

*Note to readers: I gave the following paper at a conference called “A Narrative Future for Healthcare” in June 2013 at Kings College London. Narrative-oriented clinicians and scholars from around the globe gathered to launch the International Network of Narrative Medicine.*

## **Creating Spiritual Care Interventions Based on Personal Narratives**

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### **Topics addressed:**

Fortifying clinical practice with narrative method; illness narratives in practice; life-writing, health, and social care.

### **Intent:**

The following paper gives a pedagogical description of my own and other chaplains’ methodologies in creating narrative-oriented spiritual care interventions. It aims to demonstrate the value of the chaplain as researcher, reflective writer, and designer of creative patient care.

### **Conference Presentation:**

#### **1. Exposure to Illness Narratives and Spiritual Care-Giving**

In my first clinical meeting as a chaplaincy resident, my new coordinator put a book into my hands. “Read this,” she said, “and you will understand your patients.”

Oncology was my first rotation. As part of my learning experience, I assisted with a weekly support group for ovarian cancer patients. Often thirty women would pack into a cramped lounge for a ninety-minute gathering. The book given to me by my clinical coordinator contained their autobiographies. The patients themselves chose the title

*Torch*, an acronym for Tales of Remarkable Courage and Hope. The torch image suggests metaphors of light, bravery, and community; it also alludes to a quote from George Bernard Shaw: “Life is no brief candle for me. It is a splendid torch that I have a hold on for the moment, and I want to make it burn as brightly as possible before I pass it on.” The two-volume *Torch* collection includes the first-person illness-narratives of ovarian cancer patients from Baylor. And my coordinator was right. It helped me understand.

During my six months in oncology, I encountered these women in both inpatient and outpatient settings. When they felt well, I would see them at the support group. When complications arose or the time came for inpatient chemotherapy, I would see them during my rounds on the gynecologic cancer unit. Sometimes I would find them visiting each other. As I got to know them better, I noticed that the publication of *Torch* marked time and framed relationships for the members of the group. During meetings they would order events in relation to the book’s publication. Someone might say, “When I was working on my story for *the book*...” Or, “Eva, you didn’t get to meet Joyce, but her story is in *the book*.”

Several chaplains organized, contributed, and coached the writing for *Torch*. Because of their work, I received my first view of the power inherent in writing and sharing illness narratives and the rich potential at the intersection of narrative medicine and spiritual care. I also observed a bio-psycho-social medical model in action, in which the organic illness has to be viewed in the context of the patient’s emotional state and social environment. At Baylor, the ovarian cancer support community is sponsored by the Virginia R. Cvetko Patient Education Center. The Center uses a three-pronged approach

for resourcing patients: education regarding the disease, development of coping strategies, and group support settings.<sup>1</sup> Hospital chaplains participate in the second and third aspects: formation and implementation of creative coping methods (including the writing and publication of *Torch*) and group facilitation.

By publishing their own illness narratives, these women forged a group identity. In simple terms, they became friends. They knew each other's birthdays, each other's partners and children, each other's CA 125 levels. Through the strength drawn from this community, these patients seemed to keep their disease from invading their personal identities; they had ovarian cancer in common, but they were writers and workers and torchbearers. They also became activists. When I entered their midst, the group was organizing a Texas-sized fundraiser: the opening of an art gallery linked with a fashion show to raise money for ovarian cancer research. The little group was even featured on national television. Naturally, *Torch* is part of each writer's life legacy.

## **2. Narrative in the Life and Practice of the Chaplain**

The narrative-rich setting of my first rotation incubated a certain style and priority in my pastoral care. I became oriented toward my patients' stories. In addition to this exposure in the clinic, chaplain residents themselves participate in the kind of spiritual care practices in which they receive training. For example, by studying the work of Edward P. Wimberly, the pastoral care student learns to compare narrative theory with his own life story, his understanding of ideal images of care-giving, ministry, the self, and the self in relationship to others.<sup>2</sup>

Chaplains learn to identify the stories they tell themselves and how those stories inform their practice of spiritual care. The skill obtained in this learning is called “re-authoring”; it gives the student *authority* to revise the meaning of the stories that shape the sense of self. Wimberly says that re-authoring aims at three things: to revise the story that determines personal behavior, to heal wounds, and to transform those wounds into service to others.<sup>3</sup> Meaning, if the chaplain has examined her personal narrative and experienced the significance of re-authoring, she may be able to empower patients to do the same.

