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The My Life, My Story Program: Sustained Impact of Veterans' Personal Narratives on Healthcare Providers 5 Years After Implementation

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ABSTRACT

Patient-centered care promotes positive patient, staff, and organizational outcomes. Communication is one critical element of patient-centered care. Establishing a patient–provider relationship in which a patient feels comfortable sharing their goals, preferences, and values is important to support patient-centered care and positive health outcomes. The My Life, My Story (MLMS) program was developed in 2013 to elicit and share Veterans' life stories with their healthcare providers. Life stories become part of the Veteran's chart so providers can access, read, and utilize as appropriate. To evaluate the program's sustained value and impact 5 years after implementation, healthcare staff were recruited to complete a short survey with closed and open-ended items. Descriptive statistics were used to analyze the quantitative survey responses and thematic analysis was used to analyze qualitative responses. Approximately 94% of staff indicated they had read MLMS notes and over 86% agreed or strongly agreed that reading the notes was a good use of their clinical time and helped them provide better treatment or care. Staff also described making more personalized decisions about the plan of treatment or care delivery after knowing the Veteran better from their story. Our findings suggest the MLMS program has been well sustained over time, and the use of patient stories in healthcare may be a valuable, practical, and sustainable tool to support the delivery of patient-centered care.

I think any patient wants to just feel heard. Many of them are frustrated by the number of faces in and out of their room, wondering what each person wants, what it means, sorting out all their care can be tough. Someone taking the time to discuss things OTHER than just the medical tidbits can have quite a healing effect. – VA Provider

I once had a patient, who maybe I viewed as an older person, with not a great quality of life, and I read their My Life My Story and I was blown away that they lived to be 92 years old and was left feeling like "OH MY!!! What an extraordinary life they have lived." It gave me perspective. – VA Provider

Patient-centered care (PCC) is defined in many ways but some key principles include shared decision-making (Mead & Bower, 2000), holistic patient care, respect for patient preferences and individual goals (Barry & Edgman-Levitan, 2012; Morgan & Yoder, 2012), understanding of the patient as 'person' (McCormack & McCance, 2006), and attending to non-medical and spiritual aspects of care (Shaller, 2007). There is some evidence that PCC may be associated with improved healthcare outcomes such as decreased mortality (Meterko, Wright, Lin, Lowy, & Cleary, 2010), fewer visits to emergency room, fewer hospitalizations (Bertakis & Azari, 2011), fewer medication errors (Charmel & Frampton, 2008), and improved delivery of preventative services (Flach et al., 2004). Delivery of PCC may also be associated with improved employee satisfaction, which in turn reinforces this delivery approach (Charmel & Frampton, 2008).

While research suggests that delivering PCC promotes positive patient, staff, and organizational outcomes, it is less clear which dimensions of PCC are key elements in its effectiveness. Communication appears to be one critical element (Bensing, Verhaak, van Dulmen, & Visser, 2000; Zill et al., 2014). Establishing relationships in which patients feel comfortable sharing non-clinical issues and discussing goals, preferences, and values are important consultative skills reported to support PCC. Stories create a space where that can happen.

Narrative medicine and communication theories suggest stories can; teach providers how to listen more closely to patients (Charon, 2008); educate and inspire patients (Houston et al., 2011); help us process negative experiences when we write them down (Pennebaker, 2000) or share them with others (Kellas, Horstman, Willer, & Carr, 2014); and even build resilience in the storyteller (Horstman, 2018). A major barrier to using stories in healthcare is the time it takes to tell and listen to them. Healthcare providers face a complex-care environment with rapid patient turnover, highly acutely ill patients in the inpatient setting and large patient panels and short appointment times in the outpatient setting which impose restrictions and limitations on time with patients (Friedberg et al., 2014).

To leverage the connective power of stories, without placing an additional burden on providers, our team developed the My Life, My Story (MLMS) program. The aim of this paper is to report its impact and sustainability over time.

