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Preface

Optimal terminal and palliative care requires consideration of the patient and family unit as well as cultural and religious sensitivities. The patient's well-being in terms of mobility, anxiety, stress, social interaction and pain control needs expert focus and attention. However, there is an increasing awareness that diet and nutritional support play an integral part of the patient's holistic well-being. Many books on nutrition will have material aimed at prolonging life, preventing disease, or alleviating symptoms with a long-term view of complete rehabilitation. Occasionally, such books are directed toward subgroups, for example, infants or the elderly. However, there are no comprehensive books on nutrition in terminal or palliative care that simultaneously cover physical, cultural and ethical aspects. Nor are there many nutrition books that bridge the intellectual divide and are suitable for novices and experts alike. This book is aimed at addressing such deficiencies.

The *Handbook of Nutrition and Diet in Palliative Care*, second edition, is divided into six sections:

1. Setting the scene
2. Cultural aspects
3. General aspects
4. Cancer
5. Non-cancer conditions and pharmacologic aspects
6. Case study and resources

Coverage in the *Handbook of Nutrition and Diet in Palliative Care*, second edition, combines palliative care and nutrition in relation to numerous areas. Briefly, the material includes the following: Section I: needs in palliative care, features of palliative care, religion and culture, quality of life, cancer cachexia, sedation, pain control and communications; Section II: cultural aspects of enteral feeding, Indian and Italian perspectives; Section III: stents in the gastrointestinal tract, artificial nutrition, support for hydration, dysphagia, olfaction and appetite; Section IV: preoperative assessments, gastrojejunostomy, upper gastrointestinal symptoms, head and neck cancer, appetite and nausea, vitamin deficiency, childhood leukemia and eating-related distress; Section V: end-stage renal failure, HIV, gastroparesis, severe and enduring eating disorders, neurodevelopmental disorders, appetite stimulants and cannabinoids; and Section VI: a case study on refractory cancer cachexia and recommended resources. There are, of course, other areas too numerous to mention here.

Unique features of each chapter include relevant sections on

- Applications to other areas of terminal or palliative care
- Practical methods, techniques or guidelines
- Key facts that highlight important areas within chapters
- Ethical issues
- Summary points

The *Handbook of Nutrition and Diet in Palliative Care*, second edition, is for doctors, nurses and carers and those interested in or working within the palliative or end-of-life domain. This will include nutritionists and dietitians, health workers and practitioners, hospice or palliative centre managers, college and university teachers and lecturers and undergraduates and graduates. The chapters are written by national or international experts or specialists in their field. The material is well illustrated with numerous figures and tables.

Professor Victor R. Preedy

1 Need for Specialized Interest in Food and Nutrition in Palliative Care

Eleni Tsiompanou

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INTRODUCTION

Since antiquity, it has been known that food, exercise and lifestyle, as well as our external environment, influence our health. Hippocrates, the father of medicine, advocated the treatment of illnesses through modification of diet (δΐαιτα), which in ancient Greek meant “way of life” and encompassed food, exercise and massage, baths and other aspects of everyday life. Food was a subject of interest for laypeople, writers and philosophers. In the *Deipnosophists (The Banquet of the Philosophers)*, written by Athenaeus in the early third century AD, we read the story of Democritus of Abdera, the “Laughing Philosopher” (Athenaeus, 1927–41). At the age of 104, Democritus, approaching the end of his life, had gradually reduced his food intake and was expecting to die. It was the time of the important Thesmophorian festival (a women’s festival in honor of goddesses Demeter and Persephone), and his centenarian sister, who looked after him at his home, asked him not to die during the festivities so that she could take part in them. Wanting to grant her request, he asked for a pot of honey to be brought to him. He was kept alive for three days by inhaling the fumes from the honey. When the festival finished, the pot of honey was taken away, and he passed away without any suffering. This story from Ancient Greece graphically depicts many elements of nutritional care we categorize as physical, cultural, social, ethical and emotional, which we encounter in our modern palliative care practice.

NUTRITION: AN IMPORTANT SUBJECT FOR PATIENTS AND CARERS

Every healthcare professional would agree that our duty is to take an active interest in what matters most to patients. Primarily this is about relieving suffering, pain and other debilitating symptoms.

