

Program Profile

Using Life Stories to Connect Veterans and Providers

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The My Life, My Story patient-centered program uses veterans' personal narratives by veterans to create a strong connection between patients and providers.

Anyone involved with the U.S. health care system has heard one or more of the following dispiriting comments. If you are a patient, you have heard or said, "I wish I felt like my provider understood me. He/she just doesn't have the time." If you are a provider, you have heard yourself or another provider say, "I wish I had more time to get to know my patients as people. I could do a better job or at least I could remember them without looking at the chart." This article describes a novel program—My Life, My Story—instituted at the William S. Middleton Memorial Veterans Hospital (WSMMVH) in Madison, Wisconsin. The program uses personal narratives to foster a sense of connection between providers and their veteran patients.

My Life, My Story had its origins in a small performance improve-

ment project aimed at helping psychiatric residents learn about their new outpatients during rotation. The clinic staff wanted residents to get to know their patients as people in addition to understanding the veterans' medical conditions. The veterans were first offered the opportunity to come to writers' workshops and create personal narratives that would be shared later with their clinicians. Unfortunately, only a few veterans were willing to take on this task.

A more patient-friendly approach for collecting and sharing the stories was developed and funded by the VHA Office of Patient-Centered Care and Cultural Transformation (OPCC&CT). Veterans who chose to participate worked with an interviewer/writer to create a personal narrative, which was then shared with their patient aligned

care team (PACT). Another component of the interview process was the Personal Health Inventory (PHI), a questionnaire developed by the OPCC&CT that helps veterans articulate their goals and motivations for physical, social, psychological, and spiritual well-being.¹ The PHI and personal narrative were paired, to give health care providers (HCPs) a sense of the veteran and their personal health goals.