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MLMS began as a grant-funded quality improvement project in March 2013 in a midwestern VA hospital. Three staff (two full-time, one half-time) were hired to gather initial stories. Community volunteers were brought on and trained as interviewers after the grant ended. Patients are approached in person on the hospital units to participate or providers can make a referral for an MLMS patient interview by placing an MLMS 'consult' in the electronic health record. A consult is a mechanism used to request specialists outside the primary-care team (e.g. infectious disease, renal) to assess and contribute to the care of patients. Interviews focus on what the patient wants to share rather than medical concerns. The story preserves the patient voice but is more narrative than transcript. For ease of reading by a busy provider, the story is condensed into approximately 2.5 minutes of reading time. The average story is 1,087 words in length (please see Ringler, Ahearn, Wise, Lee, & Krahn, 2015 for more details and a story example).

MLMS has continued to grow since its development and by October 2017 more than 1,400 Veteran stories had been collected. A year after implementation, an evaluation of the program suggested providers found the stories valuable and useful (Ringler et al., 2015). Approximately 78% of providers agreed or strongly agreed the stories were a good use of their time and 68% agreed or strongly agreed it would help them provide better treatment. However, literature has shown that sustaining new or innovative programs in healthcare is difficult. Rates of continuation of innovative or new programs (when reported) suggest that partial sustainability is common, whereas full sustainability of programs is rare after the initial implementation period or end of funding (Stirman et al., 2012). Given this context, it was imperative to reevaluate the MLMS program to determine how it has been sustained and what value and impact it has on providers 5 years after implementation.

Methods

Participants

We recruited a convenience sample of healthcare staff from the William S. Middleton VA Hospital in September and October of 2017 to participate in a survey regarding the value and impact of the MLMS program. We used multiple approaches including general and targeted recruitment. We sent e-mail invitations to all hospital physicians and nurse practitioners, e-mail and in-person invitations at nursing practice council meetings to all nursing staff, and targeted e-mail messages to any provider who had been cosigned to at least one MLMS note in the medical record in the previous two fiscal years.

The final sample included 107 staff from a range of disciplines and work experiences (Table 1). Most respondents were from nursing (47.92%) or medicine (30.21%). About 25% of staff were relatively new to their profession (0–5 years) and about 25% were very experienced (21 years or more). Over a third of staff worked in outpatient settings, about a quarter worked in the inpatient setting, and the remainder reported working in other areas (e.g. telephone triage).

Table 1. Sample characteristics.

Characteristic*	Frequency(%)
Discipline	
Nursing	47 (48.96)
Medicine	29 (30.21)
Social Work	9 (9.38)
Pharmacy	4 (4.17)
Therapy	1 (1.04)
Other[$]	7 (7.29)
Years in Profession	
0–5	24 (25.26)
6–10	21 (22.11)
11–15	15 (15.79)
16–20	11 (11.58)
21 or more	24 (25.26)
Patient Care Area[$$]	
Outpatient	67 (36.02)
Inpatient	46 (24.73)
Primary Care	29 (15.59)
Other[$$$]	44 (23.66)

* Not all staff answered every question so total responses for each characteristic do not always total the full sample size n = 107.
[$]Other includes: maintenance, audiologist, psychologist, and counselor.
[$$]Staff could mark multiple patient care areas; sample sizes cumulate to more than the total.
[$$$]Other includes Rehab, Mental Health, Palliative or End of Life Care, Addiction & Treatment, Emergency Department, Telephone Triage, Ambulatory Surgery, Surgery, Geriatrics, Post Anesthesia Care Unit, Case Management, and Specialty Clinics.

Procedures

Survey data collection

Staff were asked to complete a short survey with 22 closed-ended, Likert scale, yes/no and multiple-choice items with some open-ended response options for sharing examples. The survey was developed by the team for the purposes of the evaluation including the same items from the first evaluation for comparison and new additional items. Items addressed staff perception of the value and impact of the MLMS program. Closed-ended items addressed the following topics: (1) whether staff had ever read a MLMS note (and if not, the reasons for not reading notes), (2) level of agreement that reading the MLMS notes was a good use of clinical time, (3) level of agreement that reading the notes helped staff provide better care, (4) how frequently staff and teams use MLMS notes, (5) whether and how (very positively to very negatively) reading the notes impacted staff or patients, (6) whether and why staff had placed a MLMS consult, (7) how interested staff were in training on the use of stories in clinical practice and (8) professional data including years of experience, profession, and type of patient care provided. Open-ended questions asked providers to provide examples of how they and/or their team use MLMS notes (two questions) and how they felt MLMS notes impacted them or their patients (two questions). For example, providers where asked to "Please provide examples of how you use 'My Story' notes" and "Please provide examples of how you feel 'My Story' notes have impacted you." There was also an open-ended question for other comments about the program.

