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Informal Caregiving for Cancer Patients

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Abstract

According to the recent worldwide estimation by the GLOBOCAN project, in total, 12.7 million new cancer cases and 7.6 million cancer deaths occurred in 2008. The worldwide number of cancer survivors within 5 years of diagnosis has been estimated at be almost 28.8 million. Informal caregivers, such as family members and close friends, provide essential support to cancer patients. The authors of this report provide an overview of issues in the study of informal caregivers for cancer patients and long-term survivors in the United States and Europe, characterizing the caregivers commonly studied; the resources currently available to them; and their unmet needs, their psychosocial outcomes, and the psychosocial interventions tailored to their special circumstances. A broad overview of the state of research and knowledge, both in Europe and the United States, and observations on the directions for future research are provided.

Keywords

cancer; survivorship; health care delivery; nonclinical distribution; Europe

INTRODUCTION

The estimated number of cancer survivors worldwide who are within 5 years of diagnosis is approximately 28.8 million.^{1,2} Informal caregivers, such as partners, close family members, or friends, provide essential support to cancer patients along the illness trajectory. During diagnosis and the first phases of the illness, these individuals may offer practical help by accompanying the patient during the diagnostic steps and also psychological support for coping with uncertainty and fear. In the advanced phases of the illness, caregivers may provide assistance and self-care and give emotional support.

The burden of cancer is likely considerable across all cultures. Some have suggested that the experience of caregiving is not influenced by aspects like race and ethnicity,³ but others

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have observed racial differences among the type of and level of involvement in the caregiving task.⁴

In reality, there are aspects related to race and ethnicity and also aspects related to cultural values, beliefs, and family systems that may account for caregivers in different countries experiencing their role in different ways. For example, in some geographic areas, families live close to their families of origin; and, in these cases, more help may come from the extended family. In other areas, however, the nuclear family may be the only resource for caregiving. For example, if families, such as those in Mediterranean countries, are closely involved in their relative's care, then this may negatively impact diagnosis disclosure from oncologists to cancer patients despite ethical and legal obligations to the contrary,⁵ creating a discrepancy between norms and real medical practice.^{6,7} Similarly, different approaches to end-of-life care, from diagnosis disclosure, to the practice of euthanasia, to the role of family members and the availability of hospices, have been documented among European countries.⁸ Thus, there is no unique, "western" way of providing care to a patient with cancer.

The objective of the current discussion is to provide readers with an outline of the cancer caregiver literature, in both the United States and Europe, and to offer some comparisons. The focus is only on caregivers of adult cancer patients, because caregiving a child or an adolescent poses particular strains for families. We performed a non-systematic literature search using the PubMed and Web of Knowledge databases using the following search terms: *caregiving*, *caregiver*, *significant other*, *next of kin*, *spouse*, *partner*, *son*, *daughter*, *relative*, *cancer*, and *oncology*. We also considered exemplar studies from reviews authored by US or European researchers. The variety of content in the 2 literatures reflects the extant differences identified.

Defining Cancer Caregiving

First, it is useful to consider how the research literature has defined "caregiver." Unfortunately, there is no universal definition (and, at times, no definition is provided), so there is variation across studies. We asked the following questions: Is an individual a caregiver based on the provision of psychological aid or behavioral assistance, such as preparing a meal? Is the extent of support in hours per day or economic costs incurred more relevant in defining who is or is not a caregiver? Is anyone living with a cancer patient assumed to be caregiving? The American Cancer Society's (ACS) National Quality of Life Survey for Care-givers (NQOL-CG), for example, combined elements like these and defined a caregiver as a "family-like" individual, nominated by the patient, and the 1 individual providing consistent help.⁹ Similarly, we observed that some literature reported only using "caregiver" or "carer"¹⁰ as search terms, whereas others used broader terms like "family," "significant other," or "next of kin."^{11,12} Still, it is important to note that different studies and reviews can be compared or integrated only if they have a common definition of caregivers or at least if the definitions are clearly stated.

