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Case Report

Narrative medicine applications for patient identity and quality of life in ventricular assist device (VAD) patients

Robert B. Slocum, PhD *, Amanda L. Hart, RN, BSN, Maya E. Guglin, MD, PhD

Gill Heart Institute, University of Kentucky, CTW 320, 900 S. Limestone Street, Lexington, KY, USA

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ABSTRACT

Patients with advanced heart failure may experience a variety of challenges to their self-identity and quality of life due to their heart condition and treatment by implantation of a ventricular assist device (VAD). These challenges include loss of energy and stamina, loss of independence and autonomy, dependence on loved ones and caregivers for help, strained relationships with family and friends, and uncertainty about treatment outcomes and time of recovery. Narrative Medicine (NM) sessions may help patients to reflect on their situation, rediscover identity, and engage sources of meaning by telling or writing their story. This narrative process may encourage patient resilience and quality of life. The impact of illness and treatment on each patient may be understood more fully in light of each patient's unique identity and life story. Insights from NM visits may also help the treatment team as they assess patients' life situation including sources of support as well as goals and motivation for treatment. This paper provides case reports to illustrate applications of NM in the care of patients with advanced heart failure who are treated with implanted VADs. The cases include use of NM to clarify an elderly patient's motivation and consent for VAD implantation to return to favorite outdoor activities; application of perspectives from NM visits to appreciate a patient's slow but gradual improvement after VAD implantation and strong motivation for recovery; and use of a NM session to help a patient begin to overcome social withdrawal and fear after traumatic post-operative experiences.

Introduction

Narrative Medicine (NM) seeks to help patients and family members by engaging their stories of illness and treatment in the context of their life history, values, and identity. NM sessions encourage patients to share their stories through guided conversations and personal writing. Attentive listening to the patient's narrative is at the heart of NM visits. Patients are encouraged to reflect on their sources of strength, insights drawn from their experience of illness and treatment, and hopes for the future. They may also share their concerns and sources of conflict during treatment. The format of the NM visit is flexible, providing space and opportunity for patients to focus on any topic of concern for them. Vieda Skultans states that "Narratives facilitate the search for, and construction of, new meanings in situations where the old meanings no longer work."[1] Patients may begin to discover new meanings and sense of identity as they explore their own narratives, encouraging resilience and improved quality of life.[2] These experiences may be shared in conversations with a NM practitioner or written in a patient journal and discussed later.

Telling the story encourages patients to sort through feelings and thoughts about their condition. In some cases, patients who reflect on their condition will discover new insights about themselves relative to their illness and treatment. They may also recall questions or issues they forgot to raise in previous interactions with other health care providers. They may find new questions, new answers, and new meanings as they hear their own story and share it with another person who listens carefully. Rita Charon notes the reciprocal process of telling and hearing a story of illness, a "giving and receiving of accounts of self," is at the heart of health care.[3]

NM began to emerge as a discipline in the late twentieth century. Charon states that "narrative medicine began as a rigorous intellectual and clinical discipline to fortify healthcare with the capacity to skillfully receive the accounts persons give of themselves—to recognize, absorb, interpret, and be moved to action by the stories of others." She explains that NM proceeded from a group of scholars and clinicians at Columbia University in New York who "gathered at the millennium." They believed "the nature of the clinical work itself would be transformed if narrative skills and methods could become part of the fabric of clinical thought and care."[4] Tricia Greenhalgh and Brian Hurwitz of King's College, London, stated in 1998 that "Narrative provides meaning, context and perspective for the patient's predicament." Greenhalgh and Hurwitz also distinguish NM from the

* Corresponding author.
E-mail address: robert.slocum@uky.edu (R.B. Slocum).