Survey data analysis

Descriptive statistics were used to analyze the quantitative responses – the proportion of staff responses to each item were calculated. Thematic analysis was used to analyze the

qualitative responses following the six steps outlined by Braun and Clarke (2006) including 1) familiarizing oneself with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the report. Two members of the team (TJR and TR) coded all data together. Codes were inductively developed to initially summarize the essence of the responses. An iterative process of assigning new codes as new concepts and ideas emerged and reviewing previously coded data for fit with new codes was conducted. After the initial set of codes was developed, codes were reviewed for similarities and dissimilarities using constant comparison and then collated into larger themes that best summarized a group of codes. Themes were chosen to represent and reflect all lower level codes. Codes and themes were determined by consensus. The final themes and their relationships to one another were reviewed and vetted by the larger project team.

Program data collection & analysis

In addition to the survey, we collected data about program operations that would help us gauge program growth and value over time. This information included data from the start of the program in March 2013 through October 2017. We tracked the number of stories written, proportion of stories collected by staff and volunteers, and other program artifacts such as the number of MLMS consults. Descriptive statistics are reported for these data.

Results

Staff surveys

Approximately 94% of staff indicated they had read MLMS notes. The other 6% reported either not receiving a note (4 of 7 responses), did not have time to read it (2 of 7 responses), or thought it was not a good use of clinical time (1 of 7 responses). Of the 94% of staff who read the notes, the vast majority reported positive perceptions of the value and impact of the notes (Figure 1). Over 86% agreed or strongly agreed that reading the notes was a good use of their clinical time and helped them provide better treatment or care. This is higher than the proportion agreeing or strongly agreeing in year 1. Only 3% of staff disagreed that the note was a good use of their clinical time and 2% disagreed that it helped them provide better care. Just over two thirds (73.34%) of staff indicated they were 'interested,' or 'maybe interested,' in training materials that would demonstrate how providers use MLMS notes in clinical encounters. Approximately 56% of staff reported using the stories a few times per month or more.

Qualitative responses regarding the use and impact of MLMS notes clustered around seven major themes. When asked to describe how stories were used or impacted them, staff responses focused on how stories helped them know more, understand, intervene better, connect to, or empathize with Veteran patients (Table 2). Staff also indicated that in some cases, the stories helped remind them of their mission and the honor it is to care for Veterans. More than one theme

