PSYCHOSOCIAL, BEHAVIOURAL AND COMMUNICATION RESEARCH IN ONCOLOGY
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GENERAL INTRODUCTION

The main areas of current cancer research are broadly divided as follows:
- understanding and defining the characteristics of the cancer cell
- defining the environmental factors which cause or promote the development of cancer
- developing methods to detect cancer at an early stage and investigational techniques to determine the extent of the established disease
- refining the various forms of treatment of cancer which include surgery, radiotherapy, chemotherapy, hormone therapy and immunotherapy
- defining the toxicities of treatments (notably chemotherapy) and developing measures to limit them and to enable more intensive treatments to be given (e.g. antisickness therapy, blood product/bone marrow support, antibacterial prophylaxis or treatment)
- developing palliative techniques and treatments for the relief of symptoms, notably in terminal care.

Despite advances in the many areas
- there are about 5,000 new cancer patients registered each week in the UK
- one person in three will develop cancer at some time during their life
- cancer causes a quarter of all deaths
- many cancer treatments are highly toxic
- cancer causes considerable psychological distress
- cancer services are patchy, inadequate and do not necessarily include psychosocial support.

PSYCHOLOGICAL ISSUES

One important area of interest to patients and the health professionals most closely involved in their care is the high psychological morbidity associated with cancer. The role of behavioural and psychosocial factors in the cause of cancer, adjustment to the diagnosis and survival has interested research workers since the 1950s. However, until recently validated methods for evaluating these issues have not been available. Reliable instruments for assessing them are emerging and there is a resurgence of interest in these and other associated areas of cancer research. This has led to collaboration between individuals from a variety of backgrounds – behavioural, social, psychiatric, immunological – and to new and broader approaches to psychosocial and behavioural research. Thus studies are being developed in at least five main areas:
- lifestyle and behaviour
- social environment
- personality and coping strategies
- affective states and life events
- doctor/patient communications
- psychosocial and behavioural interventions.

Two of these areas of study form the basis of these proposals, namely doctor/patient communications and psychosocial and behavioural interventions.

Doctor/patient communications

The problems most frequently identified in the medical literature are:
- patient anxiety resulting from miscommunication between patient and doctor leads to increasing fear and suffering, denial and noncompliance. Patients’ inability to express their feelings means that carers cannot reassure patients about unnecessary worries.
- family and friends react unnaturally because of fear of discussing cancer leading to behaviour which may be difficult for the patient to understand, thus increasing feelings of isolation and resentment.

Recent research in linguistics shows the importance of factors such as the setting of the interview, blocking techniques, prior beliefs and informal sources of information in patient/carer interactions.

These issues have interested the Lancaster cancer services for some time. A study with the department of linguistics at Lancaster University on the ‘effectiveness of communication within the Lancaster cancer support system’ (funded by the European and Social Research Council) has recently been completed. Further studies might arise from this work when the results have been analysed.

The potential for art as an aid to communication in health care is largely unexplored in clinical practice. Schemes have been devised for writers and artists in residence in psychological units and hospices and have been reported but detailed analysis of the various art forms as tools for communicating feelings in sensitive and difficult areas of health care has not been done. St John’s Hospice Lancaster has held two residency schemes, in writing and sculpture, and both have led to descriptive publications. Our experience leads us to believe there is considerable benefit in these approaches for patients and staff. Further schemes are proposed and a more analytical evaluation is essential.
Psychosocial and behavioural interventions

Emotional distress is frequent in cancer patients (Maguire, 1983) and various forms of intervention have been used to relieve it such as individual counselling, group therapy, relaxation techniques and psychotherapy. Few have been properly assessed and evaluated. There are still methodological issues which are not resolved. Benefits are difficult to define but there is the exciting possibility that intervention may prolong cancer survival (Spiegel et al 1989).

Current areas of interest are as follows:

- refining methods of psychological evaluation
- psychosocial adaptation of survivors and families
- quality of life of cancer patients on treatments
- the role of complementary therapy in cancer treatment
- can psychotherapy prolong cancer survival?
- the consequences for a family when a parent dies from cancer
- the use of psychological interventions to reduce emotional distress and promote recovery in surgical patients.

