

Legacy Activities as Interventions Approaching the End of Life

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Abstract

We examined the efficacy of an innovative family-based intervention designed to decrease caregiving stress and increase family communication among individuals with chronic, life-limiting illnesses and their family caregivers in a randomized, contact control group design. The intervention group received three home visits in which the interventionist actively worked with the family to construct a personal Legacy, usually a scrapbook with photographs or audiotaped stories. Control group families received three supportive telephone calls. Of the 42 families that entered the project, 31 families completed follow-up assessments within 9 to 10 weeks (14 control; 17 intervention; 72% African American) for a retention rate of 74%. Intervention caregivers showed reduced caregiving stress in comparison with control group caregivers, who showed increases in stress. Intervention patients reported decreased breathing difficulty and increased religious meaning. Caregivers and patients reported greater social interaction on the part of the patient. All participants in the intervention group initiated a Legacy activity and reported that Legacy improved family communication. Legacy interventions hold promise and are simple to implement.

Introduction

TIME IS OF THE ESSENCE when a person is approaching the end of life amidst illness and debility. Socioemotional selectivity theory (SST) posits that motivational shifts caused by an increasingly limited perspective of future time (e.g., time left to live) cause the importance and depth of emotional connections to increase, and emotional experiences to become more complex.^{1,2} This shift in motivation is associated with increased salience of positive information, and increased recall of positive information is associated with better cognitive and emotional outcomes.^{3,4} Folkman's⁵ stress process model incorporates the impact of positive emotional states, or "meaning-based coping," in the maintenance of the coping process. Folkman posited that meaning-based coping including revised goals, positive events, and religious/spiritual beliefs serves as a method of reducing the impact of negative life events. Our theoretical model (Fig. 1) is a simplification of Folkman's⁵ model that attempts to target meaning-based coping in the context of a family intervention.

Ill persons worry that their illness is interfering with other responsibilities of their caretakers and family,⁶ and approximately 39% of patients with advanced cancer report mild

concern from self-perceived burden to others while an additional 38% report moderate to extreme concern.⁷ Moreover, family caregivers of individuals approaching the end of life are at risk of stress, depression, and health problems.^{8,9} Yet, as represented by Folkman's concept of meaning-based coping, elders facing adversity frequently report benefits resulting from their negative experiences.¹⁰⁻¹³

Prior research has indicated that older adults treated with 4 weeks of reminiscence structured to target specific personal memories showed fewer depressive symptoms, less hopelessness, improved life satisfaction, and retrieval of more specific events.¹⁴ Depression is linked to overall activity and to levels of positive affect (i.e., interest, pleasure, contentment, happiness),¹⁵⁻¹⁷ which may be increased by participation in pleasant activities.¹⁷ It is possible, then, that engagement in pleasant and meaningful activities can improve the quality of life of individuals approaching the end of life and their families.¹⁵⁻¹⁹ Families might be particularly responsive to interventions promoting generativity, the desire to teach and help future generations avoid the pitfalls of life by facilitating the transmission of personal and cultural values.²⁰

Life review is a brief treatment approach that has not been widely applied in palliative care settings. Activities cele-

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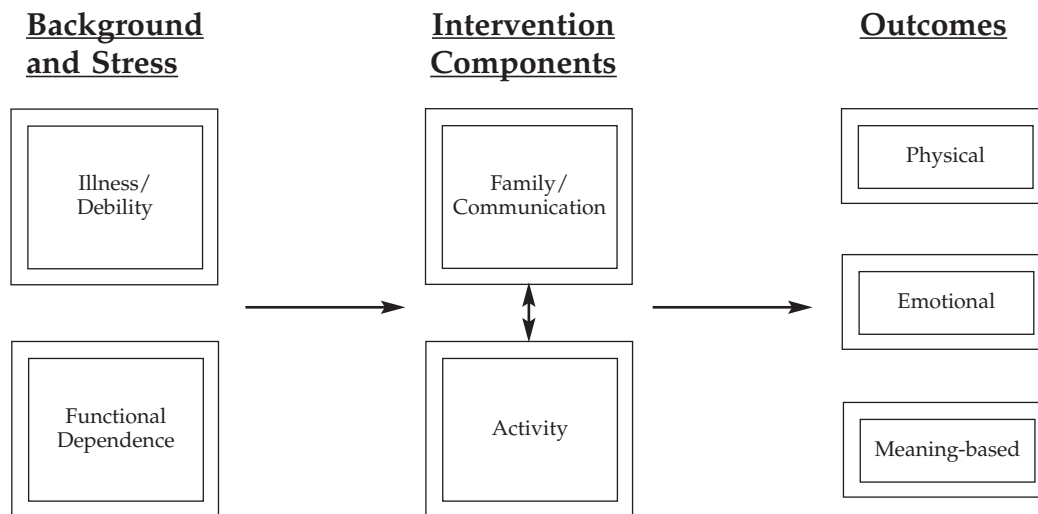