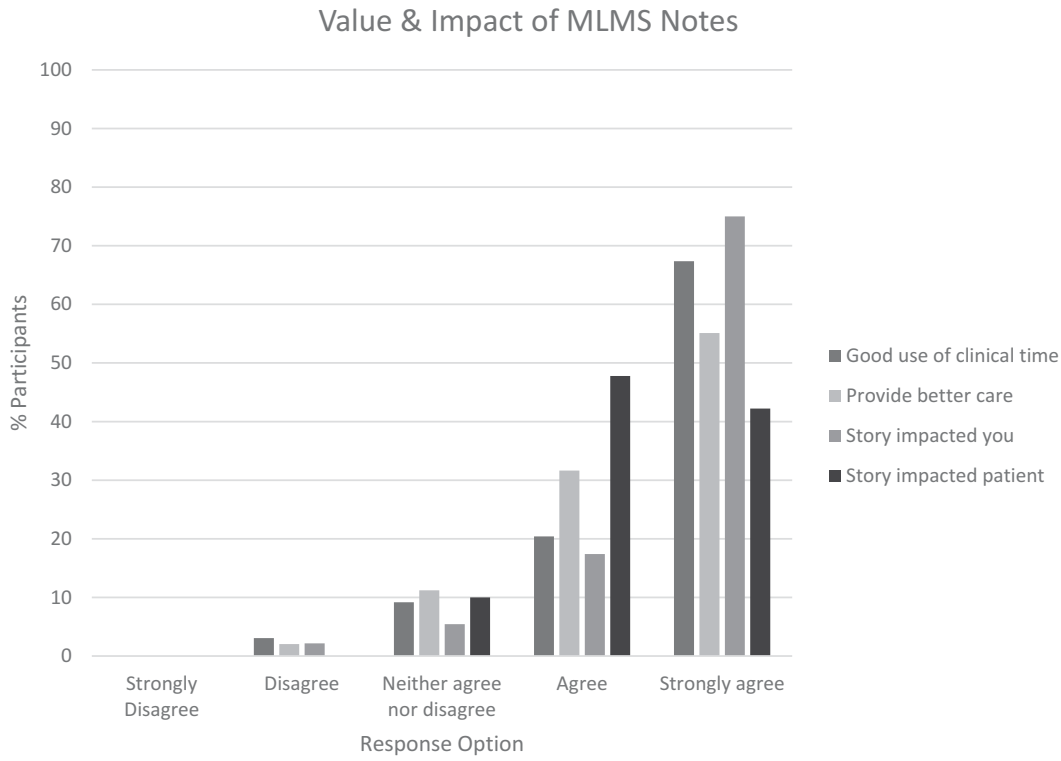

Figure 1. Staff responses regarding MLMS value & impact.

Table 2. Qualitative responses to ways the story is used and its impact on staff.

Theme	Definition	Quotation
Knowing more	Acquiring new or additional information about a Veteran	*Know more about a patient's history, know where they come from*
Understanding	Acquiring new or additional information about a Veteran that is valued for changing or influencing perspective, thinking, or understanding of who the Veteran is as an individual or human; developing an understanding of what motivates the Veteran	*The My Story notes provide insight into the mind-set and experience of Veterans … can allow us to better understand our patients' life experiences which can impact their healthcare decisions*
Intervening better	Changing, tailoring, or enhancing patient-centered care, treatment plans, goals of care, teaching, or other health related approaches based on knowledge of what is important, relevant or valued by the Veteran	*My Story notes provide a rich backdrop from which I can better frame and guide goals of care conversations.* *… Knowing more about the patient's life, values, and overall history helps me decide how to explain care for a patient.*
Honoring the mission	Feeling a sense of honor and dedication to the mission of the VA and country inspired by Veteran stories of service and sacrifice	*… remind me of the honor it is to work in the midst of resilient individuals who have endured the unimaginable.*
Starting conversation	Use of the facts and information in the Veteran story to 'break the ice', start a conversation, or know more about the parameters of what might be interesting or acceptable conversation with the Veteran	*Usually I try to note some of their interests or things about their family if they are included in there, then it is easy to use those as a talking point*
Connecting	Use of the story to build relationships, in some cases personal rather than medical relationships, and to develop trust or rapport with the Veteran	*It helps me connect more personally with Veterans – allowing us to talk about subjects that are not just medical in nature.* *… when I talked with him about details he shared re: his time in service (under General Patton) he was thrilled and it made trust and rapport stronger from the very first appt.*
Empathizing	Having a sense of identification with the Veteran; developing a new sense of concern for or need to act on behalf of the Veteran; having compassion; experiencing an emotional connection or response to the Veteran's story	*Makes me more compassionate. When a patient and I disagree, or a don't know why he isn't as 'compliant' as I'd like, the story usually gives me a glimpse into all the other battles that patient has fought and why he might come across as 'stubborn'*

was present in some responses. Responses that stories helped staff know or understand the Veteran better sometimes co-occurred with the theme that suggested the story helped staff intervene better. Staff described this as making more appropriate and personalized decisions about the plan of treatment or care delivery after knowing the Veteran better from the story. When staff responded that the story helped them start conversations with Veterans, they also described connecting better with Veterans. This was illustrated by comments that suggested knowing the details of the story was useful for increasing trust and rapport and building more personal relationships with the patient or family.

