

Recent Advances in Nursing

Cancer Nursing

Edited by Margaret C. Cahoon



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Edited by

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Margaret C. Cahoon RN PhD

Dr Cahoon is Rosenstadt Professor of Health Research at the Faculty of Nursing, University of Toronto, Canada. She has wide experience as a teacher, adviser and author. She is a former Fellow of the World Health Organisation and of the Ontario Ministry of Health and a past president of the Ontario Public Health Association. Health care research has been of major interest to her throughout her career, and at present she is the principal investigator in the Sunnybrook-University of Toronto Project for the development of a collaborative nursing research demonstration unit. She has made important contributions through her work in community health and oncology; she has been involved in studies of patient care and coping and has recently embarked upon a project for the Bayview Clinic of the Ontario Cancer Treatment and Research Foundation. In addition to her own publications on research in books and periodicals, she is a member of the editorial board of *Research in Nursing* and of the overseas panel of the *Journal of Advanced Nursing*.

Laurel Archer Copp RN PhD FAAN

As Dean and Professor at the School of Nursing, University of North Carolina at Chapel Hill and a Fellow of the American Academy of Nursing, Dr Copp is an established nursing authority, having contributed over sixty articles to international nursing journals, instigated ten research studies and served on a number of important advisory committees. Her main interest is the psychology and philosophy of pain and suffering but her studies have ranged widely to investigate many aspects of research and the nursing curriculum. She has maintained close links with work being carried out in other countries and in particular, her association with nursing research centres in the U.K. has meant a valuable exchange of views and knowledge. Her current appointments include Chairman of the Alumni Council of the Harvard Program on Health System Management and Chairman of the Task Force on Research of the American Association of Colleges of Nursing. In 1981, she received the Alumnus of the Year Award from Dakota Wesleyan University.

Lisbeth Hockey OBE PhD SRN BSc FRCN

Dr Hockey, a Fellow of the Royal College of Nursing, is well known as the Director of the first Nursing Research Unit established in the U.K. at the Department of Nursing Studies, Edinburgh University, in 1971, a post which she still holds. She gained extensive practical experience as a district nurse, midwife and health visitor before specialising in teaching, administration and, above all, research. She developed a Research Department at the (then) Queen's Institute of District Nursing, undertaking and guiding research in community nursing. Her present post involved her in research in the wider field of nursing. She is currently a member of several national committees and Chairman of the Royal College of Nursing Research Society. She is also a member of the Advisory Board of the *Journal of Advanced Nursing*. Lecturing and visiting Professorships have taken her to Canada, Australia, the U.S.A. and several European countries. She has made valuable contributions to international nursing and paramedical journals as well as being author and co-author of important textbooks and research reports.

Preface

This volume is for all nurses who are involved in the care of cancer patients and their families. Since cancer occurs in every age and since one out of four people is expected to develop cancer in his lifetime (American Cancer Society, 1979), this book is for the many nurses who are seeking information about advances in patient care.

Advances in any discipline are an outcome of the research in, or related to, the discipline. Most cancer research has been, and still is, directed toward the identification of carcinogens, the development and evaluation of new treatments, and prevention rather than care. In the report of the survey of nursing research to 1959, it was said, 'Considering the volume of published research on cancer, it is surprising to find so little that has to do with strictly nursing problems, or the nurse's role; nor have we found in many cases that nurses are identified as members of clinical research teams' (Simmons & Henderson, 1964, p. 329). Although there has been considerably more involvement in research in cancer nursing, especially in the past decade, the bulk of the research on patient care has been done by other scientists with varying degrees of involvement by nurses. As survival rates increase, attention is being focused on the care problems of the cancer patient and family, and is beginning to be directed toward assessment of quality of life as a critical outcome of care.

This book is not a 'how-to-do-it' volume. It is a reference book that will enable nurses to seek information from research reports that may have application in practice or may stimulate different interventions. Part One consists of a group of invited papers on areas of specific interest in the advancement of cancer nursing. All of the authors are nurses who are doing research in cancer nursing. The focus on research in Part One is purposeful since research is a 'means of achieving the kind of caring that includes deliberative, scientifically selected action' (Ellis, 1970, p. 444).

Dr Senga Bond, Nursing Research Liaison Officer, Northern Regional Health Authority, England, did her doctoral research on the processes of communication about cancer in a radiotherapy depart-

ment. Her chapter on communications in cancer nursing is a masterful review of the research and its implications for care. Dr Bond is especially interested in the utilization of research in practice and spent several weeks at various centers in the United States and Canada in 1979 discussing how to reduce the gap between the completion of a research report and the adoption of results that are ready for application in care.

