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Managing Cancer Care: a psycho-educational intervention to improve knowledge of care options and breast cancer self-management

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Abstract

***Objective*: We tested the feasibility and acceptability of a psycho-educational self-management intervention, *Managing Cancer Care*: *A Personal Guide* (*MCC*), to improve knowledge of care options (curative, palliative, and hospice care) among a range of breast cancer self-management skills.**

***Methods*: We conducted a one-group, pre-post-test study among women with non-metastatic breast cancer ($n = 105$). We gave participants the printed, self-guided, seven-module intervention following enrollment. At baseline and 2 months, we measured knowledge of care options, desired and actual role in self-management, medical communication skills, experience and management of transitions, anxiety, depression, uncertainty, and self-efficacy. We conducted interviews to obtain module ratings and qualitative data on strengths and limitations of MCC.**

***Results*: Knowledge of care options ($\delta = 0.40$ (1.11), $p = 0.0005$) and desired role in self-management ($\delta = -0.28$ (1.08), $p = 0.0177$) significantly improved. Less skilled medical communicators significantly improved their communication ($\delta = 3.47$, standard deviation = 6.58, $p = 0.0449$). Multivariate modeling showed that changes in our primary outcomes of medical communication and management of transitions seemed to drive positive changes in our secondary outcomes of anxiety, depression, uncertainty, and self-efficacy. Participants highly rated MCC and reported the importance of understanding care options despite non-metastatic disease.**

***Conclusions*: MCC is a feasible and acceptable means of improving knowledge of care options and other aspects of breast cancer self-management. The combination of modules offered in MCC appears to have beneficial interactive effects. We are currently testing MCC more rigorously in a randomized controlled trial to explore mediating and moderating relationships.**

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Background

Self-management

Self-management is the engagement of patients, along with family members and healthcare providers, in dealing with medical, behavioral, and emotional aspects of their health condition(s) [1,2]. A basic process of medical management is learning about one’s illness [3], which includes learning about the care options of curative, palliative, and hospice care. Understanding the goals of care for each care option is foundational to self-management because goals of care directly impact the core self-management tasks of goal-setting and decision-making.

Knowledge of care options

Curative care, the goal of which is to cure disease permanently, is the standard approach to disease. The goal of hospice care is to provide comfort care to patients in the last 6 months of life. The care option of palliative care seems to be most poorly understood. Palliative care is specialized medical care for patients with progressive, advanced disease, offering relief from the pain, symptoms, and stress of serious illness. Palliative care can be offered concurrently with curative care and is embedded in hospice care. Despite a proliferation of palliative care services [4] and rapidly growing evidence that palliative care increases quality and length of life [5–7], patients remain uninformed about its nature and benefits. Yet, a recent survey of lay people found that once knowledgeable about palliative care, 70% would consider using it if they were to become seriously ill [8]. Improving knowledge of care options, and of palliative care in particular, is important so that patients understand the range of support available to them.

Self-management of breast cancer

Among women with non-metastatic breast cancer, those with early stage disease (stages I and II) may suffer physically and psychologically months after ending treatment [9]. Those with stage III disease have even more intensive self-management needs associated with long-term monitoring. Needs include access to information, as well as management of pain, anxiety, depression, and uncertainty [9–11]. Because of the intensity and chronicity of breast cancer and its treatment, as well a preference among these patients to self-manage [12,13], improving knowledge of care options is critical to improve overall self-management in this population. Improving patients' knowledge of care options may (a) help them to consider their role in self-management based on knowing what self-management may involve for them; (b) provide an appropriate context for communication with family caregivers and healthcare providers; (c) give a sense of what transitions to expect when, which facilitates adjustment to transitions[14]; (d) reduce anxiety, depression, and uncertainty due to knowing what to expect and planning accordingly; (e) improve patients' self-efficacy to self-manage by feeling more knowledgeable and capable of working toward their goals; and (f) direct use of healthcare resources by having a better understanding of their goals of care. For these reasons, patients with all stages of disease at any point on the care trajectory (diagnosis, treatment, and end of life) may benefit from a knowledge of care options.

Most patients with breast cancer prefer to know their prognosis prior to making treatment decisions, yet, discussions about prognosis and care options may not occur, or occur late, due in part to patient or physician hesitance [12,13]. As a result, patients may not understand which care option(s) they are receiving, as evidenced by a recent study [15] that found 25% of participants unable to report if the goal of their chemotherapy was curative or palliative. Notably, participants who received printed information on chemotherapy had nearly three times greater chance of accurate reporting than those who did not receive the materials. It has also been found that when encouraged, patients will ask questions related to prognosis as an important basis for treatment decision-making [16].

Linking self-management and knowledge of care options

A few interventions have been created to assist patients with cancer to understand their disease and to communicate about treatment decisions [17,18], but the linkage between self-management and knowledge of care options is not always explicit, and interventions have not formally incorporated knowledge of care options as a component of self-management. This linkage is significant because self-management interventions span a range of chronic conditions for which consideration of goals of care is a necessity. Knowledge of care options should be a mainstay of self-management interventions. The recently updated Framework of Self- and Family Management [19], created to guide self-management science, recognizes knowledge of care options as a facilitator of self-management.

