



Research brief

A family-centered intervention for the transition to living with multiple myeloma as a chronic illness: A pilot study



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ABSTRACT

Patients with multiple myeloma and their family caregivers must master self-management tasks related not only to the disease and treatment, but also associated with transitioning to living with chronic illness. The aim of this study was to assess the feasibility, acceptability, safety, and fidelity of an intervention that had a psychoeducational approach and included a low-impact, home-based walking activity. A secondary aim was to obtain preliminary data of the effect of the intervention, as compared to an attention control group, on anxiety, activation for self-management, fatigue, depression and health-related quality of life (HRQOL). A sample of 15 adult patients with multiple myeloma and their family caregivers were randomized into either an intervention or attention-control group. The intervention was delivered to the dyad in one session and booster calls were made at 1 and 3 weeks. The control group received printed educational resources and telephone contacts. Measures were done at baseline, and 6 and 12 weeks. Descriptive statistics were used. The intervention was safe, feasible, and acceptable to patients and caregivers. Fidelity was high for the initial session, but low with booster calls. Improvement in scores for activation, fatigue, depression, anxiety, physical HRQOL, and emotional distress was seen in at least 40% of patients in the intervention group. Fewer caregivers in the intervention group showed improvement on the outcome variables. Leveraging a behavioral strategy such as walking, along with supportive and educational resources, is promising for promoting well-being within the patient/caregiver dyad. Further refinement of the intervention is needed to strengthen its efficacy for the caregiver and exploratory work is essential to understand the interpersonal supportive processes associated with the walking activity.

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1. Introduction

More than 30,000 individuals will be diagnosed with multiple myeloma this year in the United States (American Cancer Society, 2017). Although multiple myeloma is an incurable malignancy, numerous treatment options and supportive care have improved survival, shifting its illness trajectory to one that is more chronic in nature (Kumar et al., 2008). This growing group of cancer survivors is particularly vulnerable for alterations in functional status and quality of life due to their typically advanced age and high symptom burden. Clinical manifestations of the disease (osteolytic bone destruction, anemia, renal insufficiency, and hypercalcemia) are compounded by significant treatment

toxicities. Cancer occurs within the context of the family, and thus, both survivors and their family caregivers must master self-management tasks related not only to the disease and treatment, but also associated with transitioning to living with chronic illness. These chronic illness self-management tasks are substantial and include learning about and solving problems related to the illness, performing health promotion activities, engaging resources to assist in managing symptoms, processing emotions, and integrating illness into daily life (Schulman-Green et al., 2012).

Successful adoption of these self-management tasks requires sufficient activation, the state of possessing the skills, knowledge, and confidence to manage one's own health (Hibbard, Mahoney, Stock, & Tusler, 2007). Activation refers to an individual's willingness and ability to assume a role in their own health and healthcare. Hibbard describes activation as modifiable and developmental, with four levels ranging from those individuals who are passive recipients of care (level 1) to those

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who have adopted new behaviors, but may need additional support during times of stress or crises (level 4) (Hibbard, Mahoney, Stockard, & Tusler, 2005). Higher levels of activation are associated with positive self-management behaviors and outcomes in a variety of chronic health conditions (Greene & Hibbard, 2012; Hibbard et al., 2007; Rask et al., 2009). Activation is equally important for caregivers, who often neglect their own needs and health during their family member's cancer treatment. However, psychological distress, common in both cancer patients (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001) and caregivers, (Pitceathly & Maguire, 2003) impedes activation (Gerber et al., 2011) and can have a negative impact on self-management during the transition to living with a chronic illness. In a recent cross-sectional study, anxiety was significantly higher ($p < 0.05$) in family caregivers than patients with multiple myeloma and more prevalent (48.8% vs. 27.4%; Molassiotis, Wilson, Blair, Howe, & Cavet, 2011). Caregivers in this study also reported a higher number of unmet psychosocial needs than patients.

The primary aim of this IRB-approved pilot study was to assess the feasibility, acceptability, safety, and fidelity of a family-centered, dyadic intervention for distress management that included both a psychoeducational approach and a low-intensity walking activity. The secondary aim was to obtain preliminary data of the effect of the intervention, as compared to an attention control group, on anxiety, activation for self-management, fatigue, depression and health-related quality of life (HRQOL) in patients with multiple myeloma and their family caregivers.