In palliative care there is a critical interlinking of nutrition, symptoms and patient experience. Symptoms can not only adversely affect food and fluid intake, but also, importantly, a patient's nutritional intake can influence their symptoms and general state of being. Research has again confirmed that appetite and the ability to eat are very important physical aspects of a patient's quality of life. These are affected as the disease progresses and the patient experiences a series of losses: loss of weight and the desire to eat; loss of the ability to smell, taste, chew and swallow food; and loss of the ability to digest, absorb nutrients and eliminate waste products independently.

Good nutrition can enhance recovery, when healing is possible. Conversely, poor nutrition can result in poor resistance to infections, impaired wound healing, increased susceptibility to pressure ulcers and fatigue. Good, nutritious food contributes to the patient's overall sense of well-being. A drop in essential amino acids, glucose or vitamins and minerals in the body tends to affect the nervous system and behaviour adversely (Table 1.1).

Nutrition is also important as it is an avenue of empowerment for patients; it offers them the possibility to do something for themselves. Once a patient has been diagnosed with a serious illness, they become more aware of the impact their lifestyle has on their body. So they often initiate changes hoping this will help relieve their suffering and increase their chances of survival. They seek to improve their diet, physical activity and daily routine in general. Their carers want to show their love and care by providing good food and drink. Patients and carers alike often turn to healthcare professionals for information and advice. We need to assist them to appreciate the importance and relevance of nutrition and discuss with them what can help and what can harm them.

As we meet people at different stages of their illnesses we can help them understand how their nutritional needs may change as their disease progresses. We can support them, and those caring for them, to acknowledge the inevitable changes in their body and the nutritional decline prior to death.

NUTRITION AS A SAFETY ISSUE

When caring for people, one always has to consider safety matters around nutrition (National Patient Safety Agency, 2009) (Table 1.2). This becomes especially critical when these are vulnerable patients with advanced illness. In modern palliative care, understanding of the most important safety issues around oral nutrition and artificial nutrition and hydration (ANH) will help professionals provide better care for an increasing variety of conditions, minimising risk for patients.

TABLE 1.1
Key Nutrients Needed for the Optimal Functioning of the Nervous System

- Glucose
 - Fatty acids
 - Amino acids
 - B-vitamins (vitamin B12, thiamine, niacin, pyridoxine)
 - Folic acid
 - Vitamins A, D and E
 - Iron
 - Copper
-

TABLE 1.2
Safety Issues Around Nutrition

1. Lack of nutrition screening and assessment
 2. Inappropriate diet
 3. Inappropriate fluid provision: dehydration, overhydration
 4. Food allergies and intolerances
 5. Choking
 6. Nil by mouth
 7. Artificial nutrition
 8. Re-feeding syndrome
 9. Missed meals
 10. Lack of assistance with eating and drinking
 11. Catering issues
-

RECENT ADVANCES IN SCIENCE OF NUTRITION: EPIGENETICS, MICROBES AND THE ENVIRONMENT

Knowledge of nutrition has progressed from simple data about macronutrients (fat, proteins and carbohydrates), micronutrients (minerals and vitamins) and calories, to the more complex world of phytochemicals and bioactive food components which can alter our cells' phenotype and, ultimately, influence how a disease progresses. More recently, an exciting research frontier has emerged with the discoveries of the effect of gut microbiota on human health. This may have relevance to treatments for palliative care patients.

MACRONUTRIENTS, MICRONUTRIENTS AND CALORIES

The complexity and importance of nutritional care become apparent when we consider the powerful effects of macronutrients and micronutrients.

A steady supply of a combination of nutrients determines the functioning of various organs and systems in the body. The hypothesis is that during a chronic illness, if the nutrients missing in a particular case are identified and then replenished, the healing effect can be dramatic and function can improve. However, in actual practice, the situation is much more complex. For example, people who have advanced cancer quite often develop *anorexia-cachexia syndrome* (ACS) which is characterised by protein and weight loss. According to traditional dietary advice, ACS is treated with high caloric and protein foods and supplements. But when systematic reviews looked at existing trials, the conclusion was that increasing food intake and/or oral nutritional supplements does not change clinical outcomes, that is, disease status and survival, and they have a debatable effect on quality of life (Brown, 2002; Baldwin et al., 2012). This lack of evidence calls for new ways of approaching the complex issue of nutrition in advanced illness (Arends et al., 2017), which includes nutritional assessment of palliative care patients and nutritional training of all healthcare professionals. The first step to improving nutritional care is acknowledging that nutrition is everybody's responsibility.