Surveyed staff endorsed the notion that sharing a personal story is highly impactful to patients (Table 3) providing a range of benefits. On one end, staff suggested sharing stories gave patients something pleasant to do while in the hospital. Of more substantial benefit, staff felt the stories might be therapeutic, giving patients the opportunity to reflect and heal from prior trauma and share things they had not talked about with anyone else. Staff also recognized that patients who tell their stories may feel recognized and that their concerns and needs are being heard.

Program data

The number of stories written each year of the program increased rapidly over the first 2 years of the program, peaking in 2015 for an average of about one story collected per day (Figure 2). The number of stories collected declined slightly in 2016 and 2017. The number of stories collected by MLMS staff remained essentially the same since 2014, with the vast majority of stories being collected by volunteers (Figure 2). The number of consults was low in the first 2 years of the program with a large spike in 2015 to the highest level of 130 consults placed in 1 year (Figure 3). The numbers declined slightly in 2016 but increased again in the first 10 months of 2017.

Table 3. Qualitative responses regarding staff perceptions of how the stories impact Veterans.

Theme	Definition	Quotation
Being Heard/Being Care For	Sense that someone is listening and caring for the Veteran by attending to their story; who they are and their story is meaningful	*I think that one complaint many patients have about health care is that their providers don't know them well. They feel heard if we know the backstory of their lives.*
Recognition	Sense of pride or appreciation for being recognized by one's story	*Almost everyone likes to talk about themselves. Vets who've I told, "I read your story … " have expressed relief that I know a bit more about them and won't be asking them the same questions a million times.*
Therapeutic	Stories have healing effects for those that suffered trauma	*… It allows them to release painful memories to be able to start healing.*
Sharing the unshared	Belief that some Veterans are unable, unwilling, or have not been given the opportunity to tell their story and the program gives them the chance to do so	*For some, it is the first time they are telling their story! Some have mentioned that they had not even told the story to their families …*
Entertainment	Idea that Veterans enjoy having the opportunity to have something to do while in the hospital, talk with someone for an extended period, or tell their story	*A couple of patients have commented that they enjoyed telling their story.*
Legacy	Ability to talk about and share a history of who the Veteran is as a person and their experiences	*It helps them to reflect on their experiences, it allows them to leave a legacy to the VA.*