Dr Ida Martinson, Professor of Nursing and Director of Research, School of Nursing, University of Minnesota, was asked to report on her study on home care for the child dying from cancer. This study is a classic clinical investigation of patient and family care. Dr Martinson is an international authority on terminal care of the child with cancer and his family.

Professor Jane Graydon, Faculty of Nursing, University of Toronto, was asked to contribute a chapter on the physiological and psychological aspects of breast cancer. Professor Graydon is especially interested in the coping behaviors of patients and as a doctoral student at Wayne State University, Detroit, Michigan, she is undertaking a research study on coping. She holds a joint appointment as a clinical specialist in oncological nursing on a part-time basis in the Sunnybrook-University of Toronto Medical Centre.

Dr Marilyn Oberst, Director of Nursing Research, Memorial Sloan-Kettering Cancer Center, New York, was invited to prepare a chapter on nursing studies in a multidisciplinary research setting. She and her colleagues have developed a stress-coping model as a conceptual framework for the department of nursing research in this acute care cancer center, to be used as a theoretical framework for the studies to be undertaken there (Scott, Oberst, Dropkin, 1980, p. 10). Dr Oberst will be recognized by many readers as the author of 'Research Highlights' in *Cancer Nursing*. Her chapter will be of particular interest to nurses who wish to become involved in research in patient care.

Dr Madeline Schmitt, Associate Professor of Nursing and Sociology, and former Director of the Research Office, School of Nursing, University of Rochester Medical Center, has written about the role of the nurse in interdisciplinary research. She has been a member of a five-center group called PSYCOG, organized under an NCI grant for collaborative research in psychosocial oncology. Her research and writings have focused on interdisciplinary teams. She has been principal investigator of a federal institutional research facilitation grant for the development of research in the School of Nursing.

Professor Hilary Llewellyn-Thomas, Faculty of Nursing, University of Toronto, currently a doctoral candidate in the Institute of

Medical Science, University of Toronto, was asked to contribute a research proposal to this volume. A good model of a research proposal is difficult for the graduate student or novice researcher to find. The inclusion of this proposal is a unique addition to this volume since Professor Llewellyn-Thomas expects to implement it in the future. She is involved in research on the quality of life of cancer patients in the Princess Margaret Hospital, Toronto. Her research is part of a major multidisciplinary project under the direction of Dr J. E. Till, Institute of Medical Science, University of Toronto.

Part Two consists of a bibliography to enable nurses to seek references of specific interest. It is for the practitioner who wants to know what others have found but who may not have the time, or the access to a health science library, to seek the most authoritative references. This bibliography should facilitate borrowing or ordering a report or reprint. It is hoped that this volume will be useful to graduate students in nursing, and the emerging nurse-researchers, who are interested in current problems that need further investigation.

Appreciation is expressed to each of the contributors without whose assistance this book could not have been developed. Tribute is also paid to the many anonymous patients without whose participation in research studies the advances in cancer nursing would be very limited.

Toronto, 1982

Margaret C. Cahoon

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Communications in cancer nursing

In recent years there has been a growing interest in the psychological and social consequences of cancer. This trend represents a development away from earlier psychosomatic investigations which focused on psychological factors in the aetiology of cancer (Surawicz et al, 1976). While there is continued interest in the dynamics of the pre-morbid personality (LeShan, 1977) the voluminous literature now appearing on psychosocial sequelae of cancer reflects widespread concern about quality of life issues. It is suggested by some that because of the connotations of the illness, cancer patients have special coping problems shared with no other group (Weisman, 1979a) and, as such, require careful and systematic investigation. Furthermore, there are some suggestions that psychoemotional factors may influence life expectancy (Lipworth et al, 1972; Weisman & Worden, 1975). This chapter considers communication within the broader context of adjustment to cancer. It stops short, however, of dealing with the special problems of terminal care, dying and bereavement and confines itself to adult patients living with cancer, their families and the nurses who are involved in their care. The literature examined relates to the kinds of problems, their frequency, intensity and timescale that face adult cancer patients and families. The effects on nurses of working with cancer patients and the nature of communication are reviewed together with efforts to detect and ameliorate problems. It is clear from the review which follows that while there are no clear answers to the many vexing problems which continue to confront those who care for cancer patients, enough information has accumulated to justify more rational and systematic approaches to communication.

