CANCER AND THE
FAMILY CAREGIVER

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Distress and Coping

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PREFACE

This book is the product of the authors' research and clinical practice in the field of psycho-oncology, stress, and coping for a period of over twenty years. During this time, cancer caregiving has emerged as an area of mounting importance and relevance to society in light of growing longevity and the concomitant challenges involved in caregiving to cancer patients.

Although certain aspects of the topic have been examined in the literature, primarily in the realm of family and social support, a gap exists in the discussion of caregiver distress. The book thus fills a lacuna felt by both cancer researchers and psycho-oncologists in the vital area of predicting, acknowledging, and alleviating the distress of caregivers of cancer patients. Professor Ora Gilbar's research topics and interests are in the area of psycho-oncology, and Dr. Hasida Ben-Zur's expertise is in the field of stress and coping.

The book was completed a year after the death of Professor Atara Kaplan De-Nour, of Hadassah University Hospital, Jerusalem, a pathbreaking mentor to a generation of psycho-oncologists in the area of family coping with cancer. Discussions with her over a period of several years, along with the impact of her research, had an important influence on the conceptualization of the book by widening out the scope of cancer caregiving discourse.

We are grateful for the illuminating and constructive comments regarding the ethical issues discussed in the book by Professor Amiram Gafni of the Faculty of Health Sciences, Macmaster University; Dr. Abraham Mansbach, Ben-Gurion University; and Roy Gilbar, Ph.D. candidate at Queen Mary and Westfield College, University of London.

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the editorial and production stages of the book. Special thanks are due Judy Krausz for her invaluable editorial assistance with the book. Genoveba Breitstein produced the various drafts of the book with skill and devotion.

Our deepest thanks go to all the patients who agreed to share their feelings, perceptions, and methods of coping with the illness outcomes, as well as to their caregivers, who, by agreeing to be interviewed, assisted our work invaluably over the years.

INTRODUCTION

Medical progress in increasing longevity has brought with it a large rise in the number of people who live in a state of chronic or terminal illness for a prolonged period of time. The outcome of this situation is that a significant proportion of the population is dependent on others in their everyday activity. Many if not most adults will become caregivers to an ill member of their family at some time, and some people will be care receivers before they themselves reach old age. Caregiving in general, and caregiving to a member of the family in particular, therefore, constitutes an important societal issue (Biegel et al., 1991).

The family has long been recognized as the best care solution, from a psychological and psychosocial point of view, for an ill person. An awareness of the vital role of the family member who provides such care, which in some cases actually contributes to enhancing the survival of the patient, has engendered increased interest in the family caregiver by both social science researchers on the one hand and health professionals on the other. Most of the extant research on caregiving focuses on the burden of the caregiver: health problems that arise, disruption of well-being, role conflict, moodiness, and financial burdens (Haley, 1997; Steketee, 1997). These effects stem from the increasing needs of the dependent family member over a long period of time, whether dependency is caused by physical or mental illness or disruptive behavior.

While a growing body of literature discusses caregiving for the elderly with Alzheimer's, dementia, mental illness, brain injury, and mental retardation, only a few studies deal with caregiving for cancer patients. Furthermore, the terminology surrounding caregiving for cancer patients differs from that of caregiving for other chronic illnesses, in that the element of social support takes on greater importance. An explanation for this may rely on the distinctive characterization of cancer as compared to other types of chronic illness. Cancer is defined by a series of phases, all of them stressful: diagnosis, surgical intervention, adjuvant medical treatment, follow-up, recurrence, and terminal phase. The diagnosis and surgery phases are of short duration (generally not more than six weeks), while the adjuvant medical treatments can last between seven and nine months. These stages involve a threat to body image, physical independence, family role and career, in addition to a threat to life. Although in the follow-up phase patients live their lives normally, with no physical dependency and no direct threat to their family role or career, they are in a stressful situation caused by the fear of recurrence. This period depends, of course, on the prognosis and may last for years. The recurrence phase is a stressful situation caused by the awareness of the progression of the illness, heightening the threat to the patient's life. This period may be prolonged, in most cases with only brief intervals of medical treatment. In the terminal phase, both physical dependency and emotional dependency are greater, as the patient is confronted with approaching death.

The book focuses on the caregivers of cancer patients in various phases of the illness, a topic that takes on importance in light of statistics showing that three persons in four will have someone in their immediate family (parent, spouse, child) who will have cancer (American Cancer Society, 1995). The discussion of cancer-patient caregivers is divided into three aspects: theoretical (Part One), research (Part Two), and practical (Part Three) issues.

Part One presents theoretical background on the structure and progression of the caregiver role, and how caregivers cope with the illness, as explored in recent literature. This presentation is generally based on two coping-with-stress models, both of which depict the caregiver role as a stressful situation: Lazarus and Folkman's coping-with-stress model (1984), and Biegel's ABCX coping-with-stress model (Biegel et al., 1991). Chapter 1 discusses research on the factors that affect caregiver distress, including patient variables as stressors, appraisal, perception of burden, the coping process, and resources. The caregiver in the context of social support is also examined. The perception of the caregiver of cancer patients is discussed in Chapter 2, based on the premise that cancer constitutes a stressful situation for every member of the family, and especially for the primary and secondary caregiver. The chapter presents the caregiver models for cancer patients based on the work by Lazarus and Folkman (1984), Lazarus (1999), and Biegel et al. (1991).