Managing Cancer Care: *A Personal Guide* (MCC) is a psycho-educational intervention that aims to improve medical, behavioral, and emotional aspects of self-management, with knowledge of care options being a central concept. In previous work [20], we tested MCC among women with metastatic (stage IV) breast cancer ($n = 23$). We vetted MCC with these experienced self-managers to enable informed modification of the intervention. MCC significantly improved participants' knowledge of care options and role in self-management, and we observed substantive effect sizes for medical communication, anxiety, depression, uncertainty, and self-efficacy. During exit interviews, participants reported that they would have liked to have MCC earlier in their care. This finding suggested an openness to information on care options among women with earlier stage disease. Subsequently, we conducted the present study to test the feasibility and acceptability of MCC among a larger sample of women with non-metastatic (stages I–III) breast cancer. More specifically, we wanted to test the ability of MCC to improve our primary outcomes of medical management (knowledge of care options) and behavioral management (role in self-management, medical communication skills, and management of transitions) and our secondary outcome of emotional management (anxiety, depression, uncertainty, and self-efficacy) of breast cancer. An exploratory aim was to investigate the extent to which demographic and clinical factors moderate the effects of MCC. We hypothesized that the use of MCC would improve pre-post-test knowledge of care options, desired and actual role in self-management, medical communication, management of transitions, and self-efficacy and reduce anxiety, depression, and uncertainty.

Methods

Description of Managing Cancer Care: A Personal Guide (MCC)

MCC consists of seven printed, four-page modules in a magazine format: *Managing Your Symptoms*, *Managing Your Care and Setting Goals*, *Care Options*, *Talking with Your Health Care Providers*, *Talking with Your Family and Friends*, *Managing Transitions*, and *Acting Confidently During Uncertainty*. Module content was based on our studies of patients' self-management experiences [21,22] and perceived barriers to self-management [23], as well as on the Self- and Family Management Framework, which specifies facilitators and barriers, processes, and outcomes of self-management [10]. In Table 1, we describe module content along with the self-management processes, tasks, and skills [3,19] that each module targets. MCC is designed to provide patients with information, tools, and empowerment to self-manage with their family caregivers and healthcare providers. Modules include basic information on

Table 1. Content of Managing Cancer Care: A Personal Guide (MCC)

Self-management domain	Self-management process[a]	Self-management task[a]	Self-management skill[a]	Module	Selected content
Medical	Learning	Learning about condition and health needs	Acquiring information	Care Options	Definitions and access to curative, palliative, and hospice care Goals of care
	Taking ownership of health needs	Recognizing and managing body responses	Monitoring and managing symptoms, side effects, and body responses	Managing Symptoms	Reporting and addressing common symptoms Assistance with symptom management
	Performing health promotion activities	Changing behaviors to minimize disease impact	Modifying diet, nutrition, smoking, and physical activity Reducing stress Taking action to prevent complications		Healthy lifestyle behaviors
	Integrating illness into daily life	Modifying lifestyle to adapt to disease	Obtaining assistance with activities of daily living		
Behavioral	Taking ownership of health needs	Becoming an expert	Evaluating effectiveness of SM Goal setting	Managing Care and Setting Goals	Who and what is involved in SM Setting 'good' goals
	Activating healthcare resources	Creating and maintaining relationships with healthcare providers	Finding the right provider(s) Communicating effectively Making decisions collaboratively	Talking with Healthcare Providers	Importance of communication and support Communicating well Potential topics to discuss
	Taking ownership of health needs	Becoming an expert	Decision-making	Talking with Family and Friends	Family communication and support Shared decision-making
	Processing emotions	Processing and sharing emotions	Exploring and expressing emotional responses		Talking to co-workers
	Adjusting	Adjusting to new self	Choosing when and to whom to disclose illness		
	Adjusting	Adjusting to illness	Identifying and confronting change and loss Focusing on possibilities	Managing Transitions	Types of transitions Experience of transitions Successful transitioning
	Integrating illness into daily life	Seeking normalcy in life	Managing disruptions in school, work, family, and social activities		
Emotional	Taking ownership of health needs	Becoming an expert	Developing confidence and self-efficacy	Managing Confidently During Uncertainty	Living with uncertainty Reducing uncertainty
	Activating psychological resources	Identifying and benefitting from psychological resources	Draw on intrinsic resources Cultivating courage, discipline, and motivation Maintaining positive outlook and hope Advocating for self		Asking for help Empowerment
	Adjusting	Adjusting to illness	Managing uncertainty Developing coping strategies		
	Meaning making	Personal growth	Becoming empowered		

[a] Self-management processes, tasks, and skills derived from Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, Redeker N, Reynolds N, and Whittemore R. Processes of self-management in chronic illness. *J Nurs Schol* 2012; 44: 136–144. doi: 10.1111/j.1547-5069.2012.01444.x

each topic, worksheets or other means of personalizing self-management, and a 'Conversation Starters' section with suggested language to initiate important discussions. The main purpose is to promote communication that ensures agreement among patients, family caregivers, and providers about the patient's status, priorities, and goals of care. Modules also offer space to record comments or questions and provide links to additional resources. All are written at or below an eighth grade reading level. MCC is a training program intended to help patients understand their care options, incorporate this knowledge into their self-management, work toward their goals, and cope with what is happening to them.

