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Reflections on the integration of a narrative medicine and mindfulness program in hospice and palliative care

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By 2060, almost 25% (98 million) of the population is expected to be aged 65 or older. Health care professionals who provide hospice and palliative care are overtasked and demonstrate symptoms of burnout. Narrative medicine and mindfulness interventions create meaningful connections with patients, improve the delivery of patient-centered care, and enhance the health of the caregivers. In this pilot program, health care professionals in hospice and palliative care settings were invited to participate in a study to evaluate the impact of narrative medicine or mindfulness on measures of burnout and empathy. Participants completed baseline and 12-week post-intervention surveys of burnout and empathy, as well as weekly journals of their experience. Mean overall scores for depersonalization were significantly reduced at 12-week post-intervention. There were no significant changes in emotional exhaustion or empathy compared to baseline. This brief, weekly intervention may be beneficial for both patients and health care professionals in the hospice and palliative care setting.

Keywords: Hospice, Medical humanities, Palliative care, Empathy, Burnout, Narrative medicine

Introduction

By 2060, almost 25% of the population (approximately 98 million people) is expected to be aged 65 or older,[1] yet the necessity to provide trained healthcare workers to support this aging population is projected to fall far short of meeting these needs. Health care professionals in multiple disciplines and in both inpatient and outpatient settings may provide hospice and palliative care, yet the existing workforce is insufficient and overtasked, leading to concerns surrounding stress, burnout, and depression.[2,3] Even before the landmark publication by Charon,[4] narrative medicine (including poetry) has been shown to create meaningful connections with patients, improve the delivery of patient-centered care, and enhance the health of the caregivers.[5] Narrative medicine provides 'the means to understand the personal connections between patient and physician, the meaning of medical practice for the individual physician, physicians' collective profession of their ideals, and medicine's discourse with the society it serves'.[4] As well, the study incorporates mindfulness practices (with its commitment to 'self-care and compassion') to supplement narrative medical approaches as a method for achieving analogous outcomes. In this sense, both poetic and prosaic narratives and the techniques of mindfulness training (i.e. meditation and self-reflection)[6] provide the best vehicles to allow healthcare practitioners to achieve an 'understanding of the human condition'[6] in its most prevalent forms of expression and to assess the relative strengths of each approach.

Our project also expands the definition of narrative medicine to include the practices of all clinicians in hospice and palliative care medicine (physicians, nurses, social workers, etc.), with the presence of empathy acknowledged as integral to the success of narrative medicine in its varied forms. Empathy, defined as both the ability to understand patients' pain and suffering and to translate that understanding into a desire to help, has been correlated with improved patient outcomes and, when incorporated as part of a broader humanities construct, may serve as a protective barrier against burnout.[7–10]

Investigators present preliminary results from a collaboration with community and engaged partners on a mixed-methods approach to evaluate the current state

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of empathy and burnout among health care professionals in the hospice and palliative care to evaluate the following objectives: (1) Determine if the integration of a narrative medicine or mindfulness intervention enhances empathy in health care professionals, as demonstrated by assessment of Jefferson Empathy scores at baseline and post-intervention (12 weeks); (2) Determine if the integration of a narrative medicine or mindfulness intervention serves as a protective barrier against burnout in health care professionals, as demonstrated by assessment of the Two-question Maslach Burnout Inventory Scale scores at baseline and post-intervention (12 weeks); (3) Supplement the evaluation of the state of empathy and burnout in health care professionals by weekly narrative reflections from participants.

Materials and methods

Participants

This pilot project assessed the effects of a narrative medicine ('poetry') or mindfulness ('mindfulness') intervention on health care professional burnout and empathy in the hospice and palliative care setting. Our team is well-suited to address all aspects of the intervention, since clinicians and scholars bring expertise in both mindfulness practices and poetry reception as a means to cultivate resilience within highly charged and diverse medical environments.[8] Participants were employed at a non-profit organization that provides hospice and palliative care to patients and families in a large Southwest city. All health care professionals were eligible to participate, and we recruited 43 health care professionals to contribute to this effort. As well, the first 30 participants received a small monetary incentive ($50). Following consent, the participants were randomized into 3 groups: poetry (n = 14), mindfulness (n = 14), and usual care (n = 15). Participants were assigned a unique 3-digit identifier to retain confidentiality and allow data analysis over time.

