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Physical Well-Being of Oncology Caregivers: An Important Quality of Life Domain

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Abstract

OBJECTIVES—To provide an overview of research and practice related to the physical well-being of oncology caregivers.

DATA SOURCES—Literature retrieved through the PUBMED and CINAHL databases.

CONCLUSION—Caregivers play an important role in supporting people with cancer at every stage of the illness trajectory. Because caregiving is inherently stressful, caregivers should be routinely included in the assessment and treatment of patients with cancer.

IMPLICATIONS FOR NURSING PRACTICE—Oncology nurses are uniquely positioned to play a vital role in recognizing caregiver strain and intervening to break the cycle of unremitting physical and psychosocial burden.

Keywords

Caregiver burden; physical well-being; adverse physical outcomes

Physical well-being is an important component of oncology caregivers' quality of life. Physical well-being refers to physical functioning, fatigue, sleep quality, health problems and self-care behaviors such as exercise, nutrition, recreational activities, rest and sleep. Physical well-being can be influenced by caregivers' health status and health-related behaviors. Caregivers' health status is initially similar to that of the normal population. Over time, caregivers report more problems as the physical demands of caregiving take their toll and the needs of the ill person take center stage. Eventually, over half of family caregivers report their own health problems, mainly in the form of heart problems, hypertension and arthritis (1).

Caregiver burden exists at every point along the illness trajectory, including diagnosis, survivorship, death, and bereavement. Because physical well-being is so closely associated with the medical condition of the patient and the associated symptom burden, this is not a static domain but rather, one that should be assessed and reassessed over time. As the needs and symptoms of the cancer patient fluctuate, so do the needs and well-being of the

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caregiver. Generally speaking, caregivers should not be viewed as incidental to the cancer patient. Instead, caregivers should be included in routine assessment and care planning, explicitly and continuously.

This article will focus on the physical well-being of oncology caregivers, the adverse physical outcomes associated with caregiving, methods for assessing physical well-being of caregivers, the range of interventions available to manage caregivers' physical well-being, and the influence of cultural and linguistic factors.

Adverse Physical Outcomes

In order to understand the adverse physical outcomes associated with oncology caregiving, it is useful to define the nature of physical tasks that caregivers are expected to perform. Caregivers assist cancer patients with basic activities of daily living including eating, dressing, bathing, shaving and toileting. Caregivers assist patients with instrumental activities of daily living such as household tasks, cooking, shopping, running errands, obtaining medications; coordinating appointments, and providing transportation. Caregivers also provide less visible, but no less valuable physical tasks such as moving furniture, helping patients to maneuver transfers, such as moving from bed to chair, and managing paperwork, filing insurance forms and collecting prescription medications from the pharmacy (2).

As outpatient cancer treatment has moved from the hospital setting to the community, caregivers have increasingly been called upon to perform complex medical procedures at home. Since the 1980's, the US health care system has been characterized by the tendency to discharge cancer patients and others 'quicker and sicker.' This has shifted the core of responsibilities to the caregiver in the home setting. Such tasks as dispensing medication, changing medication patches, monitoring symptoms and managing prescription medication previously fell within the realm of home care nurses, but are commonly performed by family caregivers today (3).

Caregivers also take on the role of informal case managers by reorganizing the home environment, hiring and managing home care personnel, managing medical emergencies and coordinating visits to the hospital and doctor's office (4). These duties can disrupt caregivers' normal routines and as a whole, exact a physical toll on family caregivers.

The physical impact of caregiving is closely associated with the physical tasks that caregivers are expected to perform. As the symptom burden increases for the person with cancer, so too does the caregiver experience an increase in physical demands. Changes in role functioning are common, as progressing disease requires that the caregiver assume additional responsibilities once performed by the person with cancer.

Caregiver burden, distress and quality of life have been closely linked with the cancer patients' physical health in numerous studies. As the patient deteriorates, caregiver quality of life worsens, with burden reaching its peak during the terminal phase. Illness-related variables thought to be associated with caregiver well-being include stage of cancer, extent of patient disability, higher personal care needs of the patient, lack of patient mobility, patient dependency in instrumental activities, pain and functional impairment (5). As expected, living with the patient is associated with higher impairment in the physical well-being of oncology caregivers, because live-in caregivers tend to provide more physical care to the ill person with less opportunities for respite. Caregivers also tend to become increasingly distressed as they bear witness to the patient's suffering at the end of life, and the patient and caregiver become socially isolated.