Cancer Caregiving in the United States

The National Alliance for Caregiving (NAC) estimates that 4 million individuals are caring for an adult cancer patient; this estimate accounts for roughly 8% of all care-givers in the United States. In fact, the 8% estimate exceeds the numbers of caregivers (6%) for the number 1 killer of Americans: heart disease.¹³ Data suggest that, for those with cancer, the periods of care are predominantly during the first year or 2 after diagnosis (currently, 1.6 million individuals are diagnosed annually¹⁴) or when an individual is declining and dying of cancer (currently, 600,000 Americans die annually¹⁴). By comparison, there are fewer studies of caregivers at other times in the cancer trajectory, but the available data indicate

low rates of care-giving (eg 16% at 5 years postdiagnosis¹⁵) when survivors are disease free. This suggests there is a bimodal distribution of caregiving (ie, care at diagnosis/treatment, care at end of life) across the cancer trajectory. Considering the numbers of patients at both time points, roughly 2.2 million individuals may be caregiving at any 1 time. The overview of US caregiver research and data has implications for both policy makers and researchers. First, considering the numbers of caregivers (estimated at 2.2 million), their time and effort expended, and their personal financial costs (including lost wages), policy makers might consider these “hidden” costs to the United States. Absent proper guidance and skills, caregivers also may become a burden on the health care and public welfare systems. Specifically, there is a pressing need for caregiver support and education to become a part of the patient discharge plan, much like what is done for caregivers of stroke or cardiac patients.

Who is caregiving?—Although there are millions, describing the population of cancer caregivers is not straightforward. To date, studies have used a 2-step sampling process: first, identifying and sampling patients and, second, asking the patient to identify (nominate) his/her caregiver who, in turn, is surveyed. Of course, each stage is subject to sampling problems and biases, as illustrated by analyses from the first ACS Study of Cancer Survivors (ACS SCS-I), which is described below. By using this sampling strategy, Kim et al⁹ reported that patient factors, such as age, sex, ethnicity, and type of cancer, predicted the nomination of a caregiver for further study. Women (especially those diagnosed with ovarian or breast cancer) were more likely to nominate a caregiver than men. Also, racial groups other than African Americans were equally likely to nominate caregivers.

Regarding the caregiver participants, Kim et al¹⁵ and Kim and Spillers¹⁶ report that they ranged in age from 18 to 90 years (mean age, approximately 55 years), and most (65%) were women. The majority (66%) were spouses, and others were offspring (17%), siblings (7%), parents (4%), or 3% friends. Thus, it is important for population-based studies like ACS SCS-I to have an adequate representation of cancer types and disease stages. However, the nominated caregivers who eventually were surveyed were primarily Caucasian, middle-aged, women who were spouses.¹⁷ Acknowledging the limitations of sampling strategies like these, the ACS NQOL-CG, which is described below, is the most comprehensive study of US caregivers to date.

A different sampling strategy was used by the NAC in collaboration with the American Association of Retired Persons. Data were collected from anyone who was caregiving (not only cancer caregivers).¹³ Even so, the resultant sample was similar to that obtained in the ACS NQOL-CG, although somewhat older (aged 65 years). The coresidence caregivers (spouses) usually were the sole caregivers, but the majority (68%) also reported receiving help from additional unpaid caregivers, although not their adult children, as might be assumed. Thus, few studies have sampled nonspousal caregivers, such as daughters or sons (although there are examples^{9,17}) or the offspring of older caregivers.¹⁸ To our knowledge, there are no studies sampling other relatives or close friends. In the future, recruiting caregivers through community sampling (rather than patient nomination) would achieve a more representative caregiver sample and would be feasible considering the millions of cancer caregivers in the United States.

