in palliative medicine principles. This was more critical not only for pain and symptom management but for triaging treatment decisions based on functional status and the spiritual condition of the patient. Palliative medicine when initiated early not only saves money and other resources but ultimately provides better care, enhanced patient compliance, and better therapeutic relationships between physician and patient. Due to my training with a palliative care background I have been

able to ask the hard questions and be able to comfortably communicate with a family the paradox of “More is less and less is more”.

POWER AND PHYSIOLOGY OF HUMOR

The most memorable patient I have come across was a gentleman in his mid-50's who was diagnosed with Diffuse Large B-Cell Lymphoma, who had arrested weeks after having received his first course of R-EPOCH. As I approached the patient and his family shortly after being stabilized I recall the kind almost angelic face of the patient, one that was coming from a source of love and fear at the same time. Clearly the patient was in uncharted territory. I recall the patients sister and brother-in-law having been involved heavily in the patients care were equally in need of certainty, peace of mind, and clarity. I recall at that moment I felt the need to turn my pager off, hang my white coat on the hook, and sit down at eye level with the patient and his family. Having explained the intricate details of the patients lymphoma and prognosis I decided at the time to lighten the mood. I pulled out my iphone and started to play light-hearted movie clips. One such clip was of a dark disgruntled children's television star attempting to sabotage his rival in a rhino outfit. Instantly the tension in the room eased. Prior to leaving the room after laughing ourselves near the point of tears each of us gave the warmest hug. That was the start of an incredibly trusting and very special doctor-patient relationship.

I remember distinctly that when the patient required intrathecal methotrexate, here he had specifically requested I be the physician to administer the drug. It had become a tradition that I would enter the fluroscopy suite with a smile, a reassuring hug, and a 5 minute movie clip loaded on my iphone for him to watch during the procedure. By the third cycle of intrathecal methotrexate I had requested that CSF be sent for cytology, and sadly the patient had extensive CNS involvement. As the disease process continued to progress despite repeated doses of high dose IV methotrexate, the emotional and psychological relationship was that much stronger than ever. The patient expired, and the family only recalled the attention and humor during his care. This was used strongly during the bereavement process.

The physiology of laughter and hugging another human being is complex and has positive physiological effects. Opioid receptors have an improved threshold for pain, serum cortisol levels drop, anxiety is reduced, blood pressure is lowered by decreased vasoconstriction, protection from inflammation and oxidative stress occur, and the social sense of belonging is enhanced. Endorphins increase as do serotonin levels. Oxytocin is released and mediates nitric oxide synthetase resulting in vasodilatation and lowering blood pressure.

CONCLUSIONS

My extensive life journey through different phases of my own development has allowed for me to identify the cru-

cial role that palliative medicine plays in Oncology. I have been able to truly acknowledge the fact that mediating and harnessing the power of human physiology and spirit is pivotal in ultimate treatment outcomes. It is through the unique lattice of education and personal experiences that I have learned the role of the Oncology physician and clinical decision making should come from both an open mind and an open heart. I feel that Palliative Medicine should play a more integrative and pivotal role in the training of aspiring oncologists, and teaches the requisite skill set for the physician on their own life journeys.