Design

This study used a one-group, pre-post-test design with a 2-month protocol. We conducted semi-structured qualitative exit interviews to obtain feedback on MCC. The study was approved by the Human Investigation Committee at Yale University.

Participants and procedures

Eligible participants were women aged 21 years or older who spoke English, had a diagnosis of stage I, II, or III breast cancer, and had a prognosis of at least 3 months. We recruited participants in the breast center infusion clinic at a cancer hospital. Chemotherapy nurses approached potential participants to determine their interest in speaking with research staff about the study. If interested, research staff explained the study and obtained written consent. Following pre-test data collection, research staff gave participants MCC and a very brief (1 min) orientation to the modules. Orientation consisted of pointing out the module topics and format (worksheets, Conversations Starters, etc.). One month later, research staff phoned to check in about participants' use of MCC, to answer any questions, and to set a time for post-test data collection 1 month following the phone call. Research staff conducted a semi-structured interview with each participant immediately following post-test data collection. Participants rated individual modules and MCC as a whole on content and format (1 = worst; 10 = best). Research staff took detailed notes on what participants liked or disliked about MCC and what participants thought should be added or changed.

Outcome measures

We collected demographic and clinical data, followed by six outcome measures. The knowledge of care options test, content validated in the present study, is an 11-item knowledge test that assesses knowledge of curative, palliative, and hospice care using a true–false format [24]. We used an adapted version of the Control Preferences Scale to measure desired and actual roles played in self-management (with permission, we modified wording on the cards to reflect role in self-management instead of role in treatment decision-making) [25]. We used the patient subscale of the Medical Communication Competence Scale [26] to measure participants' perceptions of their medical communication. Participants completed the Measurement of Transitions in Cancer Scale, also validated in the current study, to first rate the degree or quantity of change they felt they experienced for various transitions (physical, emotional, social, spiritual, cancer status, treatment, and approach to care) and then rate how well they managed each change [Schulman-Green, Jeon, and Dixon, Unpublished manuscript]. Participants reported on anxiety and depression with the Hospital Anxiety and Depression Scale [27]. The Uncertainty in Illness Scale [28] enabled us to assess uncertainty regarding disease, prognosis, and treatment. We used the Chronic Disease Self-Efficacy Scale [29] to measure self-efficacy in cancer self-management. We did not measure symptoms as a main outcome because there are several other interventions that focus on symptom management in breast cancer [30]. We included a symptom management module in MCC primarily to help patients reduce their symptom burden and engage in other aspects of self-management.

Data analysis

We calculated descriptive statistics for demographic and clinical data and used paired *t*-tests to examine pre-post changes in outcomes. We assessed correlations between baseline outcomes using Spearman correlation coefficients. We used a generalized linear model to test associations of outcomes with demographic and clinical characteristics. We also used a generalized linear model to test the effects of increased knowledge of care options on other outcomes. We assessed how outcomes that improved with increased knowledge of care options were associated with other outcomes using a multivariate model controlling for demographic and clinical variables. To avoid inflation of type I error, we calculated false discovery rate accounting for multiple tests using PROC MULTTEST, SAS version 9.3 (SAS Institute Inc., Cary, NC) with a false discovery rate option [31]. To describe participants' ratings of MCC, we calculated descriptive statistics. We performed content analysis on qualitative data to identify intervention strengths and limitations.

Results

Sample description

Participants were enrolled between July 2011 and June 2013. Of the 165 patients who were eligible for the study, 40 were not interested in speaking to a researcher, and 15 refused participation. The sample therefore consisted of 110 participants, all of whom completed pre-test data collection. Of these participants, three were lost to follow-up, and two withdrew because of being too ill to participate; thus, 105 of the 110 participants completed post-test data collection.

Sample characteristics ($n = 105$) are detailed in Table 2. Participants' mean age was 52.3 years (standard deviation (SD) = 10.4, range 27–72). Participants were generally well educated (64.7% college graduate or more), married (61.9%), and White (78.1%). A total of 20 (19%) had stage I, 59 (56.2%) had stage II, and 26 (24.8%) had stage III breast cancer. The mean time since initial diagnosis was 4 months (SD = 2.5; range 0.7–17.6), and all were receiving treatment. Participants reported an average of 6.4 symptoms (SD = 3.9, range 0–19).