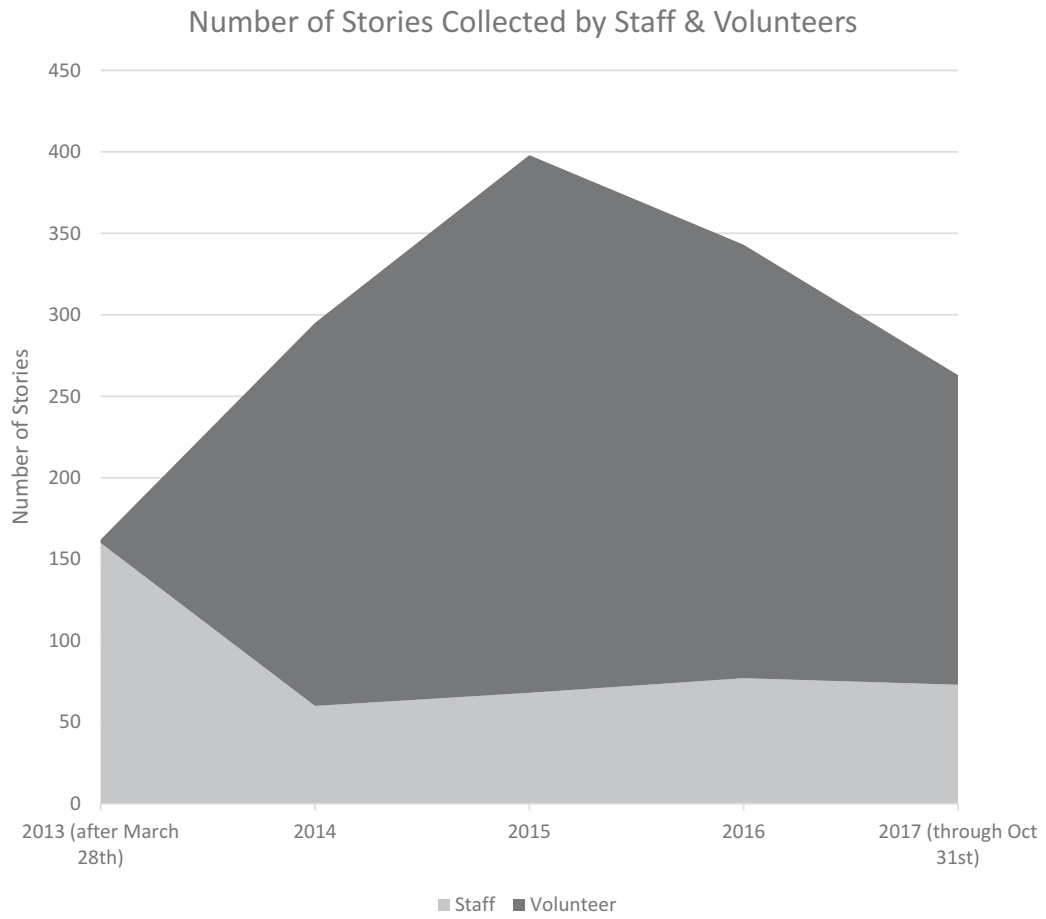

Figure 2. Number of stories collected by staff and volunteers from March 28, 2013 through October 31, 2017.

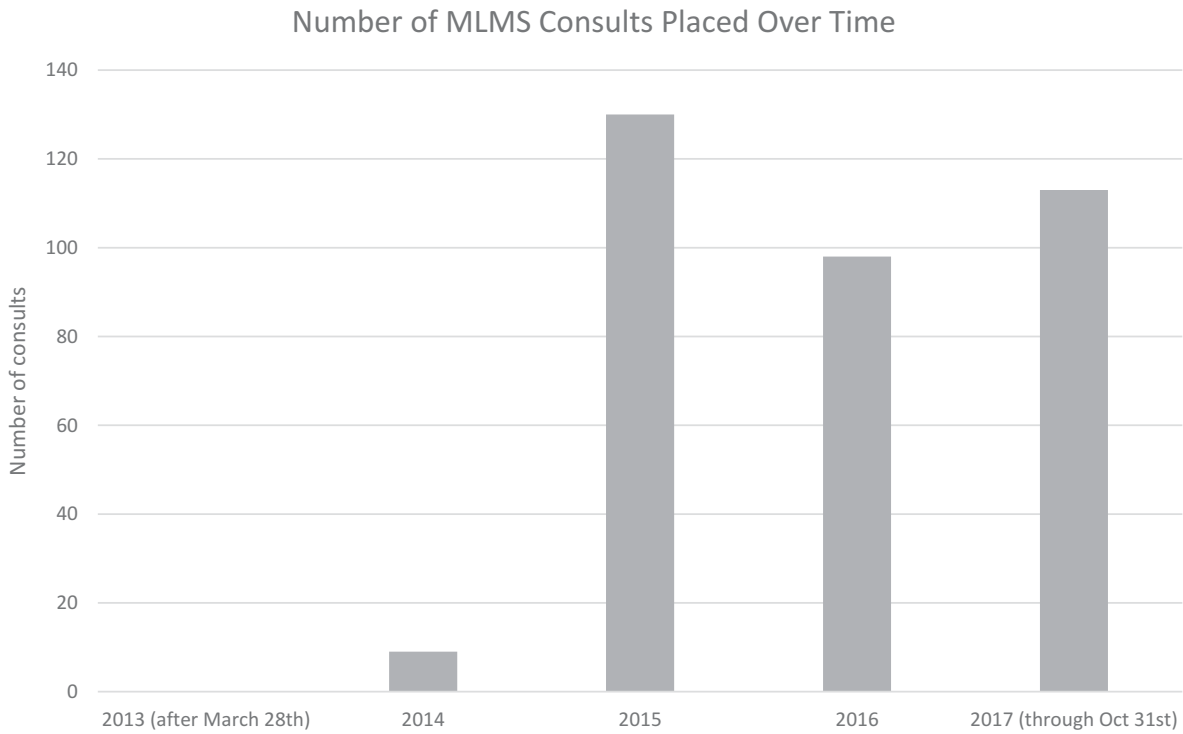

Figure 3. Number of MLMS consults placed since program inception.