In a typical prospective, descriptive observational study of 60 patients with advanced cancer and their caregivers, poor sleep was a frequent complaint for 47% of patients and 42% of caregivers. Sleep fragmentation was high in both groups. In addition, poor sleep was significantly related to higher anxiety in caregivers and pain in patients (6). In a descriptive, cross-sectional study of 68 female caregivers of patients with prostate, lung, or brain cancer, women were categorized as active or inactive based on self-report ratings and an objective measure using a wrist actigraph. Caregivers were asked a question about daytime physical activity and their responses were coded as: (a) no activity, (b) basic activity (light housekeeping, running errands), (c) mild exercise (walking, stretching), (d) moderate exercise (heavy housework, gardening), or (e) strenuous exercise (jogging, swimming). Based on their answers, caregivers were categorized into the active or inactive groups. Inactive women had a higher number of co-morbid conditions, lower levels of attentional function, less sleep time, longer sleep onset latency, and higher percentage of daytime sleep than women in the active group (7).

Generally speaking, caregiving is associated with negative physical health consequences such as fatigue, pain, sleep problems, impaired cognitive function and burnout. Caregivers report a loss of physical strength, loss of appetite and loss of weight (8). Physical stress cannot be separated from other quality of life domains, and a link has been reported between physical well-being, anxiety, depression and general health. In a study of 1635 long-term caregivers of cancer survivors, over half of caregivers reported health problems three and half years after diagnosis. Specific health problems included heart disease, hypertension and arthritis (9).

In a frequently cited, prospective population-based cohort study, elderly spouses living with the patient and experiencing caregiver strain were found to have an increased mortality risk of 63% within five years. The study concluded that caregiver strain was an independent risk factor for caregiver mortality. In seeking to explain this startling finding, the authors cited lack of time for caregivers to rest, lack of rest when caregivers became ill, and lower self-reported health care behaviors as contributing factors. The study findings suggest that caregivers paid the ultimate price by sacrificing their lives (10). In a more recent, large prospective study using a subset from the Nurses' Health Study cohort, Lee and Colditz found an association between caregiver burden and coronary heart disease. Providing nine or more hours of caregiving time to a disabled or ill spouse each week almost doubled the risk of coronary artery disease among the women studied. Caregiving for parents and other relatives did not have the same effect, suggesting that all caregiving is not equal, and caregiving for a spouse may be inherently more severe and therefore more physically stressful (11).

In seeking a causal relationship link between physical strain and caregiver health, Swedish researchers undertook a 35-year longitudinal population study, and reported a link between stress in midlife and increased risk for dementia among caregivers. This suggests that neurobiological mechanisms may result in structural and functional damage to the hippocampus, development of hypertension, and increasing levels of glucocorticoid hormones (12). In a small study involving caregivers of adults with glioblastoma, the authors reported a significant relationship between caregivers' psychological distress and measurement of their hormonal and inflammatory markers (13). Early recognition of and intervention for oncology caregivers' physical strain is therefore important in preventing the onset of major health problems for caregivers.

Assessment of Caregivers' Physical Well-being

Caregivers' reactions to care situations are multidimensional. Assessment is key to identify family problems, caregivers at risk because of their own demographic, social or medical issues, and caregivers who need additional services. Caregivers reporting higher strain tend to be older caregivers with their own concomitant health limitations, caregivers of lower socioeconomic backgrounds living in neighborhoods with poor infrastructure support, and caregivers from families with high rates of psychological or relational dysfunction. A useful conceptual model developed by McMillan and colleagues suggests that caregivers' problems can be divided into three major categories: problems specific to caregiving tasks, problems related to patient symptoms, and problems related to the broad impact of caregiving on their lives (14). For these reasons, screening tools that assess objective and subjective burden are optimal in measuring caregivers' well-being.

All care tasks are not equal, nor are they experienced by caregivers in the same way. Objective measures of caregiver burden assess the number of caregiving hours provided, the number of physical tasks the caregiver performs for the patient, and the nature of those tasks. The Activities of Daily Living Scale (ADL) measures the degree of help needed by the cancer patient for such activities as eating, bathing, and dressing (15). Measurement of the instrumental activities of daily living (IADL) is useful to assess the amount of time the oncology caregiver spends helping with shopping, housework, finances, medication management and other instrumental tasks (16). Although both sets of caregiver tasks are time-consuming and physically taxing, caregivers generally experience the personal care tasks as more stressful.

