



## My life, my story: Teaching patient centered care competencies for older adults through life story work

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### ABSTRACT

We implemented “My Life, My Story” as an educational activity for enhancing patient-centered care (PCC) competencies across health professions trainees. Four hundred and eighty-two stories were completed for patients (M age = 72.5, SD = 12.7) primarily in inpatient medical settings, by trainees from seven disciplines. Trainees spent approximately 2 hours on the assignment; 84% felt this was a good use of their time. A mixed method survey evaluated the effectiveness of the activity on enhancing PCC competencies using open ended questions and ratings on the Consultation and Relational Empathy (CARE) Measure adapted for this project. The assignment most influenced trainees’ ability to understand the patient as a “whole person” along with other PCC competencies such as showing empathy, really listening, building knowledge of values and goals, and building relationships. In addition, trainees perceived the activity enhanced patient care and was a positive contrast to usual care.

### KEYWORDS

Geriatric education; gerontology education; life story work; patient-centered care; empathy; interprofessional education

## Introduction

*“After several weeks of rounding in the internal medicine ward, I feel like sometimes each patient is more of a problem to solve rather than thinking about that patient as a person with a full life story. I enjoyed talking to my patient and getting to learn more about him that I would have never realized/known prior to this project.” (Trainee comment)*

In this paper we describe a life story intervention that aims to teach patient-centered care (PCC) competencies executed in a mostly geriatric population in an academic medical center. Academic medical centers, in which trainees learn clinical skills under the supervision of a licensed professional in their discipline, are important hubs for geriatric education across a wide range of healthcare disciplines such as social work, pharmacy, medicine, psychology, physician assistant, nursing, and rehabilitative medicine, etc. One reason for this is the large proportion of older adults who are healthcare users, particularly inpatient services. In the United States 42% of short stay hospital use is by adults age 65+ (US Centers for Disease Control and Prevention, 2010) and 85% of skilled nursing care use is by adults age 65+ (US Centers for Disease Control and Prevention, 2016), although only about 14% of the population is 65 or older.

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These numbers are even greater within the U.S. Veterans Health Administration (V.A.) where 53% of the male population and 19% of the female population is age 65+ (National Center for Veterans Analysis and Statistics, 2017). In our VA hospital, 71% of acute medical-surgical hospital admissions were age 65+ during fiscal year 2018 (10/1/2017–9/30/2018), with a mean age of 69.51 (SD = 13.06). About 50% of healthcare care providers and 70% of all U.S. physicians receive at least some professional training within the VA healthcare system (McDonald, 2015). Thus, hospitals, particularly V.A. hospitals, are critical sites for exposure to geriatric populations and training in gerontology and geriatrics.

Within academic medical centers, targeted trainee competencies vary by discipline. However, in recent years an underlying theme common to multiple disciplines is to train healthcare providers to impart “patient-centered care” (PCC) to patients of all ages (Institute of Medicine Committee on the Health Professions Education, 2003). PCC represents a shift from the traditional, provider-driven, disease-focused approach to active collaboration and shared decision-making between patients, families, and providers to design and manage personalized and comprehensive care plans (Mead & Bower, 2000). Patient-centered care has various definitions and dimensions such as “patient as person” and “doctor as person”, as well as a biopsychosocial approach, therapeutic alliance, and shared power and responsibility (Mead & Bower, 2000). Patient-centered care may improve health outcomes, particularly satisfaction and self-management (Rathert, Wyrwich, & Boren, 2013; Williams et al., 2012).

Specifically, relevant for medical education, is an understanding of patient-centered care that emphasizes patients and providers as persons, which has its roots in humanistic and narrative medicine (Tanenbaum, 2015). Despite highlighting patient-centered care as integral to quality healthcare, there is no consensus on how best to define and teach patient-centered care (Institute of Medicine Committee on the Health Professions Education, S, 2003; Lewin, Skea, Entwistle, Zwarenstein, & Dick, 2001), but many strategies aim to develop a deeper understanding of the life story of the patient (Epperly, 2012; McKeown, Clarke, Ingleton, Ryan, & Repper, 2010).