A second way narratology is active in the chaplain’s practice is through reflective writing. Journaling about my patients has helped me make connections in their stories, leading to better pastoral care during the next visit. Reflective writing also gives the chaplain an open channel to purge grief and stress and to memorialize significant events.

In acute care chaplaincy, story is like a currency. A patient might give a little of this valuable substance to the chaplain to see if she can be trusted with the gift. When the chaplain indicates that the patient’s story is a treasure, the patient can experience healing-in-relationship and companionship.

### **3. Creating Interventions**

Currently I work in the neurology service line which includes a neuro ICU, an acute stroke unit, an epilepsy monitoring unit, and two floors of acute care beds. Every Monday our hospital begins a five-day inpatient program to treat people experiencing intractable migraine headache. (Our program was modeled on the Diamond Headache Clinic in Chicago.) During this week of medical treatment, patients participate in an educational program based on a bio-psycho-social model. As a group, they meet with

members of a multidisciplinary team including a physical therapist, a dietitian, and a pain management specialist. They have private consultation with a pharmacologist, a psychiatrist, their own neurologist and a hospital chaplain (myself). Twice during this five-day period, a chaplain facilitates group sessions designed specifically for the emotional and spiritual challenges faced daily by migraineurs.

**a. Hearing the Stories**

During the first group session, we get to know each other. In order to move toward personal narratives that are not limited to medical facts, I invite the patients to “tell me the story of your headache.” This approach seems to free the patient from self-reporting that has “right-and-wrong” inclusions. It lets them decide where to begin, who the characters will be, and how the plot will advance. In other words, the patient becomes the author.

As months passed and I heard more of these self-authored accounts of migraine, I noticed something. Almost exclusively, none of these patients had ever spoken to someone else with intractable migraine. When one person would tell his story, all the other heads at the table would bob in empathetic agreement. They spoke of job loss, relationship stress, being forced to cancel all social activities, sleep disruption, impulsive behavior, medication overuse, changes in sexual intimacy, and inability to exercise. These common experiences led to feelings of anger, guilt, hopelessness, worthlessness, fear, and isolation.<sup>4</sup> Perhaps most strongly expressed were the feelings of being unfairly judged and terribly misunderstood. In fact, several times patients have told me, “I would rather have cancer because at least my family would believe that I’m sick, and my doctor would know how to help me.”

This exchange of narrative during group time often results in displays of empathy. The patients scoot their chairs and roll their IV poles to sit closer to the story-teller; they rest their hands on the speaker's shoulders and show solidarity with comments like, "It's OK, baby. *We know.*"

I still feel shocked by the social and spiritual differences of migraineurs in contrast to the women who wrote *Torch*. If she wants to, a cancer patient can wear a ribbon representing her diagnosis, connect with public life through events like 5k races and banquets, and she can acceptably seek support from her friends and family. A migraineur has the opposite experience. Social pressure instructs her to hide her pain.

**b. Chaplain as Advocate and Researcher of the Patient Population**

By digging into medical research, I found the roots of my patients' stories. I systematized their self-reporting and correlated it with clinical studies. During the first group session of the week, I distribute a list of writing prompts.<sup>5</sup> Each prompt in the list represents a concern that has been repeatedly raised by group members in the past and can also be corroborated in peer-reviewed research. The following three examples begin with a writing prompt from the list, followed by justification for the prompt in the research and pastoral practice notes documented in our support groups.<sup>6</sup>

**Example 1**

**Writing Prompt:**

I need to know \_\_\_\_\_ about my headache because:

**Justification:**

"Only about 50% of people fulfilling the criteria for migraine had received an appropriate diagnosis and treatment." (Rutberg and Ohrling)

**In Pastoral Practice:**

Many patients report fear surrounding the unknown source of their chronic migraine. They report struggling with anxious questions like, "Do I have a brain tumor?"

