

# Hearing and Heeding the Voices of those With Advanced Illnesses

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## Abstract

**Objectives:** To describe the feasibility of a chaplain-led spiritually focused life review interview and the development of a spiritual legacy document (SLD) for patients with advanced diseases and to describe changes in spiritual well-being (SWB), spiritual coping strategies (SC), and quality of life (QOL) after receiving the SLD. **Patients and Methods:** In all, 130 patients and support person (SP) pairs were recruited from July 2012 to January 2019. Following enrollment, demographic information was gathered and baseline questionnaires were administered. Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (FACIT-Sp-12) and a linear analog scale assessment (LASA) measured SWB. LASAs also measured QOL and emotional well-being (EWB). Positive Religious Coping Scale (RCOPE) measured SC. After completion of baseline forms, participants were interviewed (individually) by a chaplain. Interviews were digitally recorded, transcribed, and verified. Transcripts were edited and participants were given the opportunity to make adaptations. The participant-approved draft was then developed into a professionally printed SLD. Follow-up questionnaires were administered to assess change. **Results:** Significant improvements from baseline to post-SLD follow-up were found for patients on the LASAs: SWB (average 7.7-8.3,  $P = .01$ ), QOL (average 6.7-7.3,  $P = .03$ ), EWB (average 6.9-7.5,  $P = .01$ ), and on the positive RCOPE (average 1.8-2.0,  $P = .007$ ). Effect sizes were approximately 0.25. Considering any improvement, 61.0% improved their positive RCOPE score, 46.6% improved EWB, and 39.7% improved SWB. No significant changes were found on the FACIT-Sp-12. No significant changes were found for SPs. **Conclusion:** The results suggest that the primary participants who completed the study benefited by significantly increasing their QOL, SWB, EWB, and SC.

## Keywords

spirituality, palliative care, cancer, chronic illness, chaplain, life review

## Background

Spirituality is recognized as an essential part of holistic medical care, but it is an elusive entity and difficult to define. For some, religion may be essential in their experience of spirituality, but for others, this is not the case.<sup>1-3</sup> Some clarity is found in the Latin root of spirituality, “spiritus,” meaning breath, breath that gives life but also vitality, enriching all of our experiences.

Spirituality takes on more importance in times of challenge, including coming to the end of life or dealing with a debilitating disease.<sup>4,5</sup> Spiritual questions and spiritual distress are common at these times, and it is imperative that these be addressed, not only because this may contribute to well-being<sup>6-8</sup> but also because if left untended, spiritual questions and distress may exacerbate other symptoms, including physical pain.<sup>9</sup> The literature suggests that spirituality is most helpful when it has been well integrated into one’s approach to life,<sup>10-12</sup> and skilled clinicians can be instrumental in guiding patients toward this goal.<sup>13</sup> Chaplains, often included on palliative care teams,<sup>14,15</sup> are specifically educated to support this process.<sup>16</sup>

Hear My Voice (HMV) is a pilot study that engaged those with advanced illnesses in a spiritually focused life review with a board certified chaplain. The goal was to provide each participant (individually) the opportunity to discuss important

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aspects of his/her spirituality and to prepare a personal Spiritual Legacy Document (SLD) as a tangible record of his/her spiritual journey. For purposes of this study, spirituality was defined as a search for and connection to what is life-giving, meaningful, inspiring, and instructive. This definition was intended to be expansive and welcoming to those who were religious and those who were not.

Hear My Voice builds on the valuable work of Dignity Therapy (DT), a validated narrative intervention designed to address psychosocial and existential distress among terminally ill patients.<sup>17</sup> Like DT, HMV seeks to record and honor what is important to each patient so that he/she is seen, heard, and cared for beyond diagnoses and symptoms.<sup>18</sup>

Hear My Voice differs from DT in its specific spiritual focus and the involvement of chaplains as interviewers. Unlike DT and many forms of life review,<sup>19-21</sup> the HMV interview includes questions that encourage discussion about challenge and struggle. These were included because they address issues that are prominent during serious illness<sup>22</sup> and because of chaplains' competence in this area.<sup>16</sup>

The aims of HMV were (1) to describe the feasibility of using a chaplain-led spiritually focused life review interview and the development of a spiritual legacy document (SLD) for patients with advanced diseases and (2) to describe changes in spiritual well-being (SWB), spiritual coping strategies (SC), and quality of life (QOL) after receiving the SLD.

The results of phase 1 with the first thirty-two patients have been previously published.<sup>23-25</sup> The purpose of this article is to describe the results of the additional ninety-eight patients accrued after protocol modifications (phase 2) together with those from phase 1. Specifically, we focus on post-intervention completers from both phases combined. The article also continues the discussion of feasibility and implications for future research and clinical care.

