Self-Management: Enabling and Empowering Patients Living With Cancer as a Chronic Illness

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Abstract

With recent improvements in the early detection, diagnosis, and treatment of cancer, people with cancer are living longer, and their cancer may be managed as a chronic illness. Cancer as a chronic illness places new demands on patients and families to manage their own care, and it challenges old paradigms that oncology’s work is done after treatment. As a chronic illness, however, cancer care occurs on a continuum that stretches from prevention to the end of life, with early detection, diagnosis, treatment, and survivorship in between. In this article, self-management interventions that enable patients and families to participate in managing their care along this continuum are reviewed. Randomized controlled trials of self-management interventions with cancer patients and families in the treatment, survivorship, and end-of-life phases of the cancer care continuum are reviewed, and the Chronic Care Model is presented as a model of care that oncology practices can use to enable and empower patients and families to engage in self-management. It is concluded that the need for a common language with which to speak about self-management and a common set of self-management actions for cancer care notwithstanding, oncology practices can now build strong relationships with their patients and formulate mutually agreed upon care plans that enable and empower patients to care for themselves in the way they prefer. CA Cancer J Clin 2011;61:50–62. ©2011 American Cancer Society.

Introduction

Over the last 2 decades, substantial progress has been made in the early detection, diagnosis, and treatment of cancer. This progress means that more and more patients may be freed of their cancer. The disease of yet others may be managed as a chronic illness requiring long-term surveillance and, in some cases, treatment. With ongoing survivorship and current shifts in insurance coverage that limit time with providers, patients are expected to assume a greater role in managing their follow-up care. Because of this, the management of care overlaps among patients, providers, and health care systems. The complexities of these overlaps demand new models of care.

The Institute of Medicine (IOM)’s 2005 report, From Cancer Patient to Cancer Survivor: Lost in Transition,1 identified 6 major phases on the cancer care continuum: prevention, early detection, diagnosis, treatment, survivorship, and end-of-life care. From the IOM’s notion of the cancer care continuum, new models of cancer care need to arise. Changing health care delivery systems in the United States add to this need. New models must enable oncology providers to form partnerships with patients and families, as well as other providers, such as primary care providers (PCPs).

The cancer care continuum is a useful paradigm for planning and testing interventions that improve clinical outcomes and enhance a patient’s quality of life (QOL). However, paradigms do not change easily, especially paradigms in which providers have historically told patients what to do and expect patients to follow their orders.

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The notion of the cancer care continuum challenges this paternalistic paradigm. Providers, patients, and families need to consider that now care is long term, extending beyond an acute phase. This longer term necessitates discussing patients’ short-term and long-term goals and including these goals in action plans to the degree they are medically realistic. This kind of long-term planning requires an ongoing collaborative relationship between patients and providers instead of an acute, prescriptive relationship.

In this article, we explore self-management (SM) as a model of cancer care that involves providers forming partnerships with patients and families. These partnerships enable and empower patients and families to achieve their own goals of care, at all phases along the cancer care continuum. We review evidence from successful randomized clinical trials with cancer patients that incorporate components of SM interventions. We use the Chronic Care Model (CCM) as a paradigm for oncology practices to use to enable and empower patients to engage in SM. Our purpose is to show that by using SM interventions, oncology providers can enable and empower patients and families to care for themselves, in partnership with their providers, across the cancer care continuum in the way they mutually determine.

Self-Management

Definition of SM

The concept of SM has come of age after more than 4 decades of scientific consideration. SM has been variously defined, but all definitions are broader than the mere following of medical advice. For example, Barlow et al defined SM as a person’s ability to manage the symptoms and the consequences of living with a chronic condition, including treatment, physical, social, and lifestyle changes. Lorig and Holman point out that, even if one does not have a chronic condition, it is impossible not to manage one’s health; however, if one does have a chronic illness, SM is a “lifetime task.” Lorig and Holman identify the aim of SM as keeping wellness in one’s psychological foreground. To do this, the person with chronic illness has 3 SM tasks, which were originally described by Corbin and Strauss: managing the medical aspects of the illness; managing life roles, including changes in roles brought on by the illness; and managing the psychological consequences of chronic illness. To accomplish these tasks, people with chronic illness need the following core SM skills: problem solving, decision-making, resource utilization, forming partnerships with health care providers, and taking action. In addition to core tasks and skills, SM is defined by its being set within the context of the family, by being a lifelong dynamic process of self-monitoring and self-evaluation, and by involving a perspectival shift from illness to wellness. SM support has been defined by the IOM in its 2003 report, Priority Areas for National Action: Transforming Health Care Quality, as “the systematic provision of education and supportive interventions by health care staff to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting and problem-solving support.”

Based on this review of SM definitions, we understand SM as those tasks that individuals undertake to deal with the medical, role, and emotional management of their health condition(s).