Caregiver burden in these areas can be ameliorated by support in the form of practical help in the home, from both formal and informal sources. Help with the intimate care of feeding, washing, toileting and grooming can help the caregiver both practically and physically. Caregivers who can afford to purchase such services can hire outside help to assist the patient and alleviate some physical strain. Help with the more practical activities of making meals, managing household tasks and transporting the patient to and from medical appointments can provide caregivers with both social and emotional support. These activities can be shared by members of the caregivers' social network, including extended family members, friends and neighbors.

Because caregivers are individuals with unique personalities and circumstances, their subjective reactions to the caregiving situation are vitally important in predicting caregiver burden. Subjective measures of caregiver burden examine the oncology caregivers' subjective reaction to caregiving as well as the resulting emotional distress. The Caregiver Quality of Life Index-Cancer is a 35-item self-report questionnaire with subscales for mental health and physical health of caregivers (17). Subjective measures are more abundant in the literature, and include the Caregiver Strain Index (18); the Caregiver Reaction Assessment (CRA) (19) the Brief Assessment Scale for Caregivers (20) and general measures of caregiver anxiety and depression.

Assessment tools specifically designed to measure caregivers' physical well-being include the Pittsburgh Sleep Quality Index – sleep (21); the General Health Questionnaire GHQ-28 – health subscale (22); the Memorial Symptom Assessment Scale adapted for caregivers - burden of cancer symptoms (23); and the Caregiver Demands Scale, subscale for caregiving task burden and mastery (24). These tools can be easily administered to capture a more comprehensive view of the caregivers' quality of life in the domain of physical well-being.

In their review of nursing assessment and interventions designed to reduce caregiver burden, Honea and colleagues recommended the use of multidimensional tools that are valid, reliable and clinically useful (25). Table 1 presents a partial list of assessment tools that can be used to assess the physical well-being of caregivers.

In spite of the availability of these measures and many others, assessment of caregivers' physical well-being remains challenging for several reasons. First, it is difficult to estimate the frequency with which oncology caregivers perform specific physical tasks. There are no reliable prevalence or incidence studies, and conceptualization and measurement of physical activities for caregivers are weak. This makes it difficult to estimate the prevalence of burden in the physical well-being domain. Another challenge lies in trying to separate physical well-being from other quality of life domains. Sometimes physical symptoms such as fatigue and insomnia are confused with symptoms of depression, or used by caregivers as a proxy to communicate strain, and it becomes challenging to tease out whether a causal effect is present. While many studies suggest a link or direct relationship between caregiver's fatigue and depression, they stop short of specifying a causal relationship (26).

Second, because caregivers are so focused on the needs of the person with cancer, they may be reluctant to raise their own health issues when meeting with members of the oncology team, making their physical and emotional burden invisible to professionals who can intervene. Finally, assessment of caregivers' well-being is not formally assigned to any one member. Such services are generally unreimbursed, and treatment of caregivers is therefore considered beyond the scope of most teams. In spite of this limitation, managing oncology caregivers' quality of life benefits both the person with cancer as well as the caregiver, and therefore should be seen as within the purview of every member of the oncology team.

Interventions to Help Caregivers Manage Physical Well-being

Interventions exist to help alleviate caregiver burden and improve their physical well-being. An overview of these interventions is presented in Table 2. Because of the significant effect of caregiving on health, these interventions have been tested, but they have produced mixed results.

Generally speaking, interventions designed specifically for oncology caregivers are more effective than interventions designed for patients where secondary caregiver endpoints are added or studied after the fact. A review of palliative care studies concluded that the evidence for interventions improving outcomes for caregivers of patients with cancer was weak (27). For example, in the ENABLE II project, a well-designed, patient-focused palliative care intervention was shown to improve cancer patients' quality of life, reduce their symptom burden and lower their depressed mood compared to usual care. Yet the intervention did not have the expected beneficial effect on the burden of the 198 caregivers who participated (28). Similarly, in several other studies, effective palliative care interventions for patients with cancer failed to show improvements in caregiver outcomes (29,30). These findings suggest that interventions focused primarily on reducing patient suffering do not always benefit caregiver outcomes. Some promising results have been reported for oncology caregivers who have been the recipients of education, skills training, home care, family meetings, specialist-level palliative care and early referral to hospice. These are described below.