2. Methods

2.1. Design, sample, & procedures

A sample of 15 adult patients with multiple myeloma and their family caregivers were recruited at a National Cancer Institute (NCI) designated Comprehensive Cancer Center and randomized into either an intervention or attention-control group. Inclusion criteria were: 18 years or older, within 12 months of a new diagnosis of multiple myeloma (all stages, with or without treatment), and able to identify a family caregiver who was willing to participate. Caregivers did not need to reside with the patient. Both patient and caregiver participants were medically screened for readiness to participate in the low-impact walking activity. Exclusion criteria were: severe pain (score of 7/10), high risk for bone fracture or venous thrombosis, or an Eastern Cooperative Oncology Group (ECOG) Performance Score greater than or equal to 3.

The intervention, grounded in self-determination theory, consisted of an in-person session delivered by a research nurse to the patient and caregiver simultaneously during a clinic visit. The aim of the psychoeducational component of the intervention, was to prepare the patient and caregiver for the transition of living with a chronic illness by eliciting feelings, providing information, and assisting the individual to problem-solve. Two NCI patient and caregiver booklets, as well as the American Cancer Society website, were provided to participants. The behavioral component of the intervention involved a home-based, low-impact walking activity that could be performed as a mutual activity either as a dyad or independently. Participants were taught to function as “accountability partners” to each other by gently encouraging activity through phone calls, e-mails, or in-person contact. Although a step goal was not prescribed, an individualized walking prescription, consistent with national guidelines for physical activity, (U.S. Department of Health and Human Services, 2008) was given to both the caregiver and patient with the overall goal being to gradually increase walking to 30 min/day, five times/week. Self-monitoring with a pedometer was recorded on a calendar to reinforce walking activity. Booster telephone calls were made individually to the patient and caregiver at one and three weeks after the intervention to encourage continued uptake of the education and walking program. An exit interview was conducted after the last booster call. The attention control group

received the same printed educational resources provided to the intervention group, but were not given pedometers, counseling, or tailored instructions for walking activity. Telephone contacts that assessed general well-being were made by the research nurse at the same time intervals.

2.2. Measures

Outcomes were measured in-person upon enrollment, and then by mail at 6 and 12 weeks. For both patients and caregivers, the Patient-Reported Outcomes Measurement Information System (PROMIS; Cella et al., 2010) short forms were used to measure depression (v. 8a), anxiety (v. 7a), fatigue (v. 7a), and HRQOL (v. 1.0/1.1). The patient's skills, knowledge, and confidence for self-management was measured by the Patient Activation Measure (PAM; Hibbard, Stockard, Mahoney, & Tusler, 2004). Two measures assessed activation of the caregiver: the Caregiver Patient Activation Measure (CPAM; Craig Swanson, Insignia Health, LLC, personal communication, June 16, 2011) evaluated activation for the caregiving role, and the “Caring for Oneself” subscale of the Caregiver Inventory assessed caregiver confidence in their own physical and emotional self-care (Merluzzi, Philip, Vachon, & Heitzmann, 2011). Using the distress thermometer (National Comprehensive Cancer Network, 2012), participants rated their level of emotional distress during the past week on a single scale from 0 (no distress) to 10 (extreme distress). Physical activity was measured using the short form version of the International Physical Activity Questionnaire and responses were categorized into low, moderate, and high scores (Craig et al., 2003).

2.3. Data analysis

A change score from enrollment (Time 1) to 12 weeks (Time 3) was computed for each participant on each of the outcome variables. Descriptive statistics were used to describe sample characteristics, outcome variables, and the percent of participants who had improvement in outcome variables over time. The analyses were performed using IBM SPSS Statistics 24.

3. Results

A total of 52 patients were screened and 29 patient/caregiver dyads were invited to participate. Of these, 15 dyads (7 control and 8 intervention) enrolled, yielding a 52% enrollment rate. The average age was

Table 1
Number and percent of subjects improving in outcome variables over time.

Group	Variable	Control (n = 6) n (%)	Intervention (n = 7) n (%)
Patient	Patient activation ^a	1 (25)	5 (71)
	Fatigue	3 (50)	3 (43)
	Depression	0 (0)	5 (71)
	Anxiety	2 (33)	3 (43)
	HRQOL physical health ^a	3 (60)	6 (86)
	HRQOL mental health	3 (50)	1 (14)
	Emotional distress	2 (33)	5 (71)
Group	Variable	Control (n = 6) n (%)	Intervention (n = 6) ^b n (%)
Caregiver	Caregiver activation	5 (83)	2 (33)
	Self-efficacy	4 (67)	1 (17)
	Fatigue	4 (67)	1 (17)
	Depression	2 (33)	1 (17)
	Anxiety	3 (50)	2 (33)
	HRQOL physical health	3 (50)	0 (0)
	HRQOL mental health	2 (33)	2 (33)
Emotional distress	4 (67)	3 (50)	

^a Due to missing data in the patient control group, n = 4 for activation and n = 5 for physical health.

^b Due to missing data in the caregiver intervention group, n = 6.

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