Associations of demographic and clinical characteristics with outcomes at baseline

For demographic characteristics, older age was associated with lower anxiety but only when we controlled for income

Table 2. Sample demographic and clinical characteristics ($n = 105$)

Characteristic	
Age (years)	
Mean (SD)	52.3 (10.4)
Range	27–72
Age at diagnosis (years)	
Mean (SD)	52.0 (10.5)
Range	27–72
Time since diagnosis (months)	
Mean (SD)	4.0 (2.5)
Range	0.7–17.6
Number of symptoms	
Mean (SD)	6.4 (3.9)
Range	0–19
	N (%)
Race	
White	82 (78.1)
Black	10 (9.5)
Hispanic	6 (5.7)
Other	7 (6.7)
Marital status	
Married	65 (61.9)
Divorced/separated	17 (16.2)
Widowed	4 (3.8)
Living with partner	2 (1.9)
Never married	17 (16.2)
Education	
Up to eighth grade only	2 (1.9)
High school graduate	13 (12.4)
Trade school	3 (2.9)
Some college	19 (18.1)
College graduate	33 (31.4)
Graduate school	35 (33.3)
Income	
<$50,000	29 (27.6)
$50,000–$89,999	35 (33.3)
>$90,000	39 (37.1)
Unreported	2 (8.7)
Religion	
Catholic	50 (47.6)
Christian	27 (25.7)
Jewish	9 (8.6)
Muslim	4 (3.8)
Other	3 (2.9)
None	12 (11.4)
Stage of breast cancer	
I	20 (19.0)
II	59 (56.2)
III	26 (24.8)
Current treatment	
Chemotherapy	100 (95.2)
Radiation	4 (3.8)
Surgery	28 (26.7)
Hormone therapy	4 (3.8)
Zometa	1 (0.9)
Other	5 (4.8)

SD, standard deviation.

and education (partial correlation $r = -0.230$, $p = 0.0303$). Higher income was significantly correlated with better medical communication ($r = 0.285$, $p = 0.0035$) and less uncertainty ($r = -0.295$, $p = 0.0025$), even after controlling for age and education (partial correlation $r = 0.286$, partial correlation $r = -0.269$, $p = 0.0107$). We found education to be negatively associated with depression ($r = -0.201$, $p = 0.0396$), but this was not significant after controlling for age and income.

For clinical characteristics, stage III disease was associated with greater knowledge of care options ($p = 0.0319$) and greater uncertainty ($p = 0.0139$). These results remained significant after controlling for number of symptoms ($p = 0.0241$, $p = 0.0094$). Greater number of symptoms was significantly associated with greater anxiety ($r = 0.411$, $p < 0.0001$), greater depression ($r = 0.321$, $p < 0.0001$), less self-efficacy ($r = -0.362$, $p = 0.0001$), more transitions ($r = 0.298$, $p = 0.0020$), and poorer management of transitions ($r = -0.265$, 0.0063). All of these results remained significant after controlling for cancer stage ($p < 0.01$).

Baseline correlations between outcomes

Greater knowledge of care options was significantly associated with better medical communication ($r = 0.278$, $p = 0.0047$), less uncertainty ($r = -0.190$, $p = 0.0560$), and fewer transitions ($r = -0.220$, $p = 0.0261$). Better medical communication was significantly associated with less uncertainty ($r = -0.296$, $p = 0.0022$), greater self-efficacy ($r = 0.231$, $p = 0.0176$), and better management of transitions ($r = 0.210$, $p = 0.0314$). We observed strong correlations among anxiety, depression, self-efficacy, and both experience and management of transitions. Experiencing more transitions and poorer management of transitions was associated with greater depression ($r = 0.260$, $p = 0.0074$; $r = -0.334$, $p = 0.0005$) and anxiety ($r = 0.342$, $p = 0.0003$; $r = -0.329$, $p = 0.0006$).

Change over time

We observed significant improvements in knowledge of care options ($\delta = 0.40$ (1.11), $p = 0.0005$) and desired role in self-management, that is, over time, participants desired a more active role in self-management ($\delta = -0.28$ (1.08), $p = 0.0177$) (Table 3). While the quantity of transitions increased over time ($\delta = -0.53$ (2.13), $p = 0.0130$), management of transitions did not change ($\delta = 0.04$ (2.07), $p = 0.8539$). Among the total sample, medical communication skills decreased ($\delta = -1.58$ (7.31), $p = 0.0301$); however, decreased communication skills were associated with a high level of medical communication at baseline ($r = -0.432$, $p < 0.0001$). Among participants who were less skilled medical communicators at baseline (Medical Communication Competence Scale ≤ 100), we observed significant improvement of medical communication over time ($\delta = 3.47$, $\mathrm{SD} = 6.58$, $p = 0.0449$). We did not observe changes in anxiety, depression, or uncertainty. Change in self-efficacy varied by stage of breast cancer. Participants with stage II

Table 3. Mean and standard deviations of outcomes over time

Outcomes	N	Baseline mean (SD)	Post-intervention mean (SD)	δ mean (SD)	Paired t-test (p-value)	FDR
Knowledge of care options	101	9.42 (1.10)	9.81 (1.13)	0.40 (1.11)	0.0005	[a]0.0030
Desired role in self-management	85	2.96 (1.27)	2.68 (1.16)	−0.28 (1.08)	0.0177	[a]0.0354
Actual role in self-management	79	2.96 (1.27)	2.72 (1.58)	−0.22 (1.64)	0.2466	0.2959
Medical communication	104	107.17 (5.95)	105.60 (7.16)	−1.58 (7.31)	0.0301	[a]0.0452
Experience/quantity of transitions	105	3.75 (2.33)	3.23 (2.13)	−0.53 (2.13)	0.0130	[a]0.0354
Management of transitions	105	7.54 (1.77)	7.54 (2.00)	0.04 (2.07)	0.8539	0.8539

SD, standard deviation; FDR, false discovery rate.