## Patients and Methods

The setting of HMV was Mayo Clinic in Rochester, Minnesota. Recruitment began in July 2012, following the approval of the Institutional Review Board. The thirty-two phase 1 patients were recruited from July 2012 to July 2014. The remaining ninety-eight phase 2 patients were recruited from June 2015 to January 2019. There were two pauses in recruitment, the first, July 2014 to June 2015, during data collection and analysis of phase 1 data and planning for phase 2; the second, June 2017 to February 2018, to secure additional funding and accommodate staffing changes. The final thirty patients were enrolled after this second pause.

Primary participants in phase 1 were eligible if they were English-speaking adults, age 18 years or older, diagnosed with a brain tumor or other neurologic illness and considered able to complete all aspects of the study. Excluded were psychiatric inpatients and those for whom there were concerns about harm to self or others. The eligibility criteria in phase 2 were expanded to include those with non-neurologic advanced diseases, including those with other types of

advanced cancers and those with cardiac, pulmonary, and renal failure. This modification was initiated because of concern about completion rates and had the important advantage of increasing generalizability.

Referrals came primarily from the Mayo Clinic Cancer Center, Palliative Care Service, or Hospice. In phase 2, patients were also referred from the Renal Dialysis Unit. Additionally, some individuals self-referred. Potential participants were evaluated for eligibility, and those who met criteria were approached by a study team member who explained the protocol and gave them the opportunity to enroll. Primary participants provided written consent and were then asked to nominate a person who would complete questionnaires and assist with study procedures, if necessary. These secondary participants were consented orally and were called "support persons."

Following enrollment, pertinent demographic information was gathered and baseline questionnaires were administered to measure SWB, SC, and QOL. As in phase 1, the first set of phase 2 participants (participants 33-70) completed a 77-item questionnaire. Based on preliminary analysis which identified survey questions that did not show much change during follow-up, the items were reduced to twenty-two for participants 71 to 130. This modification was initiated out of concern for compromised patients with the intention of reducing questionnaire burden and improving completion rates.

The items common to both questionnaires were (1) the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (FACIT-Sp-12), known to be a broad and inclusive measure of SWB. It provides a total score of SWB and scores of its three subscales, faith, meaning, and peace;<sup>26</sup> (2) the single items of the QOL linear analog scale assessment (LASA) measuring overall QOL, SWB, and emotional well-being (EWB), domains most relevant to this study;<sup>27,28</sup> and (3) the positive Religious Coping Scale (RCOPE), describing SC strategies.<sup>29,30</sup> (The instruments and their selection have been more thoroughly described in previous publications.)<sup>23-25</sup>

Following the receipt of completed baseline questionnaires from each dyad, an interview with the primary participant and a chaplain was arranged. The interview was based on a semi-structured guide developed by chaplains and other research team members. The questions were adapted from recognized sources, that is, the FICA spiritual assessment tool,<sup>31</sup> DT,<sup>32</sup> and Pargament's research related to spiritual struggle.<sup>11</sup> A description of the interview guide is included in a previously published paper.<sup>23</sup>

Each interview was digitally recorded and transcribed, and verified by the interviewing chaplain. The directives for editing outlined in DT<sup>19</sup> were used as a model, but because of clinical demands, it was not possible for the interviewing chaplain take sole responsibility for editing the transcript. Other chaplains on the research team and a professional editor were involved in this process. Particular attention was given to sections of the transcript containing material that had the potential to be hurtful to the participant or others. These sections were edited in collaboration with the participant to ensure respect for all concerned. Participants were given the time they requested to make

additional adaptations to the draft, and/or to include several photos. Most took one to six months to do this. The final participant-approved draft was then developed into a professionally printed SLD and twenty-five or more copies were available to the participant as requested.

In phase 1, follow-up questionnaires were provided one month and three months after the receipt of the SLD. In phase 2, these time points were changed to two weeks after the interview and two weeks after the receipt of the SLD. This modification was initiated to determine the effect of the interview and also, to improve completion rates. Participants who completed the first or only post-SLD survey were considered to have completed the study. Satisfaction surveys were sent to study completers, beginning in phase 2, unless the participant was known to have died or to have become too debilitated to complete them.

### Analysis

The FACIT-Sp-12 survey items were scored as the sum of items within three subscales (peace, meaning, and faith, each with possible range from 0 [worst] to 16 [best]) along with the total score (possible range from 0 [worst] to 48 [best]). The positive RCOPE score was calculated as the mean of the seven items (possible range from 0 [worst] to 3 [best]). In cases of missing data among the items within a score for a participant, the mean of the non-missing items was used (and rescaled to the total for the sum scores). The three LASA items (EWB, SWB, and QOL) each ranged from 0 (as bad as it can be) to 10 (as good as it can be). These scores were all treated continuously for analysis.