Caregivers' unmet needs, tasks, and burdens—Caregivers' tasks are multifaceted and change along the trajectory of illness in concordance with patients' medical and emotional needs. Measures have been developed for assessing quality-of-life outcomes and support needs. In considering the measures used in the broader literature, Wen and Gustafson¹⁹ note that existing measures are varied in the domains assessed and whether or not they are conceptually grounded. Of course, supplying the right resources for caregivers

depends on an accurate assessment of needs. Although there is general agreement between researchers on the broad categories of needs (eg information), there is less agreement on the elements within categories. Caregivers participating in the NQOL-CG, for example, estimated the frequency of providing 4 types of support: emotional, instrumental (eg information, obtaining medical services), tangible (eg household chores), and medical (eg administering medication).¹⁷ Patients had been diagnosed for a mean of 25 months; at that time, approximately half of the caregivers reported giving all types of support, and the most common was emotional support.

The daily burdens leave caregivers with their own needs for support and assistance that, when left unmet, lead to a poorer quality of life and higher levels of distress.²⁰ Even 2 years after the patient's diagnosis, at least 33% of caregivers may need assistance in coping with their own concerns: the patient's emotional distress as well as their own, communication with the patient about concerns, changes in lifestyle, and how to get their information needs about cancer met.²¹ Five years after diagnosis, a significant proportion of caregivers (21%) still needed assistance in helping with the patients' continuing distress. At the same time, 12% of caregivers needed help with their own emotional distress, their relationship with the patient, and determining whether their medical and insurance coverage was sufficient.²¹

Research by Kim et al²¹ provides a useful categorization of caregivers' many needs and concerns. Those authors identified 5 domains: psychosocial, financial, medical, and activities of daily living.²¹ They considered these key areas when surveying caregivers 2 months, 2 years, and 5 years after the patients' diagnoses (N =162, N =896, and N =608, respectively). The prevalence of unmet psychosocial needs was 68% at 2 months and 36% at 5 years. Unmet medical, financial, or daily activity needs at 2 months remained elevated for the next 5 years. Also, unmet needs were correlated with age, sex, education, and ethnicity. That is, younger caregivers reported greater unmet needs than older caregivers, women reported greater unmet psychosocial needs than men, and Caucasian caregivers reported the fewest unmet needs at 5 years compared with non-Caucasian caregivers. Caregivers with higher education reported greater unmet needs in psychosocial and daily activity aspects at the early phase of the survivorship, but not at later phases.²¹

Caregiver outcomes—Hundreds of studies describe the untoward effects of cancer caregiving,¹² with the consensus message that caregiving adversely affects quality of life. However, there is less agreement about the nature and extent of negative outcomes. In a comprehensive review, Kim and Given²² note that the majority of studies to date have focused on psychological distress, usually that occurring within 2 years after diagnosis; considering the data described above, this is certainly the most challenging period. For caregivers, similar to cancer patients, the negative impacts are experienced to a greater or lesser extent, depending on the sociodemographic characteristics of the caregivers. Psychological distress among caregivers was higher among women, younger individuals, employed caregivers, and those with lower socioeconomic status.²² Other major life areas, such as social relationships, occupational circumstances, etc, have received little study. Stenberg et al note that anxiety, sexual problems, and a broad spectrum of physical problems (eg sleep disturbance, fatigue) are common areas of disruption among caregivers.¹²

After the first 2 years, caregivers generally adapt well. The ACS NQOL-CG¹⁶ was used to assess mental health, physical health, psychological distress, and spirituality of caregivers 2 years postdiagnosis. The results indicated that both the mental health and the physical health of caregivers were comparable to those of the US population. Only spirituality needs were heightened among the caregivers. Regarding individual differences, women and younger caregivers had higher levels of psychological distress and poorer mental health, whereas older caregivers reported poorer physical health. These results are in concordance with

findings indicating a 63% higher mortality rate among older caregivers compared with noncaregivers.²³

In the 5-year follow-up of the ACS NQOL-CG,⁹ the mental health of former caregivers (because the patient either was disease-free or had died) was comparable to the mean mental health of the general US population. However, caregivers who continued to provide care and those who were bereaved had the highest distress. The physical health of both current and former caregivers was comparable to US norms. Caregivers' age was positively correlated with lower psychological distress and better mental functioning. Nonspousal caregiving was associated with better mental functioning. For the former caregivers of patients who had remained disease free, the women caregivers, higher levels of caregiver esteem, and caring for patients with less severe disease were associated with better mental functioning. Finally, the data suggest that adult daughter caregivers, in contrast to the patient's spouse, report the highest level of caregiver stress; and it is noteworthy that caregiver sons report the lowest level of distress.¹⁸ However, this finding regarding sons may be an artifact of existing sex differences in the reporting of distress.