FIG. 1. Theoretical model modified from the Revised Stress and Coping Model.⁵

brating one's life can maintain: (1) one's sense of essence (continuity of self),¹⁸ (2) self-regard or pride, and (3) belief that prior roles are worthy of investment in the face of deteriorating health.^{17,19,21} Moreover, Chochinov's Dignity Therapy^{19,21} has been shown effective in reducing physical suffering and depressive symptoms and increasing the will to live among terminally ill inpatients and those receiving home-based palliative care.¹⁹ Patients' belief that the Dignity interviews would be helpful to family members was associated with perceptions that life is more meaningful, but no assessment of the impact of Dignity Therapy on family caregivers' outcomes was reported.

The purpose of this project was to assess the feasibility and efficacy of a family-based intervention targeting meaning-based coping⁵ (Fig. 1) to decrease palliative caregiving stress and increase perceptions of meaning by palliative patients. The project incorporates evidence-based treatment components from life review and cognitive behavioral therapy (CBT), which has been shown effective in reducing symptoms of depression among older adults.²²

We hypothesized that caregivers in the intervention would report decreased caregiving stress in comparison with caregivers in the control group as a result of more frequent and positive interactions with the patient. Second, we explored whether caregivers in the intervention and control groups would report change in the patients' symptoms at 9–10 weeks of follow-up (Time 1). It is possible that more positive interactions with the patient would influence caregivers' perceptions of patients' illness as expressed through observable symptoms. Finally, we hypothesized that caregivers in the intervention would report enhanced aspects of religiosity/spirituality in comparison with caregivers in the control group. We included this hypothesis in accordance with Folkman's⁵ conceptualization of meaning-based coping, and due to burgeoning interest in how religiosity/spirituality contribute to well-being.^{23,24}

We explored whether patients in the intervention would report change in physical symptoms (i.e., pain, nausea, drowsiness, appetite, breathing difficulty) at Time 1, and hypothesized that they would report increased interaction and decreased depression in comparison with control group pa-

tients. Second, we hypothesized that intervention patients would report better subjective well-being at Time 1 as a result of greater interaction with their caregiver. Third, we hypothesized that patients in the intervention would report enhanced meaning-based coping as reflected in aspects of religiosity/spirituality in comparison with patients in the control group.

Treatment implementation data were expected to show that master's level graduate students in psychology and social work could deliver the intervention accurately and that participants would enact the intervention in their daily lives.

Methods

Participants

Participants were recruited from community and health care agencies including hospitals and dialysis centers. Patients were screened for eligibility using: (1) age 60 or older; (2) living in the community; (3) having a life-limiting illness or combination of chronic illnesses; and (4) receiving assistance in the form of basic activities of daily living (ADL) or instrumental activities of daily living (IADL) from a family caregiver. Table 1 lists the diagnoses of participants, as identified by patient and family self-report (medical records were not reviewed). The majority ($n = 16$) suffered from general debility and functional decline due to multiple chronic medical illnesses, but others identified heart disease, stroke, chronic renal failure, cancer, and dementia (age 88; Mini-Mental State Examination [MMSE] = 14) as primary medical problems.

Caregivers were screened for eligibility based on: (1) having weekly face-to-face contact with the patient to provide assistance with ADL or IADL needs; (2) being cognitively intact as measured by a score of 24 or greater on the MMSE²⁵; and (3) not currently participating in another caregiver intervention study.