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limitations of modern medical practice: “At its most arid, modern medicine lacks a metric for existential qualities such as inner hurt, despair, hope, grief, and moral pain which frequently accompany, and often indeed constitute, the illnesses from which people suffer.”[5]

NM is relatively new, a development of the past 20 years or so, but also very old. Lewis Mehl-Madrona draws on his Native American ancestry to consider the ancient use of story in healing. He notes that “within the Lakota and Cherokee traditions with which I am most familiar, the healer diagnoses the problem through careful listening and rapport building. The healer teases out the story before a ceremony is ever considered.”[6] He also states “illness makes sense within the overall stories and contexts of a person's life. This is not a new idea. Indigenous cultures have believed this since long before recorded history.” Healing must therefore provide “an individualized solution” for the person who needs treatment.[7]

Narrative exercises such as reflective writing on emotional or serious topics have shown potential health benefits for patients and other study participants. Bourassa, Allen, Mehl, and Sbarra found that narrative expressive writing decreased heart rate and increased heart variability but did not affect blood pressure in a sample of adults who recently experienced marital separation.[8] A variety of other studies have shown health benefits of expressive writing, including decreased pain, improved health status or well-being, increased vigor, better sleep quality, and decreased doctor-visit rates. Some of these studies show benefits of expressive writing in certain areas of study but not in others.[9–13] Health benefits for patients may well be gained in NM conversations that involve the same kinds of reflections found in expressive writing exercises. More research needs to be done in terms of immediate and long-term benefits for patients who participate in NM visits and writing activities.

Narrative competence is an important qualification for anyone who serves as an NM practitioner. Charon (describing NM in the work of physicians) defines narrative competence as “the set of skills required to recognize, absorb, interpret, and be moved by the stories one hears or reads.” Sharing the patient's narrative may also allow a subject-to-subject contact of the patient and NM practitioner that encourages their therapeutic alliance. The NM practitioner's respect for the patient's worth and concern for the patient may be expressed through attentive listening that “makes room” for the teller of the story, the patient.[14] Narrative competence may also allow a deeper understanding of the patient's story and the disease itself in terms of an unfolding narrative with characters, plot, symbols, meaning, conflict, and resolution of conflict.

Advanced heart failure patients may encounter physical and mental challenges to their personal identity and sense of self. A patient who is used to working hard or being active at home may experience decreasing energy and stamina. A patient who is used to managing the tasks of daily living may have difficulty with the most basic activities of life and need help. Some patients may become angry, discouraged, or fearful. Patients who were confident about their future may be unsure about what comes next or what will happen to them. They may fear loss of independence and autonomy. Relationships with loved ones and caregivers may be strained. Patients’ motivation for treatment may be challenged by the prospect of prolonged hospitalizations, lengthy rehabilitation, and uncertain outcomes or timelines of recovery. Some ventricular assist device (VAD) patients may be disappointed they were unable to receive a heart transplant.

Implantation of the VAD itself can challenge patients’ body image and physical identity. The lifestyle of VAD patients is restricted and changed in many ways (e.g., limitations on autonomy such as no swimming; special instructions for showering and dressing changes). They may require supportive home care for maintenance of the VAD along with regular encouragement, patience, and assistance from family and friends. These limitations and changes can challenge patients’ sense of identity and independence.

Method

Narrative Medicine visits were incorporated into care for advanced heart failure patients at the University of Kentucky Cardiology program in 2016. Physicians (including MEG), nurse practitioners, VAD coordinators (including ALH), and nurses referred the Narrative Medicine Program Coordinator (NMPC) (RBS) to see patients with advanced heart failure who seemed likely to benefit from a NM visit. These referrals for NM were part of routine patient care. RBS has served as program developer and coordinator since the inception of the NM program at University of Kentucky HealthCare (UKHC) in 2015. NM is a modality of Integrative Medicine & Health (IMH) at UKHC, and funded through IMH.

Both inpatients and VAD clinic outpatients were seen for NM visits. Members of the heart failure treatment team provided background information about some patients to RBS prior to NM conversations. Patients were invited to share their story of illness and treatment along with basic information about their life history. Patients were asked about their sources of strength or support, favorite activities, frustrations or limitations, insights or new perspectives gained during illness and treatment, as well as hopes and motivation for the future. Some inpatients and outpatients were seen for follow-up NM visits. These patients were encouraged to continue to reflect on their story in light of any recent changes in their condition or life situation. They were allowed to tell their stories of illness and treatment in an open-ended manner, and some continued to develop their narratives during follow up NM visits. Attention was given to changes in the patients’ outlook or attitude. RBS shared observations and impressions about the patients’ changing situation and quality of life with clinical members of the treatment team.