There is broad agreement that cancer caregiving is stressful. Considering caregivers as a group, younger women who are caregivers may be at greater risk. In the population, there will be more women caregivers than men because of the differential survival rates for the sexes; thus, it is not surprising that study samples include predominantly women. Consequently, we know much less about the experience and needs of male caregivers. Regardless of sex, older caregivers may be doubly burdened by their distress and the risk for new or worsening physical symptoms and illnesses.

Experts have concluded²² that data are needed regarding the long-term effects of caregiving, such as poor caregiver health, caregiving for patients with recurrent disease, and caregivers' bereavement. For the next generation of data, recruiting caregivers through community sampling would be a step forward and may be more feasible than might be expected when considering the millions of cancer caregivers in the population. In addition to the individual differences that have been identified in the literature, there surely are others, such as ethnicity, relational ties (spousal vs other), and combined vulnerabilities. Within a conceptual framework, an understanding of these kinds of factors can lead to a tailoring of interventions for caregivers in the greatest need.

Intervention studies and trials—In an important meta-analysis of interventions with family caregivers, Northouse et al²⁴ summarized results from 29 randomized clinical trials of interventions that included caregivers. Of the interventions analyzed, the majority (63%) were interventions for patient-caregiver dyads. The interventions were psychosocial, behavioral, or cognitive and included psychoeducation, skills training, or therapeutic counseling. The most frequently studied outcomes were appraisal of caregiver burden and benefit, coping strategies, self-efficacy, quality of life (distress, anxiety, depression, and physical health), social functioning, and others. In general, interventions had small treatment effects (eg, 0.11–0.26 for physical functioning, 0.16–0.29 for distress and anxiety, 0.04–0.20 for marital/family relationships, 0.20–0.29 for self-efficacy) and had no effect on relief from depressive symptoms. The authors emphasized that the focus of many of these programs was patient care and that few protocols were designed to help caregivers, per se. These data suggest that, although some efforts are best addressed within the patient-caregiver unit, more robust gains likely would be achieved for interventions tailored to caregivers' needs.

Couple or family interventions can be important. To date, however, there have been few interventions tailored for caregivers, although there is agreement that such interventions should be introduced at early stages, such as when the patient begins or continues in

treatment. Specific, empirically based intervention protocols are needed to address the tasks, needs, and coping efforts of caregivers as well as any adverse effects that may occur.

Resources: Nonprofit organizations and government programs—Although a full discussion of resource and policy issues is beyond the scope of the current article, 2 salient sources of support are considered. Many nonprofit organizations (NPOs) founded with the mission to aid cancer patients have recently broadened their scope or expanded previous efforts to address caregiver needs. In the United States, the ACS and the Cancer Support Community,^{25,26} for example, offer emotional support and support groups through online or local (state or community) affiliates. Another example, the Family Caregiver Alliance,²⁷ offers discussion groups, legal advice, and financial advice and connects caregivers to local resources through a Family Care Navigator program. These and other NPOs are working to build more substantive programming and resources for family members in general and caregivers in particular.