Participant characteristics were summarized with frequencies and percentages or means and SD, as appropriate. Baseline characteristics and scores were compared between groups with  $\chi^2$  tests, Fisher exact tests, or *t* tests, as appropriate. Among the post-SLD completers, the average difference between baseline to post-SLD was calculated (along with 95% CIs) and assessed with paired *t* tests, and compared between groups with 2-sample *t* tests. Effect sizes were calculated as the average difference from baseline to post-SLD divided by the baseline SD. We also categorized the amount of change from baseline to post-SLD as any amount of improvement, maintaining the maximum score, no change, or worsening score. This categorical measure was compared between groups with  $\chi^2$  tests. *P* values less than .05 were considered statistically significant. Analyses were performed using SAS version 9.4<sup>33</sup> and *R*.<sup>34</sup>

### Results

The demographics of the primary participants who enrolled and those who completed the study are summarized in Table 1. Their average age was 63 years (SD: 18.6, range 18-102; 54.6% age 60 or older). Most were Caucasian (96.9%), female (62.3%), married (63.8%), and had at least some college/technical school (82.7%). Forty-three percent identified as Protestant, 30% as Catholic, and 15.4% as other denominations (two were Muslim, one was Jewish, four selected multiple denominations, and thirteen reported "other" religious preference). Fifteen (11.5%) specified no

religious preference. Overall, 57.7% of participants had cancer (71.9% in phase 1, 53.1% in phase 2). Among participants without cancer, twenty-five had a neurologic disease, twelve had kidney failure, eleven had cardiac failure, and eight had pulmonary failure. (Some had more than one condition.) The SP was most commonly either a spouse or partner (50.0%) or son or daughter (16.9%). Ninety-eight (75.4%) of those enrolled completed the interview, and seventy-seven (59.2%) completed the SLD. In all, fifty-nine (45.4%) participants completed post-SLD follow-up (46.9% in phase 1, 44.9% in phase 2, *P* = .99) and are considered completers (See Figure 1).

Of the seventy-one primary participants who did not complete the study, forty-eight became too ill to complete, one was withdrawn because he no longer met eligibility criteria, eight withdrew for personal reasons, and fourteen were lost to follow-up. As compared to the completers, non-completers were younger, less likely to have advanced education, and more likely to have cancer (data not shown). Religious affiliation was similar between these groups.

The key SWB, QOL, and SC measures at baseline among all participants and completers are shown in Table 2. Although overall QOL was slightly higher for phase 1 participants as compared to phase 2 (average 7.6 vs 6.5, *P* = .02), when considering the completers, no significant differences were found between study phases or by patient demographics (considering age, gender, marital status, education, denomination, and cancer diagnosis; data not shown). When comparing these same measures at baseline between completers and non-completers, no significant differences were found (data not shown).

Significant improvements from baseline to post-SLD follow-up were found on the three LASAs, EWB (average 6.9-7.5, *P* = .01), SWB (average 7.7-8.3, *P* = .01), overall QOL (average 6.7-7.3, *P* = .03), and positive RCOPE (average 1.8-2.0, *P* = .007). Each had effect sizes of approximately 0.25. Considering any amount of improvement, 61.0% of participants improved their positive RCOPE score (5.1% maintaining the maximum score), 46.6% improved EWB (3.4% maintaining the maximum), and 39.7% improved their SWB (13.8% maintaining the maximum). There were no significant changes found for the FACIT-Sp-12 (see Table 3). When comparing the likelihood of improvement (or maintaining the maximum) by patient demographics, no significant differences were found (data not shown).

Figure 2 illustrates changes in key measures from baseline to post-SLD follow-up, separately by study phase (1 vs 2) and diagnosis (cancer vs non-cancer). The meaning FACIT Sp-12 subscale worsened more among phase 2 participants as compared to phase 1 (*P* = .02). No significant differences were found when comparing participants with versus without cancer.

Satisfaction surveys were completed by twenty-four (40.7%) primary completers. All (100%) were satisfied with the care they received from the study team and indicated they would recommend HMV to others. The majority reported increased SWB (87.5%) and QOL (66.7%), corroborating improvements on the LASA. Additionally, 79% reported that the study increased their sense of dignity, meaning, and feeling respected and understood. Seventy-five percent indicated that it helped them accept things