Discussion

Overall, the results of the evaluation suggest the value of the MLMS program has been well sustained over time. Five years after implementation, staff rated the program highly and suggested that it positively influences the care they provide and their attitudes and perceptions toward their patients. In addition, a higher proportion of staff participants indicated that reading a Veteran's story is a good use of their clinical time and that the story will help them provide better care when compared to the first year of the program. Furthermore, staff also reported frequent use of the stories 5 years after implementation, with over half of staff using them a few times per month or more.

Communication theory emphasizes that storytelling is intentional and has diverse goals. Stories can be used to connect interpersonally (Kellas, 2017) or to establish the intimacy between a speaker and listener (Pasupathi, 2001). Survey responses suggest that patient stories can also motivate emotional and behavioral change. Participants described how the stories prompted them to change their thinking and perceptions about their patients, enhanced their relationships with patients, and altered their approach to care to be more tailored or patient-centered. In the context of communicated narrative sense-making theory (Kellas, 2017) this would be an example of translational storytelling, where a narrative-based intervention improves the quality of communication between providers and patients.

The qualitative findings also suggest that patient stories trigger a perspective-taking response in providers, encouraging them to see their patients in a new light. Perspective-taking has been linked to individual positive well-being (Horstman, 2018) and operationalized so that it can be rated in interactional partners (Kellas, Carr, Horstman, & Dilillo, 2017). It is possible that stories contribute to individual providers' perspective-taking ability and their ability to communicate that perspective-taking ability to their patients during clinical visits, but both of these propositions would have to be evaluated with future research.

Prior neuroscience research also provides insights into how a story program like MLMS might have an impact on provider behavior and interactions with patients. Neuroscience research has demonstrated that viewing and listening to stories can influence human emotions and behaviors, particularly promoting prosocial behaviors (Barraza, Alexander, Beavin, Terris, & Zak, 2015; Zak, 2015). Thought to be due to the release of certain neurochemicals in the brain, some stories can invoke feelings of trust, generosity, and compassion (Barraza et al., 2015; Zak, 2015). Other research has demonstrated that storytelling invokes reactions in similar areas of the brain between storyteller and story listener suggesting that stories can enhance understanding of others and increase capacity to perceive the beliefs and goals of others (Barraza et al., 2015; Zadbood, Chen, Leong, Norman, & Hasson, 2017). This prior research provides a possible explanation for why participants in our program, who have received no training on how to use patient stories in care, reported feeling empathy and compassion and tailoring care after reading the stories.

The ability of patient stories to elicit these responses in providers may be particularly relevant within the VA system. Veterans are a minority population: less than 8% of the over 18 civilian population (U.S. Census Bureau, 2017). For VA providers who have not served in the military, the stories of their patients are not just a way to know more about them but a way to know more about the Veteran experience. "The power of narrative, of course, is that if stories are told or presented well, recipients of the story are engaged, involved, and swept along, intellectually and emotionally, at times achieving vicarious or empathic understanding of a situation that is otherwise "unknowable" (Sharf, 2017). The stories often include details of momentous events in the lives of the Veterans, both within and outside of military duties that are dramatic, distressing, traumatic, joyful, riveting, and/or enlivening. Research is needed to determine how these details impact providers and their sense of connection to the patient. While respondents overall appreciated the candor and sense of connection the stories provided, stories about difficult experiences may alienate some listeners/readers (Kellas et al., 2014). It is also not clear whether the apparent effect on providers might be achieved equally well by standard PCC strategies.