NUTRIGENOMICS AND EPIGENETICS

A key number of nutrients working in combination can alter our cells' protein expression and metabolite production and, in some cases, switch certain of our genes on or off. Following these discoveries, a new branch of science, *nutrigenomics*, has emerged which studies the relationship between nutrition, genetics and health (Table 1.3). Our developing understanding of the effect environmental factors have at a cellular level has led to *epigenetics*, another new field of research

TABLE 1.3
New Definitions in Science

Nutrigenomics: a new science looking at the relationship between nutrition, genetics and health

Epigenetics: the study of mechanisms that cause changes in gene activity, without modifying the DNA sequence, which are maintained during cell division

Telomere: the end region of the chromosome that protects it from alteration during replication; its length controls how long cells live

Telomerase: the enzyme that sustains the length of telomere

which looks at the mechanisms that cause changes in gene activity, without modifying the DNA sequence, which are maintained after cell division. Epigenetics is attracting intense research activity around the world. Different environmental factors, such as a poor diet can initiate epigenetic changes: DNA methylation and histone modification. In turn, these translate into abnormal gene expression, which encourages the initiation and progression of cancer (Tollefsbol, 2009). Further research will help us understand better the impact of diet and behaviour on the development and progression of chronic diseases.

What makes the study of epigenetic changes so important and exciting is that they can be reversed with even simple lifestyle changes, including the right diet (Feinberg, 2008). For example, garlic, turmeric, broccoli, tomatoes and green tea contain a variety of active dietary photochemicals that influence the release of Nrf2 (nuclear factor erythroid-derived 2-related factor 2). Nrf2 is a “master gene” product that co-ordinates the activation of a number of antioxidant genes that maintain or restore the activity of normal cells and promote apoptosis of malignant cells (Gopalakrishnan and Tony Kong, 2008). The activation of Nrf2 by these nutrients promises to result in powerful beneficial effects that invite further study. This limited description, hopefully, provides an indication as to why some investigators think that epigenetics may, in the future, play a greater role in health and disease than genetics currently does. How this knowledge can help patients with advanced disease, needs to be tested.

THE GUT MICROBIOME REVOLUTION

The influence of gut microbes on various aspects of human health is the subject of many revolutionary research projects around the world. Clinicians are asked to find ways to support gut health, as it has become apparent that the trillions of gastrointestinal (GI) bacteria can interfere with the effectiveness of oncological treatments. Furthermore, gut bacteria have an effect on our immunity and have been linked to mood disorders such as anxiety and depression (Anderson et al., 2017). Palliative care patients can suffer from a variety of GI problems, including gut toxicity, as a consequence of cancer treatments. Healthcare professionals need to develop effective ways of diagnosing and managing these conditions, using nutritional and other therapeutic approaches (Andreyev, 2016).

CANCER SURVIVORS

Cancer survivors is a term encompassing all people who have had a diagnosis of cancer and have recovered from it following treatment or continue to live with residual or recurrent disease. In this group are included patients with metastatic and terminal cancer.

Cancer survivors have a number of medical and psychosocial needs that can benefit from palliative care. Studies have shown a survival benefit in people with cancer who are referred to palliative care services early in their disease trajectory (Temel et al., 2010) and, an improvement in their quality of life (Vanbutsele et al., 2018). Subsequently, it is increasingly common that cancer survivors are followed up by palliative care professionals who then need to be able to treat them if they present with symptoms due to the long-term and late effects of cancer treatment (Economou, 2014).

TABLE 1.4
World Cancer Research Fund/American Institute for Cancer Research Recommendations for Cancer Survivors

1. Avoid smoking and exposure to tobacco
2. Aim to be slim without being underweight
3. Maintain regular physical activity
4. Avoid drinks full of sugar
5. Include in your diet a variety of vegetables, fruits, whole grains and legumes
6. Reduce red meats and processed meats in your diet
7. Limit consumption of alcohol
8. Limit consumption of salt
9. Avoid use of supplements for protection against cancer

Source: Adapted from World Cancer Research Fund/American Institute for Cancer Research (AICR). 2007. *Food, Nutrition, and Physical Activity, and the Prevention of Cancer: A Global Perspective*. Washington, DC: AICR.