Legacy intervention

We define Legacy activities as projects that may: (1) assist individuals and families in initiating the process of life re-

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF PATIENTS AND CAREGIVERS WHO COMPLETED LEGACY

Sample characteristics	Experimental condition	
	Control group (n = 14)	Intervention group (n = 17)
<i>Patients</i>	<i>M (SD) or % (n)</i>	<i>M (SD) or % (n)</i>
Gender (% female)	79% (11)	71% (12)
Race (% African American)	79% (11)	65% (11)
Age	75.36 (11.25)	75.29 (10.49)
Education in years	11.93 (5.27)	12.65 (4.09)
Self-reported health	2.57 (0.65)	2.17 (0.81)
MMSE	24.92 (4.28)	23.65 (4.80)
Religious preference		
Baptist	79% (11)	47% (8)
Methodist	14% (2)	18% (3)
Other Protestant	7% (1)	18% (3)
Other	0% (0)	18% (3)
Diagnostic category ^a		
Heart Disease	36% (5)	12% (2)
Stroke	14% (2)	18% (3)
Chronic Renal Failure	0% (0)	23% (4)
Cancer	14% (2)	6% (1)
Dementia	0% (0)	6% (1)
General debility/multiple chronic illnesses	50% (7)	53% (9)
<i>Caregivers</i>		
Gender (% female)	79% (11)	88%
Race (% African American)	71% (10)	65%
Age	57.78 (10.42)	55.06 (15.23)
Education in years	13.71 (2.49)	14.65 (3.14)
Number assisted activities ^b	1.79 (0.43)	1.59 (0.80)
Self-reported health	3.23 (0.72)	3.37 (0.62)
Religious preference		
Baptist	54% (8)	59% (10)
Methodist	15% (2)	18% (3)
Other Protestant	23% (3)	24% (4)
Other	8% (1)	0% (0)

^aTotal is > 31 since some patients had multiple diagnoses.

^bActivities of daily living (ADLs).

Note. Caregiver and patient health were measured on the following scale: 0 = poor, 1 = poor, 2 = fair, 3 = good, and 4 = excellent. All percentages are rounded to the nearest whole percent. MMSE, Mini-Mental State Examination.

view and (2) result in a product that can be enjoyed by family and friends prior to and after the individual's death. Patients chose a Legacy project from a list of suggested activities that met these criteria. We based the development of our Legacy Participant Notebook on the Hospice Foundation of America's *A Guide for Recalling and Telling Your Life Story*.²⁶ The Legacy Participant Notebook (R.S. Allen and M.M. Hilgeman, unpublished manuscript, 2003) and accompanying Interventionist Treatment Manual consist of: (1) an introduction to the Legacy Project, (2) deciding on a personal Legacy using the steps of problem solving, (3) constructing a personal Legacy, (4) evaluation of the Legacy activity, and (5) an appendix with specific life review questions for those dyads that find generation of stories difficult. Interventionists had no assessment contact with the dyad.

Our intervention was delivered in three in-home visits scheduled approximately weekly at the dyads' convenience. Interventionists received intensive training, including reading materials, structured role-play, and practice opportuni-

ties observed by a licensed clinical psychologist (R.S.A.). The first intervention session averaged 82 minutes, the second averaged 66 minutes, and the third averaged 70 minutes in length.

Session 1. The *Legacy Participant Notebook* (R.S. Allen and M.M. Hilgeman, unpublished manuscript, 2003) and a problem-solving approach were introduced to the dyad and used to identify one Legacy project. Using a standard set of questions (Table 2), the interventionist coached the dyad to discuss positive memories of their shared past. Interventionists were trained to criterion to include both the patient and the caregiver in generating and sharing positive memories by directing certain questions to the patient and other questions to the caregiver.

Next, the interventionist helped the dyad narrow the focus to a time period in the patients' life that could be adequately represented in one tangible Legacy project (e.g., scrapbook, cookbook, audiotapes). The interventionist and

TABLE 2. ITEMS USED IN SESSION 1 OF THE LEGACY PARTICIPANT NOTEBOOK

Patient Questions—4 items
“The things I care about and value most in my life are . . .”
“The most important people in my life have been . . .”
“I would like people to remember these things about me . . .”
“The ideas, books, music, and poems that have most influenced my life are . . .”
Caregiver Questions—3 items
“My favorite memories of times with my loved one are . . .”
“The things I most want to remember about my loved one are . . .”
“The lessons/values I have learned or most associate with my loved one are . . .”
Tips for Legacy Activities
1. Writing or recording stories on paper
2. Recording on an audio cassette tape player
3. Scrapbook or photo album
4. Videotape recording
5. Family cookbook
6. Other ideas

dyad actively brainstormed potential means to portray the life story; then the interventionist helped the dyad narrow the focus to one meaningful project, directing the dyad to the *Legacy Participant Notebook* (R.S. Allen and M.M. Hilgeman, unpublished manuscript, 2003) for tips in project construction. By the end of the first Legacy intervention session, the dyad was given the homework assignment to actively work on completing a portion of the Legacy project between sessions. Dyads received \$25 to offset the costs of purchasing Legacy materials.