In addition to the perceived value to the provider, staff indicated the MLMS program had a range of benefits for patients. From entertainment, keeping patients busy while in the hospital; to helping them feel like unique, important individuals; to potentially providing some therapeutic value, staff perceive significant value in the program for Veterans. A question for future research is whether the same perceived benefits would occur in a non-VA healthcare setting. Veterans may particularly benefit from a story-sharing intervention because the stories honor their service and acknowledge their sacrifice. Veterans experience high rates of trauma, including combat, sexual, and civilian traumas, higher than the general population (Lehavot, Katon, Chen, Fortney, & Simpson, 2018). While not a mental health treatment, MLMS invites Veterans to share their stories, some of which involve difficult or traumatizing experiences. Avoidance of trauma memories is one of the key elements that perpetuates symptoms of posttraumatic stress disorder (PTSD) (American Psychological Association, 2017). In fact, exposure therapies for PTSD focus on allowing patients to talk about and process trauma in a safe therapeutic setting, eliminating their avoidance, and allowing for the extinction of symptoms over time (Cukor, Spitalnick, Difede, Rizzo, & Rothbaum, 2009; Kar, 2011). The presence of trauma in a patient story creates an opportunity for providers to encourage further treatment, but additional work is needed to better understand whether sharing the story provides therapeutic value in itself, and what the outcomes might be.

The results of the evaluation demonstrate how a life story program implemented in one VA hospital has become a practical, sustainable tool for promoting PCC. There are several factors that sustain the program. First, the impact and perceived value of stories on both providers and patients results in an intrinsic and self-reinforcing value that promotes sustainability. Individuals who participate in the MLMS program, either by telling their story or reading

one, feel the importance and need for the program and tend to support and promote the program. Second, consistent with the literature on change and sustainability in healthcare, institutional commitment to the program is instrumental (Lennox, Maher, & Reed, 2018; Li, Jeffs, Barwick, & Stevens, 2018). The hospital employs a dedicated writer/editor with the interviewing and writing skills needed to conduct the story work and maintain fidelity to the program goals, and recruit and train volunteers. Further, the program and the stories have become part of the institutional culture. Stories are shared at major hospital-wide events, such as Town Hall meetings, which keeps the program visible and promotes its spread to new areas and new uses throughout the hospital and the VA. The program has also received specific funding at critical timepoints from various VA project grants to grow and build. However, the program is sustainable even between periods of funding because it is largely staffed and executed by volunteers.

There was a slight decrease in local MLMS activity in terms of stories collected, volunteer involvement and number of consults around 2016. This decline coincides with a major movement to start spreading the MLMS across the VA system nationally and the shifting of local resources to that effort. The MLMS program was designated as a "Gold Status Practice" by the VA nationally in 2016, and 20 other VA hospitals have implemented similar programs in their hospitals. Each program that has been implemented has made changes to fit their local contexts. Programs that have been most successful in sustaining their programs over time have developed creative solutions in their context to replicate the institutional commitment and staffing to carry out the program goals. For example, one hospital enlisted student providers as volunteers in the program to collect patient stories during their rotations with the VA (Nathan et al., 2019). Future evaluations should be conducted to determine how program activity is maintained as the MLMS program staff continue to support the widespread dissemination of the project.

Limitations

This was a limited program evaluation of a quality improvement program conducted at a single site. The findings are not generalizable. However, the results may be useful for demonstrating how a story program could be useful in practice. The results are based on a volunteer survey and selection bias may be influencing the positively skewed results. The survey was developed for the purposes of the evaluation; psychometric testing was not done.

Conclusions

The use of patient stories in healthcare may be a valuable, practical, and sustainable tool to support PCC. Stories that address aspects of patients' lives beyond details collected in the standard physical or social history may prompt changes in healthcare provider knowledge of the patient. This, in turn, may influence providers' emotional and behavioral responses to the patient, particularly promoting feelings of empathy and compassion, and tailoring of care. When considering MLMS as a possible option for enhancing PCC, healthcare facilities should consider long-term sustainability. Institutional commitment is critical to sustaining a patient story program like MLMS.

While PCC most significantly impacts the interactions of individual providers and patients, it also shifts the larger culture of the hospital. A patient story program like MLMS may provide intrinsic and self-reinforcing positive value to healthcare organizations that embrace it. Stories turn our patients into people.

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