Part Two presents empirical research on caregiver psychological distress carried out by the authors during 1993–99. The first chapter (Chapter 3) focuses on measurement issues. It begins with a description of stress-related measures–the Brief Symptom Inventory (BSI; Derogatis, 1983), psychosocial adjustment (PSA; Ben-Zur, Gilbar, & Lev, 2001), the short version of the COPE scale (Carver et al., 1989), and social support measures. It goes on to explore measures specifically related to physical illness. Each instrument is described, and evidence for its reliability and validity is provided. In addition, Israeli normative data on the Brief Symptom Inventory (BSI) and COPE scales are described and are used in later chapters of the book as baseline levels to which caregiver distress and coping are compared. Chapter 4 presents three studies: the psychological distress and everyday psychosocial adjustment of seventy-three spouses of breast cancer patients; the distress and psychosocial adjustment to illness of forty-four spouses of gynecological cancer patients; and the distress and perceptions of burden of sixty elderly caregivers, as compared with that of the patients.

Chapter 5 describes the coping strategies of the seventy-three spouse caregivers to breast cancer patients, comparing them with the patients' strategies and testing their associations with distress. It also refers to the spouses' perceptions of each other's coping and their effects on adjustment. Chapter 6 assesses the distress and adjustment to illness of forty-one parents of adult cancer patients, and their associations with social support. Chapter 7 assesses the distress of primary caregivers of sixty-seven widowed cancer patients who died at home or in a hospice.

Each of the empirical chapters (4, 5, 6, and 7) presents theoretical background on the specific type of caregiver roles in the context of cancer–that of the spouse and the parent of an adult child; a description of the sample, research instruments and procedure; and findings and conclusions. Every study contains a description of caregiver psychological distress as measured by nine BSI subscales (Derogatis & Spencer, 1982). Caregiver distress is also compared with normative data and with patient distress. The primary goal of the research was to discover the possible associations between caregiver personal resources (e.g., age, gender, education, work, etc.), the patient's psychological distress, adjustment to illness and medical variables, and caregiver adjustment.

Part Three examines two important practical issues. The first, presented in Chapter 8, is intervention for reducing caregiver distress. Caregiver intervention and family therapy are compared through a review of the literature on intervention for chronically ill persons and for caregivers of cancer patients. Two interventions developed by the authors for reducing cancer distress are discussed: an individual program tailored to the various phases of the illness–diagnosis, medical treatment, follow-up, recurrence and the terminal phase; and a support group program for caregiver distress. Intervention programs related to the bereavement process are also explored, featuring counseling and therapy based on the model described in the literature.

The second issue, presented in Chapter 9, is the ethical question of caregiver involvement in the patient's medical decisions. The discussion focuses on doctor-patient-caregiver relationships based on three models of the doctor-patient relationship: paternalism, consumerism, and mutuality. The importance of maintaining the patient's autonomy in every stage of the relationship with the caregiver is highlighted. This issue becomes more complex as the illness progresses, when the patient's loss of physical independence exacerbates the caregiver's burden. A decision by the patient to undergo experimental medical treatment that will engender debilitating side effects and increase dependency, the patient's stated preference to die at home, or both are examples of issues that have a severe impact on caregiver burden. Although the physician is not obligated by law to take the family caregiver's interests into consideration, unless the caregiver is a court-appointed guardian, an ethical dilemma may arise over the role of caregiving as a factor in decisions regarding medical treatment. In the final chapter of the book, the authors evaluate the state of research in the cancer caregiver area and suggest directions for future study.

The book integrates three important aspects of the study of the role and problems of caregivers for cancer patients: theoretical, research, and practical issues. The analysis of these areas can be useful to clinicians, researchers, medical/psychological social workers, and nurses by familiarizing them with the spectrum of stresses experienced by cancer patients and their caregivers, and the coping methods that have proven most effective.

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CANCER AND THE FAMILY CAREGIVER

Part One

THEORETICAL ISSUES: CAREGIVING RESEARCH AND THEORY

Chapter 1

CAREGIVERS OF ILL PERSONS

INTRODUCTION

Over a thousand studies have been published to date on the caregiver role, caregiver distress, and caregiver burden. They include research on type of population in need of care (care receiver), type of caregiver (primary/secondary), variables that predict caregiver distress, caregiver role or tasks, and care receiver state (physical and mental). Research until the early 1980s dealt intensively with caregivers of the elderly, especially those in a state of cognitive impairment (i.e., those with Alzheimer's and dementia), and with caregivers of chronically ill children, especially those with physical disabilities and mental retardation. Research on caregiving to patients in the terminal phase of illness (e.g., cancer and AIDS) became a focus in the latter 1980s and thereafter. During the 1990s, a large number of studies also dealt with caregivers of patients with brain damage/injury and mental health problems.

The intensity of caring for an ill member of the family affects the entire immediate family, and often more distant relatives and friends as well. The variations and consequences of caregiving are distributed through the population equally, that is, adult–child, spousal, child–parent, and so forth, with far-reaching implications. It is a concern that extends beyond the boundaries of clinical interest, which was the domain of early research. Increasingly, it raises both logistic and sociological issues in the health and social service agencies of every community. Caregiving, therefore, is an issue that needs to be understood on a firm theoretical and empirical basis.