Education

Education and information have been shown to be effective in reducing uncertainty and helplessness for oncology patients. Information can help normalize the caregiver experience and enhance a sense of control as caregivers learn what to expect during the illness course. Caregivers report the need for information about the disease, symptom management, the disease course for the specific type of cancer, and what to expect in terms of prognosis (30).

Caregivers generally prefer to receive such information in person as early as possible during the disease course. However, the studies on caregiver education are mainly descriptive in nature, with important methodological flaws, especially in delineating outcome variables. In general, education for caregivers has lagged behind education for cancer patients.

Psychotherapy is designed to enhance morale, self-esteem, coping, sense of control, and reduce anxiety and depression. Models include individual, couple, and group psychotherapy. Psychotherapy is versatile, in that the intervention can be specifically tailored to the needs of the caregiver and provided in settings such as the hospital, office, home, or by phone. Psychotherapy is likely to be effective in reducing caregiver burden by challenging negative thoughts and developing problem-solving skills. Based on the psychotherapy literature, better outcomes would be predicted for face-to-face and group psychotherapy, a higher dose involving longer intervention hours, more sessions and therapy for caregivers alone. Although no specific studies could be identified that used psychotherapy to promote physical well-being among oncology caregivers, it is likely that time away from caregiving duties coupled with support and problem-solving advice could improve the physical well-being of oncology caregivers.

Psychoeducation

Psychoeducation programs are designed to provide structured education with a combination of education and support for caregivers. Most psychoeducation programs use trained leaders and the focus is primarily on the patient’s disease, with caregiver endpoints considered secondary. In a partner-guided, pain management training program, oncology caregivers were taught to help patients control pain and other symptoms. The intervention was associated with improved patient outcomes as well as significantly higher ratings in caregiver self-efficacy (31). Replicating this type of psychoeducational program tailored to caregivers could be a promising area of future study.

Skills training

Skills training programs teach both patients and caregivers a new set of skills to increase coping, and decrease helplessness. Through skills training programs, caregivers are taught specific problem solving activities related to cancer, such as management of treatment-related symptoms and other caregiving tasks. Caregivers are also taught strategies to manage anxiety and depression, which are commonly reported caregiver symptoms. A recent meta-analysis analyzed 29 randomized controlled trials for oncology caregivers. Most of the interventions were designed to address patient care. Training was delivered to patients and caregivers jointly. Skills training was shown to have a significant, positive effect on caregivers’ quality of life. Specific improvement was noted in the caregivers’ improved illness appraisal; expanded coping resources; additional sense of confidence; and enhanced family relationships. These gains were reported even within the difficult environment of hospice (32).

Family Meeting

The Family Meeting is considered by some to be the ideal forum for eliciting caregiver concerns, providing clear information about treatment, facilitating end-of-life care decisions, and avoiding inappropriate treatment. Well-organized family meetings promote a safe setting for caregivers to process emotions and receive validation for their concerns.

Most studies on the effectiveness of the family meeting have been done in the ICU setting although the family meeting is an increasingly popular clinical tool in palliative care and hospice. There is limited data regarding the definition, goals, format and outcomes of the family meeting, and an absence of data on caregivers’ physical well-being as an endpoint.

The possibility exists that changing the goals of care or moving the patient to the home setting could increase, rather than decrease physical responsibilities for oncology caregivers. However, common sense suggests that the family meeting can be extremely helpful for oncology caregivers especially if the agenda covers both practical and psychosocial issues, more than one family members is present, consensus is reached, and different professional disciplines provide expertise that covers both the physical and psychosocial aspects of caregiving. The use of the family meeting to alleviate caregiver burden may be another fruitful area for future inquiry (33).

Sleep

Lack of sleep is a frequent complaint of oncology caregivers. Sleep may be interrupted if the caregiver lives with the patient, or if the caregiver has insomnia as a result of anxiety and depression. An experimental design was used to test the feasibility and effectiveness of the CAregiver Sleep Intervention (CASI) for caregivers of patients with advanced cancer. The program included stimulus control, relaxation, cognitive therapy, and sleep hygiene elements. CASI appeared to be effective in improving sleep quality and depressive symptoms in caregivers (21).

Home care

For cancer patients, most of the last year of life is spent at home. A comprehensive review of 105 qualitative research studies (1998–2008) on home-based caregiving at the end of life found that primary caregivers played a key role in achieving home death (34). In a companion review of 123 quantitative research studies on home-based caregiving, practical caregiver burden was reported in many studies. Physical demands included the need for respite and help with household tasks. The physical health impact of home-based caregiving was sleep disturbance, insomnia and fatigue (35). Generally speaking, home care nursing services for the cancer patient seem to confer benefit for both the person who is ill as well as the family caregiver. This seems to hold true for both generalized and specialized home care programs.

