Health and Social Services Committee

HSS(2)-15-06(p.2)

Meeting date: Thursday 26 October 2006
Venue: Committee Room 3, Senedd, National Assembly for Wales
Title: Living well with cancer – the role of the Allied Health Professionals (AHP`s)

Introduction

Cancer has long been one of the most dreaded of diseases, with almost every family in Wales either affected by it or knowing someone close to them who carries the diagnosis. The cumulative effect of gradual progress on detection and treatment processes has changed how we approach cancer and even how we think about living with it. Whether living with the fear and risk of recurrence or living with metastatic disease, how patients and health care professionals (Doctors, Nurses and Allied Health Professionals) work together establishing goals for living fully can turn cancer into just another chronic disease that requires timely interventions and follow-up.

A diagnosis of cancer impacts beyond the physical manifestations of the disease to include psychological, social, economic and spiritual consequences. Cancer may be experienced as a single event for some people, with a defined beginning, treatment and end whilst for others it can take on a chronic pattern with an ever present nature. For all, however, the concept of living well within the confines of the disease requires the expertise of the AHP`s to ensure that effective programmes of care are developed.

Impact

Recommendations to enhance the lives of people living with cancer:

- Supportive care needs to be recognised as an integral component of cancer care and requires a defined programme.
- Supportive care needs to be accessible in all communities.
- Education and training initiatives need to be developed to ensure an adequately trained and competent workforce can deliver the care.
- Standards of practice and practice guidelines need to be developed for all professional groups providing supportive care.
- Community based care needs to be developed to provide supportive care programmes to enable the patient with cancer live well at home.

Constraints

The nature and level of AHP services designed to meet the needs of patients with cancer is in short supply, with there being very little expertise available outside the main Cancer Centres across Wales, situated at Cardiff, Swansea and Glan Clwyd. An AHP mapping exercise across Wales is a work in progress being conducted through the Nurses and Allied Health professions Cancer Advisory group of the CSCG. This exercise will uncover the level of services currently provided by Dietitians, Occupational therapists, Physiotherapists, Speech and Language Therapists and Podiatrists. This exercise will help inform the constraints which exist which compromise the provision of supportive care at the right time, in the right place, by the right person with the right skills.

The principles of supportive care

Supportive care to enhance the living experience should include these principles

- They should be patient centred - the patient is considered an equal partner in the care programme and has the right to autonomy and choices, provided they are sufficiently well informed.
- Early intervention is essential to pre-empt problems– starting the survivorship programme as soon as possible after diagnosis can adequately prepare an effective but adaptable programme.
- There must be an interdisciplinary team approach – this requires mechanisms to facilitate communication, collaboration and decision making and ensures the right team matrix is constructed. Currently AHP`s appear to be constrained by limited understanding of their role and lack of engagement by medical colleagues.
- Coordinated care – mechanisms such as regular team meetings and shared note writing can ensure that the patient`s perspective and needs are communicated.
- Continuity of care needs to be provided – the number of transition points needs to be minimised between service providers to avoid duplication of effort and unnecessary health professional involvement.
- Accessibility of care – patients need to be able to access care without difficulty no matter where they live or what barriers exist to accessing care at the right time in the right place.
- Professional training – is the heart of quality care
- Evaluation and quality improvement – to ensure that living with cancer programmes remain effective, appropriate for the patient, and are evidence based.

Definitions of patient needs

Some definitions of patient needs with examples of symptoms and care needs are as follows:

Physical: Physical comfort and freedom from pain, optimum nutrition; ability to carry out usual day to day functions. Examples - Weakness, fatigue, anorexia, nausea & vomiting, mobility, lymphoedema, incontinence, thirst, hair loss, cough & shortness of breath, changes in bowel habits. Insomnia, weight changes, swallowing difficulties, speech difficulties.

Emotional : Need for comfort, sense of belonging, understanding and reassurance. Examples - Fear, distress, anxiety, depression, anger, guilt, grief, abandonment, helplessness, loss of control, isolation, self blame.

Psychological: Needs related to the ability to cope with cancer, its treatments, and its consequences; the need for optimal personal control and the need for positive self esteem. Examples - Lifestyle changes, sexual problems, diminished cognitive ability, loss of control, depression, anxiety, body image, fear of recurrence.

Social: Relationships, acceptance in the wider community. Examples - Role changes, social relationships, interpersonal communication, talking to others about the cancer.

Spiritual: The meaning and purpose of life. Examples - religious beliefs, searching for a meaning, existential despair, personal values, feelings of hopelessness, priorities.

Practical: Assistance to accomplish a task or activity, leading to greater independence. Examples - Help in the home, shopping, transportation, childcare, prothesis, assistance with ADL`s provision of family relief, stresses surrounding family issues e,g children & parents, financial, legal & employment issues, menu planning, food preparation.

Individual AHP roles for supportive care.

Dietetics – registered dietitians optimise the nutritional status and quality of life of those patients who are malnourished or at risk of malnutrition. Malnutrition is a common secondary diagnosis in cancer with a positive relationship between nutritional status and quality of life. As malnutrition can compromise supportive care programmes, which aim to optimise independence, its detection and prevention or treatment is important. The dietitian provides this care through the assessment of nutritional requirements, the advising on suitable and appropriate nutritional support, by monitoring the patients progress and amending the support as necessary. Dietitians also provide education and training for other health professionals, patients and their families to increase awareness of the importance of nutrition in cancer. Additionally, as survival from cancer is ever-increasing, health promotion advice to reduce the risk of nutrition- related disease such as Coronary heart disease and diabetes should be provided.

Lymphoedema – lymphoedema is a chronic swelling due primarily to a failure of lymph drainage and occurs most commonly in patients diagnosed with breast cancer, although it can occur in other tumour sites such as head and neck. Lymphoedema by its definition compromises the independence and quality of life but it can be managed through the application of bandages and compression garments and by special massage techniques. Skin care is also fundamental in the maintenance programme and the skills of the lymphoedema practitioner encompass all these issues as well as the education of the patient in self care and other health professionals to provide basic care.

Occupational therapy – Occupational therapists are involved with the patient throughout the disease trajectory by advising on lifestyle management, fatigue management and self esteem. These interventions can exert a positive effect upon pain, fatigue, cognitive deficits, anxiety and depression which may occur. Occupational therapists are also involved in education of health professionals as well as the patient and their family.

Physiotherapy – chartered physiotherapist apply interventions to aid mobility, pain relief, the management of the side effects of radiotherapy and advising on exercise programmes during and after chemotherapy to improve and maintain muscle strength. Additionally, extensive surgery for cancer can involve the clearance of muscles which can result in functional disability. The Physiotherapist advises on ways to cope with this loss and assist the patient return to as normal life as possible.

Speech and Language Therapy - Speech and Language Therapists become involved if the patient with cancer encounters problems with swallowing, speaking or if they have had breathing aids fitted following surgery. Problems they can advise upon include poor lip sealing, reduced tongue mobility, surgery to the base of the tongue and reduced larynx closing. These problems are usually permanent and if not dealt with can have a devastating effect upon nutritional status, social relationships and quality of life.

Opportunities for development of the AHP within living with cancer programmes

Better education by experienced cancer care AHP`s of AHP`s working in more general areas of care e. g. acute hospitals, community venues, to enable them to assess and advise on the needs of the cancer patient.

Early involvement of the appropriate AHP`s to commence supportive care and health promotion programmes. This will include specific recommendations for healthy lifestyle behaviours such as diet, exercise and weight control.

Sue Acreman
Research and Development Quality Lead
Velindre Cancer Centre