**Table 1.** Participant Demographics.

|                                  | All participants, n (%) <sup>a</sup> |                     |                    | Post-SLD completers, n (%) <sup>a</sup> |                     |                   |
|----------------------------------|--------------------------------------|---------------------|--------------------|---|---------------------|-------------------|
|                                  | Phase 1<br>(N = 32)                  | Phase 2<br>(N = 98) | Total<br>(N = 130) | Phase 1<br>(N = 15)                     | Phase 2<br>(N = 44) | Total<br>(N = 59) |
| Age, years                       |                                      |                     |                    |   |                     |                   |
| 18-<35                           | 5 (15.6%)                            | 6 (6.1%)            | 11 (8.5%)          | 2 (13.3%)                               | 0 (0.0%)            | 2 (3.4%)          |
| 35-<60                           | 17 (53.1%)                           | 31 (31.6%)          | 48 (36.9%)         | 10 (66.7%)                              | 10 (22.7%)          | 20 (33.9%)        |
| 60-<80                           | 10 (31.3%)                           | 32 (32.7%)          | 42 (32.3%)         | 3 (20.0%)                               | 16 (36.4%)          | 19 (32.2%)        |
| ≥80                              | 0 (0.0%)                             | 29 (29.6%)          | 29 (22.3%)         | 0 (0.0%)                                | 18 (40.9%)          | 18 (30.5%)        |
| Mean (SD)                        | 52.3 (14.3)                          | 66.5 (18.6)         | 63.0 (18.6)        | 51.9 (14.2)                             | 72.4 (16.2)         | 67.2 (18.0)       |
| Gender                           |                                      |                     |                    |   |                     |                   |
| Male                             | 15 (46.9%)                           | 34 (34.7%)          | 49 (37.7%)         | 7 (46.7%)                               | 17 (38.6%)          | 24 (40.7%)        |
| Female                           | 17 (53.1%)                           | 64 (65.3%)          | 81 (62.3%)         | 8 (53.3%)                               | 27 (61.4%)          | 35 (59.3%)        |
| Marital status                   |                                      |                     |                    |   |                     |                   |
| Married                          | 24 (75.0%)                           | 59 (60.2%)          | 83 (63.8%)         | 11 (73.3%)                              | 26 (59.1%)          | 37 (62.7%)        |
| Single                           | 6 (18.8%)                            | 15 (15.3%)          | 21 (16.2%)         | 3 (20.0%)                               | 6 (13.6%)           | 9 (15.3%)         |
| Divorced or annulled             | 1 (3.1%)                             | 7 (7.1%)            | 8 (6.2%)           | 1 (6.7%)                                | 3 (6.8%)            | 4 (6.8%)          |
| Separated                        | 0 (0.0%)                             | 1 (1.0%)            | 1 (0.8%)           | 0 (0.0%)                                | 0 (0.0%)            | 0 (0.0%)          |
| Widowed                          | 1 (3.1%)                             | 16 (16.3%)          | 17 (13.1%)         | 0 (0.0%)                                | 9 (20.5%)           | 9 (15.3%)         |
| Support person relationship      |                                      |                     |                    |   |                     |                   |
| Spouse/partner                   | 24 (75.0%)                           | 38 (41.3%)          | 62 (50.0%)         | 11 (73.3%)                              | 19 (43.2%)          | 30 (50.8%)        |
| Sibling                          | 3 (9.4%)                             | 10 (10.9%)          | 13 (10.5%)         | 2 (13.3%)                               | 4 (9.1%)            | 6 (10.2%)         |
| Son/daughter                     | 0 (0.0%)                             | 21 (22.8%)          | 21 (16.9%)         | 0 (0.0%)                                | 12 (27.3%)          | 12 (20.3%)        |
| Friend                           | 1 (3.1%)                             | 10 (10.9%)          | 11 (8.9%)          | 0 (0.0%)                                | 5 (11.4%)           | 5 (8.5%)          |
| Other                            | 4 (12.5%)                            | 13 (14.1%)          | 17 (13.7%)         | 2 (13.3%)                               | 4 (9.1%)            | 6 (10.2%)         |
| Education                        |                                      |                     |                    |   |                     |                   |
| High school or less              | 4 (12.9%)                            | 18 (18.8%)          | 22 (17.3%)         | 0 (0.0%)                                | 5 (11.4%)           | 5 (8.5%)          |
| College/tech school <sup>b</sup> | 17 (54.8%)                           | 41 (42.7%)          | 58 (45.7%)         | 7 (46.7%)                               | 19 (43.2%)          | 26 (44.1%)        |
| Grad/prof school <sup>b</sup>    | 10 (32.3%)                           | 37 (38.5%)          | 47 (37.0%)         | 8 (53.3%)                               | 20 (45.5%)          | 28 (47.5%)        |
| Denomination                     |                                      |                     |                    |   |                     |                   |
| Protestant                       | 16 (50.0%)                           | 40 (40.8%)          | 56 (43.1%)         | 7 (46.7%)                               | 19 (43.2%)          | 26 (44.1%)        |
| Catholic                         | 8 (25.0%)                            | 31 (31.6%)          | 39 (30.0%)         | 5 (33.3%)                               | 14 (31.8%)          | 19 (32.2%)        |
| Jewish                           | 0 (0.0%)                             | 1 (1.0%)            | 1 (0.8%)           | 0 (0.0%)                                | 0 (0.0%)            | 0 (0.0%)          |
| Muslim                           | 1 (3.1%)                             | 1 (1.0%)            | 2 (1.5%)           | 0 (0.0%)                                | 1 (2.3%)            | 1 (1.7%)          |
| Other                            | 1 (3.1%)                             | 16 (16.3%)          | 17 (13.1%)         | 0 (0.0%)                                | 6 (13.6%)           | 6 (10.2%)         |
| No preference specified          | 6 (18.8%)                            | 9 (9.2%)            | 15 (11.5%)         | 3 (20.0%)                               | 4 (9.1%)            | 7 (11.9%)         |
| Diagnosis                        |                                      |                     |                    |   |                     |                   |
| Non-cancer <sup>c</sup>          | 9 (28.1%)                            | 46 (46.9%)          | 55 (42.3%)         | 6 (40.0%)                               | 28 (63.6%)          | 34 (57.6%)        |
| Cancer                           | 23 (71.9%)                           | 52 (53.1%)          | 75 (57.7%)         | 9 (60.0%)                               | 16 (36.4%)          | 25 (42.4%)        |