Review of the Literature Regarding SM Interventions in Cancer Care

Over the last 2 decades, a number of intervention studies have demonstrated significant improvements in patient outcomes at different phases on the cancer care continuum. We summarize what we believe are some of the major scientific advances in SM in cancer in the treatment, post-treatment, and end-of-life phases of the cancer care continuum.

For this review, 3 major databases were searched (MEDLINE, Cumulative Index to Nursing and Allied Health Literature [CINAHL], and PubMed) from 1992 through 2007. The terms “self-management interventions,” “illness self-management interventions,” “self-care interventions,” “psychoeducational interventions,” “cognitive-behavioral interventions,” “neoplasm,” “oncology,” and “cancer” were entered as keywords. Results were limited to English language intervention studies, and an abstract review was conducted to further limit the sample to articles that included interventions with adult cancer patients. Thirty-two intervention studies were identified. Of the 32 intervention studies, 10 either mixed or did not report phase of treatment, did not include a description of the intervention, or were not randomized; these studies were excluded. Of the remaining 22...
studies, 6 studies were coauthored by the investigators included in this review; only one example of their work was included. The remaining 16 studies reviewed appear in Table 1.10-25 We reviewed these studies to identify common intervention components that are conceptually linked or overlap with SM and have consistent outcomes. We present these results in line with phases of the cancer care continuum: SM during treatment, SM during the post-treatment phase, and SM at the end of life.

**SM During Treatment**

When cancer treatments such as chemotherapy and radiotherapy proved to be safe enough so as to

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### TABLE 1. Self-Management and Cancer Intervention Studies

| STUDY              | PHASE   | SAMPLE AND SETTING                                                                 | INTERVENTION                                                                                     | SELF-MANAGEMENT COMPONENT                                                                 | CONCLUSIONS                                                                                       |
|--------------------|---------|-----------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|
| Dodd & Miaskowski  | Treatment | 127 adult oncology patients who received chemotherapy with potential for mucositis, N&V, and infection treated at an outpatient clinic | PRO-SELF Program Written information Log to write symptoms and self-care strategies Audio-taped nurse assistance from home with telephone calls | Self-care practices performed on one’s behalf to maintain life, health, and well-being       | No difference in severity of symptoms but patients in intervention group reported greater satisfaction |
| Miaskowski         | Treatment | 174 adult oncology patients with pain and bone metastasis treated at 7 outpatient clinics | PRO-SELF Pain Control Program Nurse home visits and follow-up telephone calls Taught how to use pill box, manage pain, and communicate with physician about unmet pain control | Psychoeducational program that includes nurse coaching within a self-care framework             | Pain intensity scores decreased significantly in the intervention group Intervention group had more appropriate pain medications prescribed |
| Braden             | Treatment | 139 women with breast cancer undergoing treatment at outpatient sites (regional cancer left, private practice settings, and health maintenance organizations) | SHIP Six 90-min classes offered in a self-help course 6-wk uncertainty management telephone contact | Self-care and self-help, uncertainty management                                              | Participation in SHIP intervention resulted in higher levels of self-care, self-help, psychological adjustment, and confidence in cancer knowledge |
| Badger             | Treatment | 169 women with breast cancer with known depression                                  | SHIP with 5 treatment arms: classes alone, telephone contact alone, independent study alone, combined classes and telephone, and combined independent study and telephone over 6 wk | Self-care and self-help, uncertainty management                                              | The intervention significantly reduced women’s fatigue, pain, and nausea                           |
| McCorkle           | Treatment | 375 discharged older cancer patients after surgery and adjuvant treatment at a comprehensive cancer center | SNIP delivered by an oncology APN: home visits and telephone calls over 4 wk                     | Monitoring, teaching, counseling, and skills training to manage effects of surgery and cancer treatments for patient and caregiver | Increased survival in intervention group                                                      |
| McCorkle           | Treatment | 145 women with gynecological malignancies treated with surgery and adjuvant therapies at a comprehensive cancer center | SNIP delivered by an oncology APN and psychiatric consultation liaison nurse: home visits and telephone calls over 6 mo Use of symptom management guide | Monitoring, teaching, and counseling to help patients manage short-term and long-term physical and psychosocial effects | Uncertainty decreased significantly in the intervention group Significant improvements in symptom distress, and mental and physical QOL over time in subgroup of women highly distressed |
| Given              | Treatment | 237 patients with solid tumors receiving chemotherapy as well as their caregivers at 2 comprehensive cancer centers and 4 community cancer centers | Intervention delivered by nurse/10 contacts for 20 wk Patient and nurse identified problems together in all dimensions, self-care strategies employed to address 15 prevalent symptoms | Self-management information, problem solving, communication with provider, and counseling and support | Decreased symptom severity for intervention patients who entered the trial with higher severity scores |
### TABLE 1. (Continued)