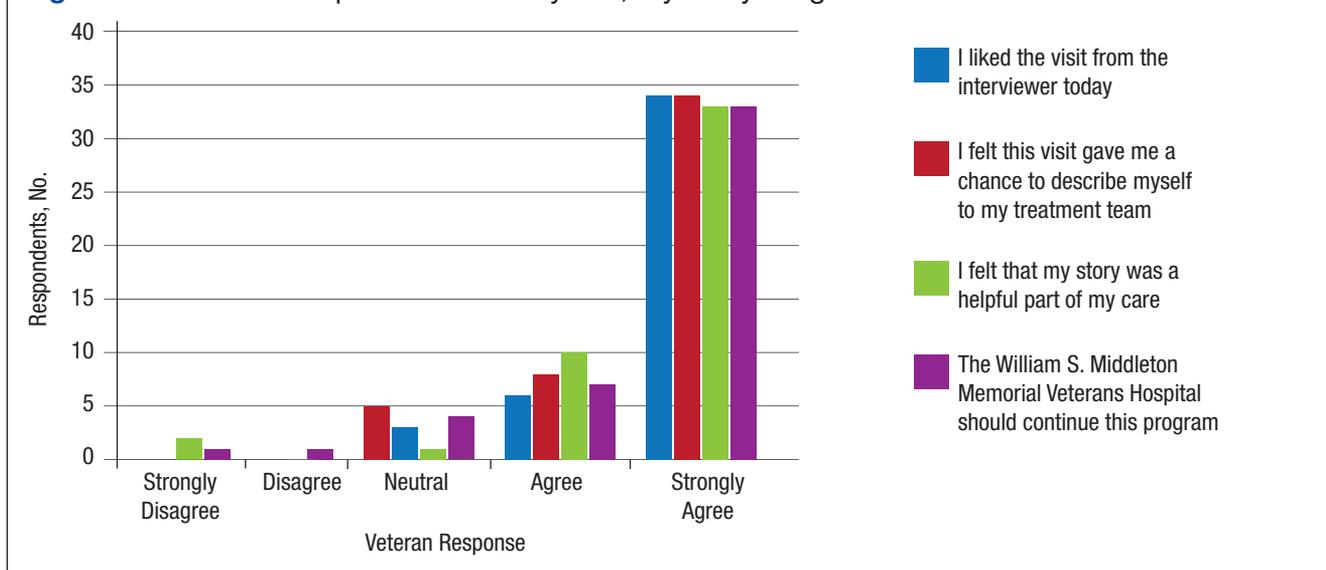
BACKGROUND

The health benefits of telling or writing the story of a difficult emotional event have been demonstrated by Pennebaker.² In varied groups, from prisoners to patients with chronic pain, the writing or talking about experiences improved mood and lowered distress. In addition, studies of medically ill patients showed a decline in physician visits in the 2 to 6 months following the narrative process.^{3,4} Improved immune response was also shown for patients with hepatitis B, HIV, asthma, and rheumatoid arthritis in response to completing a narrative.⁵⁻⁷

But the writing task is difficult for many people, especially those

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Figure 1. Veterans' Responses to the My Life, My Story Program



with advanced illness. Interviewing these patients and writing their stories is a way to give them a voice that otherwise might go unheard.

Dignity therapy with terminally ill patients, a technique developed by Dr. H.M. Chochinov, used an expert to collect the story by bedside interview and to produce a dignity-enhancing life narrative.⁸⁻¹⁰ Wise and colleagues modified this process for patients with cancer stages III and IV by using telephone interviews, which showed reduced anger, depression, tension, and an increased sense of peace.¹¹ Personal narratives in which patients tell their story and receive it in written form have been shown to reduce psychological distress, increase hope, and help the patient feel valued.^{10,12}

Pennebaker hypothesized that several mechanisms account for these improvements in health measures.² First, developing a narrative provides a contextual understanding of stressful events. Creating a personal narrative allows a patient to identify and give meaning to life's struggles. Through this process, cop-

ing is hypothesized to occur.¹³⁻¹⁵ Second, storytelling connects the teller with a wider audience.¹⁶

Another study by Pennebaker and colleagues found an improvement in social connectedness in college students in the days following the disclosure of emotional stories.¹⁷ The study speculates that nondisclosure fosters isolation, whereas disclosure connects us with others, helping us to reach out to others and improving a sense of feeling understood.

METHODS

Project staff were recruited to conduct the interviews and write the stories. Team members with varied backgrounds and experiences were selected: a nurse at the WSMMVH who served as an army interrogator in Afghanistan; a professional counselor with prior experience working for the VA; and a marriage and family therapist with a poetry MA.

Providers were recruited for participation in the project through (1) presentations to nursing staff on the inpatient units where stories were gathered; (2) compilations of de-

identified stories from veterans on those units were distributed; (3) presentations on the project at outpatient clinics, where the narratives of veterans who were patients at those clinics were read aloud; and (4) discussions of the program at monthly hospital-wide meetings.