[a]FDR of <0.05 indicates statistical significance in adjustment of multiple tests at a 0.05 significance level.

and III disease increased their self-efficacy, while those with stage I decreased self-efficacy ($p = 0.0413$).

Associations among changes in outcomes

Table 4 shows a multivariate model of associated changes among primary outcomes (knowledge of care options, self-management, medical communication, experience/quantity and management of transitions) and secondary outcomes (anxiety, depression, uncertainty, and self-efficacy) post-intervention after controlling for baseline scores and demographic/clinical information. Baseline communication skills were associated with increased self-efficacy (0.056 ± 0.020). Experiencing more transitions at baseline was associated with increased anxiety (0.500 ± 0.182) and lower self-efficacy (−0.141 ± 0.061). Better management of transitions at baseline was associated with decreased anxiety (−0.618 ± 0.186) and increased self-efficacy (0.200 ± 0.068). Improved management of transitions was associated with decreased anxiety (−0.542 ± 0.153), decreased depression (−0.348 ± 0.170), decreased uncertainty (−1.924 ± 0.512), and increased self-efficacy (0.228 ± 0.052).

Qualitative interview data

Median ratings (0–10 worst/best) of MCC as a whole were 8 (range 1–10) on content and 9 (range 2–10) on format. Frequency of use varied across modules, with median usage being 1–2 times used (range 0–15). Modules were described as 'clear', 'thorough', providing valuable information, and as most helpful to receive at diagnosis.

Table 4. Associated changes among primary and secondary outcomes post-intervention

Primary outcomes (independent variables)	Secondary outcomes (dependent variables) (coefficient ± standard error)			
	Anxiety (HADS)	Depression (HADS)	Uncertainty (MUIS)	Self-efficacy (CDSE)
Knowledge of care options (KOCO)				
Baseline	−0.188 ± 0.333	−0.457 ± 0.340	−0.136 ± 1.017	0.059 ± 0.113
δ	0.029 ± 0.314	−0.779 ± 0.320	−1.309 ± 0.926	−0.039 ± 0.104
Medical communication skills (MCCS)				
Baseline	−0.100 ± 0.054	0.012 ± 0.059	−0.158 ± 0.189	[a]0.056 ± 0.020
δ	−0.090 ± 0.043	0.060 ± 0.049	−0.201 ± 0.142	0.031 ± 0.015
Desired role in self-management (CPS)				
Baseline	−0.224 ± 0.298	−0.320 ± 0.302	−0.282 ± 0.870	0.184 ± 0.093
δ	0.290 ± 0.347	0.159 ± 0.355	0.912 ± 0.999	0.014 ± 0.108
Actual role in self-management (CPS)				
Baseline	−0.040 ± 0.299	−0.301 ± 0.305	0.063 ± 0.871	0.104 ± 0.091
δ	0.182 ± 0.223	0.113 ± 0.230	0.360 ± 0.647	−0.011 ± 0.068
Difference between desired and actual role in self-management (CPS)				
Baseline	−0.196 ± 0.277	−0.337 ± 0.283	0.120 ± 0.084	−0.290 ± 0.805
δ	−0.168 ± 0.270	-0.023 ± 0.273	0.062 ± 0.080	−0.240 ± 0.769
Experience of transitions (MOT)				
Baseline	[a]0.500 ± 0.182	0.245 ± 0.191	0.593 ± 0.635	[a]−0.141 ± 0.061
δ	0.444 ± 0.175	0.200 ± 0.186	0.582 ± 0.618	−0.138 ± 0.060
Management of transitions (MOT)				
Baseline	[a]−0.618 ± 0.186	−0.430 ± 0.207	−1.067 ± 0.638	[a]0.200 ± 0.068
δ	[a]−0.542 ± 0.153	[a]−0.348 ± 0.170	[a]−1.924 ± 0.512	[a]0.228 ± 0.052

Multivariate model includes baseline score and δ score (i.e., post-intervention score – baseline score) of each independent variable controlling for baseline outcome variable, age, income, number of symptoms, and cancer stage.

HADS, Hospital Anxiety and Depression Scale ; MUIS, Uncertainty in Illness Scale; CDSE, Chronic Disease Self-efficacy Scale; KOCO, Knowledge of Care Options; MCCS, Medical Communication Competence Scale; CPS, Control Preferences Scale; MOT, Measurement of Transitions in Cancer Scale.

[a]indicates a significant association using FDR at a 0.05 significance level.