| STUDY          | PHASE    | SAMPLE AND SETTING                                                                 | INTERVENTION                                                                 | SELF-MANAGEMENT COMPONENT | CONCLUSIONS                                                                 |
|----------------|----------|------------------------------------------------------------------------------------|-----------------------------------------------------------------------------|----------------------------|-----------------------------------------------------------------------------|
| Sikorski 2007  | Treatment| 435 cancer patients with solid tumors treated with chemotherapy at both community and comprehensive cancer centers | Delivered by an interactive/automated telephone response system vs a nurse-assisted symptom management protocol over 8 wk Use of symptom management guide | Teaching, prescription of self-management strategies for 17 symptoms, communication with provider, and counseling and support | Both interventions produced a significant reduction in symptom severity over baseline |
| Lewis 2006     | Treatment| Women with early stage breast cancer who had a school-aged child between ages 8 and 12 y from medical practices of surgeons, medical oncologists, and radiologists | The Enhancing Connections Program Five 1-h educational counseling sessions delivered at 2-wk intervals and booklets for mother to use with her child | Mother’s self-help to manage own emotions, helping mother to observe and respond to child’s behaviors, mother’s self-monitoring and self-reflection to enhance self-efficacy | Significant improvements in mother’s depressed mood, anxiety, and self-confidence and a significant decrease in child’s behavioral problems |
| Northouse 2005 | Treatment| 134 patients with recurrent breast cancer and their family caregivers from 4 large oncology centers | The FOCUS Program Initial phase: 2 home visits by a nurse every mo Booster phase: 2 prearranged follow-up telephone calls | Encourage open communication, optimistic thinking, healthy coping and lifestyle behaviors, and teach self-care strategies to manage symptoms | Patients in the family intervention reported significantly less hopelessness and less negative appraisal of illness and the family caregivers reported significantly less negative appraisal of caregiving |
| Stanton 2005   | Survivorship | 558 women with breast cancer treated at 3 academic medical centers from collaborating surgical and medical oncologists | MBC Study Peer-modeling videotape plus educational booklet or videotape plus brief counseling and educational booklet vs a control | Information described effective ways to cope with breast cancer Intervention groups developed goal-oriented action plans | Significant improvement noted in energy/fatigue at 6 mo relative to control group, education helped prepare patients for re-entry after treatment by lessening cancer-related distress |
| Cimprich 2005  | Survivorship | 25 women with breast cancer from 2 settings: an academic treatment setting and a community oncology treatment clinic | Preliminary test of "Taking Charge" intervention 4 intervention contacts and 2 small group and 2 individual counseling sessions | Informational aspects, self-regulation approach Explore and adopt relevant management techniques, develop goals | Participant rated program as having high utility in dealing with concerns |
| Damush 2006    | Survivorship | 34 women with breast cancer treated at 2 university cancer treatment centers | Single group with pre-test, post-test 3 wk self-management sessions 3 follow-up counseling telephone calls | Increase self-efficacy and problem-solving skills to change behavior surrounding physical activity and social support | Reduced perceived exercise barriers and increased the wk frequency and duration of physical activity |
| McCorkle 1989  | End-of-life care | 166 patients with advanced lung cancer from a major cancer center | Three nursing groups: specialized multidisciplinary oncology home care group, standard home care group, and office group Scheduled home care visits over 3 mo | Self-management of physical and emotional symptoms during decline in condition | Two home care groups reported less distress and greater independence 6 wk longer than the office group |
| Rummans 2006   | End-of-life care | 103 participants with advanced cancer who were receiving palliative radiotherapy | Eight 90-min structured multidisciplinary sessions over 3 wk and standardized manual that addressed QOL domains (cognitive, emotional, physical, social, and spiritual) | Education and cognitive behavioral strategies aimed at improving coping, taking charge, lifestyle changes, stress management, goal setting, spiritual distress, and conditioning exercises | Intervention patients had significant improvement in QOL and control patients experienced a significant decrease in QOL |
| Bakitas 2009   | End-of-life care | 322 patients with advanced cancer receiving cancer treatment at a rural national comprehensive cancer center | ENABLE Project delivered by palliative certified APNs over 4 wk and mo follow-up sessions until death | Education, case management to encourage patient activation to engage in open communication with family and health care team, self-management, and empowerment | Intervention group reported higher QOL, lower symptom intensity, and lower depressed mood |