Compared with emotional support or tips and advice, it is more difficult to locate financial and instrumental support resources. Expenses are incurred for months, and they are considerable. On the basis of ACS NQOL-CG data, caregivers provided help for an average of 17 months after diagnosis, providing care for an average of 8.8 hours per day. Yabroff and Kim¹⁷ estimated that the average cost of caregiving during 2 years after diagnosis was \$47,710, with the highest cost incurred from caring for a patient with lung cancer (\$72,702) and the lowest cost incurred from caring for a patient with breast cancer (\$38,334). Some NPOs may be able to provide modest funds or connect patients with other organizations that have similar resources. There are peripheral, “virtual” sources to identify financial support. For example, 1 search engine is that available through the Cancer Financial Assistance Coalition, which includes 14 different member organizations for the education of cancer patients and caregivers about existing financial resources.²⁸ Although these resources are potentially useful, older caregivers, for example, may not have adequate Internet navigation skills to take advantage of them.

Of course, many caregivers seek governmental (federal) support, like that available through Medicare (for which all are eligible) and Medicaid, the specific US program for individuals with little to no financial means. Medicare operates “Ask Medicare,”²⁹ which is a source of information for caregivers, including that for financial issues. Some Medicaid waiver programs provide funds to pay family members for providing care that otherwise may have been provided by paid professionals or more expensive facilities, such as assisted living facilities.³⁰ Still, programs like these are not available to all and may be difficult to obtain simply because of the time, expertise, and personal resources needed to seek the assistance (eg computer access, availability of social workers and related professionals), which are required to successfully navigate complex health care systems in the United States.

In an historical review of public policies on family and informal caregivers for older individuals, Scharlach³⁰ noted that, 2 decades ago (1993), the United States became 1 of the few countries to grant workers the right to unpaid leave to care for a parent, spouse, or child with a serious health condition through the federal Family and Medical Leave Act. Since then, Scharlach has noted that an integrated, comprehensive long-term care system has not been developed that considers informal caregivers as both care partners and service recipients in their own right.³⁰ Indeed, there are no “umbrella” organizations or coordination efforts enabling caregivers to learn about and access all available resources. Navigating the current maze is made more difficult for caregivers who have limited facility with or access to the Internet. However, there is hope that this circumstance will improve, because caregiving is embedded in the Patient Protection and Affordable Care Act (P.L.111–148), which promotes patient-centered and family-centered care.

Cancer Caregiving in Europe

Recent data from the EUROFAMCARE (Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage, and Usage)³¹ and SHARE (Survey of Health, Ageing, and Retirement in Europe)³² studies estimate that approximately 19 million individuals are providing care to an older individual in Europe.³³ Such an estimate includes caregivers of those who have different disabling conditions, such as adult disabled children, frail elderly individuals, or individuals with mental health problems. One study examined the problems of caregivers of nonelderly individuals, including data from England, Belgium, the Netherlands, Austria, and Italy. The data³⁴ suggest that the majority of caregivers are women aged >45 years who cohabit with the care recipient and are physically and emotionally strained from the caregiving. To date, specific data on the prevalence of cancer caregivers in Europe are lacking, including information about the tasks caregivers are required to fulfill according to the different needs of cancer patients at various stages of the disease.

Caregivers' unmet (information) needs—The European literature on unmet needs focuses on the necessity of more information for families coping with cancer. A review of 34 studies (including 20 European studies) examining the degree to which information needs of family members are fulfilled by health care professionals highlights the need for better access to information from such professionals and for health care professionals who can communicate with them in a more caring and compassionate manner.³⁵ To date, only investigations among recently diagnosed patients that had small samples and/or that were limited only to patients with breast or prostate cancer have been carried out. An exception is the 2003 report by Isaksen et al, who surveyed a mixed group of cancer survivors (<10 years after diagnosis) and their family members (N =473).³⁶ Although the majority of patients (67%) in their study reported satisfaction with the support and information received, close family members did not. Less than 30% of the family members were satisfied with either the information or the support and encouragement received from health care professionals.

Data from surveyed Icelandic family members (N =223) of cancer patients indicating an average of 6.2 unmet needs of 20 needs surveyed, and 12 important needs were unmet in 40% to 56% of the sample.³⁷ Follow-up analyses of individual differences indicated that unmet needs were significantly greater among caregivers who were women, younger, a relative other than a spouse, and/or helping patients with metastatic cancer. In contrast, family members of disease-free cancer survivors at 5 years after diagnosis reported very few unmet needs (2.7 unmet of 34 possible needs).³⁸ Also, the needs noted were those most relevant for long-term survivors, ie, information about familial risk and ways to manage the fear of recurrence.