Case histories

Patient A was a 74 year-old male farmer who loved riding his tractor, working in the fields, and going to his barn. He worked outdoors for many years. His energy had been diminishing steadily as his heart failure progressed. He was evaluated for possible VAD implant by the treatment team. Some clinical members of the treatment team questioned the wisdom of a VAD for this patient in view of his age and possible complications. They noted he was currently able to function at home and the VAD implantation surgery could cause serious complications. Some worried he did not fully understand the risks he faced with VAD implantation relative to the possible benefits in his case, and questioned whether he was giving informed consent.

The patient had been very active in physically demanding work for many years. His outdoor work and activities were central to his identity. He was very restless and impatient as he found himself increasingly confined at home. He told RBS in an NM visit, “Our house isn't very big, and the walls get closer and closer.” He wanted to get back outside, walk to the barn, and ride his tractor. In an NM visit he also said he was a risk-taker, and wanted to take a risk to return to the outdoor activities he loved. Understanding the patient's narrative and identity helped RBS discuss the *patient's* clear motivations and unhesitating consent to receive the VAD. This was relevant for the treatment team's consideration during the evaluation process that led to implantation of Patient A's VAD.

Patient A was strongly supported by his loving wife and caregiver. She was constantly with him when he was hospitalized and also on subsequent outpatient visits. For years they ran the family cattle farm and shared responsibility for taking care of their animals. Being with his wife and being able to work with her were primary motivations for Patient A as he struggled with heart failure. A VAD Coordinator (ALH) noticed that Patient A's wife was visibly relieved and supported by NM visits when he was able to share his hopes and frustrations.

After a period of recovery following VAD implantation, the patient grew stronger and more active. He was able to return to many of his favorite outdoor activities and spend time with his family prior to his death due to a respiratory infection during the winter.

Patient B was a 59 year-old man who was in cardiogenic shock on admission and required venoarterial extracorporeal membrane oxygenation (ECMO). Being an Interagency Registry for Mechanically Assisted Circulatory Support (INTERMACS) profile 1 "crash and burn" patient, his risk of VAD surgery was high, but the team felt this was his only chance to live. After left ventricle assist device (LVAD) implantation he faced severe challenges. His right ventricle failed, and he had to return to the operating room to have a right ventricle assist device (RVAD) implant, which was subsequently explanted, but he remained inotrope dependent for months. The patient had prolonged ventilation with tracheostomy. He lost kidney function and became dialysis dependent. He was unable to eat for an extended time and required tube feeding. He also had profound gastrointestinal (GI) bleeding with multiple units of blood products transfused. All of the above resulted in liver failure with high bilirubin and recurrent ascites requiring regular paracentesis.

Patient B was hospitalized for about eight months in all. At first he showed limited signs of improvement. Despite his lack of progress he remained determined to continue with his treatment and return home. Over a period of months he gradually became more active. He exercised by walking with assistance on the unit floor. Patient B expressed his continuing resolve to live and recover in a series of NM visits that became increasingly interactive as his condition improved. He welcomed these visits and seemed to draw strength from them.

After several months of hospitalization, a provider who had limited experience with this patient questioned the goals of care for Patient B. She initiated an ethics consult. She had not witnessed his very slow but steady progress over a period of months, and she may have been unaware of his strong motivation to continue to recover. It was possible for RBS to discuss the case with the Chair of the Hospital Ethics Committee to address the goals of care relative to the patient's story of slow but continuing improvement and strong motivation to recover. The patient's treatment was found to be within standard of care for his medical situation.

The patient continued to progress and improvements came more quickly. His feeding tube was removed. His appetite improved. The ascites resolved, and liver function normalized. Eventually he was weaned off inotropes and set up for chronic outpatient hemodialysis. He was discharged after several more weeks. Outpatient visits continued to show improvement and he was listed for heart and kidney transplant. Understanding his story of slow but gradual recovery from VAD implantation surgery was important to appreciate his condition and treatment relative to goals of care, and the NMPC was able to intervene at a critical point to resolve one of the questions during his battle.

Patient C was a 66 year-old man who was very apprehensive about receiving an LVAD. He hoped to get a cardiac transplantation but was rejected because of metastatic prostate cancer. After several months of going back and forth with his decision making, he chose to proceed with LVAD implant. Early after the surgery, he tried to pull out his VAD driveline while still confused and recovering from anesthesia. Restraints were required to prevent him from causing harm. The patient experienced restraint as a very traumatic situation. It troubled him greatly afterwards. He became withdrawn and mostly silent. He suffered from vivid nightmares and difficulties with sleeping. He even had trouble staying in bed to sleep. Increasing doses of insomnia medications provided little relief. The patient also had a traumatizing episode after his LVAD implant. He went into ventricular tachycardia in which he was shocked multiple times (12) and had to be airlifted back to the hospital.