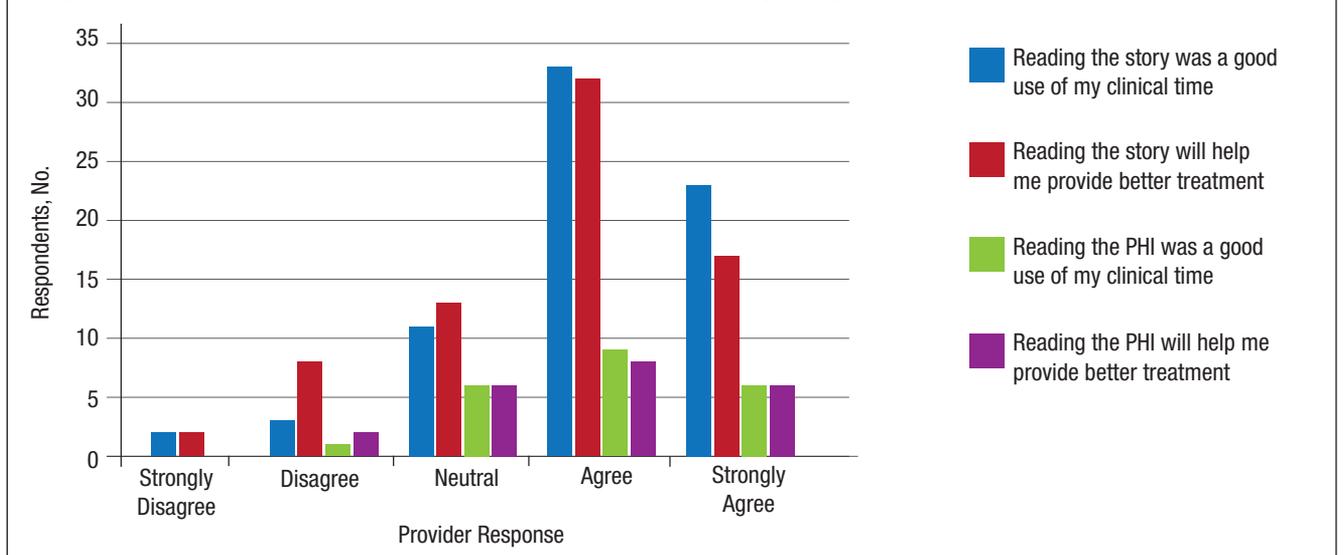
Patients were recruited from 2 inpatient units and 1 long-term rehabilitative care unit. Interviewers introduced themselves to the veterans, described the project, and gave each one a project brochure. Veterans were given the opportunity to be interviewed immediately, schedule a future interview, decide later, or not participate.

The majority of veterans who participated chose to be interviewed immediately. Scheduling interviews around procedures and discharges on busy inpatient units proved difficult. Overall participation rate was high: 60% of veterans who were told about the project eventually told their story.

Interview Process

Veterans signed a consent form before the interview, and the interviews were recorded on a digital audio

Figure 2. Providers' Responses to the My Life, My Story Program



Abbreviation: PHI, Personal Health Inventory.

recorder. They were informed they could choose to talk—or not talk—about any part of their life, the interviewer would write a draft of the story based on the interview and bring it back for their review, and the story would not be added to their patient record until they gave their approval. Spouses/partners were invited to participate if they desired.

Interviewers were encouraged to follow the lead of the veteran. Those who were clinicians were encouraged to “take off their clinician hat” during the interview. Unless guided otherwise by the veteran, the interview was semichronological and included the following subjects: birth and childhood, family, schooling, military service, relationships and/or marriage, children, career and employment, general health, and current hospital stay and presenting problem.

Interviews lasted about an hour, and 182 interviews were conducted. Interviews were frequently interrupted by HCPs who checked vitals, administering medications, rounding with

residents, and so forth. If the HCP indicated that the patient could keep talking, the interview continued. If the patient had to leave the room for a procedure or medical appointment, the interviewer paused the recording and scheduled a time to come back and complete the interview.

After the interview, veterans were told that they could expect to see the first written draft of their story within 2 days. Veterans who were to be discharged the day of the interview or the following day were told that the story would be sent to them in the mail to review at home.

Personal Health Inventory

Interviewers introduced the PHI to veterans as an opportunity to identify their wellness goals and share these with the PACT. Veterans with late-stage cancer or in hospice care were given the option to skip the PHI. Of the 103 veterans who completed the PHI, 96 chose to have the interviewer read the questions and record their answers; only 7 chose to complete the PHI on their own.

One hundred eighty-two veterans completed personal narratives, and 103 completed the PHI. Incomplete PHIs occurred for the following reasons: hospice or end of life, 12; declined, 20; could not complete, 21; discharged, 19; lost to follow-up, 7.

Writing

The quality of the written stories was critical to the success of the project. Creativity was encouraged to produce stories that captured and brought to life the voice and spirit of the interview subject. The team identified the following features of a good story: (1) written in the first person; (2) nonjudgmental; (3) captures the voice of the veteran; (4) accurately reflects the content of the interview; and (5) nondiagnostic (not labeling).