Administrative procedures

The Jefferson Empathy Scale, the Two-question Maslach Burnout Inventory Scale, and narrative reflections were deployed via password-protected, secure web-based portals. Demographic survey questions were adapted from a validated survey instrument.[11]

Instruments

The Jefferson Empathy Scale (JSE)

The JSE HP-Version is a validated 20-item survey instrument used to assess empathy in health professionals via a 7-point Likert scale.[12] Participants were assessed at baseline and post-intervention (12 weeks).

Two-question Maslach Burnout Inventory Scale (Two-question MBI)

We assessed burnout at baseline and post-intervention (12 weeks) using the validated two-question MBI.[13]

Narrative reflections

Participants were invited to complete weekly journals, reflecting on their experience in the narrative medicine ('poetry') or mindfulness ('mindfulness') intervention.

Analysis

The Center for Research in Medical Education & Health Care provided the JSE, and baseline and post-intervention data.[14] Data analyses included non-parametric and t-tests to evaluate outcomes. Narrative reflections were de-identified and entered into the ATLAS.ti software program to uncover emerging, common, and overlapping themes. Qualitative data from the journal experiences were evaluated using the grounded theory approach modeled in the medical literature.[5]

Ethical approval

The ASU Institutional Review Board reviewed and approved this project.

Methods

Following the random placement of participants in respective assessment groups, each group (whether in mindfulness or poetry groups) was provided an overview of operative protocols developed by some members of the team in a prior pilot study conducted at the Mayo Clinic in Rochester. All participants were invited to complete the baseline JSE, Two-question MBI, and demographic questions using their 3-digit identification code via Qualtrics. Participants randomized into the poetry or mindfulness group attended 90 min of training specific to their intervention. The poetry group was instructed to complete the poetry intervention each week (the patient and the day of the week varied). The mindfulness group was instructed to complete the mindfulness intervention independently (not with a patient) once per week. Both groups were provided with resources and materials for their interventions and met with practitioners of both modes of response (mindfulness/meditation and reflection and narrative medical/poetry) prior to inaugurating all aspects of the assessment. Both groups thereafter entered data documenting completion of their 30-minute intervention, date completed, and narrative reflection using a randomly assigned 3-digit identification code in a weekly web-based survey administered via Qualtrics. Participants were sent twice weekly email reminders. All qualitative

data were entered into the ATLAS.ti software program for ease of data storage and evaluation. Topics were coded by themes and correlated with frequency of occurrence to help establish significance by two authors (AE and NS). All participants were invited to complete the post-intervention JSE and Two-question MBI at 12 weeks.

Results

Quantitative results

Ninety-five percent of the participants were female. The majority were between 51 and 60 years old (32%) and identified as White (86%). Nursing (41%) and social work (43%) were identified as the highest degree. The majority (43%) worked in hospice/palliative care between 0 and 5 years, with 13% reporting a high likelihood (between 67% and 100%) of leaving hospice in the following 10 years. Most (55%) participants report working an average of 41–60 h per week (Table 1). The majority (58%) spent an average of 51–75% of their time per week on direct patient care, while 49% of respondents spent an average of 26–50% of their time on administrative duties (Table 2).

For assessment of burnout and empathy, data analyses were completed with paired samples to evaluate change over time. Measures of burnout were categorized using validated measures published in the literature.[10] Mean overall scores for depersonalization were significantly reduced at 12-week post-intervention ($N = 28$; $P = 0.038$). Mean overall scores for emotional exhaustion did not differ significantly from baseline ($N = 28$; $P = 0.174$) (Table 3). Measures of burnout did not differ significantly from baseline to post-intervention by intervention group (Table 4).

There was no change in high scores of emotional exhaustion at baseline vs. post-intervention. Baseline and post-intervention total JSE scores were compared for poetry and mindfulness groups. Mean overall scores for empathy did not differ significantly from baseline ($M = 125$; $P = 0.827$). There were no significant differences in scores of empathy by intervention group (Table 5).