A number of programmes are being developed to assist cancer survivors in making the right lifestyle choices, as it is increasingly obvious that these can influence morbidity and mortality (Demark-Wahnefried and Jones, 2008). The World Cancer Research Fund (WCRF) and American Institute for Cancer Research (AICR) in their report on “Food, Nutrition, Physical Activity and the Prevention of Cancer” make a number of recommendations, based on current evidence, to promote cancer prevention through changes in diet (WCRF/AICR, 2007). They recommend cancer survivors also observe the same advice (Table 1.4). A further report by World Cancer Research Fund International (WCRFI) published recommendations for diet, nutrition and physical activity for breast cancer survivors (WCRFI/AICR, 2014). Cancer survivors and their carers would welcome advice from healthcare professionals about diet and physical activity (Beeken et al., 2016).

MULTI-STEP APPROACH TO NUTRITIONAL CARE

Patients who are referred to palliative care services have a range of cancer and non-cancer diagnoses and are at different stages along their disease trajectory. Some of them present with a longer prognosis of many months to a few years while others are at the end of their lives. This means that patients can have a wide spectrum of nutritional needs that change throughout the different stages of their illness.

Nutritional care is complex because of its many aspects: physical, emotional, social and cultural. This has been captured in the well-known phrase: “we are what we eat”. A multi-step approach is required to recognize the patient’s needs and what is needed to help them (Table 1.5).

Step 1: Assessment of nutritional status

Patients with palliative care needs are nutritionally “at-risk” for many reasons: disease factors, medication side effects, socio-economic reasons and other causes. The first step in the provision of nutritional care is to assess the patient’s nutritional status and the factors that can influence nutrition, whether they are reversible and treatable or not. The nutrition

TABLE 1.5
Multi-Step Approach to Nutritional Care of Palliative Care Patients

- Step 1: Assessment of nutritional status
- Step 2: Development of a care plan
- Step 3: Recognition of changes in nutritional needs

TABLE 1.6
Professional Consensus Statement on Nutritional Care in Palliative Care Patients

1. Nutritional care
 - Is an essential aspect of palliative care
 - Needs to be individualized
 - May change for people at the end of life
 - Needs to be delivered safely and with compassion and dignity
 - Can have physical, social, cultural and emotional aspects
 - Is a matter for all palliative care professionals
2. All staff and volunteers should receive regular training on nutrition
3. Healthcare organisations are responsible for delivering nutritional care

Source: Adapted from the Food and Nutrition Group at Hospice UK, 2009. Professional consensus statement of nutritional care in palliative care patients. <https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/clinical-resources>.

assessment should lead to an individualised nutritional care plan (Food and Nutrition Group at Hospice UK, 2009) (Table 1.6). As Lennard-Jones said two decades ago: “only when the assessment of every patient’s nutritional status has become routine will the full benefits of nutrition treatment be realised” (Lennard-Jones, 1992).

A nutrition assessment tool called the Palliative Life-State and Nutrition Tool (PLANT) has been developed and piloted in the United Kingdom (Tsiompanou, 2017). The PLANT tool has been designed to take into account aspects of life-state, food and nutrition that are significant for palliative care patients. It highlights specific food and nutritional needs that can be translated into care plans.

Step 2: Development of a care plan

Nutritional treatment will vary considerably from patient to patient. A cachectic patient with oesophageal cancer and dysphagia needs a nutrition intervention, food consistency and diet distinct from that of a cachectic patient with lung cancer and no swallowing difficulties. An overweight patient with metastatic breast carcinoma and prognosis of months to years requires a different dietary approach to that of an overweight bedridden patient with a brain tumour and a prognosis of a few weeks. Furthermore, the needs of patients with end-stage dementia, amyotrophic lateral sclerosis, congestive heart failure, chronic obstructive pulmonary disease, chronic renal failure and chronic hepatic failure are also quite variable and complex.

Step 3: Recognition of changes in nutritional needs

Nutritional needs often change when the patient approaches the last days of their life. The primary focus of nutritional intervention can shift at this point towards maintenance of optimal quality of life and general support of patients and carers to help them recognise and accept this transition. Carers often say: “food and love” are the last precious gifts we can offer our loved one at the end of their life. Who are we to argue? Perhaps one could say that, at the end of life, food is not the only important aspect of care. The total comfort and peace of mind of the patient at this time is paramount and we can support carers to help “nourish” the dying person in holistic ways.

DIET OF PEOPLE IN ILLNESS SHOULD BE DIFFERENT TO THEIR DIET IN HEALTH

In his book *Ancient Medicine* (Αρχαία Ιατρική), Hippocrates traces the origins of dietetics and explains how cooking methods influenced human evolution (Tsiompanou and Marketos, 2013). Approximately 2,500 years ago he wrote how primitive people suffered many illnesses as a result of