Life story work (LSW) is a teaching method often used in geriatric education in which a trainee interviews an older adult (the term is sometimes also used to describe trainees’ reflections on their own life stories). LSW assignments with older adults have been used in geriatrics and gerontology for decades, often with undergraduates, (Shenk, Davis, & Murray, 2008) to promote intergenerational interaction, teach lifespan developmental principles, and reduce ageism/stigma (Villar, Celdran, & Faba, 2014). Several reports describe the use of LSW to impart competencies relevant for patient-centered care for medical trainees (Chretien et al., 2015; Keshet, Schiff, Samuels, & Ben-Arye, 2015; McFarland, Rhoades, Roberts, & Eleazer, 2006; Pennebaker & Seagal, 1999).

Within the VA system, a LSW activity entitled My Life, My Story (MLMS) was developed at the William S. Middleton VA in Madison Wisconsin using staff members as writers/interviewers (Ringler, Ahearn, Wise, Lee, & Krahn, 2015); it subsequently was implemented more widely by volunteers. In MLMS, interviewers perform a life story interview guided by standard questions from which they construct a first person 1,000 word narrative. A unique facet is that the story is read back to the veteran, corrected, and with the veteran’s approval, placed into the electronic health record. The goal of this paper is to describe the implementation of MLMS as a LSW educational intervention to enhance PCC competencies across disciplines within an academic medical center.

## Methods

We describe implementation characteristics and evaluation outcomes using mixed methods for a two-year window from 3/31/2017 to 4/2/2019, for which we have survey data. The evaluation was determined to be a non-research activity exempt from research and IRB review, as an educational evaluation in which no identifying information was collected.

### *Implementation process and characteristics*

#### *Implementation process*

The implementation process proceeded in three stages: leader training; engagement of training stakeholders; and program implementation. First, after learning about the program and trialing it with herself and a handful of trainees, the program leader [SN] traveled to Madison Wisconsin for in-depth training on the MLMS protocol. Next, rotation site directors or program directors from a variety of clinical training programs across multiple disciplines within the medical center were approached to solicit participation of their trainees into the program. Once training directors were in support, two avenues were used to disseminate program instructions to trainees: (1) in person training by the program leader directly to trainees, and, when that was not possible, (2) an email sent by the training director which includes written instructions, an interview guide, an illustrative video, and a script for how to introduce the project to patients via the director of clinical training. In addition to distributing links to instructions, trainees were provided a link to complete a survey (described below) after completing the story to provide feedback on the experience. Training directors encouraged or required students to complete one MLMS story during the course of their training.

The majority of the trainees interviewed patients for whom they were part of the direct clinical care team. Otherwise, trainees were matched with patients to interview based on suggestions from hospital staff. To complete the MLMS story the interviewer asks questions from the guide (e.g., Where did you grow up? What was it like?) – although participants are instructed they can depart from the guide, letting the interviewee guide the story wherever he or she wishes (See Appendix A for example). The interviewer takes hand written notes, then uses these notes to construct a first-person narrative, with instructions that the final story should accurately reflect the tone of the veteran. Subsequently, the narrative is read to the patient for editing and approval, with the final version placed into the medical record in a templated progress note with the patient's approval. The note is placed in a prominent location traceable as a “posting” in the same electronic location as advance directives, for example. In addition, the patient is provided a hard copy which they may choose to share with others. After completion of the story, interviewers may debrief the experience with the intervention leader; clinical concerns is addressed with the preceptor or relevant clinical team.

#### *Measurement of implementation characteristics*

Implementation characteristics were tracked in two ways. First, the electronic medical record was searched via an algorithm to identify all progress notes with the “My Life, My Story” title. From these progress notes we extracted three implementation characteristics:

patient age; unit or location at time of participation, and; trainee discipline. Second, we asked trainees who participated to complete a post-survey in which they rated PCC (see below) along with three implementation variables: time spent on each aspect of the project; whether it was a good use of trainee time, and; suggestions for process improvement.

## ***Evaluation of effectiveness for teaching PCC***

### ***Evaluation procedure***

The effectiveness of MLMS for imparting PCC competencies was evaluated by a mixed method survey. Two samples were used. First, we collected a baseline survey from 49 trainees to assess PCC competencies prior to the LSW assignment. To protect trainee confidentiality, we did not collect trainee identification for pre-post matching. Instead, we used results of the baseline survey to estimate population parameters prior to MLMS. Subsequently, we collected a post- survey from 141 trainees.