### Example 2

**Writing Prompt:**

The thing I miss the most is:

**Justification:**

“Women who reported frequent migraines [also] reported missing an average of 36.6 days [of work] per year. When these figures are taken into account on a population basis, the numbers are staggering.” (Cooke and Becker)

“In 2001, the World Health Organization (WHO) listed migraine as being among the top twenty causes of disability... Life with migraine is a burden. It is associated with high levels of headache-related disability which is affected by worry about future attacks and a lack of control over the illness. This state of uncertainty impacts upon the ability to make plans and to engage in activities. Furthermore, the burden of being afflicted with migraine extends to family, social relationships and work, which also affects quality of life.” (Rutberg and Ohrling)

**In Pastoral Practice:**

Patients usually report missing things which might seem fairly basic in the life of a healthy person: attending children’s events, eating in restaurants, driving, planning activities or outings, and participating in faith-based gatherings.

### Example 3

**Writing Prompt:**

When I have a migraine, my thoughts get stuck on:

**Justification:**

“Women who have been abused have a 50-70% increase in central nervous system stress and stress related problems. The observations [relating to] childhood maltreatment highlight the affect of abuse on our headache patients... Childhood maltreatment is highly prevalent in migraine and is associated with depression and anxiety. Unfortunately, the patients are subject to revictimization in adulthood.” (Schulman)

**In Pastoral Practice:**

In a group support setting and in individual spiritual care visits, a chaplain must be prepared to hear narratives containing painful and repeated victimizations. Social workers and the program’s psychiatrist should be alerted in cases of current abuse.

Additional writing prompts include:<sup>7</sup>

- The person who understands my headache the least/most is:
- Today my primary emotion is \_\_\_\_\_ because:
- My best coping skill is:
- The most important thing for others to know about my migraine is:
- The thing that gives me the most hope is:
- When I have a migraine, I think of this story:

During the group session, participants choose one or two prompts and take time to write down or otherwise record their answer. Then participants are invited to share their reflections with the group.

If the chaplain wishes to advocate for her patients, she must be open to the implications of these narratives. Since part of the burden of disease is feeling misunderstood, the chaplain should work to understand. So what does it mean to live with intractable migraine? It means being obligated “to endure a life accompanied by an unpredictable and invisible disorder.”<sup>8</sup> Central features of living with migraine include being besieged by an attack, being temporarily incapacitated, feeling involuntarily isolated from life, living in a constant state of readiness, worrying about the use of medication, living with an invisible disorder, living with the fear of not being believed, and struggling to avoid being doubted.

Often migraineurs live in paradox. They long for empathy. At the same time they try to keep their disease a secret.<sup>9</sup> At this point of paradox, any caregiver can support the patient through plain sympathy, demonstrating a belief that the patient’s story is authentic and reasonable. Additionally, taking the patient at her word can prevent



catastrophizing.”<sup>10</sup> These relational dynamics represent a unique place for the spiritual caregiver to create a feeling of safety for patients.

### **c. From Research to Implementing Interventions**

As the chaplain facilitating group support sessions for migraineurs, I hope to promote an environment in which patients feel heard and understood and to let them experience talking about their migraine without shame or judgment. To that end, I created the following cluster of spiritual care interventions.

#### **Example 1: “Tell me the story of your headache.”**

During the first session, I distribute the prompts listed above e.g. “When I have a migraine, I think of this story” and “The thing I miss the most is”. After introductions, patients choose a prompt that connects with their burden of illness, then they either write or talk through an aspect of their life with migraine. As stated previously, the patients get to take control of their stories and make their illness narratives something separate from themselves.