METHODOLOGY

Methods which measure various physical and psychosocial parameters have been devised and validated. They mainly take the form of rating scales and questionnaires, either self-administered or under the guidance of an interviewer, or they may be analyses of taped consultations. Some of these are listed below:

- Karnofsky Performance Rating Scale (KPRS)
- Satisfaction with Life Domain Scale (SLDS)
- Psychosocial Adjustment to Illness Scale (PAIS)
- Functional Living Index, Cancer (FLIC)
- Ways of Coping Checklist (WCC)
- Sickness Impact Profile (SIP)
- Rotterdam Symptom Checklist (RSCL)
- Hospital Anxiety and Depression Scale (HADS)
- Mental Adjustment to Cancer Scale (MACS)
- Hamilton Anxiety Scale (HAM – A)
- Hamilton Depression Scale (HAM – D)
- Beck Depression Inventory (BDI)
- Profile of Mood States (POMS)

PSYCHOSOCIAL SERVICES FOR CANCER IN THE UK

Cancer services are organised around specialist centres and there are only six cancer physicians in district general hospitals. Psychosocial support is patchy and is not generally considered by doctors to be an important element of cancer treatment. Patients try to find their own solutions. There are more than 350 self-help groups in the UK. Some patients turn to alternative treatment centres such as those at Bristol and Morecambe Bay. Others turn to BACUP, the information service which is developing counselling and supportive care in response to an unmet national need. There is a growing awareness of the benefits of supportive care and a rising demand for services to be provided alongside conventional cancer treatment. The nature of the benefits of supportive care, including complementary therapy such as the Alexander technique, yoga, meditation, art, aromatherapy and hypnosis has not been clearly defined. Furthermore the characteristics of the patients who might benefit are not known.

This is an area of increasing interest to clinical workers especially following the report of significant prolongation of life in patients with advanced breast cancer whose treatment included a psychotherapeutic approach (Spiegel, 1989).

CANCER SERVICES IN LANCASTER

Lancaster/Kendal is one of six districts in the UK where there is a cancer physician. The main hospital, the Royal Lancaster Infirmary, is 70 miles from the regional cancer centre at the Christie Hospital in Manchester. A weekly outpatient clinic is held by a visiting radiotherapist. The cancer services are unique in that they offer:

- an integrated approach of conventional medical treatment combined with complementary therapy and supportive care
- patients are cared for from the time of diagnosis to cure or terminal care by the same medical and nursing team
- community links are provided by five cancer support nurses who also work in the main hospitals and the hospice
- drop-in centres are open in the main densities of population (Morecambe, Lancaster, Kendal, Windermere, Ambleside)
- opportunities are available for patients to pursue creative skills through art, jewellery-making, weaving, pottery etc.

The cancer support services have been allowed to develop under the direction of health care professionals in response to patients’ needs alongside the NHS through charitable fundraising initiatives. They have a high local profile and are generously supported by the community. A £400,000 appeal was reached after two years and has provided a headquarters for the organisation and the annual income is in the region of £100,000. It was given a prestigious national award, the Lederle Bronze award, for 1991.

These services provide a unique opportunity for evaluating psychosocial factors and intervention in cancer care. Possibilities exist for randomised studies or comparative studies across districts in the northwest region. It is proposed that experts from various hospital and university departments develop detailed protocols to address the issues listed on page 220.

REFERENCES


PUBLICATIONS AND PRESENTATIONS ON THE LANCaster CANCER SERVICES


Supportive care and relaxation therapy in a district cancer service. BMJ (in press).


An analysis of the use of a telephone answering service for cancer in Lancaster, UK. International Conference on Supportive Care in Oncology, Brussels 1988 (abstract 184).


Time intervals from first symptoms to treatment in patients with cancer; where do delays occur? XV Conference of the European Society of Medical Oncology, Copenhagen 1990 (abstract P4:19).


QUIZ

What is it?

Answer on page 225.