Qualitative results

Participants were encouraged to write reflectively about their experience each week. The most common themes that emerged through narrative reflection and subsequent qualitative analyses, regardless of group assignment, included the following (N = number of coded entries): (1) Stress relief and focus ($N = 58$); (2) Clinician and patient relaxation ($N = 39$); (3) Ability to connect with patients ($N = 38$); (4) Influence of time on activity completion ($N = 24$); (5) Spirituality ($N = 24$) (Table 6).

Table 1 Demographics of study participants

		N	%
What is your age?	20–30	2	4.55
	31–40	7	15.91
	41–50	11	25
	51–60	14	31.82
	61–70	9	20.45
	>71	1	2.27
	Total	44	
What is your gender?	Male	2	4.55
	Female	42	95.45
	Other	0	
	Total	44	
Which category best describes your ethnicity (select one)?	Hispanic or Latino or Spanish Origin	2	4.76
	Not Hispanic or Latino or Spanish Origin	40	95.24
	Total	42	
Which category or categories best describe your race (select all that apply)?	American Indian or Alaska Native	0	0
	Asian	3	6.98
	Black or African American	3	6.98
	Native Hawaiian or Other Pacific Islander	0	0
	White	37	86.05
	Total	43	
Which of the following best describes your highest clinical degree?	MD/DO	0	0
	NP/PA	0	0
	MSN/CNS	3	6.82
	RN	18	40.91
	Chaplain (Mdiv, or equivalent)	2	4.55
	Other	2	4.55
	MSW/BSW	19	43.18
	Total	44	
How many years have you worked in hospice or palliative care?	0–5	19	43.18
	6–10	12	27.27
	11–20	11	25
	21–30	2	4.55
	≥31	0	0
	Total	44	
What is the percent likelihood of you leaving palliative or hospice care within 10 years?	0−33%	34	77.27
	34–66%	4	9.09
	67–100%	6	13.64
	Total	44	

Major theme: ability to connect with patients

Both Poetry (P = Poetry) and Mindfulness (M = Mindfulness) interventions provided a mechanism to connect deeply with patients, whether through direct engagement or increased focus. Poetry served as a platform for positive and unique interactions; patients and clinicians were able to find meaning using poetry as an instrument of communication.

Table 2 Workload of study participants

		N	%
What is the average number of hours you work, per week?	0–20	0	0
	21–40	20	45.45
	41–60	24	54.55
	61 or greater	0	0
	Total	44	
Out of all the time that you are at work in the week, what is the average amount of time you spend on direct patient care?	0–25%	0	0
	26–50%	6	13.95
	51–75%	25	58.14
	76% or greater	12	27.91
	Total	43	
Out of all the time that you are at work in the week, what is the average amount of time you spend on administrative duties?			
	0–25%	18	41.86
	26–50%	21	48.84
	51–75%	3	6.98
	76% or greater	1	2.33
	Total	43	

Table 3 Mean overall self-reported symptoms of burnout

	Baseline	Post-intervention (12-weeks)	*N*	*P*-value
Emotional exhaustion			28	0.174
Never	2	4		
A few times a year	10	14		
Once a month or less	10	6		
A few times a month	4	2		
Once a week	2	1		
A few times a week	0	1		
Every day	0	0		
High score on emotional exhaustion[27]	*2 (7%)*	*2 (7%)*		
Depersonalization			28	0.038*
Never	8	14		
A few times a year	14	12		
Once a month or less	3	2		
A few times a month	1	0		
Once a week	2	0		
A few times a week	0	0		
Every day	0	0		
High score on depersonalization[27]	*2 (7%)*	*0 (0%)*		

Note: high score defined as a self-reported score of 4 or higher on the Two-question MBI.
*Significant at $P < 0.05$.

I took a different dementia patient outside (to) enjoy the sunshine and read poetry to her. She was non-responsive, she did not engage nor show any type of reaction. However, I felt just wonderful. I felt like I was offering a dignified and meaningful interaction. (P)

Table 4 Mean overall self-reported symptoms of burnout, by intervention group

	Baseline	Post-intervention (12-weeks)	*P*-value
Poetry (N = 9)			
High score on emotional exhaustion[27]	2 (22%)	1 (11%)	0.141
High score on depersonalization[27]	2 (22%)	0	0.178
Mindfulness (N = 11)			
High score on emotional exhaustion[27]	0	1 (9%)	0.830
High score on depersonalization[27]	0	0	0.276
Control (N = 8)			
High score on emotional exhaustion[27]	0	0	0.516
High score on depersonalization[27]	0	0	0.350

Note: high score defined as a self-reported score of 4 or higher on the Two-question MBI.