A short story format was used to increase the likelihood that busy providers would read the narratives. Writers were encouraged to limit the length of the stories to 1 to 2 printed pages (650-1,300 words). Completed stories ranged from 95 words to 2,345 words with an average length

of 1,053 words. Veterans wrote 3 and the interviewers wrote 178 narratives; 1 narrative was written by a team member who was not present during the interview but listened to the audio recording.

Editing Process

The first draft of the story was printed and given to the veteran to make any desired changes. Veterans reviewed and updated their stories in different ways. Some wrote their changes on the printed copy and had the writer return at a later time to pick it up. Others read through the story with the writer present and wrote their changes on the printed copy. Some had the writer read the story aloud and alerted the writer when an item needed changing.

Drafts were mailed to already discharged veterans, including a postage-paid return envelope to allow them to mail their changes to the team. After incorporating the veteran's changes, the team member brought back a second draft of the story for the veteran to review. This process was repeated until the veteran gave final approval. Veterans could then approve whether to share their story with their PACT via the Computerized Patient Record System (CPRS).

Some participant attrition occurred at this point. Six veterans requested that their stories not go in the CPRS (although 3 of them requested printed copies). One veteran changed his mind after his story was added to the CPRS; the team then immediately removed it. Two veterans died shortly after being released from the hospital and before they could review their stories. The families of both these veterans requested that an audio file of the interview be mailed to them.

Sharing With Family and Providers

Veterans received a printed copy of the approved story and the option to have additional copies for family members. The average number of additional copies requested was 3. Family and friends responded positively to the interview process and stories. Spouses who sat in on the interviews always added something to the interview process, and some were active participants. Eight of the 182 stories were dual narratives that included the words of the veteran and his/her spouse.

Providers were alerted to the personal narratives and PHI via CPRS. The completed story was added to the veteran's record with the title "My Story." The story was then electronically cosigned to the veteran's inpatient and outpatient PACT. Typically, this included 4 people: the inpatient resident and attending physician and the outpatient provider and nurse care manager. If other providers were directly involved in the care of the veteran (mental health, specialists, surgeons), they were also cosigned to the story. If a veteran received primary care outside WSMMVH, their PACT was notified of the presence of the story in CPRS (and given a copy) via encrypted e-mail, in the CPRS "Postings" section.

PROGRAM FEEDBACK

The original interviewer/writer team members (2.5 full-time employee equivalent for 6 months) generated 182 stories. The corresponding My Story notes in the CPRS were cosigned to an average of 3.3 providers. The program received both formal (solicited) feedback and informal (unsolicited) feedback from veterans and providers.

After gathering the first 80 stories, the team solicited participant satisfaction data from interviewed

veterans, using a 5-point Likert-type scale. Veteran reaction was positive (Figure 1). The team polled VA providers with an online anonymous survey, using the same Likert-type scale to see whether the story and PHI were useful to providers in their clinical practice. The results suggested they were (Figure 2).

Perhaps the most enlightening and touching feedback were the following unsolicited e-mails and comments:

- I have so appreciated these stories, especially because they immediately become a source of connection with the veterans who come in (some for the first time) to see me about their heart failure. In the midst of a heavy "clinical" topic, knowing their stories has helped us form a stronger patient-provider relationship. It has provided moments of levity and a clear way to tell the patient that I am connecting with them and they are important. —VA employee
- I'm a veteran, and I love reading the real stories of veterans, told in their own words. For us, it's always wonderful to feel like someone is listening. It's good to feel like someone wants to hear what you've traveled through to get where you are. For those of us who put our lives, our health, our relationships, and our honor on the line for so many others, it's great when someone will just take the time to listen and understand. It most definitely is very healing. —VA employee
- This is a great way to improve provider understanding and decrease bias and eliminate first impression issues, as people are generally ill and cranky when seeking medical care. —Veteran
- The My Story note was wonderful.

ONE VETERAN'S STORY

The following story is from a personal interview with Dorothy Weber on October 8, 2014.