Palliative care and hospice

Specialist level palliative care and hospice have been shown to be associated with improved symptom management for patients, the short-term outcome of meeting caregivers' practical and emotional needs, and the long-term outcome of promoting healthier bereavement after death (36). In a multisite study of 332 patient-caregiver dyads, end-of-life discussions led to lower rates of ventilation, resuscitation, ICU admission and earlier hospice referral. In addition, earlier, longer hospice enrollment was associated with less caregiver depression and higher satisfaction. In a recent meta-analysis of randomized trials, home hospice deaths were associated with less psychiatric illness and post-traumatic stress disorder in bereaved caregivers compared with ICU and hospital deaths (37). Whether palliative care and hospice alleviate the physical burden of oncology caregivers is currently unknown.

Influence of Cultural and Linguistic Factors

Cultural factors can influence the relationship of families with the health care system as well as their willingness to use outside help. Table 3 summarizes a range of cultural barriers and interventions to improve oncology caregivers' physical well-being among Chinese Immigrants. Lower education, lower socioeconomic status, and lack of insurance are correlated with greater likelihood of presenting with higher disease stage, higher likelihood of delays in follow-up treatment, less access to care and greater caregiver burden (38). Immigrants have lower rates of service use after hospitalization, because linguistic barriers can lead to confusion by caregivers after hospital discharge. Cultural differences between professionals and patients can lead to symptom underestimation. In one study, pain severity was underestimated by physicians for 74% of African American patients. (39). This is significant because higher symptom burden often translates into higher caregiver burden Although many treatment centers make effective use of medical interpreters, it is often more convenient to use family members instead of trained interpreters. The use of untrained family members to communicate complex medical information and follow up guidelines can lead to omissions and mistakes, which can in turn compromise home care and treatment follow-up plans.

Caregivers with limited financial and social resources cannot purchase home care and transportation services to alleviate stressful care tasks, and family members and friends may be unavailable to help due to their own work and family obligations. Minority patients and caregivers may live in poor neighborhoods with limited supplies of medication, especially controlled substances, and limited access to social service agencies. These factors can add to physical strain for oncology caregivers.

A 2005 meta-analysis of 116 empirical studies compared Asian caregivers with non-Hispanic White, African-American, and Hispanic caregivers. There were three significant conclusions from the study: First, Asian caregivers provided a significantly higher number of caregiving tasks than other groups. Second, Asian caregivers provided more caregiving hours than other caregivers. Third, Asian caregivers used lower levels of formal support services than the other groups (40).

Cultural norms may account for some of these differences. Lack of acculturation can result in poor knowledge about available services. Filial piety is a popular concept in Chinese culture dating back to Confucian times. Filial piety suggests that respect and assistance for parents is a virtue above all else. This belief promotes and rewards intergenerational assistance through which children of all ages are expected to care for their parents. From a clinical standpoint, this cultural tenet is both a benefit and a challenge, because while caregiving by a family member is often the stated preference of patients with cancer, such strongly held cultural beliefs can also result in a general mistrust of outside service providers. Insularity, cultural pride, taboos against truth-telling and superstition related to the use of such terminology as ‘cancer’ and ‘death’ can undermine professional expectations from oncology staff and lead to outright refusal of home care, palliative care and hospice services by caregivers. These factors can result in underutilization of services and higher caregiver strain in the area of physical well-being among Chinese families.

What is the State of the Science?

Robust evidence regarding the causal relationships between predictor variables and caregiver outcomes is lacking. It is unclear whether physical burden is a predictor, mediator or outcome. Methodological challenges in studies of home-based caregiving include small, non-random, convenience samples, reliance on descriptive and bivariate analyses, lack of longitudinal research and the lack of theoretical frameworks. Individual studies have yielded insufficient power to draw definitive conclusions. The small sample size, lack of specificity in key definitions, cross-sectional studies, paucity of valid and reliable instruments, and lack of conceptual framework have hampered progress in measuring caregivers’ physical well-being, and meta analyses cannot compensate for these limitations.