Caregiver outcomes

Health: In general, studies of the physical problems of care-givers have highlighted fatigue, sleep disturbances, and loss of weight and appetite,¹² although few of those studies were from Europe. There is some indication that these physical problems are observed in caregivers throughout the disease process.³⁹ Caregivers of the newly diagnosed have reported the occurrence of symptoms like as sleep disruption, headaches, and fatigue.⁴⁰ Physical problems like these may result in more health care use. For instance, a Swedish study that included 11,000 partners reported increased health care costs and inpatient health care use in the 1 to 2 years after the patient was diagnosed with cancer compared with the 2 years before diagnosis.⁴¹

In contrast, when patients remain disease free, close family members or partners have health (eg mobility, health care use, pain or discomfort) similar to that of the general European

population.³⁸ However, the experience of caregiving may vary considerably, depending on both the intensity and the nature of the caregiving tasks as well as the caregiver's perception of the burden. To our knowledge, there are no studies of objective and subjective burden in relation to caregivers' physical health. Measuring the burden of care may provide a better understanding of the aspects of caregiving that pose the greatest strain on caregivers' physical health.

Psychological distress: Overall, the picture arises that most family members adapt well and may not evidence any elevated rate of emotional distress.⁴² Studies using self-report measures of psychological morbidity (usually symptoms of anxiety or depression) suggest that the prevalence of clinically significant distress among caregivers is 20 to 30%. Not surprisingly, studies that use diagnostic interviews provide lower rates of approximately 10%.⁴³ Unfortunately, there are few studies comparing prevalence rates for caregivers versus the rate in a comparison sample.⁴² An exception is a report by Hagedoorn et al⁴⁴ in which the authors also evaluated a control group of healthy couples. One recent study from the United Kingdom, however, sampled 257 family members of long-term cancer survivors and reported percentages for anxiety and depression (9% and 3%, respectively) similar to those observed in the general European population.³⁸ An exception is in the case of caregivers for patients receiving palliative or end-of-life care, in which caregiver distress is considerably higher and is also higher compared with distress in the general European population.^{45,46} Across all studies, there is the common difference with regard to sex, in which spouses who are women report more distress than spouses who are men.⁴²⁻⁴⁴

Social activities and relationships: Despite the importance of social ties to mortality,⁴⁷⁻⁴⁹ there has been little study of the negative impact of caregiving on social relationships, with the exception of studies of marital distress. Two Italian studies are available. In 2003, Rossi Ferrario et al observed that 60% of caregivers were unable to maintain their friendships or engage in recreational activities or hobbies.⁵⁰ In 2007, Giorgi Rossi et al studied caregivers of terminal patients; in that study, 68% of caregivers reported that it was either very difficult or quite difficult to manage any social or leisure activities, and some even needed to move into the patients' home. Leisure activities were more disrupted more than employment, as may be expected.⁵¹ Future research is needed to learn more about the influence on caregivers' social activities and relationships apart from the family.

Most of the research on relationship outcomes focuses on marital stress and strain. For example, it has been observed that cancer survivors and their partners are not at greater risk of divorce than members of the general population (except for women who are diagnosed with cervical cancer).⁵² Moreover, partners have reported positive changes in relationship satisfaction compared with healthy controls.⁵³ However, the effect of cancer and its treatment on the caregiver-patient relationship may be different for spouses and nonspousal caregivers, such as children or other family members. For example, in a mixed sample of significant other caregivers of patients with lung cancer, only 15% reported an improvement in relationship quality during the disease trajectory, whereas a considerable proportion (38%) reported a (temporary) decline in relationship quality.⁵⁴ Those who did report improvement were more likely to be spouses rather than significant others. The findings of the latter study also may have been influenced by the palliative illness phase. That is, the need to provide palliative care may pose extra strain on relationships. Future research might consider the phase of cancer or the nature of caregiving tasks as moderators of relationship distress in couples as well as other dyads (eg parent-child).