Some reported the Care Options module as being emotional, 'scary', or difficult to read, but many felt it was an important information to have. For example, one participant said that the module helped her to 'realize palliative care was all about managing the disease'. Another thought it was helpful to know that palliative care is 'available to people that might need it'. Some participants with stage I disease felt that they did not need to know about care options because only curative care was 'applicable' to them. One participant stated that use of this module was 'really dependent on stage because speaking of hospice at any stage is difficult'. Another participant reported that the information on care options 'didn't apply to me' but yet, she 'wished the doctor had talked about this… [that] this wasn't the first time I had heard about this'. A few participants felt that the worksheets were hard to complete or that content was not relevant to them. Qualitative data on all modules are described elsewhere [Goldberg, Hinchey, Feder, and Schulman-Green, Unpublished manuscript].

Conclusions

Quantitative data

The MCC was well received and seems to be successful in improving several outcomes across self-management domains. In the medical management domain, knowledge of care options improved. In the behavioral management domain, desired role in self-management and medical communication skills (among those less skilled at baseline) improved, but we did not observe changes in actual role in self-management or in management of transitions. Lack of change may be due to the short length of our protocol because it likely takes more than 2 months to adopt new self-management strategies. In the emotional management domain, results were mixed. Anxiety, depression, and uncertainty, which are difficult to affect in seriously ill populations, did not change. Improvements in self-efficacy varied by stage of breast cancer. However, the multivariate model suggests that changes in our primary outcomes of medical communication and management of transitions drove significant, positive changes in our secondary outcomes of anxiety, depression, uncertainty, and self-efficacy.

Qualitative data

Participants highly rated MCC and reported the importance of understanding care options in the presence of non-metastatic disease, even if uncomfortable for some. These qualitative data allay potential concerns about early introduction of palliative care among patients with breast cancer. As noted, in our test of MCC among women with metastatic breast cancer, participants wanted MCC earlier in their care trajectory. In the present study, participants with non-metastatic disease wanted MCC *at diagnosis*. While some participants were not completely comfortable reading about palliative and/or hospice care, for the most part, participants felt that this was an important information to have and to have early. Communication about care options should be tailored to patients' preferences and emotional readiness [32,33]. We feel that it is important for patients to have basic information about care options early on as part of public health knowledge. Patients should be aware of supportive healthcare services that are available to them should they be needed. Such knowledge reinforces that there is a continuum of care and facilitates adjustment to new services at times of transition.

Breast cancer self-management interventions

The MCC shares common components with other breast cancer self-management interventions such as Stay Abreast, Move Ahead [34], Taking Charge [35], Moving Beyond Cancer [36], and the Breast Cancer e-Health (BREATH) internet-based intervention [37], which address medical, behavioral, and emotional outcomes. These interventions variously include education on breast cancer, development of self-management skills, 'homework' (e.g., worksheets), and self-management tools (e.g., diet chart). Most involve trained facilitators, either in-person or by telephone, and some incorporate a peer–buddy system. Like MCC, Moving Beyond Cancer uses a printed format, and BREATH is entirely self-guided. Unlike MCC, these interventions specifically target patients completing treatment who are focusing on reintegrating into life after cancer. MCC is not only intended for use among this group of survivors but is also appropriate for patients for whom breast cancer is a chronic and/or life-limiting illness. In this respect, MCC is similar to the ENABLE II intervention [7], which is geared toward patients with various types of advanced cancer, including breast, and likewise incorporates education on care options but which is nurse-led versus self-guided. MCC is a self-management intervention that can be used by patients with all stages of cancer at all points on the care trajectory.

The MCC shares with these other self-management interventions the ultimate goal of improving quality of life for patients with cancer. Although their targeted outcomes vary, all (excluding the ongoing BREATH study) have been successful at improving various aspects of self-management. Because self-management interventions have multiple components and outcomes, it can be difficult to determine the operative mechanisms [38]. Our data suggest that our primary outcomes facilitated other aspects of self-management, intimating that the particular combination of modules offered in MCC has beneficial interactive effects. However, we treated various aspects of self-management as outcomes. While self-efficacy is generally regarded as the main mechanism through which self-management works [39], research is needed to investigate if some aspects of self-management, such as anxiety or depression, serve as mediators or moderators of other aspects of self-management.

Advantages of MCC as a printed self-guided intervention are that it requires few resources to implement (printing costs and space to display), that it may appeal to people who prefer self-directed learning, on their own time, and at their own pace, and that it is a portable intervention that can be used at any time. Our participants have found it reassuring to leave the hospital with support in hand that does not require any effort on their part to procure. However, MCC, as a printed intervention, also has a disadvantage because, in its current format, it does not have the appeal or accessibility of an app or other internet-based platform. We will likely make MCC available electronically to suit an array of potential users, but we have found across our studies that many participants confronted with serious illness prefer the simplicity of printed materials. In addition, although we have begun by testing MCC among women with breast cancer, MCC is not specific to breast cancer. With minor modifications, MCC can be used among other cancer and non-cancer populations.