Table 5 Jefferson Empathy Scale, by intervention group

	Baseline JSE	Post-intervention JSE (12-weeks)	*P*-value
Group			
Poetry ($N = 7$)	125	128	0.329
Mindfulness ($N = 8$)	126	130	0.406
Control ($N = 9$)	122	118	0.327
All ($N = 24$)	125	125	0.827

I visited a patient who is often laconic, not willing to engage and responds with one-word answers to questions. Tuesday, I read to her from Shel Silverstein's classic 'Where the Sidewalk Ends', offering lessons that are told in silly, whimsical verse. She lit up like a Christmas tree and laughed and laughed. Witnessing such a major change in her attitude made me feel absolutely giddy. (P)

Major theme: clinician and patient relaxation

Poetry and mindfulness served as an opportunity for clinicians and patients to find strength and renewal in a peaceful environment. Clinicians and patients both revealed that poetry emerged as a pleasant distraction from their usual routine; clinicians found joy from their experiences and interactions. Mindfulness provided other benefits, including restful sleep and a feeling of presence in the moment.

I really enjoyed the meditation and being mindfulness and my goal will be to continue and try to do daily because it really does help emotionally and with the stress of this job. (M)

Table 6 Themes and sub-themes from qualitative analysis of narrative reflections

Theme	Sub-theme	Narrative example
Stress relief and focus	Grief	*Patient was nearing end of life and able to converse as I read to her. She wanted to return to England to die but unable to make the flight home. One of the poems I read was Robert Frost, Stopping by Woods on a Snowy Evening. Patient repeated several times after the reading, 'and miles to go before I sleep.' It was very heartfelt and Patient had spoken of the miles between her and family in the U.K. I left her bedside heavy hearted but I know she was at peace. (P)*
	Family	*Spouse very present and … able to shed a few tears. This clinician stayed in this space of quiet and peace with patient and spouse and remained present. Patient with eyes closed said she wants her spouse to be at peace as she is ready for Heaven. (M)*
	Childhood	*Patient states as a child he often had to recite and memorize poetry. Often put music to poetry he learned. Patient is … very open with thoughts and feelings. (P)*
Clinician and patient relaxation	Joy	*I chose a patient who was mostly non-responsive. I read him poetry (and) he engaged in an old behavior that we had not seen in six to eight weeks. It was amazing! My joy was infectious, and I could not wait to share his response with his nurse! (P)*
	Enjoyment	*Time spent with a different resident reading Night Before Christmas. Patient and other residents at the group home seemed to enjoy it. Patient could remember some other verses. (P)*
	Sleep	*I did 15 minutes each morning before I start my day. I noticed it helps me throughout the day become more focused and in the present with my patients, as well as sleeping better at night. (M)*
Ability to connect with patients	Enjoyment	*I am believing that mindfulness meditation is enhancing my positivity. I am enjoying my work. (M)*
	Calm	*Patient enjoyed the poetry. It always opens up dialogue of an entirely different topic than bedside conversations of death and dying. It's calming. (P)*
	Engagement	*I had a request for poetry this morning. A patient that I visited about 2 weeks ago and took her outside to read poetry – she remembered! She has dementia and most times I don't think she remembers me. I felt so good that she remembered that intervention. It made me feel connected to her. (P)*
	Relaxation	*I went to a mindfulness class on Tuesday. It was very relaxing after a difficult hospice patient visit. I felt like at least for a little while I was able to free the tension in my body. (M)*
Influence of time on activity completion	Workload	*Overall, when I take the time to practice mindfulness, I feel less stressed. It has been a challenge to make the time with my workload. It is a catch 22. (M)* *I feel hospice/caregiving is high burn out. It is emotional exhausting and then the pressures of productivity add more pressure and exhaustion. I have done this type of work for 10 years and do sometimes feel I am numb to death. (M)*
	Make time for the activity	*I have had some of my long-term patients that have grown very close to come to end of life. Taking time to be mindful before I enter the home has been a life saver. (M)*
Spirituality	Music	*Visit with patient nearing end of life. I sat quietly at her bedside and took a few deep inhales and closed my eyes. I sat quietly in a chair … I heard a wind chime, I heard music from another patient's room. I took in the sounds around me … and touched her arm gently. (M)*
	Holiday season	*Patient talking about the upcoming holidays and how her postman gives her a poem in a Christmas card that he writes very year. Patient saved several of them. I read a few of them to her. They were comical and made us both laugh. Reading the poems brought memories of those years to patient. (P)*

Note: (P) – Poetry; (M) – Mindfulness.