N&V indicates nausea and vomiting; SHIP, Self-Help Intervention Project; SNIP, Standardized nursing intervention protocol; APN, advanced practice nurse; FOCUS, family involvement, optimistic attitude, coping, effectiveness, uncertainty reduction, and symptom management; MBC, Moving Beyond Breast Cancer; QOL, quality of life; ENABLE, Educate, Nurture, Advise, Before Life Ends.
require less intensive monitoring by health care professionals, the outpatient clinic replaced the hospital as the delivery setting. As a result, the expectation for cancer patients to participate in their care and manage treatment effects between visits emerged as a demand that could no longer be ignored by oncology health care professionals. Therefore, initial studies focused on interventions that encourage patients to take active roles in preventing or managing chemotherapy-related or disease-related symptoms. The PRO-SELF Program, for example, was designed by oncology nurse researchers as a self-care intervention for common symptoms associated with chemotherapy (eg, symptoms such as oral mucositis, nausea and vomiting, and infection). Although the initial intervention did not demonstrate a statistically significant difference between the experimental and control groups in reducing symptom severity, participants reported benefit. The PRO-SELF Program was tested again on cancer patients’ unmet pain needs. The PRO-SELF Pain Control Program (PSPC) intervention supported patients in their management of cancer-related bone pain by encouraging them to assess their pain themselves, to use appropriate analgesics, and to dose themselves around the clock to keep pain from worsening. Participants in the experimental arm of the PSPC reported significantly less pain intensity than control participants ($P \leq .001$) and used more appropriate pain medications than control group participants over time.\(^{11}\)

Researchers have recognized the role of SM in managing the psychological, emotional, and existential consequences of the cancer treatment experience. To address these issues, Braden et al\(^{12}\) tested the effects of a self-help intervention protocol (SHIP) in women with breast cancer undergoing adjuvant treatment, the purpose of which was to increase knowledge about cancer, improve problem solving, redirect negative thinking, promote effective communication with health care professionals, and minimize uncertainty. Their study found that participants demonstrated increased levels of self-care, self-help, psychological adjustment, and confidence in cancer knowledge ($P \leq .003$).

Although the SHIP intervention was not intentionally designed to decrease disease and treatment side effects, Badger et al\(^{13}\) hypothesized the SHIP problem-solving and self-help skill components could potentially alter symptom burden. As a result, the investigators modified their intervention to include content regarding early recognition and self-management of disabling symptoms. This modified intervention resulted in significant improvement in fatigue, pain, and nausea ($P = .04$) experienced by those women with known depression undergoing treatment of breast cancer.

The debilitating effect of cancer surgery on function and other parameters of QOL, along with the need to prepare for additional cancer treatments, prompted studies to address support for patients and families after surgery.\(^{14}\) Previously, we\(^{15}\) examined the effects of a standard nursing intervention protocol (SNIP) delivered by oncology advanced practice nurses (APNs) on older post-surgical cancer patients’ physical, functional, emotional, and psychological recovery in the home setting. The SNIP was comprised of clinical assessments, monitoring of potential complications, and teaching complex skills to patients and families at home in order for them to manage their own care and coordinate resources to meet their ongoing needs. The SNIP increased survival significantly for patients with late-stage disease in the intervention group ($P = .0001$). Eventually, the SNIP was modified to include a tailored intervention for both physical and psychological effects in postsurgical women with gynecologic cancer.\(^{16}\) In addition, the SNIP was extended from 1 month to 6 months to support ongoing skills training and SM of physical and emotional effects in the adjuvant treatment setting along with preparation for postprimary treatment follow-up. For this group of women, the SNIP significantly reduced uncertainty in the intervention group; the intervention subgroup that received additional psychological support showed significant improvement in mental and physical QOL ($P = .0001$), less uncertainty ($P = .0023$), and less symptom distress ($P = .0001$).\(^{16}\)

The role of nurses in delivering SM interventions with positive outcomes has been confirmed in other studies as well. For example, Given et al\(^{17}\) built on previous psychoeducational and behavioral interventions for specific cancers and specific symptoms to develop a nurse-delivered intervention to reduce the severity of 15 prevalent physical and psychological symptoms for patients with a variety of solid tumors receiving chemotherapy for the first time. In addition to counseling and support, nurses delivered
standardized information and used problem-solving approaches for symptom SM. The study found decreased symptom severity for patients who entered the intervention with higher symptom severity \((P = .01)\).17

The Given et al17 intervention was later modified to compare a nurse-assisted symptom management protocol (NASM) with an automated telephone symptom management protocol (ATSM). The NASM intervention also introduced a detailed evidence-based manual, the Symptom Management Toolkit (SMT). The SMT contained strategies patients could use at home to prevent or manage common symptoms associated with chemotherapy. Both the NASM and ATSM interventions resulted in a clinically significant reduction in symptom severity. The effect sizes were basically identical (0.56 for the NASM and 0.59 for the ATSM).18 The effect sizes were just above the median in the Cohen classification, thus yielding clinically significant improvement over baseline.

Recognizing the vulnerabilities of families and caregivers during the cancer treatment phase of the cancer care continuum, the Enhancing Connections (EC) Program19 was designed to deal with the distress experienced by mothers with breast cancer and the negative adjustment of their school-aged children. Specifically, the EC Program supported mothers by helping them gain confidence to parent their children with positive attitudes and behaviors, thereby encouraging positive coping skills in their children. The EC Program also helped study participants to deal with their depressed mood and anxieties. Participants’ pretest and post-test measures of depression \((P = .03)\), anxiety \((P = .02)\), and self-confidence \((P = .006)\) improved significantly. Mothers and fathers also reported significant decreases in their children’s behavioral problems. The children themselves reported less cancer-related worry \((P = .04)\).