Limitations

We should note a few limitations of our study. One was that our outcome measures reflect self-reports of participants' self-management versus what they actually did. Future testing of MCC should include objective measures of self-management. For example, while we found a statistically significant change in knowledge of care options, use of healthcare utilization data would help to determine whether patients with improved knowledge of care options actually request palliative care services. In addition, MCC should be tested over a longer period of time and among a larger and more diverse sample that includes men. Our population is typical of National Cancer Institute (NCI) Designated Comprehensive Cancer Centers, but not of cancer patients overall. Finally, this study used a quasi-experimental design. To address this primary limitation and the other limitations of this study, we are currently testing MCC in a pilot randomized controlled trial (R21 NR014318-01A1) with a target of 50% minority participation and a 3-month protocol that includes collection of family caregiver-reported outcomes and data on healthcare utilization.

Practice implications

There are a number of ways MCC can be used in clinical settings. Healthcare providers, including oncologists and oncology nurses, often have limited time to initiate in-depth discussions with patients on the topics covered in MCC. Therefore, most basically, MCC can be made available to patients at oncologists' offices, infusion, and/or radiation clinics, which would allow patients to choose modules of interest to them and then discuss content with their healthcare providers. Alternatively, healthcare providers can intentionally give the whole MCC to patients as 'homework', with the suggestion to complete the worksheets, write down questions, and so on, which can then be discussed at follow-up appointments. For example, patients can use MCC to develop self-management skills that help them self-assess for areas of distress and then discuss needs with healthcare providers to secure appropriate services. Nurses or social workers might use MCC to structure a series of educational sessions or support group meetings. Palliative care providers could use MCC before or after family meetings to reinforce topics discussed.

Having a knowledge of care options is foundational to other aspects of self-management. Development of this knowledge, as well as development of other self-management skills, is central to helping patients adapt to survivorship, however long that may be.

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References

1. McCorkle R, Ercolano E, Schilling L, Schulman-Green D, Lorig K, Wagner EH. Self-management: enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians* 2011: **61**, 50–62. doi: 10.3322/caac.20093
2. Corbin JM, Strauss A. Unending Work and Care: Managing Chronic Illness at Home, Jossey-Bass: San Francisco, CA, 1988.
3. Schulman-Green D, Jaser S, Martin F *et al.* Processes of self-management in chronic illness. *J Nurs Schol* 2012;**44**:136–144. DOI:10.1111/j.1547-5069.2012.01444.x.
4. Morrison RS, Meier DE. *American's Care of Serious Illness: A State-by-State Report Card on Access to Care in Our Nation's Hospitals*: Center to Advance Palliative Care, 2011.
5. Temel JS, Greer JA, Muzikansky A, Gallagher *et al.* Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;**19**:733–742. DOI:10.1056/NEJMoa1000678.
6. Emanuel EJ, Ash A, Yu W *et al.* Managed care, hospice use, site of death, and medical expenditures in the last year of life. *Arch Intern Med* 2002;**162**:1722–1728. DOI:10.1001/archinte.162.15.1722.
7. Bakitas M, Lyons KD, Hegel MT *et al.* Effects of palliative intervention on clinical outcomes in patients with advanced cancer. *JAMA* 2009;**302**:741–749. DOI:10.1001/jama.2009.1198.
8. Public Opinion Research *on Palliative Care: A Report Based on Research by Public Opinion Strategies* 2011. Public Opinion Strategies. 2011.
9. Pauwels EE, Charlier C, De Bourdeaudhuij I, Lechner L, Van Hoof E. Care needs after primary breast cancer treatment. Patients' associated sociodemographic and medical characteristics. *Psycho-Oncology* 2013;**22**:125–132. DOI:10.1002/pon.2069.
10. National Institutes of Health. State-of-the-Science Conference Statement on symptom management in cancer: pain, depression,

and fatigue. *J Nat Canc Inst Mon Weather Rev* 2004;**32**:9–16. DOI:10.1093/jnci/djh201.