The patient's perspective

Patient's reactions to cancer

Cancer remains a disease with frightening connotations. Sontag (1979) describes how cancer is used as a metaphor when awful aspects of

society are given the characteristics of a disease overlaid with mystification and charged with a phantasy of inescapable fatality. Despite recent advances in cancer treatment, beliefs about its terrible consequences are not unfounded and it has been suggested that the newly diagnosed patient faces the following threatening possibilities: disabling illness, mutilation, loss of an important body part, loss of physiological function or death (Mastrovito, 1972). Currier (1966) and Hinton (1973) described the many uncertainties facing the cancer patient not only in terms of its physical and social consequences but also in explaining its origins and development as well as its meaning for the future. These actual or threatened consequences have been described as a severe form of stress and a number of authors have used a stress model to illuminate reactions to cancer by newly diagnosed patients (Hinton, 1973; Miller et al, 1976; Peck, 1972; Rosillo, 1973). Lazarus (1966) describes stress as an extreme disturbance of biological and psychological functions brought about by unusually threatening, damaging or demanding life conditions. The four main classes of reaction — disturbed affect, motor behaviour, cognitive functioning and physiological changes — have been widely reported among newly diagnosed cancer patients (Morris, 1979).

It would be surprising indeed if patients did not react in some manner to a diagnosis of cancer and the variety of response is infinite. Some patients come to terms with their illness and apparently experience little distress, but some studies of heterogeneous groups of cancer patients (Craig & Abeloff, 1974; Hardman et al, 1979; Worden & Weisman, 1977) report substantial levels of psychiatric morbidity. This is not universally the case (Silverfarb et al, 1980a). Between the extremes of complete adjustment and the presence of psychiatric symptoms are patients described by Weisman (1976) as being 'vulnerable' and harbouring signs such as anguish, anxiety, anger, hopelessness and abandonment. These patients may suffer great distress which does not readily manifest to others.

Reaction to cancer is not a once only or static phenomenon and Holland (1973) has indicated the need for longitudinal studies which take account of the different stresses met in the variable clinical courses that cancer may take. Recently Weisman (1979b) has hypothesised the usefulness of psychosocial phasing which integrates typical problems, concerns and distresses that patients meet with clinical staging, treatment and disease progression. The idea that patients face particular concerns and communicate differently in sequence with the clinical staging of the illness was proposed Abrams (1966) based on clinical observation. Patients demonstrate different amounts of distress at different points in their clinical careers. Jamison

et al (1978) and Chesser & Anderson (1975) report that the period prior to surgery was more stressful for some patients than that after surgery. Silverfarb et al (1980a) in a cross-sectional study showed that patients being treated for a first recurrence of cancer exhibited greater distress than those newly diagnosed or those having final stage chemotherapy. Craig & Abeloff (1974) found a gradient between severity of disease as measured by survival time and levels of anxiety and depression.

Response to the diagnosis of cancer per se is often compounded with reactions to the treatment procedures used. Up to 25 per cent of women who have mastectomy are likely to suffer from depressive illness or an anxiety state within a year of surgery (Maguire et al, 1978a; Morris et al, 1977; Worden & Weisman, 1977). Furthermore, up to one-third may develop sexual problems (Silverfarb et al, 1980a; Maguire et al, 1978a). Social life can be greatly curtailed because of self-consciousness about appearance (Morris et al, 1977) and, despite being physically capable, some patients do not return to previous employment (Schonfield, 1972). Surgery for ano-rectal cancer with the formation of a colostomy also creates psychiatric morbidity and profoundly influences sexual and social functioning. (Devlin et al, 1971). Amputation of limbs (Parkes & Napier, 1972), head and neck surgery (Rosillo et al, 1973) and extenterative surgery for gynaecological cancers (Lamont et al, 1978) have been found also to produce deleterious psychological and social consequences.

When radiotherapy is the treatment of choice, then anxiety and depression levels are found to be high in substantial numbers of patients (Forester et al, 1978; Mitchell & Glicksman, 1977; Peck, 1972; Peck & Boland, 1977; Rotman, 1977). Lyon (1977) reported 51 per cent of patients experienced a severe depression and that 13 per cent of patients harboured thoughts of suicide during their treatment. Feder (1965) observed that being given therapy was a very forceful reminder to patients that their illness was cancer and that those who may have believed their illness to be benign would find great difficulty in maintaining this view. The connotations of the treatment therefore created a significant increase in dysphoric symptoms among patients who were not initially aware of their diagnosis (Forester et al, 1978). Its denervating effects have been found to continue to create mood disturbances for some weeks beyond completion of treatment (Maguire, 1976; Worden & Weisman, 1977). The combination of cancer, surgery and radiotherapy is a particularly potent cause of psychiatric and social morbidity (Maguire, 1976). The adverse effects of chemotherapy on quality of life for patients is also problematic and Silverfarb et al (1980b) found cognitive impairments to be associated with a wide variety of chemotherapeutic agents.