Session 2. This session consisted of the interventionist coaching, reinforcing, and problem-solving the dyad's progress toward creating one tangible and lasting Legacy. Dyads were strongly encouraged to use the Legacy materials in their daily lives. For example, the patient was encouraged to share their Legacy with other family members and friends. If progress was not made on the Legacy project chosen in Session 1, time was used to identify and address barriers to completing the previous week's goals. If needed, the problem-solving skills rubric was used to identify either: (1) another time period of the patient's life to represent in a Legacy or (2) another project to represent the time period of the patient's life agreed upon in Session 1.

Session 3. The final intervention session consisted of sharing the dyad's Legacy project with the interventionist and evaluating the intervention procedures. Specific questions provided in the *Legacy Participant Notebook* (R.S. Allen and M.M. Hilgeman, unpublished manuscript, 2003) guided dyads in evaluating the experience of constructing a Legacy. The dyad was encouraged to construct other Legacies and share their Legacy work with other family members and friends in their daily lives on an ongoing basis.

Contact control group

Our emotional support contact control was administered individually via telephone, and provided minimal, nonspecific support. Patients and caregivers participated in separate calls with a member of the research team. Phone con-

tacts coincided with the frequency of intervention group contacts. Our control group provides a contact but not full attentional control. The first control call with patients and caregivers averaged 16 minutes, the second averaged 13 minutes, and the third averaged 14 minutes in length.

Control callers asked general questions of patients and their caregivers in individual calls and then engaged in supportive conversations using empathic listening and reflection. No information was provided regarding Legacy. At the end of Time 1 assessment, control group dyads were scheduled for one in-home visit to receive the *Legacy Participant Notebook* (R.S. Allen and M.M. Hilgeman, unpublished manuscript, 2003) and guidance in how to construct a Legacy. These sessions involved both members of the dyad in the same fashion as Legacy intervention visits.

Measures

Dyads completed the following measures at baseline and Time 1.

Demographics. Participants provided their age, race, gender, years of education completed, health status, and marital status at baseline.

MMSE. The 11-item MMSE²⁵ includes several tasks that cover orientation, memory, attention, ability to name objects, follow verbal and written commands, write a sentence, and copy a complex design. Scores range from 0 to 30 with scores equal to or below 24 indicating cognitive impairment. This well-validated measure has test-retest correlations of 0.80 to 0.95.²⁷

Physical Self-Maintenance Scale and IADL Measures. Caregivers completed these measures in reference to their patient's functional status at baseline. Six physical care domains (i.e., toileting, feeding, dressing, grooming, locomotion, bathing) and eight IADL domains (i.e., medications, finances, housekeeping, meal preparation, shopping, telephone use, laundry, transportation) were represented by five-point Likert-type scales with higher numbers indicating

greater disability. This scale has satisfactory interrater reliability and construct validity.²⁸

Subjective well-being. Psychological well-being was assessed via three questions ($\alpha = 0.67$) regarding the participant's perception of life-satisfaction (four-point scale from very dissatisfied to very satisfied), overall happiness (three-point scale indicating not to happy, pretty happy, very happy), and goal attainment (achieved goals mostly or less; range, 3 to 9) with higher scores indicating greater levels of subjective well-being (SWB).²⁹

Edmonton Symptom Assessment Scale—modified (ESAS). Patients and caregivers independently completed this six-item visual analogue (0 to 10) scale in reference to the patient's experience with summed scores ranging from 0 to 60 and higher scores indicating worse symptoms. Studies have confirmed the validity of the ESAS in palliative care patient populations.^{30–32} We included standard ESAS items measuring pain, tiredness, nausea, drowsiness, appetite, and breathing difficulty. However, we omitted items measuring anxiety, depression, and well-being in the interest of brevity as these variables were measured by other instruments. We substituted agitation for anxiety for reasons described below.

Additional symptom assessments. Patients and caregivers independently completed visual analogue (0 to 10) scales in reference to the patient's symptoms including weight loss, talkativeness, and agitation. Talkativeness and agitation were included due to interest in whether participating in the Legacy intervention increased the frequency of family communication without causing agitation. Agitation is a more general construct than anxiety and may be easier to detect in another person's behavior. Weight loss was included due to interest in monitoring a physical symptom that is strongly associated with proximity to death.