Abbreviation: SLD, Spiritual Legacy Document.

<sup>a</sup>N and % shown, unless otherwise specified. Frequencies not adding to column total indicate missing data.

<sup>b</sup>Includes those with at least some (without degree).

<sup>c</sup>Includes 2 patients with meningioma.

and gave them a sense of attending to unfinished business. Almost all expected the SLD to be of value to others (91.7%) and to influence how they were seen by them (87.5%). Some participants also reported that the study lessened their sadness (41.7%), suffering (41.7%), and feeling of being a burden (50%).

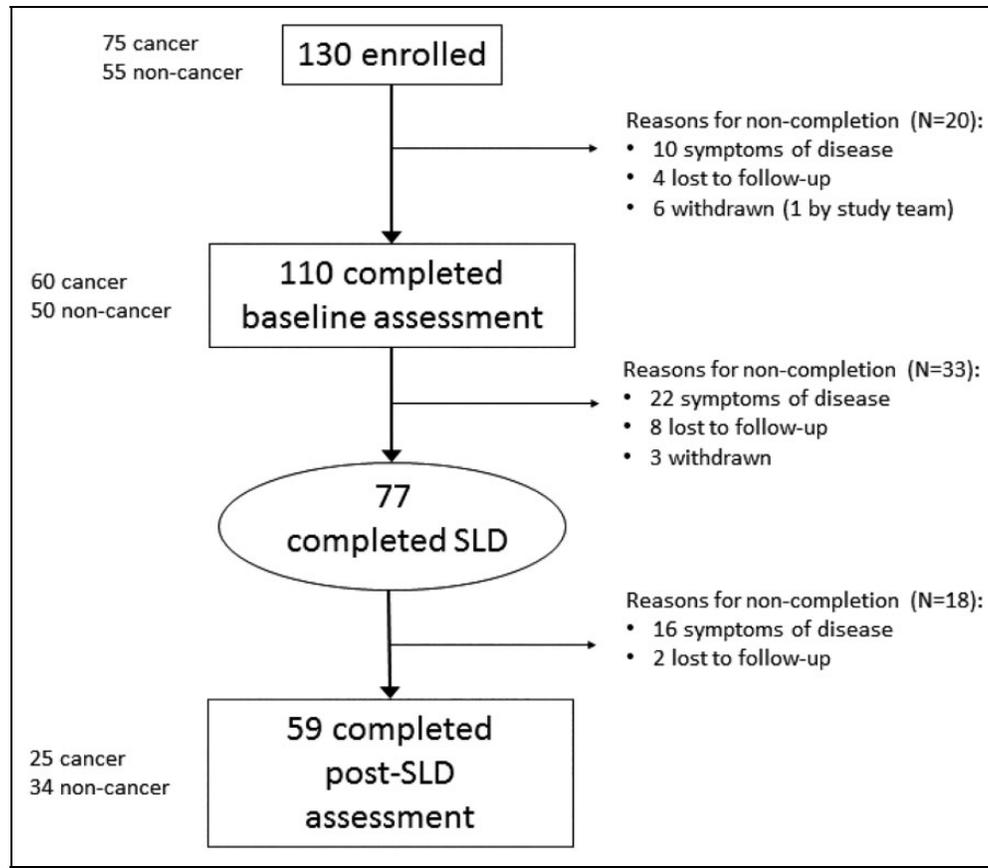
Among the SPs, fifty-five completed baseline and post-SLD assessments. No significant differences by time were found for key measures (FACIT-Sp-12, LASA, or positive RCOPE), but SPs reported high satisfaction with the study (data not shown.)