Symptoms experienced by patients during the course of illness and treatment could be anticipated to influence psychological states but Derogatis et al (1976) found no relationship between physical performance status and psychiatric symptom levels. Woods & Earp (1978) further report a strong association between numbers of persistent physical symptoms and mental outlook, while Worden & Weisman (1977) and Thomas & Maguire (1980) include the presence of persistent physical symptoms within a constellation of factors which predict distress.

The effect on families

It is not only the patient who faces problems of adjustment to cancer; the family is similarly invaded by the illness and its consequences. Spouses of patients interviewed toward the end of a course of radical radiotherapy (Bond, 1978) demonstrated that a substantial proportion were under severe stress. One-half had visited their own General Practitioner during the period of the patient's hospitalization, most strikingly in response to symptoms created by worry about the patient. Over two-thirds reported feelings of anxiety or behavioural responses indicative of anxiety. Wellisch et al (1978) found similar kinds of reactions continuing until after the patient's discharge from hospital.

Cassileth & Hamilton (1979) describe how cancer imposes on the family in three ways: it threatens or disrupts existing patterns of interaction within the family unit; it can upset the family's future plans and orientations; it alters the constellations of external reference groups with which the family interacts. While there may be family disintegration and disruption under the strains (Dyk & Sutherland, 1956), Parkes (1975) notes that the outcome is more often a lengthy and painful process of restructuring.

As well as the family unit changing in the face of new circumstances, the ongoing processes within the family will influence the patient's adjustment. Klein (1971) describes how families may be insensitive to the patient's cues or find problems equally difficult to face. When families have successfully mediated stress in the past then they may be more equipped to assist the patient member mobilise resources. However Klein et al (1967) found that the most often stated needs of relatives of patients ill at home concern information about the patient's status, help in giving psychological support to the patient, information on how to manage pain and other distressing symptoms and the administration of medications. Furthermore Krant & Johnston (1978) found that in late stage cancer many close family members do not perceive that they have a communicative link with the hospital medical staff closely involved in the patient's treatment. McIntosh (1977) and

Bond (1978) observed that the onus was very much on relatives to approach both medical and nursing staff to receive information about the patient's diagnosis, condition and care on discharge from hospital. The low frequency and limited nature of communication between close relatives and hospital staff described by Bond (1978) precluded assessment of how families were dealing with the realistic and symbolic implications of cancer as well as interventions to assist relatives to deal with the kinds of problems that they were currently facing and were likely to encounter once the patient was discharged home. This virtual neglect by professionals in busy hospital environments of the implications of cancer for the family reveals a more widespread avoidance of emotional involvement among those who work with cancer patients not only with patients and their families but also among the caregivers themselves.

Highly reliable evidence on the extent of emotional distress, psychiatric morbidity, sexual and social dysfunctions created by different types of cancer is not readily available because of the paucity of well controlled studies and the variety of methods and samples used. Together with this is an absence of information about the clinical care given to particular populations and its influence on patients' adjustment. Nevertheless, there are sufficient indications in the literature of assessments of patients and their families together with clinical observations of the psychological and social distress created by cancer that efforts to detect and reduce it are warranted.

Adjustment to cancer

Several theories of adjustment to threatening circumstances have now been developed and adjustment to cancer may be interpreted by these wider ranging theories. Lipowski (1970) suggests that individuals adopt a particular coping style which reflects a relatively enduring aspect of personality. The basic style would continue although its operationalism would vary depending on circumstances and what would be manifested would be particular coping strategies.

Other writers have suggested that rather than individual styles, adjustment to extreme trauma takes place through a process of realisation (Parkes, 1972; Falek & Britton, 1974). In making this adjustment the previous view of the world must be abandoned and another, created by the new set of circumstances, substituted in its place. This theory proposes that such psychosocial transitions are characterised by identifiable stages each involving changes in appraisal as well as particular psychosocial characteristics. Adjustment then necessitates working through each stage, but stages are by no means clear cut as the individual meets obstacles in the process of coming to