11. Vivar CG, McQueen A. Informational and emotional needs of long-term patients of breast cancer. *J Adv Nurs* 2005;**51**:520–528. DOI:10.1111/j.1365-2648.2005.03524.x.
12. van Vliet L, Francke A, Tomson S, Plum N, van der Wall E, Bensing J. When cure is no option: how explicit and hopeful can information be given? A qualitative study in breast cancer. *Pat Educ Couns* 2013;**90**:315–322. DOI:10.1016/j.pec.2011.03.021.
13. Singh JA, Sloan JA, Atherton PJ *et al.* Preferred roles in treatment decision making among patients with cancer: a pooled analysis of studies using the control preferences scale. *Am J Manag Care* 2010;**16**:688–696.
14. Schumacher KL, Meleis AI. Transitions: a central concept in nursing. *Image J Nurs Sch* 1994;**26**:119–127.
15. Lennes IT, Temel JS, Hoedt C, Meilleur A, Lamont EB. Predictors of newly diagnosed cancer patients' understanding of the goals of their care at initiation of chemotherapy. *Cancer* 2013;**119**:691–699. DOI:10.1002/cncr.27787.
16. Butow P, Dowsett S, Hagerty R, Tattersall M. Communicating prognosis to patients with metastatic disease: what do they really want to know? *Support Care Cancer* 2002; **10**:161–168. DOI:10.1007/s005200100290.
17. Hoerger M, Epstein RM, Winters PC *et al.* Values and options in cancer care (VOICE): study design and rationale for a patient-centered communication and decision-making intervention for physicians, patients with advanced cancer, and their caregivers. *BMC Cancer* 2013;**13**:188. DOI:10.1186/1471-2407-13-188.
18. Bakitas M, Lyons KD, Hegel MT. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA* 2009;**302**:741–749. DOI:10.1001/jama.2009.119.
19. Grey M, Schulman-Green D, Knafl K, Reynolds N. A revised self- and family management framework. *Nurs Outlook* 2015;**63**:162–170. DOI:10.1016/j.outlook.2014.10.003.
20. Schulman-Green D, Jeon S. Printed guide improves knowledge of curative, pallative, and hospice care among women with metastatic breast cancer. *Support Care Cancer* 2013;**21**: 2651–2653.
21. Schulman-Green D, Bradley EH, Knobf MT, Prigerson H, DiGiovanna MP, McCorkle R. Self-management and care transitions in women with advanced breast cancer. *J Pain Symptom Manage* 2011;**42**:517–525.
22. Schulman-Green D, Bradley EH, Nicholson NR, George E, Indeck A, McCorkle R. Managing "One step at a time": Self-management and transitions among women with ovarian cancer. *Oncol Nurs Forum* 2012;**39**:354–360.
23. Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self-management of chronic conditions. *Patient Educ Couns* 2005;**57**:300–307.
24. Schulman-Green D, Ercolano E, Jeon S, Dixon J. Validation of the Knowledge of Care Options instrument to measure knowledge of curative, palliative and hospice care. *J Palliat Med* 2012;**15**(10):1091–1099.
25. Degner LF, Sloan JA, Venkatesh P. The control preferences scale. *Can J Nurs Res* 1997;**29**:21–43.
26. Cegala DJ, Coleman MT, Turner JW. The development and partial assessment of the medical communication competence scale. *Health Commun* 1998;**10**:261–288. DOI:10.1207/s15327027hc1003-5.
27. Zigmond AS, Snaith PR. The hospital anxiety and depression scale. *Acta Psychiatrica Scandanavia* 1983;**67**:361–370.
28. Mishel M. Reconceptualization of the uncertainty in illness theory. *J Nurs Schol* 1990;**22**:256–62.
29. Lorig K, Stewart A, Ritter P, González V, Laurent D, Lynch J. Outcome Measures for Health Education and Other Health Care Interventions, Sage: California, 1996.
30. Brem S, Kumar NB. Management of treatment-related symptoms in patients with breast cancer. *Clin J Oncol Nurs* 2011;**15**:63–71. DOI:10.1188/11.CJON.63-71.
31. Glickman ME, Rao SR, Schultz MR. False discovery rate control is a recommended alternative to Bonferroni-type adjustments in health studies. *J Clin Epidemiol* 2014;**67**: 850–857. DOI:10.1016/j.jclinepi.2014.03.012.
32. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* 2010;**28**:1203–1208. DOI:10.1200/JCO.2009.25.4672.
33. Maciejewski PK, Prigerson HG. Emotional numbness modifies the effect of end-of-life discussions on end-of-life care. *J Pain Symptom Manage* 2013;**45**:841–7. DOI:10.1016/j.jpainsymman.2012.04.003.
34. Loh SY, Packer T, Chinna K, Quek KF. Effectiveness of a patient self-management programme for breast cancer as a chronic illness: a non-randomised controlled clinical trial. *J Cancer Surviv* 2013;**7**:331–42. DOI:10.1007/s11764-013-0274-x.
35. Cimprich B, Janz NK, Northouse L, Wren PA, Given B, Given CW. Taking charge: a self-management program for women following breast cancer treatment. *Psycho-Oncology* 2005;**14**:704–717.
36. Stanton AL, Ganz PA, Kwan L *et al.* Outcomes from the Moving Beyond Cancer psychoeducational, randomized, controlled trial with breast cancer patients. *J Clin Oncol* 2005;**23**:6009–6018.
37. van den Berg SW, Gielissen MF, Ottevanger PB, Prins JB. Rationale of the BREAst cancer e-healTH [BREATH] multicentre randomised controlled trial: an internet-based self-management intervention to foster adjustment after curative breast cancer by decreasing distress and increasing empowerment. *BMC Cancer* 2012;**12**:394. DOI:10.1186/1471-2407-12-394.
38. Schulman-Green D, Wagner E, McCorkle R. Self-Management Support in Holland J, Breitbart W, Jacobsen P, Lederberg M, Loscalzo M, McCorkle R (Eds). *Psycho-Oncology*, (3rd Ed). New York: Oxford Press
39. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med* 2003;**26**: 1–7.