## Discussion

Hear My Voice has proven to be feasible to conduct. Enrollment suggests that the study was appealing to people of all

ages, men and women, and those of varying educational backgrounds, diagnostic groups, and life expectancies. Those identifying as Protestant or Catholic were most likely to enroll, probably due to the religious demographics of Minnesota and the surrounding areas, but several with no defined religious preference were also involved.

The results suggest that the primary participants who completed the study benefited by significantly increasing their SC, QOL, EWB, and SWB (on the LASA). The satisfaction surveys support these findings. Although the magnitude of improvements and clinical significance were modest, this outcome is quite remarkable considering the downward trajectories of participants' disease processes and the fact that baseline scores of well-being and coping were above average at baseline



**Figure 1.** Study flow.  
SLD indicates Spiritual Legacy Document.

(and therefore did not have substantial room for improvement). Seen in this context, even marginal increases or simply maintaining high levels of well-being over time could be seen as a successful outcome. It is important to note that a minority of participants reported decreases in well-being and coping after receiving the SLD. Future research could explore the reasons for such decreases, and perhaps arrange for follow-up support for this group.

It is interesting that the improvements detected on the total score of the FACIT-Sp-12 (and its peace and faith subscales) did not reach significance. This might in part be attributed to the fact that the FACIT-Sp-12 scores are calculated from multiple items, offering more opportunity for subjective response variability in the scores (more variability leads to smaller effect sizes and lower statistical power to detect differences), as compared to the LASA single-item measure. Beyond that, it is not clear why this outcome is different than that of the SWB LASA, but it has been noted before.<sup>27,35</sup> Based on our findings, it is possible that the SWB LASA would suffice in assessing SWB.

A major strength of this study is its intervention. At its heart, HMV provides respectful attention for persons living with the vulnerability that comes with serious illness. The positive results could be attributed to this attention which has been described elsewhere as a transformative “just and loving gaze.”<sup>36</sup>

Certainly, such attention is important in holistic care. However, as beneficial as it can be, we would argue that the intervention provided more than this. Its spiritual focus and the involvement of spiritual professionals facilitated participants’ engagement with spiritual matters, a task deemed very important in the midst of serious illness.<sup>8,37,38</sup> Additionally, prompted by questions about challenge and struggle, participants assigned meaning to their situations, an activity which has been shown to be of benefit in earlier research.<sup>39</sup> The discussion of struggle also provided an opportunity for participants to recall SC during past adversity and discuss its role in the current experience of illness. Also, the SLD was a tangible memory and gift that would survive participants and could be said to have helped them fulfill the developmental task of generativity, considered essential for well-being and growth.<sup>40</sup>

The main limitation of this study is related to its design. It was not a randomized controlled trial and clearly, the development of such a trial is essential to provide compelling evidence of the importance of this kind of life review for persons with advanced illnesses.<sup>41</sup> There are several changes we would recommend if this is undertaken:

To increase completion rates, it would be advantageous to establish a more rigorous screening process that accounts for functional decline. Despite modifications, many participants

**Table 2.** Baseline Assessment, Mean (SD).

|                          | All participants    |                     |                    |         | Completers          |                     |                   |         |
|--------------------------|---------------------|---------------------|--------------------|---------|---------------------|---------------------|-------------------|---------|
|                          | Phase 1<br>(N = 27) | Phase 2<br>(N = 83) | Total<br>(N = 110) | P value | Phase 1<br>(N = 15) | Phase 2<br>(N = 44) | Total<br>(N = 59) | P value |
| FACIT-Sp-12 <sup>a</sup> | 38.7 (7.8)          | 36.5 (8.1)          | 37.0 (8.0)         | .21     | 39.5 (6.4)          | 35.8 (8.6)          | 36.8 (8.2)        | .09     |
| Peace <sup>b</sup>       | 11.3 (3.3)          | 10.9 (3.6)          | 11.0 (3.5)         | .61     | 11.4 (2.8)          | 10.8 (3.5)          | 10.9 (3.3)        | .51     |
| Meaning <sup>b</sup>     | 14.2 (2.6)          | 13.3 (2.5)          | 13.5 (2.5)         | .13     | 14.3 (2.6)          | 12.8 (2.8)          | 13.2 (2.8)        | .07     |
| Faith <sup>b</sup>       | 13.3 (3.4)          | 12.3 (3.3)          | 12.5 (3.3)         | .21     | 13.7 (3.0)          | 12.3 (3.6)          | 12.6 (3.4)        | .12     |
| LASAc                    |                     |                     |                    |         |                     |                     |                   |         |
| Overall EWB              | 7.2 (2.3)           | 6.7 (2.5)           | 6.8 (2.5)          | .34     | 7.3 (2.3)           | 6.8 (2.4)           | 6.9 (2.4)         | .49     |
| Overall SWB              | 7.7 (2.0)           | 7.4 (2.5)           | 7.5 (2.4)          | .57     | 7.9 (1.7)           | 7.5 (2.5)           | 7.6 (2.3)         | .51     |
| Overall QOL              | 7.6 (1.9)           | 6.5 (2.4)           | 6.8 (2.4)          | .02     | 7.3 (1.7)           | 6.5 (2.4)           | 6.7 (2.3)         | .14     |
| Positive RCOPE           | 1.8 (0.9)           | 1.8 (0.8)           | 1.8 (0.8)          | .97     | 1.8 (0.8)           | 1.9 (0.8)           | 1.8 (0.8)         | .67     |