### ***Measurement of patient centered care competencies***

As we were unable to identify a PCC survey specific to teaching PCC, we adapted the Consultation and Relational Empathy (CARE) Measure (Mercer, Maxwell, Heaney, & Watt, 2004) for our purposes. The CARE Measure is a validated tool designed to be answered by patients to describe their experience of empathy in a one-on-one clinical encounter. For the purposes of this study, trainees rate their self-perception of their ability in each of the five PCC competencies on a 5-point Likert scale (poor, fair, good, very good, excellent). For example, in the original CARE Measure the patient rates “how good was the practitioner at making you feel at ease” whereas in our adapted measure the trainee rates “please rate your ability to make the patient feel at ease.” The project team selected five of 10 items most relevant to patient-centered care competencies potentially imparted by MLMS participation based on team consensus (Table 1). Internal consistency reliability for these five items was .88 in the baseline sample, and .88 in the post sample. After a period of initial data collection, it might be useful to also ask how much the patient-centered care competencies improved as a result of MLMS as these competencies could also improve in other ways (such as modeling of such competencies by a supervisor). Thus, we amended the survey by asking trainees to also rate how much each of the five PCC changed as a result of MLMS. As such, we have trainee responses for only 39 of these ratings. Finally, we asked open ended questions as to what was most valuable about MLMS and why, if at all, MLMS was important. The majority (N = 127) provided responses to open ended questions.

## ***Analyses***

### ***Qualitative***

Thematic analysis was applied to responses to open ended questions. Two members of the research team [SN, JM] independently coded each response in batches (n = 10), after which discrepancies were discussed and the code book revised. We used an inductive approach, coding content for observed semantic meaning rather than a deductive

**Table 1.** Qualitative themes, codes, and relative frequency (N = 127).

Theme and Code	Frequency %
<b>Perceived Effects on Patient-Centered Care Competencies</b>	
Understanding the Whole Person	65.4
Showing Empathy	32.3
Builds Relationship	20.5
Really Listening	15.7
Building Knowledge of Values and Goals	14.2
<b>Perceived Effects on Health Outcomes</b>	
Leads to Better Care	21.3
Contrast to Medical	58.3
<b>Perceived Positive Impact for the Family, Patient, and Professional</b>	
Positive for Patient	61.4
Positive for Professional	47.2
Positive for Family	15.0

Note. 127 of 141 participants provided comments. Percent refers to the number of times the code was assigned in N = 127 comments.

approach. However, our coding was informed by our knowledge of PCC. After the first coding session, inter-coder agreement ranged from 85% to 100% per code, with an average of 94%. After the final coding session, inter-coder agreement ranged from 93% to 100% with an average of 98%. Data were analyzed using both NVivo and Excel software.

### **Quantitative**

Descriptive analyses (percent, mean) describe implementation characteristics, trainee ratings of PCC competencies, and self-perceptions of whether PCC competencies improved as a result of MLMS. For the purposes of comparing baseline and post-MLMS ratings of PCC competencies we used one sample *t*-tests (with the baseline mean as a specified constant or test variable) as we were not able to use paired scores due to the anonymous nature of the survey. Analyses were performed in SPSS version 22.

## **Results**

### **Implementation process and characteristics**

#### **Medical record data**

During the period 3/31/2017 to 4/2/2019, 482 stories were entered into the medical record. Patient age ranged from 22–101 (M = 72.5, SD = 12.7); 77% were age 65 + . Stories were completed for patients in acute medical/surgical wards (56%), post-acute care (e.g., rehabilitation; 15%), long-term care (including medical and spinal cord long term care; 10%), and other inpatient settings (e.g., intensive care unit; 5%), with the remainder in outpatient settings. Discipline type was available for 425 trainees in the medical record. The most stories were completed by PA students (40%), followed by trainees in medicine (e.g., internal medicine residents, 22%), pharmacy (10%), social work (9%), mental health (e.g., psychology or psychiatry, 6%), nursing (2%), and a few individuals from other disciplines (e.g., speech language pathology, health administration, 3%).