Looking ahead, the time is ripe to think outside of the box and think creatively about research studies with promising clinical utility. Future studies should focus on dyadic analysis of caregiver-patient units to elucidate the interaction between cancer patients and their caregivers as they relate to quality of life. Studies should target caregivers who may be predisposed to higher physical burden – caregivers who are poor, spousal caregivers,

caregivers who are older, caregivers with their own health issues, caregivers who are disenfranchised by virtue of language or culture, and caregivers who live with the patient – for maximum effect. Studies should target specific and measurable outcome variables, such as reduction in caregiver burden and increase in physical well-being as study endpoints. Clinical programs which have shown early promise should be replicated, such as the successful nurse-led transition coaching programs, though which nurses provide continuity of care through a single point of contact in the hospital and in the community. The use of navigators to help close the quality chasm should be explored so that equal access could be provided for oncology caregivers regardless of background culture and socioeconomic factors.

It is evident that the physical well-being of oncology caregivers has been under-studied. This is both a limitation and an opportunity. More studies are needed to fully characterize the unmet physical needs of caregivers and to develop targeted interventions to meet those needs. Yet at the same time, physical well-being must be understood within the larger context of caregiver burden as a whole, and the inter-relationship between the psychological, social, spiritual and cultural domains of well-being must be sustained.

Oncology caregivers may be at risk for future health and mental health problems if their stress levels are unchecked and they fall under the radar of the oncology team. On the other hand, health care professionals can intervene to break the cycle by including caregivers as a routine part of assessment, and by recommending self-care behaviors. Caregivers' physical strain can be ameliorated by healthy behaviors in the areas of sleep hygiene, physical activity and nutritional status, by providing additional physical and psychosocial support, and by encouraging caregivers to address their own health issues in a timely manner. Only with proactive and comprehensive assessment and treatment can we prevent caregivers of today from becoming patients of tomorrow.

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Table 1

Assessment Tools to Measure Physical Well-Being in Oncology Caregivers

Instrument	**Source**
Activities of Daily Living (ADL)	Katz et al., 1963
Instrumental Activities of Daily Living (IADL)	Lawton and Brody, 1969
Caregiver Quality of Life Index-Cancer (CQOLC) scale	Weitzner et al. 1999
Caregiver Strain Index - Physical	Robinson, J Gerontol., 1983
Caregiver Reaction Assessment - (CRA) Health	Given et al., Res Nurs Health, 1992
Brief Assessment Scale for Caregivers (BASC)	Glajchen et al, 2005
Pittsburgh Sleep Quality Index	Carter, 2002
General Health Questionnaire GHQ-28 - Health	Walsh, Br J Psychiatry, 2007
MSAS adapted - Burden of Cancer Symptoms	Portenoy et al., Eur J Cancer. 1994
Caregiver Demands Scale - Caregiving Task Burden and Mastery	Stetz, Cancer Nurs, 1987

TABLE 2

Interventions to Improve Physical Well-Being for Oncology Caregivers

Intervention	**Target Area**
Education and information	• Disease course • Symptom management • Prognosis • Self-care
Psychotherapy for individuals, couples, groups	• Enhance morale • Improve self-esteem • Enhance coping • Improve sense of control • Reduce anxiety • Lower depression
Psychoeducation	For pain and other symptoms
Skills Training	• Increase coping and problem-solving • Improve confidence • Enhance self-efficacy • Decrease helplessness • Lower anxiety • Decrease depression
Family Meeting	• Promote safe setting to process emotions • Validate caregiver concerns • Provide treatment information • Facilitate end-of-life care decisions
Sleep	Promote sleep hygiene and relaxation
Home care	Help with symptom burden, Provide respite Alleviate fatigue
Specialist level Palliative Care and Hospice	Improve symptom management for patients Help meeting practical needs Promote healthy bereavement

Table 3

Cultural Barriers and Interventions to Improve Oncology Caregivers' Physical Well-Being among Chinese Immigrants

Barrier	Intervention
Filial piety - sense of obligation for children of any age to take care of parents	• Respect family-centered care • Support caregivers' efforts to provide caregiving in the home • Promote shared decision-making through family meetings
Reliance on informal system	Use Chinese-language newspapers and church newsletters to promote community education
Lower rates of home care services	Reframe home care services as routine and expected part of treatment
Limited financial and social resources	Access entitlement programs on behalf of minority and immigrant families
Poor treatment follow up	Provide reminder phone calls, single contact person, free transportation, patient navigator
Language barriers	Use professional translators rather than family members