Major theme 4: influence of time on activity completion

Time limitations served as a barrier for participants. Administrative responsibilities, patient caseloads, and family obligations also served as barriers to activity completion.

> I continue to have difficulty finding patients to read poetry to. I am continuing to read poetry out loud to myself during my work day and after work. It helps me relax and be present in the moment. (P)
>
> On a week when I probably needed mindfulness the most … .it just didn't happen. (M)

Major theme 5: spirituality

Finally, the inclusion of spirituality as a common theme throughout participant narratives should not be surprising given the patient population, patient needs, and multidisciplinary hospice and palliative care team.

> Met with a new patient about whom I knew nothing other than her reticence. She did not engage in conversation though she was awake and could hear me. I read poetry to her and as I read, found that it was comforting to me personally. I felt a bit uncomfortable since I'm supposed to be the one offering comfort. I have

always believed, though, that spiritual support is a two-way street. (P)

Certain themes emerged more naturally according to group assignment. For example, stress relief and focus, and clinician and patient relaxation emerged more frequently in association with the Mindfulness group, while the ability to connect with patients emerged more frequently with the Poetry group. When data were stratified by intervention group, participants in both study groups identified the interventions as a mechanism to relax (M, 25; P, 14). Participants in the mindfulness group were more likely to report factors related to focus (M, 28) and stress relief (M, 29), while participants in the poetry group were more likely to report factors related to patient engagement (P, 18), patient relaxation (P, 14), and patient enjoyment (P, 12).

Meditation has taught me how to stop and train my mind to stay in the present, thus it has enabled me to be able to explore feelings, thoughts, etc. without judgment. This means for me that I don't just react on emotions but can create a space to process. (M)

Discussion

Despite the small sample size, this pilot study demonstrates significant and generally favorable effects of narrative medicine and mindfulness interventions on health care professional burnout, as the growing body of results incorporated in this study suggest. This participant population demonstrated low reported symptoms of burnout, and high scores in empathy, compared to those reported in the literature.[6,9] Qualitative responses reveal the potential value of these interventions for patient-clinician connection and communication, and clinician well-being, and these outcomes will provide the foundation for the next studies to be undertaken by our research team, which included academics, administrators, clinicians, scholars and volunteers.

Limitations

This was a small pilot program completed in partnership with one community-based hospice and palliative care non-profit organization. The study population was small, relatively homogenous (female, white), and self-selected (volunteered) which may limit generalizability. Participation was inconsistent, despite twice-weekly email reminders (Tables 4 and 5). There may have been confusion over (and retention of) the assigned codes used to complete the web-based surveys, and these concerns will become a significant cautionary element for our subsequent studies. The study period overlapped with the holiday season, which may have adversely impacted participation. Mindfulness participants periodically reported completing 15 min, or separate blocks of 10 or 15 min, which may or may not be as effective as the instructed 30-minute block. Also, a few participants in the poetry intervention group expressed discomfort with reading poetry aloud. These factors may have adversely impacted the frequency and quality of participation. Researchers intend to evaluate sustained engagement with activities over time.

Conclusion

Preliminary data suggest that brief, weekly narrative medicine and mindfulness interventions may be beneficial for both patients and health care professionals in the palliative care and hospice setting. While the current study primarily focuses on the positive impact of mindfulness and poetry on healthcare professionals and volunteers working within these environments, related studies have confirmed the positive impact on patients through the use of similar techniques.[8,9,11] Given the continued work projected by the current research team, future studies will engage larger, more heterogeneous populations to grapple with new variables (i.e. demographic and educational differences) as the methods and techniques are deployed in more analogous environments.

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Conflicts of interest None.

Ethics approval None.

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