Abbreviations: EWB, emotional well-being; FACIT-Sp 12, Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale; LASA, linear analog scale; QOL, quality of life; RCOPE, Religious Coping Scale SWB, spiritual well-being.

<sup>a</sup>Combination of faith, meaning, and peace subscales, possible range 0 (worst) to 48 (best).

<sup>b</sup>Possible range is 0 (worst) to 16 (best).

<sup>c</sup>Items range from 0 (as bad as it can be) to 10 (as good as it can be).

<sup>d</sup>Possible range is 0 worst to 3 best.

**Table 3.** Summary of Change in Scores from Baseline to Post-SLD.<sup>a</sup>

|                | Mean (SD) score |            |      | Mean difference<br>(95% CI) | Effect<br>size <sup>b</sup> | Score change, N (%) <sup>c</sup> |                   |            |            |
|----------------|-----------------|------------|------|-----------------------------|-----------------------------|----------------------------------|-------------------|------------|------------|
|                | Baseline        | Follow-up  | P    |                             |                             | Improved                         | Maintained<br>max | No change  | Worsened   |
| FACIT-Sp-12    | 36.8 (8.2)      | 37.2 (8.3) | .57  | 0.5 (−1.2 to 2.2)           | 0.05                        | 31 (52.5%)                       | 0 (0.0%)          | 4 (6.8%)   | 24 (40.7%) |
| Peace          | 10.9 (3.3)      | 11.3 (3.4) | .32  | 0.4 (−0.4 to 1.1)           | 0.12                        | 27 (45.8%)                       | 2 (3.4%)          | 9 (15.3%)  | 21 (35.6%) |
| Meaning        | 13.2 (2.8)      | 12.9 (3.5) | .40  | −0.3 (−1.1 to 0.4)          | 0.11                        | 22 (37.3%)                       | 9 (15.3%)         | 4 (6.8%)   | 24 (40.7%) |
| Faith          | 12.6 (3.4)      | 13.1 (3.3) | .25  | 0.4 (−0.3 to 1.2)           | 0.15                        | 24 (40.7%)                       | 11 (18.6%)        | 10 (16.9%) | 14 (23.7%) |
| LASA           |                 |            |      |                             |                             |                                  |                   |            |            |
| Overall EWB    | 6.9 (2.4)       | 7.5 (2.0)  | .01  | 0.6 (0.1 to 1.1)            | 0.25                        | 27 (46.6%)                       | 2 (3.4%)          | 14 (24.1%) | 15 (25.9%) |
| Overall SWB    | 7.7 (2.3)       | 8.3 (1.8)  | .01  | 0.6 (0.1 to 1.1)            | 0.26                        | 23 (39.7%)                       | 8 (13.8%)         | 16 (27.6%) | 11 (19.0%) |
| Overall QOL    | 6.7 (2.3)       | 7.3 (2.0)  | .03  | 0.6 (0.1 to 1.1)            | 0.26                        | 24 (40.7%)                       | 1 (1.7%)          | 21 (35.6%) | 13 (22.0%) |
| Positive RCOPE | 1.8 (0.8)       | 2.0 (0.8)  | .007 | 0.2 (0.1 to 0.3)            | 0.25                        | 36 (61.0%)                       | 3 (5.1%)          | 4 (6.8%)   | 16 (27.1%) |

Abbreviations: EWB, emotional well-being; FACIT-Sp 12, Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale; LASA, linear analog scale; SLD, Spiritual Legacy Document; QOL, quality of life; RCOPE, Religious Coping Scale; SWB, spiritual well-being.

<sup>a</sup>N = 59.