In another study, the FOCUS (family involvement, optimistic attitude, coping, effectiveness, uncertainty reduction, and symptom management) study20 tested whether women with advanced breast cancer and their family caregivers reported better QOL compared with other patients and families not participating in FOCUS. In the FOCUS intervention, a nurse guided, supported, and taught patients and their families more effective coping skills, such as open and effective communication, ways to deal with uncertainty to maintain hope, and strategies to deal with common symptoms. Women who participated in the FOCUS intervention reported significantly less hopelessness \((P = .002)\) and less negative appraisal \((P = .04)\) than women who did not receive the intervention, and family caregivers reported significantly less negative appraisal \((P = .04)\) associated with caregiving.

**SM During the Post-Treatment Phase**

Evidence suggests that SM strategies may benefit patients as they transition from the end of primary treatment to survivorship. The demands of survivorship include regularly participating in routine but less frequent oncology visits, understanding the signs and symptoms of disease recurrence, adjusting to and managing the late-term effects of cancer and cancer treatment, re-establishing normal routines and social roles, and dealing with residual psychological distress to minimize negative impact on QOL and relationships.

Stanton et al21 and Ganz et al26 conducted a multisite randomized clinical trial of psychoeducational interventions in a cohort of postsurgical breast cancer patients. The intervention was designed to assist breast cancer patients with improving fatigue and energy and cancer-specific distress. Energy and fatigue of the Short Form (SF)-36 Health Survey vitality subscale improved in the intervention group \((P = .018)\). The group who received the education component reported significantly less cancer-related distress \((P = .037)\) as measured by the SF-36 mental health subscale and the Center for Epidemiologic Studies Depression Scale (CESD) at 6 months.

The period after primary treatment carries with it its own set of psychosocial and QOL adjustments. The aim of the Taking CHARGE intervention,22 based on principles inherent in SM, was to help a group of women with breast cancer address and overcome concerns associated with the end of primary treatment and concerns about life experiences in the post-treatment phase. Process evaluations of the program revealed that participants rated it as having high utility in dealing with their post-treatment concerns.

Evidence is also growing about the importance of a healthy lifestyle during the post-treatment phase. Studies testing health-oriented lifestyle modifications during the post-treatment period have primarily focused on cancers with good prognoses and
extended survival. One exception is the study by Damush et al.\textsuperscript{23} Their study tested the effects of an SM physical activity program on older breast cancer survivors. The physical activity program successfully reduced participants’ perceived barriers to physical activity ($P < .02$). Moreover, the older women in the study increased their weekly frequency and duration of physical activity ($P < .04$).

**SM at the End of Life**

The needs of patients and families living with advanced cancer intensify as death grows closer. The physical changes associated with a disease that is unable to be controlled results in loss of the capacity to manage aspects of medical regimens and activities of daily living. In addition, the stress of living in this context of ongoing loss brings new challenges, such as when to turn over illness and general life responsibilities to others and whether to talk about or act on emotional and spiritual concerns. Health care professionals and researchers recognize that the inevitable increasing symptom burden does not preclude patients acting on their own behalf in terms of maintaining a reasonable QOL, maintaining their current level of independence, and obtaining support for their preferences about their dying course and letting go. For example, we previously conducted a randomized clinical trial with 3 intervention arms testing the effect of a specialized oncology home care and usual office care on the QOL and level of dependency of individuals with progressive lung cancer.\textsuperscript{14} In the specialized oncology home care intervention, oncology APNs counseled and prescribed care around symptoms, physical function, emotional needs, and psychosocial needs. APNs also taught patients and families to manage aspects of their physical, emotional, and social concerns. We found that even in the context of advancing disease, patients in the specialized oncology home care intervention had less distress ($P = .03$) and greater independence ($P = .02$) than participants in the usual care group.

Rummans et al\textsuperscript{24} implemented a structured, multidisciplinary intervention targeting 5 QOL domains (cognitive, emotional, physical, social, and spiritual) in patients with advanced cancer undergoing radiotherapy. Intervention sessions addressed components of SM, including goal setting, taking charge, problem solving, redirecting negative thoughts, building interpersonal relationships, and managing emotional and spiritual responses. Even in the context of advanced cancer, the intervention patients reported stable QOL outcomes by 2 weeks compared with control group patients who experienced a significant decline in QOL at Week 4 ($P = .046$). Furthermore, participants in the intervention group reported similar QOL scores at follow-up 6 months later ($P = .992$).\textsuperscript{24}

For newly diagnosed patients with advanced cancer living in a rural setting, Project ENABLE (Educate, Nurture, Advise, Before Life Ends)\textsuperscript{25} was implemented to test the effects of an APN intervention on QOL, symptom intensity, depression, and use of health care services. The intervention included SM and patient empowerment, with the APN serving as coach and educator. In these roles, the APN facilitated problem solving around symptoms and treatment decisions and helped patients to communicate with their health care team. Results of this study demonstrated higher QOL outcomes ($P = .02$) and lower depressive symptoms ($P = .02$), but a limited decrease in symptom intensity scores ($P = .06$) and health care service use ($P = .14$ for days in the hospital; $P = .53$ for emergency department visits) on the part of intervention patients.