### **Trainee feedback**

Participants completed 1–3 interviews (mode = 1). Participants spent the most amount of time in the interview ( $M = 59.7$  minutes;  $SD = 33.4$ ), followed by writing the story ( $M = 42.7$ ;  $SD = 26.9$ ), reading it to the patient ( $M = 16.6$ ;  $SD = 12.7$ ), and editing ( $M = 11.0$ ;  $SD = 12.3$ ). The majority (84%) of trainees said the program was a “good use of my time” to a great or large extent. In qualitative comments, most recommended “no changes” to the program, but a portion spoke to recommending more time be allotted for the project or specific writing challenges (e.g., being hard to write the story in the first person).

### **Evaluation of effectiveness for teaching PCC**

#### **Qualitative data**

We coded 10 content areas and grouped these into three thematic areas (Table 1): perceived effects on PCC, perceived effects on health outcomes, and more general comments about the experience being positive for the patient, family, or clinician in training (Table 1). Exemplary responses appear below.

**Understanding the whole person.** The most frequently (65%) observed content related to better understanding the whole person.

- *We can sometimes forget that our patients are more than their medical/psychiatric conditions. They are whole people with a lifetime of history that is influencing how they are coping with their condition and interacting with their providers. I think that the project allows us as providers to remember this and might also be a reminder to the patient that they are more than their medical condition.*
- *Getting to know a patient beyond the medical side of things that is often lost while caring for patients in the hospital; I think it is important because it allows you to more wholly know the patient; treat them more as an individual than just another patient. I think it is important for these reasons; I got the opportunity to witness how important her family is to her and the joys and hardships she has dealt with and deals with.*
- *It takes the patient and makes them more of a human being; I really think this was essential to learn more about who my patient was overall.*

**Showing empathy.** About one-third (32%) of comments related to perceived effects on empathy.

- *Gives us a better opportunity to understand the patient better, to have more empathy for them.*
- *Very humanizing experience. Helped me get in touch with my compassion.*
- *I think it goes a long way in helping understand the patient at a much deeper level. In my particular instance the patient was not doing what we needed him to do in order to be able to receive his treatment, and it was frustrating. By having this story to add, it*

*really helped to show him as a person, and seeing the hardships he's been through made us more understanding of his lack of cooperation.*

***Builds relationships.*** Finally, about one-fifth (20%) reflected on the way in which the learning activity built their relationships with patients.

- *I think that I had a better relationship with the patient after I heard about his past and what he has valued in his life.*
- *This project was a wonderful way to build a relationship that is far beyond daily care.*
- *This is important to do to let the patient know we are here to help them and genuinely want to work with them for their best interest. This affects me, because I now am able to develop a relationship with the patient.*

***Really listening.*** Some (16%) comments related to listening and “hearing” the person.

- *For me, it taught me how to listen empathetically and appreciate my job as a caretaker to these patients ...*
- *It was interesting hearing the veteran's story and getting an idea of what events in their past contributed to their personality. I thought it was also great that listening to the patient was helpful for him as well.*

***Building knowledge of values and goals.*** Some (14%) comments revealed that the story enhanced knowledge of the patient's values and goals.

- *Personally, it helped me understand how the patient's longstanding values influenced their medical decisions and interactions with providers, which evoked compassion.*
- *It allowed me to better understand where this patient was coming from, her perspective and get a better understanding of how she thinks.*
- *Learning about the patient's values, goals and frustrations in life; helps manage their care by making their values and goals clear.*

### ***Perceived effects on health outcomes***

***Leads to better care.*** About one-fifth (21%) specifically linked the completion of MLMS with a perception of improved care.

- *Helps patients trust their providers and possibly increase compliance to prescribed regimens, leading to health and wellness.*
- *Helps to make better medical decisions as it directly impacts that patient and their situation.*
- *It helps to bring patient care to a higher level.*

***Contrasts to medical care.*** Interestingly, a majority (58%) reflected that the value of the MLMS activity is in its difference from a usual medical approach to care.