Brief Multidimensional Measure of Religion and Spirituality (BMMRS). This study used three of the indices from the Brief Multidimensional Measure of Religion and Spirituality³³ (BMMRS; 9 Likert-type items): Religious Preference (1 item) assessed primary religious affiliation. Daily Spiritual Experiences (6 items; range, 6–36; $\alpha = 0.91$) was included to measure "the individual's perception of the transcendent (God, the divine) in daily life and the perception of interaction with, or involvement of, the transcendent in life."^{33(p11)} Two items suggested for consideration as a short form measure of "religious meaning"³³ were "I believe in a God who watches over me" and "I feel a deep sense of responsibility for reducing pain and suffering in the world" (2 items; range, 2–8; $\alpha = 0.64$). These items assessed an individual's sense of having a "unique, externally given purpose in life."^{33(p19)}

Depression. The 20-item Center for Epidemiological Studies-Depression scale (CES-D) asks about the frequency of depressive symptoms within the past week, with a score of 16 or greater indicating clinically significant levels of depression.³⁴ The CES-D has good internal consistency: Cronbach $\alpha = 0.73$ to 0.81.³⁵ This measure was omitted during the

first weeks of data collection due to project personnel error, limiting our preassessment/postassessment to 22 dyads.

Caregiver Stressors Scale—Revised. Caregivers completed this 25-item measure³⁶ of caregiving competency, strain, role overload, role captivity, and emotional control, with higher scores indicating greater caregiving stress. Internal consistency estimates range from 0.60 to 0.82, with stability coefficients ranging from 0.61 to 0.74.

Project Evaluation Survey. This nine-item survey asked participants whether they would recommend the Legacy Project to others, about their satisfaction with their progress on the Legacy Activity, whether they would continue working on the Legacy, whether the Legacy Activity helped communication, how recalling family memories made the participants feel, likes/dislikes about Legacy and what aspects of Legacy worked well or did not work as well.

Procedure

Baseline and Time 1 assessments were completed in separate, concurrent interviews with the caregiver and patient at the home of one member of the dyad. Time 1 assessments occurred approximately 1 week after the completion of the intervention or control contacts. Two members of the research team who had no intervention contact with the dyad conducted the concurrent interviews and measures were administered with response cards available to participants to facilitate accuracy. Each participant was given a notebook during baseline and Time 1 assessments so that the research interviewers could cue the participant to answer specific items to specific assessments with specific response options. After baseline, dyads were stratified by race and randomly assigned to either an intervention or control condition. Interventionists were graduate psychology or social work students supervised by a licensed clinical psychologist (R.S.A.). Intervention sessions and control telephone contacts were audiotaped. Patients and caregivers who completed both assessments each received a \$20 Wal-Mart gift certificate for participation.

Data analysis

We conducted two (group) by two (time of assessment) mixed-model analysis of variance for each of the primary outcomes. Missing data reflects omission of the CES-D at baseline in the initial nine dyads or death of the patient. Significance levels for all comparisons were set at 0.07 given that this was a pilot efficacy study. Table 1 presents demographic information for patients and caregivers by intervention and control group. Means and standard deviations for study variables at baseline and Time 1 are reported in Table 3.

Results

Demographic, recruitment, and retention data

Although many individuals indicated initial interest and were referred to the project ($n = 134$ dyads), only 47 dyads met entry criteria and scheduled a baseline assessment. Common reasons for not scheduling a baseline included not hav-