#### **Example 2: Re-authoring before discharge.**

The final session of the week is dedicated to reflecting on what happened during the five-day inpatient stay and identifying the most important learning experiences. Re-authoring is encouraged through questions like, “How do you want to edit your story when you get home? What will you strike out? What will you leave in? What’s the first change you want to make in your story?”

### **Example 3: Sharing narrative to build community.**

My patients invented an effective support technique. In November 2012, an extraordinary group came through the headache program. Together they decided that they wanted their illness narratives to benefit all of Baylor's migraineurs. One of the patients bought a blank journal from the hospital gift shop. They handed it around during the week, chronicling their stories for others who would come later. They left the journal with me, and I read it to patients almost every week. This intervention proves to be particularly helpful when we have a small number of people (2 to 4 versus 5 to 12) enrolled in the program. Through the journal, an isolated patient can still experience community, empathy, and normalization. And, they have a place to tell their own stories.

### **Example 4: Continuing community.**

The week spent in the hospital provides essential treatment, support and information for our patients, but then they leave. Patients repeatedly requested a form of on-going community and connection. Now Baylor sponsors a monthly group meeting that provides continuing education about migraine and a support group facilitated by a chaplain. This happens at our outpatient clinic in the center of the city.

### **In closing:**

The group that invented the journal defied the typical experience of intractable migraine headache. They moved from keeping their illness hidden to using their stories to help others heal. In their honor, I will close with two excerpts from of their journal entries:

### Excerpt 1:

“To anyone following behind us, we wanted to take this time to share our love, encouragement, and inspiration. If nothing else, please know that you are not alone. You are on a journey of your own with your family and loved ones. My prayer is for you to continue seeking the things that work specifically for you. It’s important to take a wholistic [*sic*] approach and dedicate to a lifetime of continued health and wellness.”

### Excerpt 2:

“I wanted all of you to know that, before I came to this program, I thought I was the only one suffering from all this anxiety, depression and severe pain. Trust me, all of us in the room are going through the same emotions...the group has [helped me find] peace and hope and encouragement. And now instead of constantly wanting to die, I want to find reasons to live and enjoy my family, friends, and my love of life.”

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<sup>1</sup> Baylor oncologist Dr. C. Allen Stringer’s foreword to *Torch* says, “Virginia Cvetko, a breast cancer survivor, believed that doctors were not the sole owners of knowledge about a particular disease; rather, patients also possessed knowledge, and through group supportive activities this knowledge could be shared with others.”

<sup>2</sup> Wimberly, E. *Recalling Our Own Stories*. San Francisco, CA: Jossey-Bass, 1997: xii.

<sup>3</sup> *ibid*, 97.

<sup>4</sup> The emotions expressed by the group participants were documented weekly through an exercise developed by my colleague Joy Boutakov, a psychiatric nurse and Christian counselor. I used the data given in the patients’ self-reporting as a starting point for my research on the psycho-social implications of chronic migraine.

<sup>5</sup> Not all patients are comfortable in a writing exercise, of course, and I keep in mind the possibility that a broad spectrum of educational levels may be present in the room. I emphasize that nothing needs to be written down. Participants can express themselves through talking, drawing, really anything *including* writing. Also, in a group of chronic pain patients, it can be literally nauseating for people to focus on a white piece of paper. Some patients wear dark sunglasses or rest their heads on the table. Participation is always voluntary, but giving voice to their experience seems critical to many of them.

<sup>6</sup> Citation for Example 1: Rutberg, S. and K. Ohrling. (2012), “Migraine—more than a headache.”

Citation for Example 2: Cooke, L. and W. Becker, (2010), “Migraine Prevalence, Treatment and Impact.” and Rutberg, S. and K. Ohrling, (2012), “Migraine—more than a headache.”

Citation for Example 3: Schulman, E. A. (2010), “The Elephant in the Room.”

<sup>7</sup> See Appendix A for documentation of justification for each writing prompt.