<sup>b</sup>Effect size = average post–pre difference (in absolute value) divided by the baseline standard deviation.

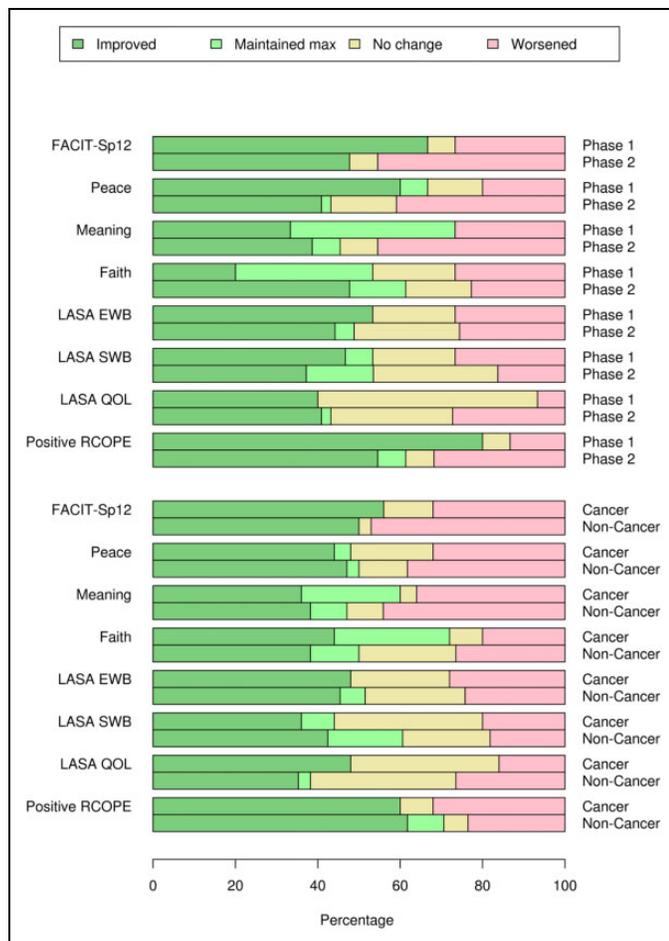
<sup>c</sup>Frequencies not adding to 59 indicate missing data.

became too ill to complete the study. However, we would recommend against excluding those who are most likely to lose functional ability quickly or those who are closest to death, as to deny them participation may deprive them of an opportunity to participate in important life completion tasks and the opportunity for improvement in QOL, SWB, EWB, and SC. In order to facilitate the involvement of these more vulnerable patients, we recommend that transcription be completed within twenty-four hours of the interview and that time be allocated for the interviewing chaplain or proxy to edit the transcript promptly and remain the primary contact with the participant until the SLD is finalized. This would be more in keeping with the time effectiveness established in DT.<sup>19</sup>

It may be informative in future research to assess the influence the HMV intervention in a population of patients who

have lower-than-average spiritual and emotional well-being. To accomplish this, those entrusted with recruitment would need to sensitively approach those who are struggling and may be reluctant to participate. Recruiting a more religiously and ethnically diverse sample would be also desirable to determine whether HMV is most beneficial for specific groups.<sup>42</sup> It may also be helpful to focus on one disease type at a time for the same reason.<sup>43</sup> Additionally, the timing of the administration of questionnaires could be set to acquire data about which aspects of the intervention contribute most to the outcomes.

Considering ways to integrate the HMV intervention into clinical practice is vital. The interview guide could be used to encourage spiritual life review for patients and an SLD, letter, art, or music form could be made for them based on the



**Figure 2.** Change in scores from baseline to post-SLD: by phase (15 participants in phase 1, 44 in phase 2) and by diagnosis (25 participants with cancer, 34 with non-cancer).

EWB indicates emotional well-being; FACIT-Sp 12, Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale; LASA, linear analog scale; QOL, quality of life; RCOPE, Religious Coping Scale; SLD, Spiritual Legacy Document; SWB, spiritual well-being.

interaction. As a means of addressing grief, loved ones may benefit from help preparing an SLD based on their memories. The development of a group intervention<sup>44</sup> or a manualized approach<sup>45</sup> may also be effective. All would support the fulfillment of a need often expressed by patients that they be listened to, understood, and not forgotten.

Hear My Voice offered those with serious illnesses, an opportunity to recall, discuss, and preserve one of the most intimate and essential aspects of human nature, their spirituality. In this process, they had the benefit of interacting with chaplains who have competence in sensitive listening and encouraging spiritual dialog and integration. The patients have spoken in their interviews and in their survey responses. The results urge researchers and clinicians to both hear and heed their voices by finding ways to continue the important work of HMV with others grappling with the challenges of advanced illness and issues at the end of life.

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