Patient C began to open up during an outpatient VAD Clinic appointment that included a NM visit with RBS. Patient C discussed his traumatic experiences during his NM visit. This may have been the first time he told the story of his trauma in detail to anyone. He shared his nightmare of being strapped to his bed in the intensive care unit. After telling his story during this outpatient visit he went home and was able to go to bed and sleep better that night. He later stated to a support group of patients and family members that he kept talking after his NM visit and he was no longer withdrawn from others. He provided encouragement and shared experience for other VAD patients and prospective VAD patients through patient visits and support groups.

Patient C's improved outlook and affect were apparent during two follow-up outpatient VAD clinic appointments with NM visits in the five months following his initial NM visit. In one visit he said he was working part-time four to five days a week, and in a later visit he said he enjoyed spending time at the lake during the summer. He expressed his eagerness to help others during both visits. Patient C's VAD changed his life. He spent time with his wife and family, and returned to work. He was generous and energetic in helping others. Patient C identified his outpatient NM visit as a turning point in his recovery.

Discussion

The "first topic" of Arthur W. Frank's *The Wounded Storyteller* is "the *need* of ill people to tell their stories, in order to construct new maps and new perceptions of their relationships to the world."[15] NM visits invite patients to share their stories of life and illness, probing "deeper than any structured questionnaire of medicine" and highlighting "the complexity of the human being."[16] This distinction is clear in Oliver Sacks' critique of modern case histories in medicine: "There is no 'subject' in a narrow case history. . .. To restore the human subject at the center—the suffering, afflicted, fighting, human subject—we must deepen a case history to a narrative or tale; only then do we have a 'who' as well as a 'what,' a real person, a patient, in relation to disease—in the relation to the physical."[17]

Telling the story may help patients reclaim their place as the main character in their own story with autonomy and responsibility. This may encourage the patient to take an active and collaborative stance during treatment instead of being passive. Rosenblatt states that individuals permitted to tell their stories "regain control over the plotline of the illness, reclaim the central role as protagonist, and thus diminish the sense of helplessness, marginalization, and isolation that are inevitable aspects of serious disease."[18]

The conversation with a NM practitioner can help patients draw out their stories and connect with personal sources of meaning. Winslade and Cotter note that "From a narrative perspective, each telling of a story is a new version, and each new version is likely to have a shaping effect on the consciousness of the person telling it."[19] If the patient's sense of self is challenged by illness and treatment, the telling of the patient's story can be a starting point for rediscovering identity during treatment. Lossignol notes that serious illness challenges the patient with "a biographical disruption because it is a potential threat to maintenance of a coherent self, in which the relations between body, mind and everyday life are threatened."[20]

NM visits provided opportunities for patients with advanced heart failure to come to terms with their stories of illness and treatment in light of their identity and sources of meaning. In some cases it was possible for NM to help patients begin a new story in light of the changing circumstances of their life and health. This narrative process may encourage patient resilience and improved quality of life. NM visits in the cases mentioned above helped clarify Patient A's motivation and consent for VAD implantation in order to return to his favorite outdoor activities and spend time with his family; helped to identify and

appreciate Patient B's slow but gradual improvement after VAD implantation and post-operative complications as well as his strong motivation for recovery; and helped Patient C begin to overcome his isolation and fear after traumatic post-operative experiences.

NM visits may encourage patients with heart failure to rediscover identity and quality of life during treatment. NM may also help the treatment team to appreciate the impact of illness and treatment in light of their patients' unique identity, sources of meaning, and hopes for the future. Another possible benefit is that improved rapport and empathy may help providers understand their patients more fully and respond more effectively to their patients' concerns and needs during treatment. Effective practice of narrative competence and skills can encourage "interest in humanity," and ongoing discovery of the truth in Francis Peabody's statement that care *for* the patient is "the secret of the care of the patient."[21] NM stands at the intersection of treatment and quality of life concerns for patients with VAD implantation.

Compliance with ethical standards

This article does not contain any studies with human participants performed by any of the authors.

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