- *Being able to understand the veteran as a person more fully, not just as a patient from a medical perspective.*
- *Having a time to simply get to know about and promote a Veteran without the competing interest of advancing his or her clinical care in a more traditional way.*
- *Firstly, a patient is more than their diagnosis; they are a person with a past and a life and feelings. Knowing their background may make it easier for the team to empathize with them or understand their current behavior better.*

### **Perceived positive impact for the family, patient, and professional**

In addition, participants commented on the positive value of MLMS generally. Most (61%) commented that it was positive for the participant, such as *“I think the veteran got a lot out of doing this project and told me so on several occasions after we completed it.”* Many (47%) commented that it was positive for the trainee, for example *“Chatting about peoples’ lives is one of my favorite aspects of medicine and getting to really dive in and do a complete history of one of my patients was very gratifying. For example, discovering that he had nearly escaped being lynched in Georgia by catching a bus up to Boston made an abstract historical period very, very real for me.”* Finally, as the story is provided to the family with the patient’s permission, some (15%) commented on observing a positive impact on the family, for example, *“It is also a good opportunity for the family members to hear the stories of their loved ones and reflect their pasts with the family.”*

### **Quantitative data**

Table 2 presents percent endorsement for the trainee ratings on five PCC competencies on the CARE Measure. One-sample *t*-tests found higher ratings on the post survey in four of five PCC competencies as compared to baseline means. At post-assignment more positive ratings were found for “let the patient tell their story” (baseline  $M = 3.94$ ,  $SD = 0.75$  v post  $M = 4.13$ ,  $SD = 0.86$ ,  $t(140) = 2.72$ ,  $p = .007$ ), “really listen” (baseline  $M = 3.92$ ,  $SD = 0.79$  v post  $M = 4.16$ ,  $SD = 0.80$ ,  $t(140) = 3.51$ ,  $p = .001$ ), “be interested in the patient as a whole person” (baseline  $M = 4.00$ ,  $SD = 0.71$  v post  $M = 4.33$ ,  $SD = 0.78$ ,  $t(140) = 5.07$ ,  $p < .001$ ), and “show care and compassion” (baseline  $M = 4.23$ ,  $SD = 0.65$  v post  $M = 4.41$ ,  $SD = 0.66$ ,  $t(140) = 3.39$ ,  $p = .001$ ), but not “make the patient feel at ease” (baseline  $M = 4.18$ ,  $SD = 0.64$  v post  $M = 4.27$ ,  $SD = 0.64$ ,  $t(140) = 1.59$ ,  $p = .115$ ). The PCC competency trainees believed to be most impacted by MLMS was to “be interested in the patient as a whole person”, for whom 54% reported this PCC competency increased “a great deal” as a result of MLMS ( $M$  difference baseline to post = .33). The PCC competencies believed to be least impacted by MLMS were “make the patient feel at ease” ( $M$  difference baseline to post = .09).

## **Discussion**

Patient-centered care competencies are considered a core element of quality care and necessary elements of health professions education. Formal didactic experiences that intend to enhance or teach PCC competencies often occur on the periphery or outside direct medical care (Kumagai,

**Table 2.** Ratings of patient centered care competencies (N = 141).

Item	Definition	Your Ability To				How much improve as a result of MLMS		
		Fair to Good %	Very Good %	Excellent %	Not at all %	Somewhat %	A great deal %	
Make the patient feel at ease	Introducing yourself, explaining your position, being friendly and warm towards patients, treating patients with respect; not cold or abrupt	10.6	51.8	37.6	10.6	61.5	28.2	
Let the patient tell their story	Giving time to fully describe their condition in their own words; not interrupting, rushing or diverting	23.4	36.2	40.4	2.6	53.8	43.6	
Really listen	Pay close attention to what the patient is saying, not looking at notes or computer as patient is talking	21.3	39.7	39.0	7.7	51.3	41.0	
Be interested in the patient as a whole person	Asking/ knowing relevant details about the patient's life and situation; not treating the patient as "just a number"	14.9	34.8	50.4	5.1	41.0	53.8	
Show care and compassion	Seeming genuinely concerned, connecting with the patient on a human level; not being indifferent or detached	9.2	40.4	50.4	10.3	61.5	28.2	

The question "How much did this improve (if at all) as a result of MLMS" was added later to the survey. For these questions N = 39.

2008; Kumagai, Murphy, & Ross, 2009). Patient-centered care is critical in the hospital setting where most patients are older adults.

We implemented a LSW intervention, *My Life, My Story*, which uses active participation and partnership with the patient, directly integrating the patient's story into the electronic medical record. We evaluated its effect on patient-centered care competencies of trainees from various health professions. Although not designed specifically as a gerontology intervention, such LSW assignments are commonly used in gerontology education and the majority of our interviewees were older adults.