This systematic review suggests that SM interventions among cancer patients positively affect symptom distress, uncertainty, problem solving, communication, and general QOL domains, and potentially survival. These interventions, however, depend on oncology practices organizing themselves and functioning in a way that supports patients and families in their SM efforts.

A variety of interventions and changes to the organization and functioning of medical practice have been proven to help patients meet their needs and to improve care and outcomes across chronic diseases.\textsuperscript{27-30} Based on this evidence, we developed the CCM in the 1990s to help medical practices improve the quality of their care for patients with chronic illness.\textsuperscript{31} We discuss this model so that oncology practices may understand the components necessary to support SM interventions.

**The Chronic Care Model**

The CCM includes the features of a health care system that encourages high-quality care. These features fall into 6 components: SM support, delivery system design, decision support, clinical information systems,
health care organization, and community resources. When put together, they limn the contours of productive interactions between informed, activated patients on the one hand and well-prepared, proactive practice teams on the other.

**Productive Interactions**

Patients’ SM needs are met through productive interactions between patients and families and their practice team. By “productive,” we mean that patients’ needs and goals are systematically and consistently addressed to develop mutually determined care plans. Productive interactions are more likely to occur when patients actively participate and are invested in their own care and are competent, confident managers of their health and illness. To be competent and confident managers, patients must have the relevant information and skills to set priorities and manage their illness. See Table 2 for common needs.

**Enabled and Empowered Patients**

Patients who have the relevant information, skills, and confidence to engage in SM interventions are enabled. Interventions that encourage patients to be involved in their own care enable patients. Such enabling interventions are those through which collaboratively patients and providers identify goals that are important to patients, develop realistic action plans to meet those goals, and identify aspects of the plans that patients can self-manage.

Patients whose concerns, priorities, and resources are considered important enough to be included in the plan of care are empowered. Time-limited courses facilitated by peer or professional leaders and focused on empowering patients to manage their own illness have been shown to improve disease control. However, sustained support focused on assisting patients in managing their own illness may be optimal. Such support is most efficiently provided in the context of ongoing chronic illness care.

Ongoing advice and encouragement from the practice team are important to enable and empower patients. Yet many clinicians have neither the time nor the expertise necessary to train and counsel patients effectively. In cancer care, several randomized trials have demonstrated that clinicians with good communication skills and additional training in counseling methods, such as motivational interviewing or cognitive behavioral therapy, perform these functions well. More recent evidence suggests that individuals with limited clinical training can also be trained to provide the support necessary to enable and empower patients to participate in SM.

Another way to enable and empower patients is to use community-based programs and organizations, which often most effectively meet many of the needs of chronically ill patients. Such needs include transportation, homemaker services, smoking cessation, physical activity, weight control, peer support, caregiver support and respite care, SM training, financial counseling, and assistance. Many clinical practices, however, do not have enough time and information to assist patients with such services. For commonly needed services, practices should at least have the information necessary to advise patients on best options, and to make referrals to and initiate connections with other service providers. For critical services, practices might consider developing partnerships with community-based organizations that can access for patients the services that will be of value to them.

Enabled and empowered patients—patients with the skills, information, and community-based resources necessary to tackle problems related to the care of their chronic illness—are partners in productive interactions. They are not alone, however. The other partners are the primary practice teams.

**Proactive and Prepared Practice Teams**

Practice teams must be prepared and proactive if they are going to see major improvements in chronic illness performance measures. Prepared practice teams integrate evidence-based reminders into the flow of clinical decision-making. They review key patient information before visits and review patients’ goals during visits to determine what services are needed and to develop mutually determined care plans. They use clear task assignments and standing
orders to ensure the delivery of those services, and they have the necessary trained staff.

Effective chronic care management also depends on careful and proactive follow-up by practice teams, follow up tailored to each patient’s disease severity and preferences. Chronically ill patients at higher risk of emergency room use, hospitalization, or major complications have been shown to benefit from more intensive follow-up and clinical management by a care manager. Clinical care management, generally provided by a health care professional such as a nurse or clinical pharmacist, includes clinical assessment, medication management, SM support, and care coordination, including among post-surgical cancer patients..