When President Roosevelt called for volunteers, I wanted to join the toughest outfit to get into, so I chose the Marines. I was sworn in at Chicago in 1943 and went to Camp Lejeune for boot camp then to Washington, DC, to set up barracks there before attending Specialist School at Headquarters. From there I was assigned to Parris Island. They wanted me to attend OCS (Officer Candidate School), but stupid me, I didn't want to leave my friends. So I didn't go. I ended up as a technical sergeant.

I was one of the female auditors who replaced men who were freed for other roles. Also, I drilled a platoon of women twice a week, was on the uniform board (at first we didn't even have overcoats or uniforms), and was on the board of the NCO club. One of the toughest aspects of my auditing job was the consequences of the inventories we performed. A couple of times items like cigarettes went missing. The father of a young child was found guilty and went to jail. I was so sorry for him.

While in the service, I met Gloria Swanson's husband, an officer and very nice man. Back then, I performed one time on the popular Major Bowes amateur radio show, which came to an officers' camp near Washington, DC. I did a tap dance with a boy "hooper" from New York City. During our performance, I was interviewed and asked why I had joined the Marines. Of course I told them about wanting to answer the president's call by joining the elite Corps.

I served for 27 months until the war ended and female military personnel were released. Once I made it back home to Wisconsin, I got a call asking me to come back to be the bookkeeper of the Officer's Club at Parris Island. I would have loved that, but my father had just had a heart attack. I was the youngest of 6 children. My 2 brothers were still in the service. One had served in the Battle of the Bulge; the other was to retire as an officer after serving as an engineer in the South Pacific. The rest had family and other responsibilities. I couldn't leave Mother alone caring for Dad, so I declined the offer. I often wonder where I'd be today if I'd accepted that call. I would have liked to make a career in the Marines; I enjoyed it a great deal, even though I worked like a dog, often with 12-hour days.

I grew up in small cities in southern Wisconsin, where my dad worked as a builder. I was a tomboy who'd be called "Tommie." You could see me running, climbing trees, hopping freight trains, or hanging onto buses while riding sleds in the winter-time. My folks never knew about the short train ride I took in town, but when they found out about the sled rides, I was ordered to not do that again. My dad was the disciplinarian in the family; when he spoke, we better jump and do what he said.

I was even known for fighting my older brother's battles for him at times. I was the faster, bolder person. For instance, when I was 5, I persuaded the librarian to give me a card, even though I wasn't old enough, by promising to take good care of the books without turning down the pages or anything. I liked playing with marbles without realizing it was considered a boys' game. At a new

I truly feel it has helped me to understand my patients better and to know where they are coming from. This is invaluable to the VA where experiences shape our patients in such a profound way.—VA employee

Recent developments at the WSMMVH suggest that veteran stories are becoming an accepted component of clinical care. The

heart/lung transplant team requested that the My Story note be part of the transplant workup process for all new patients. The team also found that new HCPs who were assigned to a veteran regularly cosign that veteran's My Story note to other providers on the care team. In addition, My Story referrals come from all types of HCPs and staff, both within the hospital and at primary care clinics.

RECENT DEVELOPMENTS

Two WSMMVH employees suggested using volunteers to gather stories and became the first volunteers: One was a housekeeper who had served in the U.S. Army during the Gulf War, and the other was a registered nurse; both had writing experience.

In 2014, staff trained 12 volunteers from the local community who have been trained to inter-

school, I tried to get the girls to play with me but instead was sent to the principal's office. She informed me young ladies did not play marbles, so I had to play with my brothers back home.

I guess I might be bragging a little about myself, but I did get a blue ribbon for being the best girl athlete in school. I was the best in archery, fancy diving, softball throwing, and swimming, being the first to complete enough laps for our 14-mile marathon. I used to ride horses and showed them at the county fair. Mom and Dad came from Indiana. Mother's father was a traveling minister and Dad's was a blacksmith. Our family has military roots going back to the Civil War, where my mother's grandfather rode a white horse into battle. The story goes that the enemy easily spotted him and was heard to say, "Get that SOB on the white horse."