We found it feasible to implement MLMS across multiple disciplines and a wide variety of clinical settings. Of interest, the majority of the stories were completed on an inpatient service (acute, post-acute, long term), demonstrating the assignment is feasible to complete even with individuals undergoing medical treatments. We did not collect information on the rate of refusal, but participants did not indicate difficulties identifying patients or completing the assignment, which took a bit more than two hours to complete for all four components. Most trainees felt the assignment was a good use of their time. This type of extended time spent with one individual is more common earlier in the clinical educational process but becomes less common later in training and practice with as little as 10–12% of trainee time in direct patient contact in certain clinical settings (Block et al., 2013; Mamykina, Vawdrey, & Hripcsak, 2016).

Our results support that MLMS is an effective training tool to teach PCC competencies. Both quantitative and qualitative analyses identified that program participation most enhanced trainees' skills in understanding of the patient as "a whole person" – the most frequently cited benefit in qualitative comments, and the PCC competency rated most highly in terms of ability and improvement as a result of MLMS. In addition, results suggest MLMS is helpful for building skills for showing empathy, building relationships, and really listening, as well as building knowledge of values and goals (qualitative finding only).

Several aspects of MLMS may contribute to its apparent impact on PCC competencies. First, the intent is to listen and document the patient's life story, not strictly the illness story, without a clinical agenda, and then to take that information and transform it into a first-person narrative with the direct involvement of the patient. There is an interview guide which helps to elicit reflection in addition to historical facts, but the interview is a collaboration in which the interviewee is permitted to tell their story in their way. These aspects seem clearly aligned with PCC competencies of letting the patient tell their story and really listening. In addition, the story is written in the active, first person voice, rather than the subjective or third person voice that is typically used when writing about a patient in their chart. This first person perspective may promote empathy and a person-first approach (Legere, Nemec, & Swarbrick, 2013). This exists in contrast to the patient chart filtered through the lens of the health professional.

In qualitative analyses, some trainees also stated that MLMS likely led to better care, and interestingly, was seen as providing a contrast to typical medical care. One unique facet of MLMS is the placement of the story into the electronic medical record in a prominent location (with the patient's permission). This provides an opportunity for the trainee to observe the relationship between the personal story and the clinical story. Further, the placement of the story in the electronic record creates a unique opportunity for the patient to present their life story through the chart – potentially impacting care in the moment and on subsequent occasions.

## **Limitations**

There are numerous limitations in our program evaluation. The anonymous methodology, while protecting trainee identity, did not allow to match pre- and post- responses for repeated measures analysis. Moreover, self-ratings of competencies are subject to bias by the participants who may not have a strong sense of their competency level (Barnsley et al., 2004; Morgan & Cleave-Hogg, 2002). Another potential limitation is the distribution of participants. A large portion of the sample were Physician Assistant students – owing to the high numbers who rotate through our academic medical center and the strong engagement of the director of clinical training in this discipline, which may have resulted in differences in participation and resulting patient-centered care competencies. This may reduce the generalizability of our results across professions. In addition, some trainees received in-person training, and others, owing to the rotation structure, received email training which contributed to variability in the implementation process and could have affected trainee comprehension. We had 482 stories completed, with data from 141 trainees, for an approximate response rate of 29% (although some students did more than one story, so the response rate may be somewhat higher). Nevertheless, there may be bias in that the trainees who opted to complete the survey may have had a meaningful and positive experience. Program administration and evaluation was completed as a collateral duty, without administrative support. With more resources we may be able to enhance program training and evaluation – for example through more observation, direct feedback, and by eliciting trainee feedback directly through an email request to the trainee (rather than hoping the trainee remembers and is willing to complete the post-survey). There are also limitations in that we adapted the CARE questionnaire from its original format, which was designed as an empathy measure, not specifically a PCC measure. Further, although the authors are geriatric educators and most of the patients interviewed were older, we did not specifically evaluate the impact of the assignment on age-specific competencies or age-related stigma. Finally, although some trainees perceived the activity to positively impact patient care, we did not directly measure this impact.