<sup>8</sup> Rutberg, S. and K. Ohrling.

<sup>9</sup> *ibid*.

<sup>10</sup> MacDonald, M. (2004), Catastrophizing, coping and validation for chronic pain: a comment on Boothby et al. *Pain*, 112:221.

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## Appendix A

Documented justification for writing prompts. Full reference information is provided in the Works Cited list above.

1. **Prompt:** The person who understands my headache the least/most is:

**Justification:** “Seventy-nine percent of migraine sufferers reported that their headaches had an adverse effect on relationships and daily activities with family and friends... One-third of partners of migraine sufferers felt that arguments were more common because of headaches.”

(Cooke, L. and W. Becker, (2010), “Migraine Prevalence, Treatment and Impact.” p. 584)

“Misunderstanding by others was highlighted as being an area people with migraine found most difficult to live with.”

(Rutberg, S. and K. Ohrling. (2012), “Migraine—more than a headache.” p. 333)

**In Pastoral Practice:** Brings attention to a central issue for migraineurs: feeling misunderstood, allows the patient to express difficulty with partners and relatives (parents and adult children) and allows patient to express appreciation for a supportive relationship.

2. **Prompt:** Today my primary emotion is \_\_\_\_\_ because:

**Justification:** “Depression and anxiety may exacerbate experienced pain... Anxiety and major depressive disorders occur in 28%-57% of chronic pain patients compared to 5%-26% in the general population.”

(Smeeding, S., Bradshaw, D., Kumpfer, K., Trevithick, S., & Stoddard, G. (2010), “Outcome evaluation of the veterans affairs Salk Lake City integrative health clinic for chronic pain and stress-related depression, anxiety, and post-traumatic stress disorder.” p. 824)

“Moloney et al. referred to women’s feelings of guilt because of the stigma that migraine could be avoided if the women exerted sufficient self-discipline.”

(Rutberg, S. and K. Ohrling. (2012), “Migraine—more than a headache.” p. 334)

**In Pastoral Practice:** When patients experience difficulty naming emotions, I employ an intervention designed by my colleague, psychiatric nurse Joy Boutakov, which helps patients identify emotions such as anger, pain, loneliness, fear, impulsivity, conflict, hopelessness, and helplessness. This starting point can help patients move toward accessing their own storied experiences.

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3. **Prompt:** My best coping skill is:

**Justification:** “The women in our study struggled to fulfill their obligations and not cancel things when they had a migraine attack to avoid being doubted.”  
(Rutberg, S. and K. Ohrling. (2012), “Migraine—more than a headache.” p. 334)

**In Pastoral Practice:** Since this issue is lifted up early in the week, patients can watch for coping strategies that can be implemented at home.

4. **Prompt:** I need to know \_\_\_\_\_ about my headache because:

**Justification:** “Only about 50% of people fulfilling the criteria for migraine had received an appropriate diagnosis and treatment.”  
(Rutberg, S. and K. Ohrling. (2012), “Migraine—more than a headache.” p. 329)

**In Pastoral Practice:** Many patients report fear surrounding the unknown source of their headache. The report struggling with anxious questions like, “Do I have a brain tumor?” When appropriate, patients receive medical interventions like MRI during their five-day admission.

5. **Prompt:** When I have a migraine, my thoughts get stuck on:

**Justification:**  
“Women who have been abused have a 50-70% increase in central nervous system stress and stress related problems. The observations on childhood maltreatment...highlight the affect of abuse on our headache patients... Childhood maltreatment is highly prevalent in migraine, and is associated with depressions and anxiety. Unfortunately, the patients are subject to revictimization in adulthood.”  
(Schulman, E. A. “The Elephant in the Room.” p. 3)

**In Pastoral Practice:** In a group support setting and in individual spiritual care visits, a caregiver must be prepared to hear narratives containing painful and repeated victimizations. Social workers should be alerted in cases of current abuse.