Efforts to improve cancer care must address the realities of the fragmentation of care, that is, of not knowing just which provider is accountable for the whole picture of what is often complex treatment. The disease itself may increase patients’ distress, but this fragmentation of care adds to it. Therefore, efforts to improve cancer care must address the quality and the coordination of all the medical practices and providers involved in patient care. The CCM is a model that oncology practices can adopt to address the quality and the coordination of all the medical practices and providers involved in a patient’s care.

A Practice Home for Patients With Cancer
The most effective cancer care requires a practice home for each patient. This home is the one practice team that holds itself accountable to patients; it is the practice team that takes on the responsibility of guiding and supporting patients along the cancer care continuum, a continuum that is not straight, but rather, labyrinthine. Although this labyrinth begins with diagnosis, its circuitous path leads from staging to treatment planning, from treatment planning to treatment, and from treatment back to staging; if staging suggests progression, the path leads back to treatment planning. Patients walk along this circular labyrinth as survivors. Given this complexity, the linear sharing of information across providers or the mere holding of tumor boards will unlikely satisfy patients’ needs. The CCM’s notion of a practice home, however, offers a model to facilitate centralized, consistent care.

The CCM’s notion of a practice home may, at first glance, give the impression that PCPs must be the practice home of cancer patients. Although it is true that PCPs must play a major role in coordinating care, PCPs often feel as if they do not have enough information to answer cancer patients’ questions. Oncology providers can serve as the practice home if patients were referred to oncology immediately on suspicion or diagnosis. Through coordination of care with PCPs, oncology providers can ensure that patients’ general preventive needs are met and comorbid conditions are well managed. A care manager or coach that links PCPs and oncology providers can help patients navigate the early phases of care, and provide information, skills training, and emotional support, among other services. This care manager (a patient champion, as it were) ensures optimal care on a patient’s journey along the twists and turns of the cancer care continuum. This champion embodies for patients the cancer care system; as such, this champion holds himself or herself accountable for a patient’s entire journey on the cancer care continuum.

Collaborative Care Plans
The task of being patients’ champions (that is, of being their practice home), may seem impossible. It is not. Developing and maintaining care plans make it possible. The 2005 IOM report emphasized the importance of explicit care plans. Care plans form the bond that holds together the partnership between patients and practice teams, but they must be mutually determined. Care plans developed collaboratively with patients make for informed and enabled patients, and they contribute to better coordination of care. The development of a collaborative care plan should be an integral part of the work of the home practice team, and subsequent providers must continue the process to keep the plan current.

We have expounded on the CCM and applied it to the problem of providing care to cancer patients, care that involves the complexities and nuances of chronic illnesses. We have suggested that oncology practice teams serve as the practice home for cancer patients. We have also suggested that the CCM’s notion of productive interactions holds true between cancer patients and oncology practice teams. Oncology practice teams can enable and empower cancer patients to arrive at multidisciplinary, collaborative care plans that serve as guides for SM interventions along the cancer care continuum, for patients and oncology practice teams alike. SM interventions are fundamental to enabling and empowering patients.
so they can take care of themselves along the cancer care continuum in the way they prefer. We now highlight current applications of successful SM clinical programs in cancer care in which components of the CCM are used.

**Current Applications**

For the past 30 years, the Stanford Patient Education Research Center has been developing and evaluating community-based programs for the management of chronic conditions. In the past few years, this work has been expanded specifically to include cancer survivors. Two programs are currently undergoing evaluation: a small group program developed with the Macmillian Cancer Trust in the United Kingdom (Cancer: Thriving and Surviving program) and an online program developed with the University of Hawaii (Cancer: Thriving and Surviving Internet program).

Content for the Stanford cancer survivors programs is based on information obtained from cancer survivor studies and discussions with survivors themselves. Many of the problems survivors face involve stress, depression, sleeplessness, fear, and lack of skills in making decisions about how to resume a normal-but-changed life. In addition, many survivors must cope with changes in body image or side effects of treatment, such as incontinence or lymphedema. Finally, cancer often causes changes in relationships with family and friends.

The process of each program is developed specifically to enhance self-efficacy, or patient confidence in their ability to be an activated survivor. The process is built on the Social Learning Theory of Bandura. Self-efficacy can be enhanced through skills mastery (operationalized as weekly action plans with feedback), modeling (operationalized by having peer facilitators help survivors with problem solving and difficult emotions), reinterpretation of symptoms (operationalized by reframing some common problems such as friends falling away when they learn about the cancer), and social persuasion (operationalized by group members systematically sharing their problems, difficult emotions, and celebrations).

In addition, rather than teach 1 or 2 topics a week, the Stanford programs teach 4 to 5 topics each week, with many topics repeated and built on week after week. Two peers (cancer survivors themselves) facilitate each program. Facilitators receive several weeks of online training. There are currently 3 ongoing trials of the Internet program. Survivors who are interested in participating in the Internet program can go to https://hawaiisurvivors.stanford.edu.