Once we had a centennial celebration in town, and we formed a special equestrian group to perform the Virginia Reel on horseback. The fellow in charge of the stable was excellent with a whip and wanted me as part of his act. There were objects in my hands and mouth, which he removed with his whip. When my mother found out, she said that wasn't a suitable activity for a 12-year-old, so that ended.

Life was a lot different in those days. We could stay out until 9 o'clock at night in the summertime, playing games like Run, My Good Sheep, Run, a sort of hide-and-seek. You played all around the neighborhood without worry. When I got to be about 12, I babysat for friends and family for spending money. As I got older, I ushered with a flashlight in the movie theater. Later, I worked at

the dime store for \$2 a day, which doesn't seem like much, but you have to remember that the movies only cost 10¢ back then.

In the summer, the city playground had all sorts of activities, such as crafts and basketwork, for the kids. I played on a city softball league as running shortstop and substitute catcher. I was full of it, I guess, when I was a kid. We had fun growing up.

After the service, I married, had 2 daughters and now have 6 grandchildren, 10 great-grandchildren, and 1 great-great-granddaughter. I was a homemaker, even though my husband wanted me to get a job. I said no, I'm not leaving other people to raise my children. I had a Brownie troop and was chairman of the camp committee. I got it all organized so that for the first time in scouting history in our town, all girls who wanted to attend camp that summer did.

Currently, I'm a member of the local Marine Corps League, a social and service club, which I helped start 28 years ago with other veterans. I continue to be active and independent and hope to live to be 100 or older. I'm not ready to give up yet, and people here can't believe how agile I am. That's who I am, take it or leave it. You have to have a sense of humor in life. It's also true what someone, I think my mom, told me years ago: Cry and you cry alone, smile and the world smiles with you. I haven't thought about so many things in this story for many years. I hope I've gotten all the information right.

I'm thankful for the wonderful treatment I get here at the VA hospital—it's absolutely marvelous. The staff is always nice and polite and they provide excellent care.

view and write stories. The volunteers have varied professional backgrounds. All have a background and interest in writing or experience working in a health care setting; 2 are veterans. These volunteers are adding to the team at no additional cost. In development is a standardized training program and a method to look at story collection and writing fidelity, which

will allow for further expansion of this program.

My Life, My Story continues to expand significantly. A total of 610 veterans have been interviewed, and 348 of these interviews were conducted by volunteers. The project now has 18 active volunteers with 4 more on a waiting list. A pilot has been launched at a WSMMVH outpatient clinic, which interviews VA

primary care providers about their life stories and shares them with their veteran patients. There is now collaboration with the University of Wisconsin School of Medicine and Public Health in Madison to offer a 2-week My Story elective to fourth-year medical students in spring 2016. In March 2015, My Life, My Story expanded to 6 pilot facilities across the VA: Asheville, North Carolina;

Bronx, New York; Iowa City, Iowa; Reno, Nevada; Topeka, Kansas; and White River Junction, Vermont.

Future Projects

- The team is currently analyzing the themes appearing in veteran stories, using grounded theory methodology
- The process for outpatients is being revised, using phone calls and telehealth modalities to collect stories
- The team members are examining relationships between themes in stories and health/wellness goals identified on the PHI
- Eventually, the team will study how this process might improve the veteran/provider relationship on measures of satisfaction with care, quality of care, and health outcomes. The authors will also assess the effects of this process on provider satisfaction and burnout

CONCLUSION

Veteran stories, when skillfully elicited and carefully crafted, give providers an opportunity to know their patients better, without impinging on their time. For veterans, the experience of being interviewed and the knowledge that their story will be shared with providers is an important recognition that they matter and have a voice in their health care. In a world of high-technology health care, where time is the only thing in short supply, My Life, My Story leverages the old-world technology of storytelling to bring providers and patients closer together. ●

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verse effects—before administering pharmacologic therapy to patients.

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