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6. **Prompt:** The most important thing for others to know about my headache is:

**Justification:** “Three quarters of women with migraine...reported feeling a lack of understanding or cynicism from those around them. Nearly all patients felt that they experienced a lack of control over their lives because of their migraines.” (Cook, Lara J., and Werner J. Becker. “Migraine Prevalence, Treatment and Impact: The Canadian Women Migraine Study.” p. 584)

**In Pastoral Practice:** In our support groups, the most common response to this prompt is, ““People need to know that my pain is real. I’m not a hypochondriac. I’m not looking for attention. I’m not lazy.”

7. **Prompt:** When I have a migraine, I think of this story:

**Justification:** “Regarding life events, obvious gender differences were seen... Overall, women reported approximately three times more experiences of strongly negative events. When separated by individual event category, higher female rates for such experiences were reported in all 32 categories... It has also been found previously that migraineurs experience much more negative life events during childhood than healthy persons. Furthermore, an independent support for a correlation between life events and migraine was provided by Peterlin et al.” (Hedborg, K., Anderberg, U. M., Muhr, C. “Stress in migraine: personality-dependent vulnerability, life events, and gender are of significance.” p. 193)

**In Pastoral Practice:** Through this prompt, some patients are able to connect significant life events with the progression of their headache, including first onset and frequency.

8. **Prompt:** The thing I miss the most is:

**Justification:** “Women who reported frequent migraines reported missing an average of 36.6 days [of work] per year. When these figures are taken into account on a population basis, the numbers are staggering.” (Cooke, L. and W. Becker, (2010), “Migraine Prevalence, Treatment and Impact.” p. 585)

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(Justification for Prompt 8, cont)

“In 2001, the World Health Organization (WHO) listed migraine as being among the top twenty causes of disability... Life with migraine is a burden as it is associated with high levels of headache-related disability which is affected by the worry about future attacks and a lack of control over the illness. This state of uncertainty impacts upon the ability to make plans and to engage in activities. Furthermore, the burden of being afflicted with migraine extends to family, social relationships and work, which also affects quality of life.”

(Rutberg, S. and K. Ohrling. (2012), “Migraine—more than a headache.” p. 329)

**In Pastoral Practice:** Patients usually report missing things which might seem fairly basic in the life of a healthy person: attending children’s events, eating in restaurants, driving, planning activities or outings, and participating in faith-based gatherings.

**9. Prompt:** Do you want to say anything about hope?

**Justification:** “Where then is my hope—who can see any hope for me?”  
(Job 17:15)

**In Pastoral Practice:** This prompt gives freedom to call on personal spirituality and faith systems, consider how they are framing the future, and express their expectations for the five-day admission.



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## **Appendix B: Abstract**

(Published prior to conference.)

Every Monday our hospital begins a five-day inpatient program to address intractable migraine headache. During the week, patients meet with members of a multidisciplinary team including a physical therapist, a dietitian, a pain management specialist, a pharmacologist, and their own neurologist. Twice during this five-day period, a chaplain facilitates a support group for these patients. When asked during the group session, “Tell me the story of your headache,” these patients routinely recount experiences of isolation and feeling misunderstood.

In response to the consistency in these patients’ personal narratives, I designed a cluster of narrative-oriented interventions to help them tell their stories: a group session dedicated to personal story-telling, a list of writing prompts to help process the week’s experiences, a community journal to be read by patients who follow them through the program, and opportunities to share their writing with each other. Patients report that this emphasis on story-in-community helps them feel understood for the first time, forge supportive networks, and recognize the potential for their stories to help heal others.

This paper describes the creation and implementation of these and other spiritual care interventions based on the personal narratives of acute care patients. As a chaplain in a Level 1 trauma center, I receive stories from patients and families every day. My discipline, spiritual care, allows and requires me to take time with these stories, hold them sacred, and choose supportive responses. Careful listening and assessment are integral to giving appropriate spiritual and emotional support and, over time, empower the development of new, narrative-based interventions.