At Smilow Cancer Hospital at Yale-New Haven in New Haven, Connecticut, 2 of the authors (R.M. and E.E.) have begun implementing the Taking Early Action to Manage Self (TEAMS) program to help newly diagnosed patients recover after cancer surgery. The program facilitates patients’ communication with their providers across services and settings so they are better informed to manage their symptoms and understand their emotions vis-à-vis what they are experiencing. The TEAMS program is based on a series of evidenced-based studies and is in its early stage of translation. The APN in medical oncology serves as the champion for coordinating patient care and mutually determining the care plan with the patient. The SMT developed by Given et al is an important resource to assist patients with managing their own symptoms.

**Limitations to Establishing SM and the CCM in Cancer Care**

A major limitation in establishing SM and the CCM in cancer care heretofore has been the lack of a common language. The development of a language that is usable across professions and disciplines and understandable by patients and families is a critical and necessary first step to move SM forward.

Another limitation of SM in the context of the cancer care continuum is the lack of a common set of actions to teach patients and families how to take care of themselves. Expectations for patients and families to manage themselves have outpaced the development of effective SM interventions, interventions that impart the knowledge and skills and facilitate the social networking patients and families require for managing themselves. Patients and families need to be assessed to determine their willingness to manage their cancer care themselves, including managing treatment schedules, side effects, emotional turmoil, and family dynamics. It also involves navigating through different specialty groups and interacting with numerous people to schedule diagnostic tests, appointments, and procedures. A common set of SM actions would involve eliciting from patients and families their preferences for their
involvement in their care and developing a common set of interventions that enable them to participate in accordance with their preferences and abilities.

Clinical Implications

This overview has highlighted important scientific advances over the last 2 decades in applying the CCM and SM interventions to the cancer care continuum. Although unanswered questions remain for future research efforts, oncology practices can now incorporate aspects of the CCM and some SM interventions discussed in this article. Specifically, oncology practices can recognize the importance of patient-provider partnerships, and they can implement the standard that care plans be developed mutually with patients and families.

The Importance of Partnerships

For SM interventions to become an essential component of quality cancer care, the partnerships inherent in the CCM must be formed among providers, patients, and families. Figure 1 provides a view of how patient-provider productive interactions may be facilitated through partnerships that support patients to manage themselves and to accomplish their goals. The delivery of quality cancer care is dependent on productive interactions between patients and providers. All the studies in Table 1 included interventions for improving communication with health care providers (eg, managing symptoms, expressing feelings, asking questions, and requesting help). In particular, there are many more challenges in the oncology setting, given the number of specialties that have to be organized and integrated into the care. These specialties may change as patients progress along the cancer care continuum. Although further exploration of what productive interactions in the cancer care setting look like is warranted, oncology practices can lead the way by forging strong patient-provider relationships and becoming the practice home for patients in their care.

Development of Mutually Determined Care Plans

The phase of the cancer care continuum sets the context for individuals’ preferences for how to manage their own care. It is assumed that most patients want to take care of themselves and remain independent, but these preferences may change over time. SM involves daily behaviors that individuals and their families perform to manage their cancer and their treatment, including the short-term and long-term effects of both. These daily behaviors may change because depending on where patients are on the cancer care continuum, the cancer treatment they undergo, their symptoms, their personal goals, and their ability to take care of themselves may also
change. Our review of the research to date suggests that SM is critical across all the phases of the cancer care continuum. However, SM may be more challenging at some phases compared with others. The demands patients experience within a particular phase may influence their level of participation in SM interventions. Patients may become more passive during active, aggressive treatment due to being physically or emotionally overwhelmed, whereas during the post-treatment phase they may feel better physically and may want to manage the demands associated with their cancer treatment and surveillance schedule independently. Degner et al.\(^4\) have successfully determined patients’ preferences to participate in the decision-making related to treatment options. Although a similar approach might be useful with patients to determine how much responsibility they want for their own care within each phase of the cancer care continuum, from our review of the literature, we feel confident that oncology practices should engage patients and families in formulating a mutually agreed upon plan of care. This plan of care needs to be revisited as patients enter into different phases of the cancer care continuum.

**Conclusions**

Research related to SM interventions in cancer care has increased over the last decade. Significant progress has been made in helping patients manage the symptoms associated with cancer during the treatment phase of the cancer care continuum. SM interventions have been part of this progress, including interventions that have focused on SM of physical symptoms and psychosocial distress. There is an urgent need to translate this scientific evidence into clinical practice. Fewer studies have assessed the utility and benefit of SM interventions during the post-treatment and end-of-life phases of the continuum. The studies that have been conducted, however, suggest that the phase of the cancer care continuum sets the context for patients’ and families’ preferences for how to manage their own care. We have suggested here that, by adopting the CCM, oncology practice teams can become practice homes for their patients. In these homes, proactive oncology practice teams can use the SM interventions we have described to enable and empower patients and families to care for themselves across the cancer care continuum in the way they prefer.

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