TABLE 3. CHARACTERISTICS OF PATIENTS AND CAREGIVERS WHO COMPLETED LEGACY

Participant characteristics	Experimental condition			
	Intervention group (n = 17 dyads)		Control group (n = 14 dyads)	
	Baseline	Time 1	Baseline	Time 1
Caregiver				
Subjective Well-being	4.24 (1.03)	4.18 (0.95)	4.14 (1.17)	4.50 (9.21)
CES-D ^a	13.45 (8.38)	12.58 (9.41)	8.08 (7.78)	9.17 (6.98)
Caregiver Stress	49.65 (7.35)	48.94 (6.82)	43.64 (7.13)	46.57 (7.10)
Edmonton Symptom (total) ^b	19.94 (8.53)	24.53 (15.07)	22.50 (10.90)	21.71 (9.54)
Pain	4.06 (2.66)	4.59 (3.41)	4.36 (2.37)	4.86 (2.48)
Tired	5.06 (1.75)	5.76 (2.75)	5.29 (2.97)	5.00 (2.22)
Nausea	1.53 (1.33)	1.94 (2.54)	1.93 (2.06)	2.93 (2.62)
Drowsiness	3.65 (2.34)	4.76 (3.36)	4.21 (2.91)	4.00 (2.35)
Appetite	3.06 (2.28)	3.88 (3.14)	2.93 (1.81)	3.36 (2.50)
Shortness of breath	2.59 (2.18)	2.89 (2.89)	3.79 (3.47)	4.14 (2.80)
Additional Symptoms				
Weight loss	3.24 (2.14)	3.59 (3.32)	2.93 (3.03)	1.57 (1.10)
Talkativeness	3.35 (2.64)	4.94 (2.77)	4.14 (2.83)	2.64 (1.69)
Agitation	2.76 (2.14)	4.35 (2.89)	3.93 (2.79)	4.64 (2.76)
BMMRS Subscales				
Daily Spiritual Exper.	30.82 (2.9)	30.71 (3.50)	31.21 (2.81)	31.29 (3.73)
Meaning	7.06 (.90)	7.06 (0.75)	7.21 (.80)	7.00 (0.78)
Patient				
Subjective Well-being	4.53 (1.81)	4.47 (1.73)	4.79 (1.37)	4.93 (1.07)
CES-D ^a	18.80 (12.06)	15.30 (11.54)	13.92 (9.92)	14.58 (9.55)
# of ADLs Assisted ^c	1.59 (.80)	—	1.79 (.43)	—
Edmonton Symptom (total)	15.82 (8.46)	14.27 (9.19)	11.43 (5.88)	15.35 (10.29)
Pain	2.80 (2.32)	2.60 (2.29)	1.93 (1.86)	3.43 (3.06)
Tired	3.87 (2.98)	4.13 (2.88)	1.79 (1.85)	2.57 (2.98)
Nausea	1.80 (2.2)	1.40 (1.30)	1.36 (1.34)	1.50 (1.40)
Drowsiness	2.79 (2.88)	2.60 (2.20)	1.50 (1.29)	1.79 (1.25)
Appetite	1.47 (1.0)	2.20 (1.86)	1.86 (1.88)	2.57 (2.82)
Shortness of breath	3.00 (2.19)	1.43 (0.85)	3.00 (2.6)	3.50 (3.06)
Additional Symptoms				
Weight loss	4.00 (3.12)	3.93 (3.06)	3.43 (3.16)	3.93 (3.61)
Talkativeness	3.47 (2.88)	4.47 (3.34)	3.71 (2.92)	2.71 (2.27)
Agitation	3.14 (2.42)	3.43 (2.62)	1.71 (1.2)	2.21 (2.58)
BMMRS Subscales				
Daily Spiritual Exper.	30.93 (3.8)	28.86 (4.19)	30.71 (3.52)	31.36 (2.76)
Meaning	6.64 (1.58)	7.21 (0.80)	6.93 (.92)	6.43 (1.28)

^aCES-D data was only collected for 22 of the dyads.

^bEdmonton Symptom Data refers to the caregiver's appraisal of the patient's well-being.

^cADL information was only collected at baseline (Time 1).

Note. * $p < .05$, ** $p < .01$.

MMSE, Mini-Mental State Examination; BMMRS, Brief Multidimensional Measure of Religion and Spirituality; CES-D, Center for Epidemiological Studies-Depression Scale.

ing a family caregiver, death of the patient, patient was too healthy, or discontinued interest.

Of the 47 dyads entering the project, 42 completed baseline (89%). Reasons for discontinuing baseline for the other 5 dyads included the patient being too cognitively impaired to consent to research ($n = 2$), the patient changing his or her mind about participating ($n = 2$), and the patient changing her mind because she "can't seem to get [herself] together" ($n = 1$). This final patient is grouped separately due to questions regarding her subjective cognitive abilities and the possibility that she was experiencing cognitive decline that was not detected by the MMSE. Thirty-one of 42 dyads complet-

ing baseline completed the study through Time 1 assessment (74%). Patients and caregivers comprising the 11 dyads that completed baseline but did not complete the study were not significantly different than those who completed the study in age, education, MMSE,²⁴ or self-reported health status. Control dyads averaged 9.26 weeks (standard deviation [SD] = 3.56) between baseline and Time 1 assessment; intervention dyads averaged 9.92 weeks (SD = 4.91).

Two of the 31 patient and caregiver dyads only completed the first Legacy Intervention session (94% completed all three sessions) but received Time 1 assessments and are included in all of our analyses using an intention-to-treat design. This

sample contained 19 (30.65%) Caucasians and 43 (69.35%) African Americans. There were no differences between intervention and control caregiver or patient groups on any demographic variable or on MMSE scores.