The sexual life of couples also has been studied, including many studies of patients with genitourinary cancers⁵⁵ (eg prostate, bladder, kidney, testicular, or penile cancer). For example, sexual satisfaction, but not marital satisfaction, reportedly is lower for couples in

which 1 partner is a survivor of testicular cancer compared with couples that are cancer free.⁵⁶ In the future, additional studies on sexual satisfaction and functioning among couples coping with cancer other than genitourinary cancers will be needed.

During the last decade, attention has shifted to studying relationship consequences, emotional outcomes, and benefit finding in dyads.⁵⁷⁻⁵⁹ Instead of examining patients and partners or caregivers separately, data from patient-partner pairs are able to account for their interdependent relationships. The dyadic approach views couples reacting to the distress caused by cancer as an emotional system rather than as individuals. Thus, partners (or caregivers) have to deal with their own and the patients' emotions and responses to the cancer, and vice versa. It is believed that the dynamics and the (prior) functioning of the pair play an important role in maintaining or even improving the relationship during the disease trajectory.⁴² Hagedoorn et al,⁵⁹ for example, reported that both healthy partners and patients were able to maintain their relationship satisfaction even if their spouses were currently not responsive to their needs, but this was the case only if they perceived that past spousal supportiveness was high. In the future, dyadic studies that include the testing of mediator and moderator factors will provide further insight into relational processes, eg clarifying which dyads (including patient-nonspouse dyads) are able to maintain relationship satisfaction and emotional well being and under which conditions.

Benefit finding—To our knowledge, only 2 European studies have been conducted on benefit finding, and both came from Switzerland. In a small qualitative study, women who were partners of patients with head and neck cancer reported positive changes with respect to attitudes toward life, personal strength, and relationships with others; they also reported more positive changes within the partnership compared with the affected spouses.⁶⁰ Another study with a large sample (224 couples) indicated that patient and partner growth covaried, especially in couples that included a patient who was a man and a woman partner. This suggests that patients and partners may experience parallel growth.⁵⁷ Obviously, more research is needed, including studies on nonspousal caregivers. Future studies should investigate which mechanisms are involved in the perception of growth in patient-caregiver dyads when the caregiver is the partner and also when the caregiver is not the intimate partner of the patient. Cancer-related factors (eg prognosis) may moderate the association between patient and caregiver perceptions of growth, but interpersonal processes within patient-caregiver dyads also may stimulate benefit finding in both members of the dyad.

Financial issues—Although health care systems in Europe are socialized, financial costs for individuals and families still may be substantial. Some medications, nursing assistance, and/or physician home visits are costs usually not included in state-funded health care. For example, 2 large studies from the United Kingdom reported that between 16% and 32% of participants stated a need for more financial help.^{61,62} In an Italian study, of the 1249 bereaved care-givers studied, 26% used all or most of their savings in providing care for their loved one.⁵¹

Employment-related problems also are common, particularly for caregivers of terminally ill patients. For example, 49% of Italian caregivers of working age (<65 years) had difficulties in managing their regular employment in the last months of terminal care.⁵¹ Research on the financial/employment problems among caregivers of patients in other phases of the illness and at the end of life would be important. In such research, objective outcome measurements, such as the amount of expenses or reduced incomes, would be more direct measures of adverse financial impact.

Intervention studies and trials—To date, the research literature on interventions for caregivers is limited. In a recent review,⁶³ 8 of 33 studies were from Europe, specifically the

United Kingdom and Sweden. The majority (7 of 8 studies) focused on caregivers of patients in advanced or palliative phases, and 2 of 8 studies focused on bereaved caregivers. None of the studies was intended for patient/carer dyads.