## **Conclusion**

My Life, My Story empowers patients to tell their stories and provides clinicians a mechanism to learn how to elicit and listen to those stories, take the patient's perspective, and bring that to the healthcare record. In doing so, MLMS appears to be an effective educational tool to teach patient-centered care competencies for trainees across health professions and the continuum of training. Future studies might randomize trainees to complete one or more stories, or to participate versus not at all, in order to compare patient-centered competencies in a randomized trial. In addition, future studies might examine how frequently providers read the narratives and the impact of the narrative on other providers (who read but do not author the narrative), and whether participating as an author has a longitudinal impact on patient-centered care, as well as the impact on patients and families.

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## Appendix A

### Example Story

Note. This story is told by a female patient who was interviewed with her husband in the room. She insisted that their story be told together because “It is a love story”. The story is told from the perspective of “Mary Beth” with quotations from her husband “Robert” added. Names and details are changed to protect confidentiality. This story is shared with consent of the participants.

We were both the babies of our families, but I’m six months older and smarter. Robert was from an Italian family, which was different than my straight-laced Irish family. I think my mom was mortified when she met the in-laws.

When I was 18, I decided to join the Marines. I can’t tell you why except I signed up with my cousin. I guess I didn’t want to go into the family electrical business. A Marine recruiter came to our high school, and I decided to sign up for boot camp with another girl. But, her parents wouldn’t give her the permission required to go to basic training. So, it was just me. I was terrified. My dad would visit me to make sure I was doing OK. I cried and said I wanted to go home, but he was gung ho and said no.

We finished basic training around the same time and met in Quantico, VA in 1953. Robert was stationed at Camp Upshur as an MP and I was at the main base. I worked in communications as a telephone operator. Robert came to the main base because his appendix was taken out.

Robert: When I saw her, I asked to walk her back to the barracks. Then I would sneak off from the base to see her.

We loved to go dance on the base. We would jitterbug and buy a pitcher of beer for 25 cents at the EM club.

We knew it was inevitable that Robert would get shipped off. He asked if I would wait for him and I said “good luck! I’m on a base full of guys”. So, we had Dad come down for a wedding and we got married in the base chapel. We had 48 hours for a honeymoon, and wouldn’t you know it, I got pregnant two months later. Robert was sent to Japan.

My first baby girl was born while Robert was away. The separation was actually good and forced me to get out of the house when other pregnant women had to stay at home.

Robert: I was in a weapons company in Japan and shot 81 mortar. We didn’t have earplugs back then and I had a bad injury from training. They flew me back to Tripoli. They were going to send me on a plane back to a hospital in California, but my ear flared up, and I couldn’t go. The plane I was going to go on crashed and everyone died. I was put on a later plane. When I was 25 I was being treated with a penicillin shot and I lost all of my skin including from the roof of my mouth. They had to take blood samples from my ear. I was in the VA hospital for a long time, but got better.

We got our 1st house on my GI bill and our second on his GI bill. I would have liked to have stayed in the Marines but had to leave. I didn’t want to leave. But, they weren’t set up to have girls with babies in the military back then. My father owned an electric company and we went into business with him. He taught Robert how to be an electrician. I wanted to be an electrician too, but it wasn’t something a girl could do back then. I did the bookkeeping for the electrical business and for some properties my dad owned.

Robert: I wanted to leave the Marines because they were chickenshit! And they were tough on us. They would tell you to do something you already did. It made you grow up, but it was scary. In basic training they once made me eat a letter my girlfriend mailed to me! I worked as an electrician for 42 years. Retired in 2008 and worked a bit for my son who was an electrician. We were stubborn. I’d say, I have 42 years’ experience, and he’d say, ‘I’ll wait until 43!’

We were proud to wear the uniform. I still know our serial numbers.

(Robert: I don’t remember them. Mary Beth: You didn’t have to write them on all the letters!).

It’s not all a love story. We had some rough times. A marine married to a marine is hard. We’ll be married 65 years in June. We had five kids, 11 grandchildren and 13 great grandchildren. We had the kids spit polish their shoes and were all gung ho about it. Semper Fi! We were active in the American Legion and the parades and all that. Robert would walk honor guard with a straight face. (Robert: I’d never crack a smile when walking honor guard.) Not one of the kids went into the Marines, but some were Army.

Five to six years ago we went back to Quantico and went to the same places we used to go.

Robert: The beer was more than 25 cents!

I love the VA organization. We are so blessed. Blessed is the word. I’d like to see more women. I get really excited when I can pick out the female military folks.