Feasibility and treatment implementation data

A specialist in treatment outcomes and cognitive behavioral therapy with no formal ties to the Legacy Project reviewed audiotapes and transcripts from 5 of the 17 intervention dyads (29.41%) and 4 of the 14 control dyads (28.57%). Data from four primary interventionists were evaluated during sessions 1 and 3. Accuracy of treatment delivery averaged 91.55% (range, 87% to 100%).

Data from four primary control callers were evaluated during calls 1, 2, and 3 for evaluation of restraint from injecting Legacy treatment components into contacts with control group families. Accuracy of control calls averaged 90.45% (range, 78% to 100%).

Completion of Legacy activities and project evaluation data

All 17 intervention dyads initiated a Legacy project (100%), mostly photo albums or scrapbooks with a significant subset including family recipes. Three of these dyads (18%) reported active participation of at least one additional family member. On average, interventionists rated patients as more active than caregivers in working on the Legacy (83.55% participation versus 72.51% participation, respectively).

We found that 97% ($n = 30$ dyads) of all participants ($n = 31$ dyads) would recommend the Legacy Project to others. Among the 17 intervention families, 91% ($n = 15$ dyads) reported that the process of life review, Legacy selection and Legacy making evoked *no* feelings of discomfort. Eighty-one percent ($n = 14$ dyads) were "very satisfied" with their progress and 14% ($n = 2$ dyads) were "somewhat satisfied." Ninety percent ($n = 15$ dyads) believed that they would continue working on Legacy postintervention. The majority of participants reported that Legacy improved family communication "a great deal" (84%, $n = 14$ dyads) or "somewhat" (16%, $n = 3$ dyads).

Caregiver outcomes

Caregivers in the intervention group showed reduced caregiving stress at Time 1 in comparison with control group caregivers, who showed increases in stress $F(1, 29) = 4.93$, $p = 0.034$, $\eta^2 = 0.145$. Although the depression measure was added later in data collection ($n = 22$ dyads), caregivers in the control group reported increased depressive symptoms at Time 1 while caregivers in the intervention group reported modest reduction in depressive symptoms.

No such changes for caregiver estimates of pain, tiredness, nausea, drowsiness, decreased appetite, weight loss, or breathing difficulty were found. However, we found a significant group by time interaction for caregivers' report of patients' social engagement or talking, $F(1, 29) = 6.52$, $p = 0.016$, $\eta^2 = 0.184$. Caregivers in the control group reported that their patients decreased in social engagement while intervention group caregivers reported that their patients be-

came more talkative. We also found a significant main effect of time on caregiver report of patient agitation, $F(1, 29) = 7.24$, $p = 0.012$, $\eta^2 = 0.20$. Both groups of caregivers reported an increase in agitation among patients.

We found no such changes in aspects of religiosity/spirituality in comparison with control group caregivers across time.

Patient outcomes

We found no change in patients' self-report of agitation, tiredness, nausea, drowsiness, appetite, or weight loss. However, we found a significant group by time interaction for self-reported talkativeness, $F(1, 27) = 6.21$, $p = 0.019$, $\eta^2 = 0.187$. Intervention patients reported an increase in talkativeness across time while control group patients reported a decrease.

We found modestly improved physical symptoms among intervention patients. Specifically, we found a significant group by time interaction for patients' self-reported breathing difficulty, $F(1, 26) = 5.54$, $p = 0.026$, $\eta^2 = 0.176$ and a marginally significant group by time interaction for patients' self-reported pain, $F(1, 27) = 3.77$, $p = 0.063$, $\eta^2 = 0.123$. Patients in the control group reported increased symptom burden while intervention patients reported decreased breathing difficulty and pain.

Patients did not report increased well-being. Although the depression measure was added later ($n = 22$ dyads), patients in the control group reported increased symptoms of depression at Time 1 while patients in the intervention group reported reduction in depressive symptoms.

Patients in the intervention group reported an increased sense of religious meaning while control group patients reported a decreased sense of meaning $F(1,26) = 5.10$, $p = 0.032$, $\eta^2 = 0.164$. Curiously, we found a marginally significant group by time interaction for daily spiritual experiences, $F(1,26) = 3.72$, $p = 0.065$, $\eta^2 = 0.125$; intervention patients reported decreased experiences while control group patients reported an increase.

Discussion

These initial data suggest that our three-session Legacy intervention holds promise as a treatment for individuals with chronic, life-limiting illnesses and their palliative family caregivers. The Legacy intervention is simple and time-efficient, leading to the possibility of real-world translation in a variety of treatment settings.