Similarly, according to a recent review, few European-based studies of psychosocial interventions are specifically designed for couples.⁶⁴ Only 3 of 14 studies reviewed originated from European countries—the Netherlands,⁶⁵ Greece,⁶⁶ and the United Kingdom⁶⁷—and each had a unique focus. From the Netherlands, the efficacy of a brief counseling intervention to restore relational equity among partners was examined. The intervention was identified as effective in improving relationship quality, but psychological distress was reduced only in patients and not in partners. From Greece, the efficacy of a combination of couple and sex therapy was tested postmastectomy: patients' depression levels improved after the intervention, such as their satisfaction with body image and their relational and sexual life. In the United Kingdom, a case report qualitatively described an attachment theory-based psychotherapeutic intervention that was used for a partner and a patient with breast cancer aged 83 years who was terminally ill; the intervention helped the couple cope with bereavement.

A recent German longitudinal study on 72 couples indicated that a dyadic-skills intervention, mainly based on training in communication skills and dyadic coping, was more effective in reducing avoidance in communication within the couple and enhancing relationship skills during the first 16 months after diagnosis with respect to a control psychoeducational intervention.⁶⁸

Taken together, the literature on caregiver interventions is limited. Consistent with a developing literature, there is heterogeneity of topics and modest methods (eg small samples, short-term qualitative outcomes, unknown long-term benefits of the interventions, etc). Expansion of the literature to include caregivers across the cancer continuum also is needed.

Web-based resources—Across Europe, each country may have its own resources for helping caregivers through the web. The web-based resources of the 2 countries of the European authors of this report, however, have been analyzed by way of example. In both Italy and the Netherlands, there are some associations dedicated to cancer patients who offer information, advice, and support for various aspects of illness, treatments, and patients' life during the trajectory of disease. These groups also may provide information on health care use and facilities for both patients and caregivers. Some have created discussion forums for caregivers or information booklets with some advice on coping with an ill relative. In Italy, no web-based resource for caregivers of cancer patients was identified except for bereaved relatives.

Summary and General Conclusions

To paraphrase an observation of Leo Tolstoy, each family with cancer has cancer in its own way. Still, there are many similarities between the United States and Europe in caregivers and caregiving. For example, most cancer patients are supported by informal caregivers along the trajectory of the illness. Of these, the majority of caregivers are women, usually spouses. Also, caregiving exacts emotional, social, and physical health tolls.

Yet, the overview revealed broad differences and gaps of knowledge that may serve as directions for future research in the respective regions. One prominent difference is the lack of “basic” data concerning caregivers in Europe compared with data available in the United States, indicating a need for European data concerning demographics, tasks, and resources for caregivers. We suspect this is partially because of the obvious differences in the

feasibility of data collection; much of the US data come from the ACS NQOL-CG, which samples cancer survivors identified through a national cancer registry. The task of gathering basic data concerning caregivers of cancer patients is beyond the capabilities of an individual research team. Thus, a combined effort of national and international cancer registries may be useful and may facilitate survey efforts in Europe. Data coming from such surveys provide 1 basis for decisions made by policy makers and eventually may facilitate collaborative research between the 2 continents.

There is also a lack of data concerning specific populations (eg minorities) in the United States and in northern and eastern European countries. Strategic decisions by policy makers may help to channel appropriate funding and resources for such studies. Data are lacking both in Europe and in the United States concerning long-term adaptation of disease-free cancer survivors and their caregivers. Although there is evidence that long-term cancer survivors and their caregivers adapt well, it remains important to learn whether caregivers cope with residual physical or emotional consequences. There is also a need for more studies in both the United States and Europe concerning caregiving for patients with progressive disease or at the end of life, and more studies are needed on cultural differences regarding variations in family structure and caregivers' coping, burdens, and outcomes. Such studies also may have implications for understanding resilience and protective factors and how interventions can build on positive aspects of adjustment and coping. In conclusion, international and cross-cultural collaborations and comparisons will provide a better understanding of the basic principles of the cancer experience for survivors and caregivers.

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