We found a large effect ($\eta^2 = 0.145$) in the expected direction for intervention caregivers reporting decreased caregiving stress across time in comparison with control caregivers. Notably, caregiving stress was somewhat higher among intervention caregivers at baseline (Table 3). It is not surprising that stress increases with time among individuals caring for loved ones in the community with chronic debility and multiple, life-limiting illnesses. Future intervention studies should investigate whether this effect holds for caregivers across longer periods of time and whether it is generalizable to other negative affective states such as depression.

Although we found no changes in caregivers' report of patient physical symptoms, we found that intervention care-

givers reported that patients were more talkative across time in comparison with control patients. Talkativeness has been conceptualized as a measure of social engagement in previous studies³⁷ and patients near the end of life give great emphasis to family communication over and above symptom control.³⁸ Convergent evidence from patients' self-reports and project evaluation data seem to suggest that indeed, patients in the intervention group were more socially engaged with their family caregivers than patients in the control group. Future intervention research should attempt to replicate these findings, extending the positive communication effects to additional family members and/or friends.

Although enhancing spiritual aspects of the end-of-life experience for patients and families highlights one aspect of Folkman's⁵ concept of meaning-based coping, we found no support for the hypothesis that intervention group caregivers would report increased transcendence or meaning in comparison with control caregivers. It could be that, among palliative caregivers, religiosity/spirituality may not be the best measure of meaning-based coping. Perhaps it would be better to maintain focus on enhancing patients' religious/spiritual experiences near the end of life and examine a meaning-based outcome more proximal to the caregiving experience. Such a variable may be caregivers' report of positive aspects of caregiving,^{11,39,40} which would focus on caregivers' responses to the immediate caregiving situation rather than caregivers' relationship with the transcendent.

Chochinov and colleagues¹⁹ have also found decreased symptom burden among patients receiving Dignity Therapy. Symptoms such as breathing difficulty and pain may have significant psychosocial components, and Legacy or Dignity Therapy seem to have beneficial effect on the burden of these symptoms, although more research is needed. Curiously, caregivers in both groups reported increased agitation among patients, although patients did not report increased agitation. Future research should explore caregivers' perceptions of patient agitation to discover the reasons for this finding. It could be that meaningful activities trigger the bittersweet, or expectations in life that are not met.

We found no support for the hypothesis that patients in the intervention group would report increased well-being. It may have been that our three-item measure of well-being was inadequate to detect changes due to our three-session intervention, partly due to modest internal consistency ($\alpha = 0.67$). Future studies should examine other variables including positive and negative affect,⁴¹ hope,⁴² and more comprehensive measures of well-being.^{43,44}

We found partial support for enhanced aspects of religiosity/spirituality among patients in the intervention group, suggesting that palliative patients may be engaged in aspects of meaning-based coping in the face of negative health outcomes that they have limited ability to change. Specifically, patients in the Legacy group reported an increased sense of religious meaning across time in comparison with control group patients. However, patients in the intervention group reported marginally reduced daily spiritual experiences in comparison with control group patients. Future research should use qualitative interviews with patients nearing the end of life to explore these issues.

We acknowledge the limitations of this study. Our sample was primarily African American, Protestant and urban, representing a limited geographic region (i.e., the south-

eastern United States). Moreover, we do not examine the longevity of Legacy treatment effects, but only examine pretest–posttest outcomes in this initial randomized, contact control group design. Additionally, although our patients were all living in the community with chronic, life-limiting illness, their proximity to death varied. Thus, the potential efficacy of the Legacy intervention among dyads of other racial/ethnic or spiritual backgrounds, of patients nearer the end stage of the disease process, of patient and caregiver dyads living in different geographical locations, or across longer periods of time is unknown. Longitudinal research is needed with intervention designs incorporating greater attention to the progression of patients' disease process and greater attention to how effective interventions can be implemented and maintained in the real world. Additionally, future studies should include measures of life expectancy or patient prognosis as inclusion criteria.

Results regarding the efficacy and acceptability of the Legacy intervention suggest that the combined treatment components of life review and engagement in pleasant events, targeting meaning-based coping,⁵ may improve patients' and caregivers' communication and emotional aspects of quality of life. Although better measures of effective coping are needed, enhancing family communication may facilitate patients' generativity, the desire to give of oneself to future generations. Future research should investigate the potential of implementing the Legacy intervention through community volunteers to increase the likelihood of real-world translation, widespread implementation, and enhanced cost effectiveness.

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